



## Taking the Plunge

What's breast reconstruction really like?

**It's not difficult to see why many women who are forced to have breast surgery following a diagnosis of breast cancer find the idea of reconstruction highly appealing. It offers the opportunity to enhance your appearance, it can make you feel 'whole' again, and for many women it can minimise the psychological impact of losing a breast. But regrettably it does not come without its drawbacks.**

**If you choose to have breast reconstruction at the same time as your mastectomy, your recovery time will be prolonged. Reconstruction often involves major surgery, and frequently more than one operation, and because**

**women's expectations are usually very high the results are sometimes disappointing. As with all surgery, there is also the chance of complications occurring. Yet despite these factors, many women feel that reconstruction is right for them. We've spoken to many Amoena Life readers about what it was really like.**

### One flesh

There are two main types of reconstruction – 'tissue flap' reconstruction, which uses a woman's own flesh, and the use of an implant. Let's take a look at 'tissue flap' reconstruction first.

### TRAM flap

This operation is known as a TRAM flap because it uses the transverse rectus abdominis muscle, the large muscle that runs from below the ribs to the groin. There are two types of TRAM flap operation. The first involves taking a piece of muscle with its overlying fat and blood supply, rotating it and moving it under the skin of the stomach and chest, where it is brought out over the area where the new breast is to be made. Usually there is enough fat in the flap to make the new breast the same size as the other one, without the need for an implant.

This is major surgery, involving a long operation (around six hours if done at the same time as your mastectomy), and at least a week's stay in hospital. You will experience pain – particularly in your abdomen – for some time following the operation, and reduced strength in the abdomen for lifting or sports. There is also substantial scarring; the scar on the abdomen can be vertical or horizontal, and the scar around the breast will be oval. You can expect it to take up to six weeks before you can walk fully upright, and tightness in the abdomen can last for a year or more following the operation.

**Pamela** decided on reconstruction when, following a right lumpectomy and mastectomy, she was told she would have to lose her other breast. “I was offered bilateral reconstruction at the same time as my left mastectomy. Prior to that I had got on very well with my prosthesis, but the thought of having a completely flat chest wasn’t acceptable to me,” she says.

“I decided on the TRAM flap. I had lots of information from my breast care nurse, and I saw a couple of ladies who had had the operation by the same surgeon – I would certainly recommend that to anyone considering reconstruction. I thought it was the right operation for me, and the idea of a tummy tuck was appealing. I think at first I expected to achieve lovely breasts. I was told that I would probably go down a cup size, and in a way I’m not as big as I thought I would be. But I am delighted with the result. I feel as good as I did before I was diagnosed.”

Pamela was told about the possible complications associated with her surgery, “But I didn’t feel that concerned. After the shock of being told you have breast cancer, this was something that was going to make me feel well again. I thought ‘I have to go for it’. I had always looked after myself as far as exercise and eating well were concerned. And before my operation I made sure to build up my immune system and take plenty of light exercise. I was mentally and physically ready for it.”

Pamela was in surgery for 12 and a half hours. “When I woke up there was no pain at all, thanks to a morphine drip in my spine. I was numb from the top of my chest to half way down my side. Because of the surgery to the abdomen you are bent over slightly and you can’t straighten up for some time. My husband came to see me the next day and was surprised at how well I looked. I was in hospital for about 12 days. The most discomfort I had was under my arms. There was quite a lot of swelling there, and I felt as though I had a kitchen roll stuck underneath each armpit. My upper abdomen was quite puffy and swollen, too.”

Recovery took about three months. “I stayed in bed for a week when I got home. You do feel very weak – as if you’ve been knocked down by a bus. But I was determined to come out of it and I just hung onto that thought. My movement was restricted in terms of my stomach wound – you have to be careful, you can’t just sit up. Then after three or four weeks this eased off. The reconstruction site itself was fine – I continued to do the exercises that you have to do after mastectomy. I would say that it took me a good six months to return to full mobility.”

Pamela had nipple reconstruction almost a year after her breast reconstruction. “They advised me to let them settle down first. The surgeon used the ‘dog ears’ from the edges of my tummy scar. It is done under local anaesthetic. They twist the skin round into a ‘bobble’ and sew it on, making sure to connect the blood vessels. The dressings were on for about a week. When I went for my next check-up I was offered tattooing, which I opted for, and now I am really pleased.”

Pamela has had a total of five procedures to achieve her current look. “I feel super now,” she says. “It has definitely lived up to my expectations. It hasn’t stopped me doing anything I used to do – in fact I feel it has given me the life I had before. I go mountain climbing, hill walking, gardening, swimming and I am happy to show off a bit of cleavage. I would recommend the procedure to anyone. I’m quite open about it

– I want to say to people ‘this is what I have been through and I have come out the other side’.”

**Judith's** experience of the TRAM flap has not been so positive. “I don’t think I was given accurate information at the time – or perhaps it was the best they could do five years ago. I was told that it was a case of having a reconstruction at the same time as my mastectomy, or having no reconstruction and then opting for a silicone implant at a later stage – and I didn’t want that.”

“I thought I would regret it if I didn’t have a go. A close friend of mine had just had a similar operation by the same surgeon when I was making my decision, and I thought hers was very good.” Judith wasn’t given any information about this type of surgery, apart from her interview with the surgeon, and talking to her friend.

Judith had a total of four surgical procedures. Ten days before reconstruction, she had an operation to split the blood vessels in her abdomen: “apparently this gives the reconstruction a better chance of success,” she explains. “Then I had the big operation, which took twelve hours. Later I went back to have nipple reconstruction, and then I went back a fourth time for areola tattooing. Unfortunately the new nipple didn’t take, so I have a flat area on the front of the reconstructed breast. And the tattooing wasn’t done very well, although I have since found someone who is an expert in semi-permanent make-up and she has tattooed it again and achieved a better result.”

Judith was unprepared for her post-surgery ordeal. “It is awful,” she says. “You have to sit up for five days and five nights. You can’t get out of bed, or move, or lie down. It’s much worse than they tell you it’s going to be. In fact, my friend and I have produced a leaflet called ‘A patient’s guide to surviving the TRAM flap’, which is now being used by hospitals in our area.”

She was in hospital for ten days. “Recovery is much longer than for many other types of reconstruction. But the pain relief was brilliant, and I have no complaints about the level of care. When I came home I could only walk a few hundred yards. I had been sitting in bed for a long time and my stamina was very low. I have been told that this is due to the amount of anaesthetic you have. The problem for me has been that my stamina has never come back.”

As well as twinges in her abdomen which, she says, have never gone away, Judith had a lot of pain in the reconstructed breast, “where all the flesh and muscle had been fixed inside.” She couldn’t wear anything with a waist or a zip for 18 months after the operation, due to the tenderness in her abdominal scar. “I still have a hard patch up the middle, and my reconstructed tummy button was sore for a long time. Even now I don’t tend to wear things round my waist.” Movement in her arm was restricted for a while following surgery, although it has come back now. For Judith, the follow-up and long-term care following reconstruction have been unsatisfactory. “There are questions that need answering. For example, I didn’t realise that if you gain weight – which I have done since starting tamoxifen – your reconstructed breast does not gain weight as well. Now my natural breast is much larger than my reconstructed one. Also the reconstructed breast has changed shape over the years. Originally it was a fairly good match – now it is extremely flat, and more square than round.”

In addition, Judith is unhappy with the amount of scarring that results from this procedure. “I have a ‘T’ shaped scar and two ‘ears’ that stick out on either side of it, which actually protrude if I am wearing anything tight. But the biggest problem I have now is with clothes. Thanks to the surgery I have gained two to three inches around my waist. I wear a lot of drop-waisted clothes because luckily they are fashionable now. But generally I can't get garments that fit because my waist is so much bigger in proportion to my hips.”

As to her feelings about her reconstruction now, “I hate it,” says Judith. “I sometimes feel I would be better off without it, although I can't say I regret it because I would always have wondered whether I should have had it done. It hasn't lived up to my expectations though.” Judith wears a partial prosthesis to help disguise the difference in size between her breasts and is now considering the possibility of a reduction on her other breast.

“I would recommend that women look very carefully into reconstruction before going ahead,” she concludes. “I think the difficulty with it at the beginning is that you are on the roller coaster of treatment and you tend to get swept along. If people are in doubt then they should opt for a mastectomy first and reconstruction at a later date. I think it is the asking of questions and getting information that makes all the difference.”

### **Abdominal free flap**

The second type of TRAM flap, the abdominal free flap operation, involves the complete removal of muscle, fat and skin from the abdomen. The surgeon forms a breast from a piece of muscle and fat and connects it to a series of blood vessels, usually inside the chest. Because this flap is detached from its original blood supply, the operation to build a new breast is much longer and more difficult. If the flap of tissue doesn't get enough blood it will die and the reconstruction will fail. The main advantages of a free flap reconstruction are better circulation to the new breast, fewer problems with the abdominal wall and more flexibility in shaping the new breast. However, this is a bigger operation, with a greater risk of complications and a longer recovery time.

**Jane** hated not having a breast following her mastectomy, despite having successfully worn the Contact breast form for 20 months. “Although I got on well with the prosthesis, when I went onto tamoxifen I got hot flushes and I found that it got sticky when I sweated.” Her Macmillan breast care nurse recommended the abdominal free flap as she felt it was best for Jane: “I play golf and was afraid of the restricted movement that might result from a Lat flap or TRAM flap, and I didn't like the idea of a synthetic implant.”

Jane says she hoped to look “like a woman again” following her surgery. “Deep down, you do hope to look exactly as you did before. I saw someone slightly older than me who had had it done and I thought it looked great. It was something I wanted to do ‘for me’.”

She decided to have her reconstruction under private medical care, although in retrospect she feels she would have had better support through the NHS. “The hospital did nothing to prepare me. Nobody showed me any pictures or booklets. It was only my Macmillan nurse who helped. I decided against nipple reconstruction

because I had been told it could be quite painful. I have since had some prosthetic nipples made, and they are great.”

Jane decided to opt for a reduction to her remaining breast, to achieve the symmetry she wanted. This was done at the same time as her reconstruction. She was told about the possible complications, and about the scarring. “However, it was a huge operation, and I didn’t realise how huge it was,” she says.

“Immediately after surgery I felt like a little old lady who couldn’t stand up, and I thought I was never going to recover. I didn’t want to leave hospital, because I felt safe there. Most of the discomfort was in my abdomen. Psychologically I felt my insides might fall out if I disturbed the operation site. I didn’t want to cough or laugh. I remember I was even scared to go to the loo.”

Jane says her mental recovery was much more rapid than the physical recovery. “I was bandaged like a straightjacket for about two weeks. Also I now have a false tummy button, and no-one had told me about that. I was back on the golf course, chipping and putting within four weeks, but I didn’t play golf properly until eight weeks after surgery. I wasn’t given any exercises to do, although I did exercises to make sure I kept the movement in my arm. I didn’t actually get much pain – it was mostly discomfort, although even that was not too bad.”

She says she doesn’t regret having the surgery: “If I look in a mirror I can see the scarring is fading, although it is still ghastly across my stomach. And now I have my new nipple I am happy that I had it done. But if someone said to me you have got to go through it again, I would say ‘oh God, no!’.”

Having reconstruction has not restricted Jane’s activities in any way, and she says she is happier with it now than she was when she first had it done: “Although my bump is much wider than my other breast. My surgeon is all for reducing it but I have had enough of surgery. I think I would want to talk to somebody in great depth before recommending it to them. It is a huge operation – much bigger than I appreciated before I had it done.”

### **DIEP flap**

It is possible to take a free flap of skin and fat from the abdomen without any muscle by tracing some small blood vessels that keep the skin and fat alive, through the muscle down to the larger artery and vein in the groin. This technique is known as the deep inferior epigastric perforator (DIEP) flap.

The advantage of this type of reconstruction is that no muscle has been removed. This means that recovery is much quicker than with a TRAM flap and the strength of the abdomen is not affected. However, like the free TRAM flap, the DIEP flap is a long and complex operation.

**Yvonne** chose reconstruction following a radical mastectomy which left a hollow in her chest: “I didn’t like the way I looked. I just wanted to have a cleavage again and be more balanced.” Although she was given plenty of information about the DIEP flap procedure – the one her surgeon recommended for her – she admits that she probably wasn’t realistic about the sort of breast shape that would result from reconstruction: “I think I expected a miracle” she says.

Yvonne decided against nipple reconstruction because she felt it unnecessary. She also opted not to have a reduction on her remaining breast: “I realised they would not be able to achieve perfect symmetry, but I just wanted something there when I looked down.”

She has had three procedures, beginning with the DIEP flap operation itself, which took nine hours. “But because the surgeon had a job connecting the blood vessels, he didn’t have time to shape the breast properly, so he needed to go back and tidy it up.” The second operation involved liposuction to help lower and reshape the new breast, and finally Yvonne has now had an expanding implant inserted. “The idea is to expand the tissue of the reconstructed breast so that it will droop in the same way as my other breast.” Yvonne accepts that this is the best way for her, although initially she hadn’t wanted an implant – which was one of the reasons for opting for the DIEP flap in the first place. “I also got a tummy tuck, and I now have the flattest stomach I have had since I was about 16!”

“Immediately after the initial surgery, I was extremely distressed because I didn’t realise how hard and high the new breast would be. When I came out of hospital I thought I would end up with a rock on my chest for the rest of my life. I now know it takes about four months to soften and settle down. But this wasn’t explained to me before the operation.”

After a week’s stay in hospital, during which she experienced quite a lot of pain, Yvonne went home. “There was tightness and numbness in my new breast, and where the skin of my stomach had been pulled down I couldn’t stand up straight. Also my arm was sore, but I did the exercises to prevent cording and I soon had full mobility there.” Once home, her recovery was rapid: “I was back at work after a week. The only thing I couldn’t do for a few weeks was the Hoovering – which was no great loss! My abdomen stretched eventually and I could stand up straight.” After the initial operation Yvonne used a gel insert in her bra to even out her breasts’ appearance, although she is hoping that this will be corrected with the latest surgery.

Yvonne is very pleased with her reconstruction. “I would definitely have it done again, and I would recommend it to anyone.”

When she had her mastectomy, **Steffanie** was adamant that she wanted to wake up with an alternative breast in place, “Even though it would not be my old breast, having it would help me cope better with the loss.” Her doctors were very helpful, answering all her questions, although she says: “I relied mainly on my own investigations – especially on the internet.” She opted for the DIEP flap because she felt it was more natural to use her own tissue than to have an implant, and she was keen on the idea of the tummy tuck.

Unfortunately, Steffanie’s reconstruction had to be removed: “Soon after my operation, it was noticed that the breast form was still cold, and I was rushed back into surgery. Apparently I had developed a small blood clot in the breast and this was removed. I was closely monitored for the next two to three weeks. Then the doctor advised me that in his opinion the reconstruction had failed and would have to be removed. I was devastated.

“Before I was due to go into hospital to have it removed, I noticed that the new breast seemed to be coming away from my body, and I was afraid that the scar might open. I was also feeling unwell. So my husband took me to casualty. I was admitted immediately and operated on the following day. According to the doctors, my body had rejected it.”

Steffanie was extremely upset that the operation had failed: “I felt disappointed and cheated. Although I am grateful for the tummy tuck, I still do not feel quite whole.” She feels that, having had such high hopes for her reconstruction, her options have now been narrowed. “I miss my breast during lovemaking. I miss not being able to wear the kind of clothes I enjoyed wearing before my breast was removed and the breast area scarred. Before my mastectomy I had the choice of whether to wear a bra top or not. Now the choice has been taken away.”

Despite her experiences, Steffanie is considering a Lat flap reconstruction in the near future, pending her surgeon’s approval. “After the failure of my last reconstruction I had decided that I would never go through it again,” she says. “However, since I am fortunate enough to be given the option of trying to reconstruct my body into something I am more comfortable with and that will bring me more pleasure, I have decided to go ahead with another major operation. The last time I was very afraid of the procedure, but having gone through it once I feel more comfortable and relaxed because I now know what to expect.”

### **Back flap or Lat flap**

This procedure uses the latissimus dorsi muscle – a large muscle that lies below the shoulder blade. The skin and muscle is cut away from the back but the blood vessels of the flap remain attached to the body at the end nearest the armpit.

The flap is then rotated and carefully threaded through a cut made below the armpit. In this way, it is brought round to the front of the body to lie over the chest wall and form the new breast. If you are against the use of an implant, it’s worth noting that it is frequently necessary to use an implant in this operation, in order to make the new breast the same size as the other one.

The operation takes up to five hours if conducted at the same time as your mastectomy, and will result in a hospital stay of up to a week. Recovery time is around four weeks, although you may feel tightness in your chest area for several months following the operation. Possible complications include capsular contracture, where the body forms scar tissue around the implant and the breast becomes hard, which will result in the need to remove the implant. Another consideration is that implants usually have a life span of 10 to 15 years, so you may require periodic surgery to replace the implant.

Following her mastectomy, **Pauline** thought she would not want reconstruction. However, once her radiotherapy treatment was completed, she saw the results of a close friend’s reconstruction and changed her mind. “I was really impressed,” she says. “I play a lot of golf and I enjoy swimming. I could feel my prosthesis slipping when I moved, and it would get very sweaty in the summer. I was always a person to go without a bra if I can and I couldn’t do that with just one boob.” She decided on the Lat flap in consultation with her surgeon. “I couldn’t have an expander because of my radiotherapy, which often leaves the skin less elastic, and

my surgeon wasn't keen on the TRAM flap because it may have restricted my movement during sport. He advised the Lat flap and said he could reduce my other breast and give me a new nipple as well.

"I am very glad I went for this procedure. Initially I thought I didn't want the other breast tampered with, but the surgeon told me he couldn't match them if I didn't have a reduction, and it has helped with symmetry. My new nipple was created from my existing nipple, which was quite large." The reconstruction entailed two separate procedures: the first for the reconstruction and the second for reduction and nipple reconstruction.

"Being able to see my friend Sarah's reconstruction in the flesh was very important. I had every confidence. I did know about the risk of complications; they warn you that it is a very long operation and you are going to be very sore for three weeks."

Immediately after surgery, Pauline felt fine. "I looked down and I could just see where the top of my new breast was raised above the bandages. That meant the whole world to me. I thought 'this is brilliant – I have gone through the worst now and I've got my boob back.' I was really on a high."

Although she felt tightness in her back, Pauline didn't experience any pain. "I must admit I felt really queasy when I saw my scars. I thought 'what have I done to myself?'. The bruising was bad too. But I was driving again two weeks after having my stitches out, and that's when the tightness in my back began to ease off. I was quite surprised at how high the new breast was, but then it began to settle and drop and it's fine now."

Pauline was playing golf again three weeks after returning home. "The only slight problem I have is reduced strength in my arm. I don't have the pulling power. For example, pulling myself out of a swimming pool is difficult. But it hasn't stopped me doing the majority of things."

The second operation, for the reduction of her remaining breast, took about an hour. "I felt great after that," she says. "Although, again, when I saw the scar I was nearly sick! It's just like someone has done a big running stitch around your nipple. But when it started to heal I was really pleased." She was home within three days, and did not feel any pain at all.

Now, on the first anniversary of her reconstruction, Pauline is delighted. "I feel A1. The scars have faded very well. At the hospital they have told me that mine is one of the best reconstructions they have ever done. I am really pleased with my body. I'm balanced out now. It was worth putting up with the procedures and the mental hassle. I'd definitely recommend it to others."

**Suzanne** felt swept along by events when she was diagnosed with breast cancer eight years ago. "My consultant more or less told me I was having reconstruction at the same time as my mastectomy," she says. "You are in shock – you don't realise all the pitfalls. They did show me pictures, but I felt embarrassed to look at them in front of my breast care nurse. But nobody really sat me down and explained the procedure or told me what to expect in terms of the final result."

Immediately after her operation, Suzanne found it very difficult to get comfortable in bed. "I couldn't lie on my side. My back was the most painful area. I still get a burning pain there, where the nerves have been cut." The back wound did not heal well, and Suzanne had to have it re-stitched before leaving hospital.

Two weeks after her surgery, she had to be re-admitted. Some skin had died where the new breast was joined to the chest wall and this had to be removed. Then a year later, when she returned to have her port removed, Suzanne had to have a nerve cut because her new breast was jumping every time she breathed. "They actually took a film of that because they hadn't come across it before. It was terrible. I couldn't go anywhere." At around this time, Suzanne became aware of lumps in her reconstructed breast. "I was taken off chemotherapy and put onto radiotherapy immediately, because the cancer had spread to my skin. They said they had never done radiotherapy on an implant before."

Recovery took a considerable time. "My movement was restricted for many months. I had a tightness across my chest that felt as though my bra was too tight. I was off work for six months and then when I did go back to work I found it was too much for me, so I had to leave. I was very down, and had to go on antidepressants."

Some years later, Suzanne became aware that her reconstructed breast was misshapen. "My husband really drew my attention to it one day when he said I looked deformed. The new breast had gone hard, but I was scared to acknowledge that there was something wrong." The implant had become encapsulated and it had to be removed. "It had been so uncomfortable for such a long time that I thought that was the norm. When it was removed I felt that I had grown about three inches. I could move again and stretch up."

Suzanne was adamant that this should be the last surgery on her reconstructed breast. "I wanted the least invasion – no more operations. So I opted to keep the back muscle in the breast mound and have the silicone implant removed." She now wears a partial breast form to achieve symmetry. "It's not ideal and I wish I had had the courage to have the back muscle removed as well, so I could have a stick-on breast form. But I wasn't brave enough."

She feels unable to recommend this procedure to others. "It is a very difficult situation, and I know it would be different for other women. But I would like to be honest and say 'this is what happened to me'."

### **It's in the bag**

Although many women prefer to have their own flesh used to construct a new breast, sometimes an implant is the only option for those with little body fat, where tissue flap reconstruction would not be viable. It is also often chosen by women who want a shorter operation and a faster recovery time.

This procedure can be done in one of two ways. In the first, an implant is simply placed beneath the muscles covering the chest. This is called submuscular reconstruction. It is very simple but is usually only suitable for women with fairly small breasts. There are various different types of implant, including silicone capsules filled with saline (salt water), with a mixture of silicone gel and saline, and with silicone gel alone. New types of implants are being developed all the time, and recent

developments include the use of soya bean oil and a substance called hydrogel (a mixture of water, sugar and salt).

In the second method, tissue expansion is used. This takes advantage of the elasticity of the skin, and involves two operations. In the first, an expandable bag, with a valve for filling, is inserted under the chest muscle. This is slowly filled, over several months, by injecting sterile saline solution during weekly or fortnightly out-patient visits. When the correct size is reached, an operation is done to remove the bag and insert a permanent silicone implant. Another form of tissue expansion uses a silicone implant with an expandable inner chamber. This is inserted under the muscle and gradually filled with salt solution over several months. There is then a further small operation to remove the filling valve from the implant.

Sometimes, the body reacts to the 'foreign' material of the implant by isolating it (forming a capsule or scar around the implant) and then trying to squeeze it into the smallest possible space. Known as capsular contracture, this means that a breast reconstructed with an implant can become hard, contracted and misshapen, and it usually results in the need to remove the implant.

**Sue** found that summertime, with its strappy tops and bikinis, was when "I wanted my own boob. I had a stick-on prosthesis from the word go, and it was fine. But I like my sport and I felt it would be so much easier to have a reconstruction."

Sue had met with women who had chosen the Lat flap operation, "But I didn't want anyone taking muscle out of my abdomen or back, so I opted for the tissue expander. The surgeon told me that this type of reconstruction would not produce the ideal cosmetic result because it would be firmer than my remaining breast," she says, "but I just wanted to wear strappy tops and bikinis again."

Having had the tissue expander inserted, Sue has just had her final inflation. While her reconstructed breast is now bigger than her other breast, she hopes to achieve a good match once it has settled down. She can then choose to keep this implant or have it replaced, and will also have nipple reconstruction at a later date.

Sue felt quite sore and groggy after her initial surgery but, she says, "I was thrilled even then. It was so nice to have something there. There was hardly any pain, although it felt very tight. Once the swelling had gone down, it was fine. I was driving again within a week, and the tightness had gone within a fortnight. My movement was hardly restricted at all. Four weeks after the operation I was mountain biking, caving and running. I now do everything I always did.

Although Sue's procedure isn't finished she is really pleased with the result. "During the recent hot weather I could wear my bikini and not worry about anything. I would definitely recommend it to others. If you fit the criteria, as I did, it's just right."

**Cherry** found it very difficult to cope psychologically with being 'lopsided'. "I am quite thin, and I had ribs sticking out where my breast had been. Because I am only a 32A I was suitable for the implant with expander. I had always wanted to have it done, but it wasn't until ten years after my mastectomy that I had the operation." Cherry had seen lots of photographs and read as much as she could about the operation. Like many other women who opt for this procedure, she felt she did not want the

extensive surgery involved in reconstruction using her own tissue, and her surgeon was reluctant to perform a Lat flap because she had suffered from lymphoedema in the past.

Cherry experienced quite a lot of pain from the initial procedure to insert the expander. "It was also painful when they injected into it." She was back at work after a month, but had considerable discomfort in the breast area, and was stiff for some time. "The scar was very raised and angry."

Although she now has full mobility and is no longer in discomfort, Cherry is disappointed with the result. "What nobody told me – and what I didn't seem to pick up from anything I read – was how different the reconstructed breast would be from my other breast, and from the silicone breast form I had been wearing. It is high, and hard. When I talked to my breast care nurse about it she implied that this is what you would expect from an implant. But I don't feel my expectations were managed. And since the surgery no-one has asked me if I am happy with the result."

Cherry is glad she had the operation, but has some reservations: "It has lived up to my expectations to a certain extent, but I am lopsided. I have to wear a push-up bra in order to achieve the same height and roundness with my remaining breast. If I take the extra padding out on the reconstructed side, the result is very good." Cherry feels that a better option would be further surgery to achieve the look she wanted, but when she discussed this with her surgeon he indicated that the outcome couldn't be improved. She would recommend this type of reconstruction to others but, she says, "I think people need to know how it is going to look and feel, because some might be put off. I also believe that the surgeon should tell you what he is prepared to do in terms of correction if you are not happy. I don't feel the after-care is really there."

### **Going in with your eyes open**

Many women feel overwhelmed by the number of decisions they have to make following a diagnosis of breast cancer, which is why it's probably better to delay reconstruction – although the downside is that you will have to undergo two serious operations rather than just one.

From the many conversations we've had with Amoena Life readers who have had reconstruction, several key themes emerge. One is the disparity of levels of care and the choice of procedures available, depending on where you live. If you feel strongly that a certain type of operation is best for you, but it is not offered by your hospital, insist on being referred somewhere else. Another very valid point was the need to manage your expectations – both short- and long-term. The best way to do this is to be as informed as you possibly can before going ahead. Insist on talking to women who have had the operation you are considering – if possible, women who have had the surgeon who will be performing your procedure.

Don't be frightened to ask lots of questions of your healthcare team. Read books, join support groups, search the internet until you are convinced you know enough to proceed. Ask your surgeon what he/she will be able to do for you if your reconstruction fails, or if for some reason you are unhappy with it. Be realistic about recovery times, levels of pain or discomfort, the extent of scarring, and the possible physical impact later in life. For example, will your reconstructed breast gain weight if you do? Will you need to have your implant replaced after ten or fifteen years? Will

you be able to carry out all the physical activities you enjoyed before reconstruction? Will the surgery affect your ability to perform your job? Also, what can you expect your reconstructed breast to look and feel like? How long is it likely to take to 'settle down'? Insist on follow-up appointments, and do go back if you have any queries or problems – no matter how much time has elapsed since your reconstruction.

We hope that this article has provided some useful background on reconstruction for anyone who is considering it. Women who are pleased with their reconstruction simply can't imagine any alternative, and are keen to share their experience with others. However, those who have had complications are often faced with a future which at best is tainted by disappointment and at worst leaves them feeling more negative about their bodies than they did prior to surgery, with a new shape that they dislike and in some cases permanent discomfort. Remember, knowledge is power. As with all surgery, reconstruction is never risk-free, so it's up to you to weigh up all the factors involved and be as certain as possible before taking the next step.

### **Contacts**

For further information on breast reconstruction, contact the organisations listed below:

Breast Cancer Care: Kiln House, 210 New Kings Road, London, SW6 4NZ Tel: 0808 800 6000 [www.breastcancercare.org.uk](http://www.breastcancercare.org.uk)

CancerBACUP, 3 Bath Place, Rivington Street, London, EC2A 3JR Tel: 0808 800 1234 [www.cancerbacup.org.uk](http://www.cancerbacup.org.uk)

British Association of Plastic Surgeons (BAPS): Royal College of Surgeons of England, 35-43 Lincoln's Inn Fields, London, WC2A 3PE. Tel: 020 7831 5161  
Website: [www.baps.co.uk](http://www.baps.co.uk)

Breast Implant Information Society (BIIS): Highway Farm, Horsley Road, Cobham, Surrey, KT11 3JZ. Tel: 07041 471225

Further reading:

A Woman's Decision: Breast Care, Treatment and Reconstruction – by Karen Berger and John Bostwick III MD  
Saint Martin's Press Inc, 1998  
ISBN 0312182295

Amoena Life is grateful to Breast Cancer Care, CancerBACUP and The Department of Health, for the medical information provided in this article.

## Life line

**Sarah Fowler is a qualified life coach, NLP practitioner and hypnotherapist. She was diagnosed with breast cancer in 2002 at the age of 35, and took an active role in her recovery using a range of NLP and hypnotherapy techniques. Here she answers your questions on a range of lifestyle and emotional issues that can arise following a diagnosis of breast cancer.**

If you would like to reply to Amanda's letter, or have a question you would like to ask our life coach, please write to us at: Life Line, Amoena (UK) Ltd, FREEPOST, Eastleigh, Hampshire, SO53 4BJ or e-mail: [agrwhw@amoena.com](mailto:agrwhw@amoena.com). We regret that Sarah is unable to reply to your enquiries individually and is unable to answer medical or treatment queries. If you are interested in life coaching Sarah offers a thirty minute telephone session absolutely free of any cost or obligation. For further information contact Sarah on 020 8341 1155.

### **Will I ever be cured?**

At the moment I'm thinking that I've got no future. I had a lumpectomy in August 2002 followed by a full mastectomy in September 2003. I had 12 lymph nodes infected and I've since had chemotherapy and radiotherapy and am now taking tamoxifen. I went for my check up with my surgeon who said I'm doing well and looked fantastic. But then I started to ask questions and she told me I've got a 65% chance of still being alive in 10 years time. I'm now in total shock as I wanted to feel this was totally gone. Can breast cancer ever be cured after all this treatment? I now feel that my life has come to an end and I'm waiting to die.

Is there anyone who is a long term survivor that can give me some encouragement for the future? I'm sorry that I am so weak, but all I wanted was to see a future for myself and my family. I've had a full bone scan and abdomen scan, plus a chest x-ray which are all clear. If anyone wants to write to me I'd be so grateful.

Thank you.

**Amanda C**

### **Dear Amanda,**

For many of us a diagnosis of breast cancer can make our own mortality feel real to us for the first time and it can seem that the future looks bleak. You use the words 'at the moment'; at present you are still dealing with the emotional fallout from your diagnosis and treatment but your feelings about what's happened *will* change. Create a bit of hope somewhere within you that you will get through this and allow that hope to get stronger and pull you through. There are also a number of ways that you can help yourself to move on. But before I outline them, don't give yourself a hard time if you have days where negativity takes over as you need to be your own best friend right now. It's all right to have a down day but just decide that tomorrow you're going to do a couple of things to help yourself feel better.

A diagnosis of breast cancer can feel like a bookmark in your life; before cancer when you were secure in your health, and the uncertain future that you now face. But the truth is that both states are just perceptions of your own health rather than reality; no-one can ever really be certain about their own health just as no-one knows what the future holds for them. Another woman of the same age as you who has never

had a day's worry about her health might die of a heart attack tomorrow, whilst there's a good chance that the cancer that you had will never recur.

If you feel down try to detach yourself from the feelings by imagining that you can step out of your body and leave the feelings behind. Become aware of negative thoughts as they arise and challenge them; don't allow yourself to make generalisations such as 'I'll always worry about the cancer coming back' but be specific, 'right now I'm feeling anxious about recurrence but that will pass.' Ask yourself if negative thoughts can be proved objectively and measurably – the chances are they can't.

Imagine that you are project manager of your own life and start to think of this diagnosis as an opportunity to change things that weren't working for you. Write a list of all the things that you have ever wanted to do, however trivial, and start carrying them out. There's nothing like action to change your state of mind. Plan for your future and visualise yourself looking happy and healthy in five, ten, thirty years' time. Do this several times each day, accompanying it with an affirmation such as 'I am in perfect health' and allow these images to become stronger and stronger.

When you are in the hospital system it's easy to get caught up with statistics and survival rates but they don't relate to you. Scientific advances are focusing more and more on the very individual nature of cancer, and you really can't compare the cancer that you have had to anyone else's. Surround yourself with positive role models; women who have been through breast cancer and beaten it. After all, there are plenty of them about. Be open to looking out for stories of hope and they will come to you.

Every time you take your tamoxifen do another affirmation (e.g. 'my body is healed and healthy') and imagine the drug servicing your body; ensuring that all of your cells are working properly and disposing of any potentially faulty ones.

You will find your own way forward. Your life has changed and so allow yourself to grieve for the way things were and the woman you used to be but then move on – there is a future waiting for you when you're ready to take that first step.

**[Click here to read our report Living in Fear: Overcoming the fear of recurrence](#)**

**Several readers identified strongly with GB, whose letter "*Breast cancer is forcing us apart*" was published in our last issue of Lifeline. Here are some of the replies we received.**

### **We're in this together**

My wife showed me "Lifeline" in issue 18 featuring the letter from GB, which I feel the need to comment on. Like GB, my wife and I have been in a long marriage of 41 years. Like her husband I was a bit of a "boobs man". My wife had her breast off in March '02 and like GB reconstruction was not an option due to my wife's heart condition.

She'd found the lump in January and asked my opinion, and we both felt that a visit to the doctor was necessary. I accompanied her to the doctor and subsequent visit to the consultant, who explained that an operation was necessary. She had a

lumpectomy in the February followed by a mastectomy in the March.

When the time came to take off the dressing she asked what I thought if she undressed in front of me. I of course was a little apprehensive, but she always undressed in front of me, so what's the difference? It was a nasty scar at first but the main thing is my wife is still with me. I now look on it as a reminder of the pain and suffering that she's been through and I'm proud that she's my wife. She continues to be a fighter, with my support, as we discovered the cancer had returned in her bones and liver in December 2002.

The point that I am trying to make is that women should not push their men away, but trust in them. Get them involved from the outset and remember "it's good to talk".

On a final note we have gained lots of new friends, many of whom are in the same predicament as ourselves, along with the hospital/hospice staff who are so helpful and kind.

Don't forget - be positive.

**Vern M**

### **We don't talk anymore**

My heart goes out to GB about the effect breast cancer has had on her relationship with her husband. I have experienced exactly the same reaction from my own husband of almost 30 years and I feel very hurt and confused.

I was diagnosed with breast cancer in March 2002 and had a mastectomy followed by chemotherapy. Everyone said how well I coped with the diagnosis and treatment except my husband, who decided that if he did not admit to himself that I had cancer then it would go away. He has seen my scar only once and he always makes sure that he is not in the room when I am changing. If I am feeling a bit down or weepy he goes into another room or goes out and I am left feeling guilty.

I have tried to talk to him about his feelings, but he is not prepared to discuss anything about cancer with me. His attitude was making me feel very bad about myself, so I asked my GP to refer me to a counsellor. Although I found it very helpful to speak to someone about what had happened to me, we kept coming back to the same thing. If my husband was not prepared to talk to me, there really was nothing I could do. I was encouraged to be positive about myself and the way that I had coped, and this is what I try to do, but it can be difficult sometimes.

I have tried to reason with my husband, I have been angry with him, I have cried but to no avail. In November he agreed to speak to a counsellor. He attended two counselling sessions and then told me he was too busy to attend.

The final straw came at the beginning of this year when I discovered that when he was alone in the house he would surf the internet for pornographic sites. When I asked him about it, he told me he did not know what the fuss was about. I asked him if he had considered the impact his actions had on me, but he said he had not thought about it. He has never seemed very interested in pornography or girlie magazines in the past so this has just added to my feelings of inadequacy.

I do not know what the future holds for my marriage, but at the moment I am just

concentrating on getting myself really well again. To be told you have breast cancer is devastating enough, but to find that the person you always thought you could rely on is adding to your worries is heartbreaking.

**Marion M**

**We've gone our separate ways**

I have just read your Lifeline page in Amoena Life. I had a radical mastectomy in November 2002, aged 64. I have always been an active and social person, but I developed the "hospital bug" which was debilitating and slowed my recovery. My husband's attitude changed, he never saw my scar and each time I undressed he would look at my back and cry.

I am now in the process of a divorce and he cites the fact that although he helped with the chores during my illness, I never appreciated him. He says he received no counselling and to that end he is right. I feel partly responsible but my common sense says I had no control over the cancer.

The support of friends has been invaluable, but the loss of femininity is hard to bear and even writing that sounds ungrateful to the wonderful hospital team. Since my husband left I have lost 3 stone in weight so obviously now have to concentrate on healthy eating.

Reading your magazine this morning has made me see there are many of us feeling a little helpless, so thanks.

**Mary L W**

## 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 [agrhwh@amoena.com](mailto:agrhwh@amoena.com)**

### **As good as new?**

I had a mastectomy in 1986 on my 46th birthday. Unfortunately reconstruction was never offered to me (I suspect it wasn't available at that time). Although I have come to terms with losing a breast, my late husband wouldn't look at me after the surgery. Not daunted I got on with my life and 4 years after his death I remarried a person who accepted my "loss" and said that as long as I was healthy he didn't notice. He had lost his wife from lymphoma cancer and she had also had surgery – a lumpectomy, so he knew all about breast cancer.

At my last visit to the prosthesis clinic at my local hospital I was given a Classic Contact prosthesis. This is just marvellous; I now feel more like my old self (pre-surgery) and my confidence is even better now. I am looking forward to wearing lower tops than before and perhaps occasionally going "bra-less", who knows!

I also had problems taking tamoxifen as I was prescribed tablets for a lot longer than 5 years, in fact I was only told in January 2003 that I could stop taking them (I started in 1986). This length of time created some problems, thinning hair, nasty discharges and weight gain, to name but a few. I have now started with Weight Watchers and in the 5 weeks since I began have lost 8lbs.

**Hazel B**

### **Be positive!**

After being diagnosed with grade III breast cancer in December 2003, I would like to share my ways of positive thinking with other sufferers of this disease.

At times in the first 2 months it was hard to cope. Friends kept telling me what a strong and brave person I was. I never thought of myself that way, but the more people tell you, the more you believe in yourself. It is so important to talk about your feelings, negative ones especially, don't be afraid of being scared. At first you seem to have more bad days than good, but being more open with everyone seems to open up doors and bring you all together emotionally. They appreciate your honesty and you theirs. This disease doesn't just affect you but everyone around you, so talk as much as you can, don't avoid the subject.

In Feb 2004 I joined a wonderful support group (The Lily Centre, Liverpool) and met a great bunch of ladies, all of whom were in different stages of recovery and treatment. It was a great boost to my confidence to see so many survivors with great attitudes. It gave me bags of hope for the future.

Now I am at the stage of acceptance, small trivial things that would bother me to the point of stress, are now firmly in the past. I now focus on getting better and welcome my chemo every 2 weeks instead of dreading it. These things happen for a reason, I have realised. To make us stronger, better women. If like me you have a wonderful

husband and family be thankful for the joy they bring. It makes you appreciate their beauty – enjoy life and be positive.

**Debbie W**

### **Thanks for the support**

I would like to thank Amoena Life and its readers for helping me through the last 5 months of my life.

I'm 32 and was diagnosed with breast cancer in January 2004. I have had a mastectomy followed by 6 sessions of chemotherapy, and I'm now waiting to start 5 weeks of radiotherapy.

January 5th is a day I will never forget, hearing the words "it's cancer" brought my world crashing down. My surgeon and breast care nurse were really great, they explained everything to me, but I don't know how much of it I took in because it all kept coming back to that "c" word and thoughts of how I was going to tell my family.

We have always been an open family so I didn't want to hide anything from my children. I wanted them to know everything so that they weren't frightened. I called my husband Lee at work, he was devastated but just hearing the words "we will get through it together" was all I needed.

When I talked to my daughter Lauren it was the first time the word "dying" was mentioned. I couldn't give her any promises that I didn't know if I could keep. I don't know how my life will turn out but the one thing I could promise her was that I would fight it every step of the way.

I went for my surgery at the end of January. When I woke up after the operation the first thing I did was look at my chest. My boob was gone but I was amazed at how well it looked. My surgeon had done a wonderful job. Then came the chemotherapy; it was tough. I had the cold cap at my first session, which was uncomfortable, but if there was a chance I could hold on to my hair then it was worth a try. Sadly my hair started falling out before my second session so Lee got out the hair-clippers and shaved it off. I now have a skinhead just like him! I wear bandannas when I go out and my son's friends say that I'm really cool!

It's been 5 months since I was diagnosed and I live one day at a time; I'm grateful for every morning I wake. I'm not saying it's been easy, I've had many days when I've said "why me?" but my life still goes on.

I've decided I won't be having reconstruction done - I've read the stories, good and bad. I'm happy and I've come to terms with the way my body looks - I still look great with my prosthesis in. My husband loves me just as much with the one boob, so why change it?

Reading your stories helps me to be strong. I've come through a lot and will continue to live my life to the full. When I'm not sure about anything, and I want to learn more, I go to the Amoena website and find out all I need to know.

I would like to thank my family and friends and the teams of doctors and nurses at the hospital for all their support. They keep me focused on the important things in life, I couldn't have got this far without them. And to my husband, my rock, my world, my

best friend, thank you for everything, I love you.

Keep up the good work Amoena because people like me need people like you, to show us that life still goes on.

**Natasha P**

### **Everyday is a bonus**

I am one of the “Survivors” having had a breast lump removed in 1972 followed by radiotherapy when my skin was very badly burned. In 1975 the cancer returned in the same place and I had a mastectomy. No prosthesis was given to me at the hospital so I made my own from a couple of old shoulder pads and sewed a pocket into my bra so that I could walk out of hospital looking normal. Later that year I had my first flight and also went ski-ing for the first time. I regard my life since 1975 as a bonus!

**Audrey R**

### **Comment**

**Readers share their points of view on articles featured in the last issue of Amoena Life.**

#### **How will I know?**

I was very surprised, having read your feature in Issue 18 of Amoena Life “Reconstruction – Do I, Don’t I?” that the subject of recurrence of lumps under the reconstruction was not discussed.

I was diagnosed 7 years ago and was automatically given an appointment with the plastic surgeon at the time I was booked to have my mastectomy. I had battled for nine months to get anyone to find the lump I could feel myself, and having a mastectomy gave me peace of mind as I could be sure that all was clear in and around the rest of the breast.

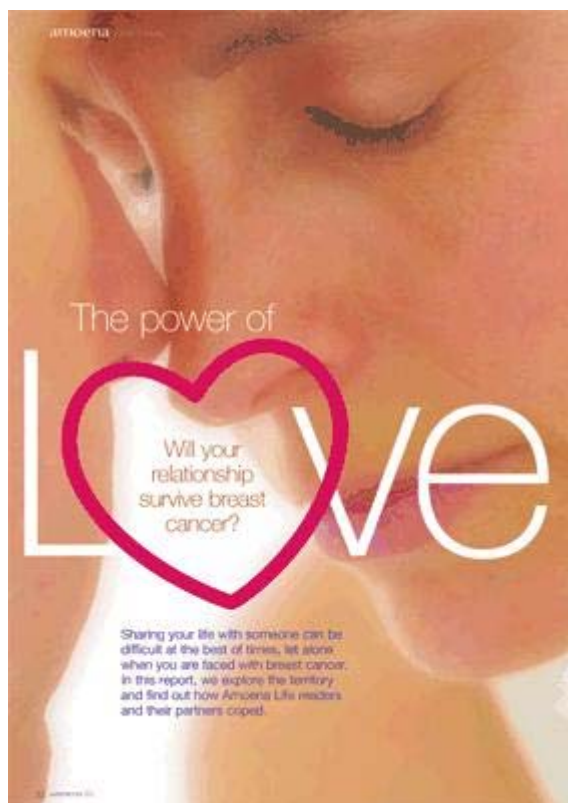
I was repeatedly asked if I wanted reconstruction, but no one could explain how I would know if a lump appeared underneath it. As I was told I would not be able to have a mammogram on that side, the risk for me was too great, so I decided not to go ahead.

I now wear Amoena underwear and swimsuits and have the Contact breast form. On a recent holiday in Spain, whilst sunbathing in an Amoena bikini, I was talking to a lady whose sister had lost a breast and was not coping well. Having told her that I had breast cancer in 1997 she said: “yes but you didn’t lose a breast”. If I had any doubts about not having reconstruction then this simple statement dispelled them for me. I realised that even in a small bikini I looked normal to other people and I could forget my experience and get on with living.

**Barbara L**

#### **We reply:**

**According to Cancer BACUP: “After mastectomy, mammograms are not usually necessary, except to check the health of the opposite breast. Your doctor will advise you on whether mammography is still suitable for your reconstructed breast. If you are ever worried that you have a recurrence of breast cancer in the reconstructed breast, an MRI scan can show any abnormalities. Silicone or saline implants hide part of the breast during mammography, but experts believe that any cancer around an implant is still simple to detect using ultrasound. Your doctor can advise you on how any possible recurrence of cancer will be found.”**



## The Power of Love

Will your relationship survive breast cancer?

**Sharing your life with someone can be difficult at the best of times, let alone when you are faced with breast cancer. In this report, we explore the territory and find out how Amoena Life readers and their partners coped.**

Anyone who has read John Gray's book will often find themselves agreeing that women *are* from Venus and men from Mars, we often seem to be coming from such different places in our approach to relationships. One thing we all agree on is that we should be there for each other during the good times and the bad. But men don't always cope that well with emotional strain: they're designed to put a brave face on things and just get on with it,

whereas what we need in times of crisis is extra consideration – not to mention a lot of practical support.

Sometimes just trying to preserve a sense of normality during treatment can put extreme pressure on both partners. It's difficult to achieve a balance, because you're both likely to bottle up your feelings, and lack of communication can compound the problems.

**So how do you keep things together? What can you learn from those who succeeded – and from those who failed?**

### What women want

Psychotherapist Ronnie Kaye has written a book based on her own experience of breast cancer and her extensive work with many other women who have had the disease. In "*Spinning Straw Into Gold: Your Emotional Recovery from Breast Cancer*", Ronnie deals with the many problems that couples face as a result of breast cancer. She is adamant that a strong, successful partnership will not be threatened by the disease. "Good relationships *never* fail because of breast cancer. In fact, they often grow and become stronger as a couple faces these challenges together. However, any crisis can push a bad relationship over the edge."

Ronnie advises women to be very clear about what they want from their partners at this time. "Even if you are a strong and independent woman, you may find that what you need from your partner now is very different than it might be if you were not in crisis."

Although every relationship is unique, and people's needs and reactions will vary, Ronnie says there are five key things that most women want from their partner at this time:

**Practical Help:** Surgery, radiation and chemotherapy can all make demands on your energy levels. In addition, you may have some temporary physical limitations after surgery. Normal household and family responsibilities may sometimes be too much for you. At times, you may need your partner to take over some of the chores like cooking, cleaning and shopping. If you have children at home, you will need your partner to maintain their schedules with as little disruption as possible.

**Emotional Support:** While emotional support means different things to different women, most want to be able to express their feelings and have their partner respond with understanding and acceptance.

**Partnership in Treatment:** Because it is so difficult to process all the information coming your way, having a partner with you while you and your doctor are discussing treatment options can be enormously helpful. This is a time when two heads really are better than one. You may also need to have someone accompany you to treatments, and it can be very comforting to have your partner there for you.

**Reassurance:** Even if your relationship is very solid, you may still want some reassurance that your partner won't leave you because of breast cancer, that you will still be desirable despite the changes in your body, and that you will not be considered a burden as you go through the demands of treatment.

**Comforting Touch:** Being hugged and held may be one of the nicest and most comforting things your partner can do for you right now. Many women find that they must put their lovemaking on hold temporarily because of the side effects of treatment. A partner who is ready and willing to cuddle is a real gift.

Knowing what you need and getting it, however, may be two different things. According to Ronnie, even in the best and most supportive relationships, there can be times when a woman feels hurt or disappointed by her partner's behaviour. There are a number of ways in which you can help yourself, however:

**Communicate:** Your partner is not a mind-reader. You have a much better chance of getting the emotional and practical help you need if you keep the lines of communication open. For example, if you are willing to talk about your fear of rejection, you may be surprised to find that your partner cares much more about your survival than about the changes in your appearance.

**Be specific:** Don't assume that your partner will know exactly how to meet your needs without some specific direction. You are both in new territory at the moment, and a little coaching goes a long way. For example, when you are expressing your feelings, let your partner know whether you want to be hugged, just listened to, or involved in a real dialogue.

**Give constructive feedback:** If your partner responds in a way that feels uncomfortable or unhelpful to you, don't criticise, pull away, or shut down. Instead, give him an example of what would work better for you.

**Let go:** Once you have asked your partner for practical help, resist the temptation to supervise or nag. It may be that your partner has a different way than yours to

accomplish something, but the result may be just as good.

**Use your network:** This is a time to use other family members and friends to help share in some of the responsibilities. Even the most wonderful partner can feel overloaded. Choose which things you want most from your partner, and distribute the rest of your needs among the other people who care about you.

**Give your partner time out:** If you want to get what you need from your partner, you must remember that partners are people, too, with their own needs and concerns. Ask regularly how your partner is doing. Find out if there is something you can say or do that will make a difference. Consider having some talking time where neither of you mentions cancer. Suggest that your partner work out at the gym, go for a run, take a walk, or see a film with a friend. A little time out will give him an opportunity to replenish and come back to you with renewed energy and goodwill. It will also make a difference to you. At a time when your self-confidence may be rather low, it can be very gratifying to know that you have something of value to offer your partner.

### **Let's talk about sex**

One of the most important priorities after breast cancer is to start to reclaim the parts of your life that give you pleasure or meaning. Sex and intimacy is one of those crucial areas. Yet it can be an emotional minefield. While for some couples physicality comes a poor second to their spiritual bond, for others it is at the very core of their relationship.

Problems with intimacy usually fall into one of two categories – either there are physical barriers to resuming your love life, or emotional ones.

### **You've lost that lovin' feeling**

Many of the side effects of treatment play havoc with a woman's hormones, greatly reducing any interest in sex and drying out vaginal tissues so that sex can become very uncomfortable. Some chemotherapy drugs can also cause profound fatigue, and when a woman is exhausted it's very difficult to generate any sexual feelings.

If intercourse hurts, it may be helpful to apply water-based lubricants such as KY jelly or Astroglide. Some women find that spermicidal gel or even natural yoghurt works for them. And several Amoena Life readers recommend Sylk, a totally natural vaginal lubricant derived from an extract of the kiwi fruit (available from [www.sylk.co.uk](http://www.sylk.co.uk)).

Oestrogen pessaries, creams such as Ortho-Gynest, and the vaginal ring, Estring, act locally on the vaginal tissues and relieve dryness effectively. The exact amount of oestrogen absorbed into the rest of your body is not fully known, but it is thought to be low and therefore safe in the short term – for example, three months at a time. The vaginal tablet, Vagifem, is not thought to be absorbed into the blood stream. However, it's a good idea to discuss the use of these locally acting oestrogens with your cancer specialist.

Meanwhile the fatigue caused by some chemotherapy drugs, although debilitating and often depressing while you are experiencing it, is only temporary. Your energy levels, and your love of life, will return.

If intercourse is off the agenda, though, this would be a good time to explore other ways of being intimate. Try some old-fashioned kissing on the sofa, give each other

back rubs, or take a shower or bath together. You may find that after a while your sex life is even better than it was before!

And remember, when physical intimacy is temporarily suspended, it's important that your partner realises he shouldn't take it personally. He is not being rejected, and soon things will be back to normal again. Talk to him honestly about your feelings and take advantage of a different kind of closeness – hugging, holding and giving comfort to each other.

Although confronting these issues can be difficult, it is vital to keep communicating, be honest, and respect each other's needs and beliefs.

### **Always a woman**

If surgery resulted in significant changes to your appearance, you may be afraid that you will turn your partner off. You might feel awkward, unsure about your own femininity and desirability. The more self-conscious you feel, the more difficult it can be to relax and really participate fully in love-making.

Ronnie Kaye has this advice:

**Give your partner some credit.** It is easy to assume that your partner will feel as negative about your body as you do yourself. It is also easy to assume that he will be so influenced by society's standards about beauty and sexuality that accepting you will prove almost impossible. It is sad to say that women can be their own worst enemies here. In a good relationship, a partner will care much more about your survival and being close to you than about the status of your chest.

**You are not your breasts.** It is vital to stop seeing yourself as simply defined by the way you look. You are not your body. You are a heart and soul. You are your ideas and your emotions, your accomplishments and your dreams. Whatever changes may have resulted from breast cancer treatment, you are much more than a body and you are whole. The fact that your body looks different than it used to—different than the bodies of women who have not had breast cancer—doesn't mean that you won't be loved or cherished or touched. *Different than* does not mean *less than!*

**Set the pace.** If sexual intimacy is your goal, but you feel too uncomfortable with your body to imagine yourself participating just yet, start by taking small, manageable steps in that direction. You and your partner can begin with some basic hugging and cuddling, some gentle touching or caressing, some words of affection and reassurance. If the idea of nudity seems too threatening at first, you can always choose a piece of lingerie or sleepwear that will cover just enough to make you feel more secure.

**Do your homework.** If you have negative feelings about your body, there are many things you can do to regain a positive body image. For overall body health, exercise regularly and eat well. Consider pampering yourself a bit with massage, baths, a facial, or pedicure. Most importantly, start reshaping your attitude by finding role models. There are many women out there who have already come through their breast cancer experience, completed their healing, and feel confident, sexual and attractive once more. Breast Cancer Care (tel: 0808 800 6000) can put you in touch with women who are willing to share their experiences with you. Find out where they started and how they got to where you would like to be. If they can do it, so can you!

You can also read more about body image and find out how our readers have learnt to restore their self confidence again following breast surgery, in issues 16, 17 and 18 of Amoena Life.

### **Stand by your man**

It's not always women who are reluctant to resume intimacy after surgery; men can sometimes feel very confused about their own feelings and responses when their partner has undergone a procedure that can scar her both mentally and physically.

A major concern for some men is that they are afraid or reluctant to look at the scar – and this can naturally hamper your sex life. Ronnie Kaye's practical and down-to-earth approach is very useful here.

“Usually, people move past their anxiety about seeing the scar for the first time very quickly. However, some men get stuck in their fear and don't know how to get out of it. And the situation needs to be resolved before it affects your entire relationship.

“The first order of business is for you to tell your partner that you love him and that you miss the intimacy you used to have together. Next, explain how his unwillingness to look at your scar is hurting your feelings and making it harder for you to come to terms with your new body image. Let him know that other men have had these feelings and have moved past them, so you know that he can do it too. Then suggest that the two of you work this out together. If your relationship is basically sound, the chances are that he will agree.

“The next step involves detective work. It's hard to fix a problem like this if you don't understand the cause. Here are some of the possibilities:

- He is afraid of what he will see
- He is afraid that he will have a bad reaction
- He is afraid of hurting your feelings by saying or doing something wrong
- He is afraid he will be turned off sexually
- He is afraid to confront some serious underlying issues.

“All of these fears can be resolved! Here's what he needs to do.”

**Confront his fears.** To begin with, there is no fear as powerful as the fear of the unknown. Some people who have never seen this type of surgery conjure up some terrible pictures in their minds. The truth is that a mastectomy is normally a very tidy surgery. Basically, it looks like a pre-adolescent chest without a nipple. It's not ugly and it's not horrible. It's just flat. However, words alone are not enough to convince someone to let go of fear. Before he sees your scar, it would be very helpful if your partner could see a picture of a woman who has had a mastectomy.

**Take a look.** As far as being turned off sexually, good lovemaking takes concentration and focus. It's hard to do two things at once – make love to your partner and adjust to her missing breast. Arrange a 'show and tell' session outside of the bedroom with the understanding that there will be no lovemaking at that time. After you have shown him your scar, allow some time so that both of you can share your thoughts and feelings. You can also show him how you would like to be touched

so that he won't be afraid of hurting you. Once he becomes accustomed to the change in your appearance, lovemaking should not be a problem.

**Face the issues.** Your partner may have been trying to avoid issues such as mortality, vulnerability and loss. Seeing the scar can sometimes force a confrontation with these issues because it makes the breast cancer experience so much more real. The issues are certainly challenging, and the desire to escape is understandable. However, when people are willing to face the issues and explore them, they often discover amazing opportunities for personal growth.

**Seek support.** It might be a good idea for your partner to speak with other men who have gone through the same experience. Your hospital or breast care nurse can put you in touch with support groups for partners and please remember that if you are unable to resolve these problems for yourselves, a few sessions with an experienced counsellor can make all the difference in the world.”

### All things considered

There is no question that after any life-threatening challenge, you come to realise what is important to you and how precious you and the people in your life are. If you find yourself in a relationship that is unfulfilling after breast cancer, you may suddenly feel an urgency to make it great. It is worth stopping, looking around, listening and thinking about what you share and what you hoped you could have in a relationship together. Be patient, but also be open-minded about making changes if you think they are necessary. Problems in a relationship are often not the result of the breast cancer itself; they are simply highlighted as a result of the experience.

From our discussions with Amoena Life readers, we know how tough it is to nurture your relationship while coping with breast cancer, and we know it is different for each couple. But the core issues remain the same – communication, honesty, intimacy (in whatever way is best for you), and not being too proud to say what your needs are.

### Readers' Stories

#### I Couldn't Deal With Her Scar

**Gary was always a loving and attentive husband to his wife, Beverley. And when she was diagnosed with breast cancer he was determined to give her all the love and support she needed. But he found that he was unable to confront Beverley's mastectomy scar, and was very nervous of hurting her during hugs or lovemaking. The result, he says, was that they drifted apart. Beverley felt starved of affection and resented the fact that Gary was unable to overcome his squeamishness and look at her scar. Regrettably, the couple decided to part and are now going through a divorce.**

“During Beverley's treatment, I accompanied her to as many hospital appointments as I could, and I told her I loved her every single day. But I couldn't bring myself to look at the operation site straight away,” explains Gary. “What I wanted to do was take her away for a weekend, once she was feeling a little bit better, and have some time together – just the two of us – when I would have looked at the scar and we could have got our physical relationship back on track. But after the first operation she had to go in for further surgery to remove all the cancerous cells. She was very ill for quite some time, and we never did get away. We had to get on with our family life

– our youngest son was only nine – and Beverley said she wanted things to remain as normal as possible.

“With hindsight I am well aware that there was a breakdown in communication between us. I told her I would do anything for her, and I still love her to bits, but I couldn’t look at the scar. She felt that I didn’t care enough, and began to reject my offers to accompany her to chemotherapy, preferring to take her sister with her. When we discussed it later, she said I should have insisted on coming.

“I think she will admit that we have never loved anyone else as much as we loved each other. But our physical relationship, which had been very good for 20 years, dwindled away after her cancer. I felt I couldn’t cuddle her because I didn’t want to hurt her, but I didn’t say anything because I didn’t want to put pressure on her. The same went for making love, and we actually only made love twice in the two years following her operations. I didn’t want her to think that was all that mattered to me, but she thought I didn’t find her attractive any more.

“I think men deal with trauma differently. Beverley found it easy to talk to people about her experience of cancer, but I didn’t. I bottled up my emotions and threw myself into my hobbies. Yet it’s so simple to talk. I realise that now.

“I really hope that other people in a similar situation might be able to learn from what happened between my wife and myself. I have lost my wife not to cancer but in love and understanding, because I didn’t take time out from everyday life. You’ve got to make time to concentrate on each other and communicate. Don’t put it off, and don’t make assumptions. You can’t think ‘she is thinking this so that’s all right’ – you need to explain your feelings, expectations and needs to each other.”

### **I Needed Him To Be There For Me**

“When I was initially diagnosed, Gary was there for me. But during my treatment, without my sister I don’t think I could have got through it. He thinks he was there for me, but he wasn’t.

“The major thing for me is that he has never seen my operation site. I know he is squeamish, so I didn’t expect him to look at it straight away. But subsequently my family saw it and even our children, and no-one said it was that awful. I can remember when we went to the hospital to sort out my chemotherapy. We were in a small room with the consultant and up to that point Gary had not been put in a position where he had to look at the scar. In this room there was no private cubicle and the doctor wanted to see the scar. When I got undressed, Gary turned the other way. That made me feel terrible.

“We never talked properly about it, and a lot of resentment built up. I slept on the sofa while I was having my chemotherapy, so as not to disturb Gary if I felt ill. But he should have insisted that I slept in the bed. By that time, however, I didn’t want to be there. When we eventually talked about him not having seen my scar, he told me about wanting to take me away somewhere so it could be special, but by that time it was too late. I didn’t want to go. During my treatment I thought he was being distant because of the way I looked. You need to know you are still attractive and he was keeping away from me.

“As for emotional support, Gary never actually sat me down and asked me how I felt. When we were splitting up he said he wanted to go for a long walk to explain to me how he was feeling. Afterwards I said I could understand everything he was saying, but he still hadn’t said one thing to me that had dealt with how I was feeling.

“I told him, ‘I have to live with this every day of my life: I worry about whether I’m going to see my grandchildren, I don’t know if it is going to come back’. He said ‘Don’t say that because it really upsets me.’ But I said ‘That’s how it is’.

“We came to the point where we didn’t talk, we lived in the same house but we didn’t sleep together. I didn’t want to be unhappy any more. I felt alone. I kept a diary during my treatment and when it started I wrote how supportive he was and how much I loved him. But as the months passed by I was writing that I was fed up and didn’t want to be there any more.

“I agree with what Gary says that the two main problems were his inability to look at my scar, and our failure to communicate about our feelings and needs. I don’t think I could have done anything differently, though, because I had the children to think about and I needed to stay positive. I was giving everything I had to give, and I needed somebody to be there for me at the end of the day.”

### **I Can’t Imagine Being Closer To Anyone Else**

Diane Eyre had never had a day’s illness in her life before she found a lump in her breast. A single mother, with two young children, Diane had been in a relationship with Phil for just six months before her diagnosis. “I told him I thought we should end it. I didn’t want him to stay with me because he felt sorry for me,” she says. “But he was very upset and simply wouldn’t let me end it. He could see the light at the end of the tunnel, whereas at that point I couldn’t. He said ‘I will be here for whatever you need me for’.

“I never rely on anyone but myself, and it was hard to share anything – particularly this. But Phil did his best to keep our lives going as normal. During my treatment he gave me lots of emotional and practical support when I needed it. I occasionally found I didn’t tell him things that I should have told him, like when I was feeling dreadful after chemotherapy. I was trying to protect him. Sometimes I think I tried to be too normal.

“Losing my hair, especially so early in our relationship, was awful. I remember saying to Phil ‘You can’t possibly want to sleep with me’. He suggested we try just one night, and that was OK. It led to another and another. It doesn’t bother him. I wore a towelling turban at night and he said he wouldn’t care if I wore it every night for the rest of our lives.”

Diane says that her operation did not affect their sex life: “Physically between us everything has gone on as normal. In some ways I became more adventurous in bed rather than more inhibited. Perhaps I had something to prove. Phil found that very flattering. He was always consistent in telling me how desirable and lovely I was, and tender when it was needed.

“I did feel vulnerable, though. I was trying to tough it out and he had to break through that. I insisted that he still had a social life because I didn’t want to go out during my

treatment. I didn't want cancer ruling his life as well as mine. But when he came home from work and I'd been alone all day, it was lovely to have somebody to talk to."

Diane feels that breast cancer has made her relationship with Phil stronger. "Even if it doesn't work out in the long term (although of course I hope it does!) we got through it together, and I can't imagine being that close to anyone again. It has bound us together – almost in a telepathic sense. It has given us an extra level of togetherness.

"I am a very confident and outgoing person normally, and that is the Diane he met. But I changed. I became an introvert; I couldn't be lively or jolly. Not many people have seen me like that. All along, Phil used to say to me, 'Diane, you will get through this. Think of this time next year'. I used to say 'This time next year I will be dead' – I couldn't see beyond that. But he continued to encourage me. Just little things like planting flowers in the garden that summer. I couldn't see the point, but we still did it and we looked after them together. Then we went away for a weekend, and I think that was a turning point for me. It was so romantic, just the two of us, and it made me want to plan another weekend away; something to look forward to."

Diane believes that their ability to share things, coupled with Phil's positive outlook and loving honesty, were what pulled them through. "You can't share things with every man, though. Some find that their way of coping is to be very active, and often they can't face talking about their emotions. I do realise I'm lucky."

### **I Love My Wife Beyond Body And Soul**

For Dave Abbott, there is no doubt that breast cancer has strengthened the bond between him and his wife. "I loved Sharon deeply, but it wasn't until I thought I was going to lose her that I realised how important she was to me. During her treatment, I realised that Sharon was my soul mate. I know it sounds like a cliché, but it is perhaps not until something like this happens that you really understand what that means.

"I love my wife beyond body and soul. She is my best friend, my lover and my life. Throughout this period she has been my pillar of strength, which seems weird as she was the one going through the agony of diagnosis, surgery and treatment. I think I shed more tears than her during this time. I would lie awake at night and watch her sleep, and during the daylight hours my mind wandered constantly.

"Sharon was diagnosed five years ago, aged just 29. We took the diagnosis quite badly – we simply couldn't believe it related to us. During her treatment I tried to be with her all the time. Like all families, we had other responsibilities, and we were both in employment. At the time, we were not married, and one of our priorities was for me to obtain guardianship of Sharon's son so that, in the event of the worst happening, he would not have to go back to his natural father. Eventually, we achieved this, but it was a struggle.

"One thing I wanted to do to make the future seem bright was to plan our wedding for six months' time. It gave us both something to look forward to, and it was my way of demonstrating to Sharon that I wasn't going anywhere – although she did give me the option to leave when she was diagnosed. In the event Sharon walked down the

aisle with her wig on and a false boob, and believe me, she looked as beautiful as ever.

“Our physical relationship has always been great, although after her operation Sharon did become very conscious about being seen naked. I fought hard to get her to believe that the mastectomy made no difference to me at all – I remember her saying ‘It does to me,’ so in the end it was about how she felt, and I respected that.

“We communicated more over that period of time than ever before. I did my best to think about how vulnerable she must be feeling. I am very organised and I think ahead and plan what to say before I say it. I was trying to compliment her without sounding cheesy. But everything I said was true.

“I think our sex life could have gone one way or the other. I think I would have put up with not having sex again, but it got to the stage where we were ready to make love again. The scarring for about the first year was very red and angry, and I was worried about hurting her. So it was mainly a matter of being sensitive and keeping communications open.

“My main regret is that I wasn’t able to be with Sharon 110% of the time. I had a job to do and our son to look after. But really we are closer than ever before, because we both realise what we could have lost. One of the worst things for me was not being in control. Suddenly, it was down to other people and down to the cancer itself, and there was no longer anything I could do to change a thing.

“I hated the fact that she had been hurt – her scar was quite deep, right down to the breast bone – and I wanted to protect her from the pain and psychological torment. I remember when her hair was falling out because of the chemotherapy, I would wake up and find a clump of hair next to me, and I would try to hide it under the pillow so that Sharon wouldn’t see it when she woke up and be upset.

“Coming to terms with Sharon’s surgery wasn’t easy for me. I work in the army, but I hate the sight of blood and I’m scared stiff of the dentist. But I made sure I didn’t allow this squeamishness to affect the way I responded to her scar or her treatment. And now I can honestly say that I don’t even notice that her breast is missing. I kiss, massage, rub and enjoy every part of her body, and worship the ground she walks on.”

## Balancing Act

### Partial breast forms for perfect symmetry

There was a time when a diagnosis of breast cancer meant a woman was faced with no other alternative than mastectomy, resulting in the loss of one or both of her breasts. However, earlier detection and advances in surgical procedures mean that more women can now choose breast-conserving surgery following a diagnosis of cancer. And, of those who do have to have mastectomy, many are now opting for reconstruction.

It's easy to see why women find these options appealing. Perhaps the most compelling reason is that they get to keep their cleavage, which is a great advantage if you love wearing low-cup tops. Yet it's important to be realistic in your expectations. Because, while women expect to look the same following these procedures as they did before surgery, this is not always the case. A lumpectomy can result in the removal of anything from 1 to 50 per cent of your breast, while breast symmetry following reconstruction can be affected by weight gain and sometimes women can also feel a little 'uneven' as the new breast can be firmer and rounder than their natural breast.

Women who find that their breasts are quite dissimilar in size or shape also experience problems in finding a bra that fits well. This can mean that they are reluctant to wear the tight tops they used to love, because they fear that the difference will be too obvious. But there is a solution. Partial breast forms can help you achieve the outline you really want.

#### **Designed with you in mind**

Similar to the breast enhancers that are fashionable at the moment, Amoena's partial breast forms can be worn by any woman, discreetly, in any bra. But unlike the breast enhancers you can buy in your local lingerie store, they are designed to fill in any areas that are lost through surgery, moulding to your form wherever needed, and the edges taper to give a smooth transition to the body.

This proved to be just the solution that Amoena Life reader, Ann Clarke, was looking for: "My surgeon suggested I could have a lumpectomy and I thought this would be better for me because I wanted to keep my breast. However, I didn't realise they would take quite so much away. I felt very self-conscious because I looked so uneven, particularly in T-shirts and so I started wearing baggy shirts that weren't me at all. Now I've got a partial breast form I'm back to wearing the types of tops I really like – I feel just like my old self again."

Meanwhile, Sally Travis found that Amoena's partial breast forms helped to even out her reconstruction following weight gain: "When I had my surgery I was a dress size 12, but after two years of tamoxifen I have gained quite a lot of weight. Unfortunately, my reconstructed breast has not increased in size, so I am now quite uneven. I hope I'll lose the additional weight once I stop taking the tamoxifen, but in the meantime, using a partial breast form makes me feel more confident."

#### **Help for uneven breast development**

Cathleen Bergmann has not had breast surgery, but she found during puberty that her breasts grew at a different rate – not as the result of a disease but caused by a genetic defect. Eventually one side was more than twice the size of the other. Even in loose tops Cathleen, a qualified nurse, was unable to conceal this. She remembers: "For years I felt unattractive and suffered from an inferiority complex."

She did not dare to ask anyone for advice about her problem and only found out about the possibility of a partial breast form through colleagues at the hospital where

she worked. She was pleasantly surprised by the products available to help with her problem. “When I saw the Amoena lingerie, I was thrilled”, remembers the 25-year-old. “I had always imagined this type of underwear to be old-fashioned and unattractive.” At home she showed off her new partial breast form and lingerie to her mother. Finally she could wear tight-fitting tops and T-shirts, like any other young woman. “It was a great feeling to look just like everyone else.”

**Product Information:**

Amoena’s partial breast forms are made from an extra-soft silicone material developed exclusively by Amoena. Despite their exceptional softness, these shells have a clearly defined shape and hug the body firmly and securely. Partial breast forms are worn inside your bra and are curved to match your body shape, filling the cup perfectly.

**Benefits:**

- Naturally soft silicone, clings gently to the operated breast
- Finely tapered edges give a natural join to the body
- Balances any irregularities in shape and size
- Variety of sizes, shapes and thicknesses available to give every woman a perfect fit
- Suitable for use after lumpectomy, breast reconstruction and for uneven breast development

**Product Description Order Code Sizes Price**

Balance Extra Soft Tear drop shape 259 0-5 £80

Balance Delta Triangular shape 271 S-XXL £80

Available in tawny and ivory 271TW

Balance Upper Part Partial to replace upper 277 S-L £75  
part of breast A/B

Balance Lower Part Partial to replace lower 275 S-L £75  
part of breast A/B