

Breast cancer follow-ups were replaced with an education programme. Women had sufficient care and valuable clinical resources were directed to patients in greater need

Supportive care after breast cancer surgery

In this article...

- › Traditional breast cancer follow-up treatment
- › An alternative to follow-up appointments in hospital
- › Benefits of an education programme to help women self-care

5 key points

1 After treatment for breast cancer patients are routinely offered follow-up appointments for five years

2 Most recurrent symptoms of breast cancer are detected by patients

3 An education programme for patients after treatment can allow clinical resources to be focused on patients with greater need

4 The education programme increased patients' knowledge of their disease and treatment

5 Patients found that it was beneficial being able to meet others who were in a similar situation

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Abstract Allinson V, Dent J (2014) Supportive care after breast cancer surgery. *Nursing Times*; 110: 41, 20-23. Routine follow-up after treatment for breast cancer aims to monitor for recurrence, manage late effects of treatment and give patients information, support and reassurance. However, most symptoms of local recurrence are first identified by patients so time spent following up women who are essentially well may not be clinically beneficial or cost effective. To better use its resources, Calderdale and Huddersfield Foundation Trust developed a follow-up education programme for patients at low-to-moderate risk; after two years an audit showed it reduced overall patient anxiety and routine hospital appointments, maintained standards of care and provided patient with an effective support network.

Traditionally, women who have had breast cancer and completed all their treatment are offered follow-up hospital appointments for five years, attending the hospital up to 15 times for those appointments. A study by Morris et al (2008) indicated, however, that only 10% of routine recurrences were detected at clinic follow-up, while 48% were detected by patients themselves; this supported the theory that attending follow-up appointments at an outpatients department was neither a good use of time nor expertise.

Allen's (2002) research indicated that women who are otherwise living free from anxiety about their breast cancer can become anxious when attending clinics, and that the actual appointment does not fulfil their expectations. Clinic attendance may cause women to revisit the threat of cancer, particularly if they share a waiting room with others who have recurrent disease. Reassurance is commonly described as the main benefit patients derive from check-ups, but a study by Stark et al (2004) suggested that attending clinic is counterproductive for those patients who are very anxious.

Further work by Montgomery et al (2007) looked at breast cancer follow-up; they concluded that there was little concordance with guidelines and cast doubt on the efficacy of constant follow-up. Sheppard (2007) reviewed the evidence for long-term follow-up and concluded that there was little that related to improved survival, quality of life issues, access to specialist advice, or management of symptoms and anxiety.

The research argues that patients should be able to determine their own future needs, and that assessing their risk and offering a personalised package of care with an educational programme would empower them towards self-management (Sheppard, 2007).

Previous studies have demonstrated that many patients are willing to take responsibility for seeking medical attention in the event of symptoms occurring (Gulliford et al, 1997), and Foster and Fenlon (2011) suggested that regaining self-confidence is important in enabling patients to manage recovery and wellbeing after cancer treatment.



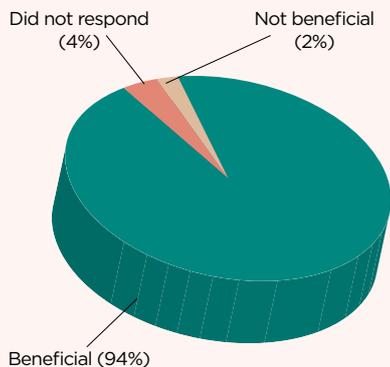
Almost half of breast cancer recurrence is detected by patients rather than doctors



“Patient safety is at risk when wards are insufficiently staffed”

Tony Clapham p24

FIG 1. VIEWS OF THE PROGRAMME



More than two-thirds of women who attend for regular follow-up after completing breast cancer treatment still feel that they have information needs that are not met, and feel rushed and unable to ask any questions they may have. It is also frequently reported that, within the busy environment of the medically orientated breast clinic, issues remain unaddressed and contact with breast care nurses is often sporadic (Beaver and Luker, 2005). A study addressing information priority among patients with breast cancer who were undergoing follow-up found that concerns persist at the two-year follow-up stage, with the additional concern of genetic risk to their family becoming more apparent (Luker et al, 1996).

Evidence that breast cancer follow-up may not be meeting patients' needs prompted the breast cancer service at Calderdale and Huddersfield Foundation Trust to develop a supportive care model of follow-up. The programme aims to give patients the tools to help them to regain their confidence. This article reports on an audit of women who have attended the follow-up course after receiving a breast cancer diagnosis and treatment.

The new programme

We undertook extensive research to determine what breast cancer follow-up procedures were offered within the Yorkshire Cancer Network and found no conformity in the services available. Working with Breast Cancer Care and the University of Huddersfield, we developed an educational programme to replace the existing follow-up services.

The programme, known as Moving Forward, was based on a shorter one offered by Breast Cancer Care; the shorter programme addressed key issues women were concerned about after their diagnosis but we decided we needed a longer programme

to ensure it covered all the issues that would be pertinent to women if they had no hospital follow-up. Moving Forward consists of four three-hour sessions that are held on consecutive Wednesday mornings. Initially these were held in the hospital, but they have now moved and are based in a local hotel. Breast Cancer Care manages the day-to-day running of the programme: the sessions are run by a Breast Cancer Care representative and a breast care nurse. Sessions are split in two, with a coffee break in between, and cover topics including:

- » Managing breast cancer;
- » Coping with diagnosis;
- » Menopausal symptoms;
- » Lymphoedema;
- » Exercise;
- » Relaxation and diet.

Pilot of the programme

A pilot study of Moving Forward was undertaken to ensure it was acceptable and comprehensible to patients, and could be delivered within the resources that were available. The pilot, which was approved by the trust's ethics committee and supported by the Yorkshire Cancer Network and University of Huddersfield, started in 2008, with data collected for five years. Early results from the pilot study in 2010 confirmed it was viable, acceptable and did “no harm”. The local multidisciplinary team approved Moving Forward for use as the follow-up plan for women who had undergone surgery and had a low-to-moderate risk of their breast cancer recurring.

Patient eligibility

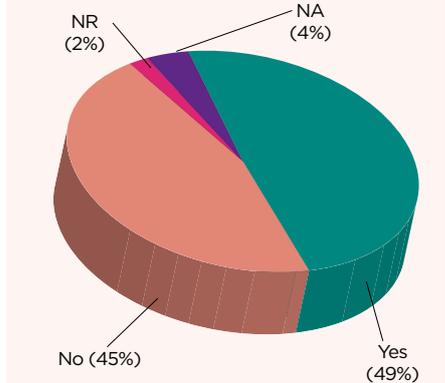
When women have undergone surgery for breast cancer, the multidisciplinary team determines their final treatment plan; after risk stratification, those considered suitable can be invited to take advantage of Moving Forward. This is in line with Department of Health (2010) recommendations to provide a more personalised care of approach based on individual risk.

Women who have chemotherapy as part of their treatment are currently excluded from the programme because their risk of recurrence is generally higher and they may need more “hands on” follow-up to detect recurrence earlier; however, there is potential to extend the programme to include this group in future.

The audit

The audit was conducted over a 12-month period. This was after the programme had been running as the routine follow-up for

FIG 2. CONTACT WITH OTHER SERVICES



eligible women for 18 months. The audit sample was recruited from women who had attended the course in the previous year. We developed a questionnaire with Likert-style questions giving respondents a scale of 1-5, from “completely agree” to “completely disagree” and opportunities to give free-script feedback.

From a sample of 73 women, we had a response rate of 51 (70%). Forty-three (84%) of those had attended all sessions in the programme. Reasons given for missing sessions included clashing with radiotherapy appointments, illness and other commitments such as childcare. Forty-eight respondents (94%) reported finding the programme beneficial (Fig 1).

Impact on other services

One of the concerns raised before the programme began was that if hospital-based care was not an option, patients might look for support elsewhere such as their GP or the breast cancer nursing service. In the audit, 35 (69%) participants had contacted the breast care nurses with queries about tablets and mammograms, prosthetic appointments and work issues. Although these nurses offered a drop-in service, only 12 (24%) respondents had attended the drop-in clinic, with the remainder telephoning or emailing. Reasons for contacting the breast care nurses included further lumps, concerns about scars or generally feeling unwell or worried.

The audit demonstrated that there has been no significant increase in attendance at the drop-in since hospital-based follow-up was replaced by Moving Forward. Those women who presented at the drop-in with concerns said they were successfully investigated and reassured. They also reported that attending the drop-in was better than waiting for an appointment as the nurses were always extremely helpful at difficult times.

TABLE 1. OTHER SERVICES ATTENDED BY RESPONDENTS

Service	Attendees
Breast care nurses	16
Prosthetic/bra service	14
GP	12
Breast clinic	8
Reconstruction clinic	6
Genetics service	5
Breast Cancer Care	4
The Haven (a charitable breast cancer support centre)	4
Living Well "patient-run cancer support group"	1
One-to-one service	1
Lymphoedema service	1
Endoscopy service	1
Holistic therapist	1

When the programme started, the breast care nurses took over managing mammogram requests and the delivery of results, which were previously handled in hospital follow-up. Results on satisfaction with this change were inconsistent – 32 (63%) respondents had undergone mammograms and 23 (72%) of these said their results were delivered rapidly and gave them reassurance. However, nine (28%) complained about the wait for results; this issue is addressed in the discussion section of this article.

We asked whether respondents had contacted any other health professional, apart from breast care nurses, for breast cancer-related issues during the audit period; in total, 25 (49%) had done so (Fig 2). Table 1 indicates the variety of professionals and services that were contacted by participants.

Benefits of the programme

To inform the development of future programmes, we asked the audit respondents what elements of Moving Forward they had found beneficial. Responses included:

- » Being in a group with other women who had experienced the same or similar treatment paths;
- » Hearing about other treatments women had received;
- » Finding out why they had not been offered other treatments (radiotherapy, endocrine treatments, chemotherapy);
- » Professional speakers' sessions, especially those on diet, exercise and menopause;

» Sharing experiences and being able to speak openly to other women in the same situation.

The women were less keen to hear about secondary cancer issues or how diagnosis has been made and treatments decided, but liked the class size, which was restricted to a maximum of 20, as they felt it gave time for everyone to speak if they wished and would not be too intimidating for those who were less confident. Positive responders also stated that the speaker's delivery was perfectly gauged, realistic, practical and sympathetic, and said they had the time and opportunity to ask questions, unlike during a busy hospital appointment.

Comments from respondents included: "It helped me learn more about my cancer and understand the other types of breast cancers. I also learnt some of the things I can do for my future wellbeing."

"I enjoyed all of it more than I thought I would have done."

Some respondents appreciated having the sessions on diagnosis and treatment because they were able to question the process more and understand why they had been offered the specific treatment plans that they had received:

"I appreciated all the content of the course and was able to take from it what I wanted to know."

The psychologist's session is sometimes difficult for attendees but, overall, it was appreciated:

"The psychologist's input in the last session enabled them to discuss feelings which brought people together, give them (in some cases) a good laugh and was enjoyable and uplifting."

Forty (78%) respondents felt that the format and programme length were acceptable and no changes were necessary. One respondent said:

"I welcomed the opportunity for the course and felt it was a closure to my treatment and didn't feel I needed anything further. I am reassured that I can be in touch with the clinic if I have any concerns."

Negative views

When asked to comment on what they did not like about the programme, respondents cited the venue, transport and parking issues, and air conditioning; these have been addressed by moving the sessions to a local hotel. On programme content, remarks about information on secondary cancer were fairly consistent – some respondents described this information as depressing and frightening:

"I enjoyed the entire course but at times I found it too involved and a little frightening."

Some respondents had not been keen to revisit diagnosis and treatments:

"The first part [a session on diagnosing and treating breast cancer], where we did not need to be reminded."

"Talking about the diagnosis and treatment felt like teaching your grandmother to suck eggs."

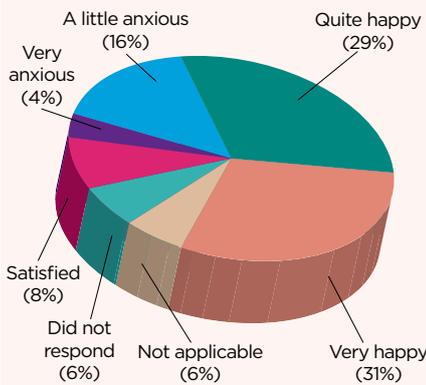
QUICK FACT
10% The percentage of breast cancer recurrences that are detected at clinic follow-up

It is not easy for everyone to participate in groups and despite the group size some respondents did find the programme challenging and felt unable to speak. However, most of these said that they enjoyed listening to the sessions and chatting to the other group members during the breaks.

Some respondents would have liked the programme to be longer with an extra session to recap, or a follow-up session a year later to refresh their knowledge, while others felt it could have been shorter. Some would have liked to attend earlier in their pathway (before starting radiotherapy).

When asked if there was any way in which the programme could be improved,

FIG 3. FEELINGS ONE YEAR AFTER THE PROGRAMME



respondents made suggestions around support for partners and the timings of the sessions.

Confidence

One of our original concerns had been whether replacing hospital appointments with an educational programme would result in women lacking confidence in self-management. However, roughly a year after attending the programme, 35 (68%) were “very happy”, “quite happy” or “satisfied” that they had not had to attend any appointments; only 10 (20%) described themselves as “a little anxious” or “very anxious” (Fig 3).

Other results

There were consistent comments about the caring support from the breast care nurses. Respondents said this made them feel that their care was individualised and that at no time were they alone in trying to deal with worries. People appreciated hearing the decision process for offering chemotherapy and understood more clearly why they did not require it:

“I found it extremely beneficial; it was helpful to meet other people who had not had chemo so I did not feel like I was the only one!”

Responding to feedback

The main issue we dealt with after the audit was the inconsistency regarding the receipt of mammogram results; of the 32 respondents who had undergone a mammogram 23 (72%) had received their mammography result (by letter) within three weeks. However, the remainder said they had not received their results within three weeks and there were some concerns that, for some patients, this process took too long. We have since addressed this issue (which was administrative) and all results are now processed within two weeks.

Although negative remarks in evaluations about discussing metastatic disease during the programme have been consistent, we feel that this content needs to be included as it is a possibility and we should, therefore, make patients aware of it (DH, 2011). We have modified the presentation to be more positive, but the basic message is the same: patients must be aware of the possible risk to their health in the future. *Improving Outcomes: A Strategy for Cancer* (DH, 2011) supports this thinking, and recommends a change in approach to care so that there is an emphasis on recovery, while still enabling early recognition of signs and symptoms of further disease.

Conclusion

Regarding what patients liked most about the content of the course, the most common positive themes were:

- » Being reassured;
- » Sharing experiences;
- » Meeting people who had gone through similar experiences.

Themes that emerged highlighting what patients liked least were:

- » Talking about the diagnosis and treatment;
- » Diet and healthy living talks;
- » Relaxation and psychological skills talk (which was rushed).

However, there were no sessions that were disliked by all respondents.

Sheppard et al (2009) compared a model of care providing point-of-need access with routine six-monthly appointments; after the 18-month study most participants did not want to return to regular visits and the authors concluded that patients did not feel isolated. This finding was supported in our audit results, with the majority of respondents being “very happy” that they had not been required to attend any hospital appointments a year after finishing the programme.

The audit demonstrated that Moving Forward is acceptable to the vast majority of women attending the programme and, for most patients, can replace hospital appointments without causing any extra anxiety or increased attendance in primary care. Kimman et al (2007) suggested that brief interventions based on self-education and information have improved quality of life in patients who have undergone breast cancer treatment, and hypothesised that this would result in a better acceptance of a reduced follow-up protocol by patients and professionals alike. The Moving Forward programme and audit supports that view.

We aim to offer women a place on Moving Forward as close to completing surgery and radiotherapy as possible. Unfortunately we are only able to offer the programme in alternate months so it is not always possible to offer all women a place on a course between their surgery and radiotherapy treatments, which would be the ideal. However, this educational programme has proved to be a valuable and acceptable alternative to asking patients to attend hospitals for appointments and experience the anxieties and inconvenience that are associated with those appointments. It also frees up clinical time that can be used to see patients with complex needs in a timely manner. The programme could be transferred to other specialist areas. **NT**

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