Module 5 - Case studies

Emma Bennett
Lead Clinical Nurse Specialist in Breast Cancer
Western General Hospital, Edinburgh

Background
Until recently, within NHS Lothian, there had been no dedicated breast clinical nurse specialist service for patients diagnosed with secondary breast cancer. The department has a well-established service for patients presenting with early breast cancer. However, support for those with metastatic disease was less systematic. With increasing numbers of patients with early breast cancer presenting to the unit, the perception was that those with secondary disease were receiving a less consistent level of care. In addition, given the widening availability of treatments and resulting increase in overall survival, the numbers of patients living with secondary breast cancer continues to rise. Acknowledging this inequity, it was recognised a service redesign was required.

Pulling all of this together resulted in managerial and financial support being made available to allow a reconfiguration of the specialist nursing service with dedicated provision for patients with advanced disease. Following a period of planning and regular meetings with all those involved, including palliative care colleagues, the secondary breast CNS service was launched at the beginning of March 2009 with the remit of providing expert nursing care to all metastatic breast cancer patients seen within the Edinburgh Breast Unit and Cancer Centre.

The potential benefits were perceived to be: providing the patients with the tools to support self management; supporting the development of practical and emotional coping skills, and enhancing their health and wellbeing.

The service today
As of June 2012, our caseload stands at 293 patients, with 62 new referrals so far this year. Given the nature of the workload and variable patient pathways, we may not be in regular contact with all patients but maintain an open access policy throughout for patients and their carers. As a service we maintain our own nursing database comprising new patients, ongoing caseload and patient deaths (including place of death). This allows us to quantify increasing workload versus current resource and so provide justification for increasing CNS hours for this patient group. This was clearly supported by a 27% increase in total caseload from 2010 to 2011.

Our main referral guidelines can be seen below. The majority of our work is with outpatients, either in a clinic situation or through telephone contact. As most chemotherapy is offered on an outpatient basis, admissions to oncology beds relate in the main to either a deterioration of their cancer resulting in new symptoms, difficulties at home or a complication of their treatment.

- Provision of information on their diagnosis and treatment options to allow informed decision-making.
- Psychological support.
- Advice on symptom control and liaison with specialist palliative care.
- Link between hospital and liaison with specialist palliative care.
- Signposting and referral to other agencies, for example, welfare and benefits advice.

Our first contact with patients is usually either at new diagnosis of metastatic breast cancer or progression of their disease. This initial meeting is often a time of assessment in terms of their individual needs, their understanding of the diagnosis and treatment plan, and an explanation of our role and the support we can offer. All new patients also have a telephone contact (unless a clinic appointment is booked) within two weeks of this meeting, having allowed the process of adjustment to begin for patients in terms of their diagnosis and the impact this will have on their life and that of their family.

The impact that a diagnosis of secondary breast cancer can have cannot be underestimated and psychological care is as important as meeting physical needs. Coping strategies and ways of managing a diagnosis are individual and, given the ever-changing nature of their disease trajectory, it is likely needs will change at varying points. We are fortunate to have access to clinical psychology services, utilising both indirect (through joint working) and direct referral dependent on the complexity of a patient’s care needs. They also provide a vital support for the team in terms of advice and reflective practice.

Patients will often have a range of symptoms as a result of both their cancer and treatment. As a service we offer direct advice, but also provide a vital link to community services including local hospices and community palliative care teams. This allows ongoing review of a patient’s symptoms and good anticipatory care; hopefully providing a seamless service for patients throughout their journey.
Access to and signposting to other support services was an area highlighted by the work of the Breast Cancer Care Taskforce. Given the often protracted pathways for patients with secondary breast cancer, living with the diagnosis can impact on numerous aspects of a patient’s life including finances, employment, help supporting children and family, lifestyle changes, in addition to the emotional burden. Offering guidance as to where they can seek out specialist advice, in addition to direct referral if appropriate, highlights again the importance of a ‘key worker’ role in providing coordinated, high-quality care based on individual need.

The patient experience

Any new service development requires a degree of tailoring and adaptation dependent on need, so formal evaluation is important. As healthcare professionals we may think we are offering the right service for patients (and other staff) but only by gathering the experiences of services users can we be assured.

A year after the implementation of the service, a purpose-designed patient satisfaction questionnaire was distributed to patients. With the aim of focusing on patient awareness of the service, reasons for use and perceived benefits or not of the breast care nursing specialist role.

The final question asked specifically whether it was felt that having dedicated breast care nursing specialists for patients with secondary disease improved quality of care. Response to this was resoundingly positive in terms of improvement in care and was supplemented with various free-text comments as highlighted below. Sixty-eight questionnaires were distributed in total with a 93% response rate.

‘A vital link between patient and consultant.’

‘...reassuring – the fact that you have personal knowledge of my condition and treatment history.’

‘A valuable and necessary service supporting people at very difficult times.’

‘It was particularly good to have contact with a service dedicated to secondary breast care as the issues faced can be so different to having an initial breast cancer diagnosis.’

Ninety-five patients stated they knew how to contact the team, with 97% of respondents finding the breast care nursing specialist service helpful. In terms of improving care generally, over 95% felt the role was of benefit in terms of quality of care. We also wanted to determine that the referral criteria and remit of the team were meeting patients’ needs and responses confirmed this was the case. Given that the remit of and our aims in developing the BCNS service were based on the Breast Cancer Care Secondary Breast Cancer Taskforce report, it has been helpful to clarify and provide evidence that we are going some way to delivering the right service to patients.

We felt it important also to obtain feedback on the service from colleagues so that we can continue to deliver a service useful to others involved in the care of these patients. A second questionnaire was sent to the clinicians we work most closely with.

Again, responses were positive with acknowledgement of our role in emotional and practical support for patients, improved communication between the different component parts of patient pathway and the importance of liaison between primary and secondary care.

Ongoing developments and challenges

Services need to be continually evaluated and adapted to ensure they are delivering high-quality care to patients. We are continuing to look at how we can effectively manage the rising patient numbers within the resource allocated to this side of the specialist nursing service. Maximising resource is fundamental and initiatives such as secondment opportunities are important in developing expertise. The specific secondment model we have developed is an 18-month opportunity whereby one of the breast care nursing specialists from the early breast cancer service joins the metastatic side with the aim of ongoing development of skills and competencies associated with caring for patients with advanced breast cancer. Feedback to date has been very positive in terms of an increased knowledge base and the development of transferable skills.

The patient satisfaction survey was also used as a tool to provide us with ideas for service improvements in line with the views of our patients. One such initiative has been the launch of a support group for our patients, with facilitation by Breast Cancer Care’s secondary breast care nursing specialist.

Psychosocial support is a large component of the breast care nursing specialist role and plans to implement the use of a psychological support assessment tool are currently ongoing. By using a framework such as the Distress Thermometer© (NCCN 2007) or similar, it is hoped we can provide a more structured approach to assessing emotional distress and concerns with plans to run a small pilot prior to wider implementation.

Ongoing multidisciplinary working is paramount to ensure a collaborative approach to any future service developments. Support for the secondary breast CNS service from our clinicians has been positive
from initiation to the present and this was highlighted by their feedback as part of the satisfaction survey. Encompassed within this is consideration of further expansion of the remit of the breast care nursing service for example through the development of nurse-led services around telephone review of those patients where it is more appropriate for their care to be focused within primary care setting.

**Top tip**
Probably the most important thing in terms of developing this type of service is a period of planning to encompass remit, referral criteria and day-to-day working, while ensuring support from colleagues within all disciplines including palliative care. This is key, followed up with ongoing evaluation, and the patient experience work outlined here emphasises the benefits our patients have already gained, providing some evidence that we are meeting their expectations and the difference a dedicated secondary breast cancer CNS can make to a patient’s journey.

**Reference**
I work 28 hours per week seeing approximately 120 new metastatic breast cancer (MBC) patients per year. The overall caseload is approximately 300-350 patients at any given time. This is increasing as patients live longer with the improved treatment available. A business case is in progress to provide additional CNS hours to manage caseload demands.

Most referrals to the service come from the surgical breast CNS team based at our local district general hospital. Any healthcare professional can refer to the service and self-referrals are also accepted. MBC patients are discussed accordingly in conjunction with adjuvant patients at the Sheffield breast MDT.

I model my role on Davis and Oberle’s work (1990) which comprises six dimensions: valuing; connecting; empowering; doing for; finding meaning and preserving own integrity (Figure 1).

I feel this helps to reflect the work of the CNS with MBC patients throughout the disease trajectory and also links well with the supportive care section in the National Institute for Health and Clinical Excellence (NICE) guide to resources for advanced breast cancer and NICE quality standard 12 for breast cancer (see Appendix 3).

As a rapport is built up with patients, assessments can be made regarding their physical, psychological, social, spiritual and financial needs. This is an ongoing process. Different issues are more prominent at different times. Holistic needs assessments are offered using the adapted SPARC tool (Sheffield profile for assessment and referral to care).

Initial contact after referral to the service is made by telephone or in person. Most patients are seen in the oncology outpatient setting, with the chance of a further appointment outside clinic as required. Patients are also seen on the wards, in the chemotherapy unit and the radiotherapy department. Patients are offered Breast Cancer Care’s advanced breast cancer resource pack, a leaflet about my role and contact details. Patients can access the service by telephone.

On initial presentation of metastatic disease, most patients require a lot of support while they adjust. Once they are stabilised and responding to treatment, less support is often required. Patients access the service according to their need. The most relevant times for them appear to be at initial diagnosis of metastatic disease, when disease progresses (which can be on more than one occasion) and when treatment stops working. At this time patients may want to discuss end-of-life care and their preferred place of death.

Relationships with other services
Patients require support from different professionals during their disease trajectory. I can make referrals as appropriate (see Figure 2) and continue to liaise with other professionals involved. The CNS role is to maintain a constant link with the patient. Relationships with other healthcare professionals are fluid and require close joint working relationships, particularly with the oncologists, nursing teams, specialist palliative care team and clinical psychology.

Benefits for the trust
• I can offer a high-quality service for patients with metastatic disease. However, due to limited CNS hours, not all patients have a key worker.
• Money can be saved by CNS involvement by helping patients remain at home, preventing unnecessary admissions through accessing timely and appropriate community support.
I can also help to facilitate quicker discharge home from the hospital by involving key members of the multidisciplinary team.

I am well placed to identify oncology emergencies early, such as spinal cord compression and hypercalcaemia, by identifying symptoms when seeing patients or when they ring for advice.

**Benefits to the patient**

A service evaluation identified the following:

- 93% of patients who accessed the service required emotional support; 80% evaluated this aspect of the service as excellent, 20% as good
- 78% of patients required telephone support between hospital visits. This was positively evaluated particularly in relation to prompt reply and action taken following phone calls
- 96% of patients found it useful to know they had support if needed
- 74% of patients required support for information/advice about symptom control, which was evaluated to be excellent (70%) and good (30%).

**Patients comments from service evaluation**

‘Although practical support is given at the meeting with doctors, it gives me emotional support and doesn’t make me feel so alone. I appreciate this support.’

‘Jo has been very supportive throughout my treatment. Life for me has become a bit like a rollercoaster ride; my emotions all over the place, and she has been there to listen and offer direction to the various support networks.’

‘The difference in the overall feeling of general support, (information given in a clear manner) and the 100% reliability of the service is inestimable. I have used so many different aspects of this excellent service with very positive outcomes.’

‘I couldn’t emphasis enough how important Jo’s prompt return of calls and coming back with a “plan of care” is to someone in my position. She has been a real help to me at these difficult times.

**Challenges**

- As more patients with MBC live longer, it is difficult to meet their ongoing complex needs without an increase in CNS hours.
- Awareness that it is not possible to see all MBC patients who come to the hospital. We may therefore at times provide an inequitable service.
- Difficulty gaining funding for additional CNS hours.

**Top tips**

- It is important to foster close relationships with key members of the MDT. This improves the patient pathway but also provides a valuable source of support for the CNS.
- The role is demanding and can be stressful. The CNS needs to have a high level of self-awareness and access to clinical supervision.
- Recognise the unique needs of patients with MBC and develop services that meet their complex needs.

**References**

Becky Rix  
Secondary Breast Care Clinical Nurse Specialist,  
Essex County Hospital, Colchester

I started working as a breast care nurse in April 2009. I had previously worked in oncology clinical trials and it was during this time I realised that when I went with the consultant to discuss metastatic breast trials with patients there were no breast care nurses present. I often found I was providing a support network for these patients and their families alongside completing all the trial requirements.

When I researched for the interview for the breast care nurse role, I decided to look into the lack of secondary support and this is when I first became aware of the Breast Cancer Care Secondary Breast Cancer Taskforce. Unfortunately, due to funding at the time, my line manager was unable to act on the Taskforce’s recommendations. I carried out the role of breast care nurse with the vision that in the future this could be possible.

In April 2010 my manager and I decided to carry out a patient satisfaction survey. We called it ‘Breast care nursing support and information for patients diagnosed with secondary breast cancer’. We felt that, depending on the results, we could use this as evidence to support the funding for an additional breast care nurse so that I could pursue the role of developing a secondary service for the trust.

The survey was sent to 30 patients treated for secondary breast cancer between July and December 2009. There was a 66% return rate, which was a good response considering the patient group targeted. The results proved largely what we had expected. It highlighted that patients felt that they had adequate support when diagnosed initially with breast cancer. However, when diagnosed with secondary disease there was little support.

The findings from this survey gave strong evidence for the need for local development of a secondary service for our patient population within the trust. My line manager and I also used the Secondary Breast Cancer Taskforce to support our request for funding. At this time there were only four secondary breast care nurses in the country and we wanted to be the next trust to develop this role.

We were very fortunate in that we were able to get funding to advertise for another breast care nurse to join the team, so that once she was up to speed, I could become the secondary breast care nurse and develop this service.

My manager and I started looking into a secondary service in April 2010 and eventually I came into post at the beginning of 2011, so it took nearly a year to instigate the service.

I was on maternity leave from April until October 2011, so the service was covered as much as possible by my breast care nurse colleagues. Since returning from maternity leave I have really started to develop this role and I am currently waiting for the results of a survey similar to the initial survey carried out in 2010, to evaluate patients’ opinions of the secondary service now that it is functioning. The results should be available in late August/early September 2012 and I will use the findings to analyse the service I provide.

My role largely involves advice and support for metastatic breast patients and their families in the clinics and on the telephone. It also involves liaison with departments, that is. the oncology wards, CT, MRI, physiotherapy, dietitians and the counsellor. I also work very closely with the local hospice and the Macmillan nurses. I attend the oncology clinics, ward rounds and recently expanded my role by assessing patients in the clinics, which our oncology consultant is happy for me to do and the patients seem at ease with this because I build up a good relationship with them during their cancer journey. I am considering carrying out a mini audit to find out patients’ opinions on seeing a nurse in clinic as opposed to seeing a doctor.

I don’t have any hard evidence that the secondary service saves the trust financially. However, due to the number of complex phone calls that I have with patients and relatives, I would think that I save outpatient appointments and emergency attendance. The consultant I work with is happy for me to admit patients to the oncology wards if required because he trusts that I would only do this if there was a genuine need.

When setting up a new service there are always challenges. It took quite a while to get the consultants to use my service and also quite a lot of work was involved in promoting the service, including a presentation for the Chief Executive of the trust. The best way I found was by doing presentations to different departments and by making sure I was
present in clinics and on the wards and by generally being a pest!

My advice to any nurses wanting to improve their service to secondary patients is that it's emotionally quite a challenging role and can be quite complex. However, it is very rewarding knowing that you make such a difference in the lives of the patients and their families at such a difficult time.

I am happy to help anyone if they are trying to set up a service or if they just want advice and support.

Jane Watts
Oncology Breast Clinical Nurse Specialist
Frimley Park Hospital NHS Foundation Trust

My role as Oncology Breast CNS at Frimley Park Hospital NHS Foundation Trust started in August 2009.

For the first year, 15 hours a week was funded by service improvement money from SWSH Cancer Network and the remaining 15 hours a week were existing breast care nurses’ hours. The aim of this post was to provide a key worker for patients with metastatic breast cancer (MBC). This has become 70–80% of my workload. The other 20–30% is used to support primary breast cancer patients having chemotherapy and those with survivorship issues.

The benefit for patients that this role brings includes having a breast CNS present at a diagnosis of MBC and, whenever possible, at key points/changes in their cancer journey.

The GP and district nurse are informed of new diagnoses and timely referrals to palliative care and other relevant agencies are made when required. There is face-to-face support in the clinic and on the wards plus telephone support whenever the patient requires it during working hours.

Along with support at diagnosis, another significant change is ongoing support for those patients with well-controlled MBC. I attend the chemotherapy clinic weekly at the Cancer Centre, which provides on-going support for both primary and secondary breast cancer patients receiving chemotherapy. Having completed level two psychology training I have been able to reduce the wait for, and sometimes the need for, clinical psychology appointments.

Three years on, the post is now well integrated into the Macmillan breast CNS team, which consists of 2.6 whole time equivalents with a case load of 293 new primary breast cancer diagnoses in the past financial year (2011/12); 40 new MBC diagnoses and 82 existing MBC cases in the same period.

Over the past three years there has been an average of 40 new MBC diagnoses a year. We cover each other’s workload as required, ensuring continuity of the service. Having come from a background of oncology and palliative care I have been developing my knowledge and skills not only about the needs of patients with MBC but also the primary breast cancer journey. Meanwhile, my colleagues have found their skills in palliative care developing as they provide support for MBC patients in my absence. We are running a six-week ‘Moving On Programme’ for patients who have completed their treatment for primary
cancer, which is proving very successful. I hope to be able to provide a similar programme for those patients living with secondary breast cancer in the future.

I am a core member of the breast multidisciplinary team (MDT) and all newly diagnosed MBC patients are discussed at the MDT meeting. This is invaluable as, from April 2012, it’s been a requirement to collect data on new MBC diagnoses and recurrences for the Department of Health. I am working with our MDT coordinator to help ensure this data is captured. Patients with existing MBC are discussed whenever there is a need for the expertise of other teams members, such as radiologist or surgeons. One of my objectives for the coming year is to investigate the role and feasibility of an MDT specifically for MBC.

The diverse nature of MBC means my links with other specialities now spread around the hospital. The breast MDT receives referrals from other MDTs and I can find myself, for example, in a lung or upper GI clinic with a patient receiving a diagnosis of MBC. I can be liaising with acute oncology, orthopaedics, respiratory, haematology, palliative care or others when helping patients manage their symptoms, side effects of treatments, advanced care planning or supporting a hospital discharge.

The temporary funding for half the hours from service improvement funding was stopped after the first year. This left the challenge of proving this was an improvement on the existing service in the hospital. Data was collected from the new and existing patients, demonstrating the workload with the number and types of interactions with patients. The challenge for me was to be able to prove this was, and still is, a cost-effective service. However, reducing length of stay, avoiding unnecessary admissions, reducing oncological emergencies and appropriate use of outpatient appointments can all improve efficiency, have the potential to save money and, most importantly to the patients, improve their quality of life. With this in mind, I collected further data that included actions where there were money-saving outcomes. At the end of the year I converted this data to bed days saved, timely outpatient appointments made and converted this into a monetary amount. Some of the actions are demonstrated below.

### Avoiding unnecessary admissions
- Timely referral to palliative care.
- Early OPA/investigation to prevent oncological emergency such as spinal cord compression, brain metastases, pleural effusions.
- Liaising with community palliative care.
- Advanced care planning.

### Reducing length of stay
- Symptom control.
- Knowing the patient and their wishes.
- Coordinating non-emergency admissions for drainage of ascites.
- Carer support and their needs identified and addressed.
- Liaising with ward/oncology/palliative care.
- Transfer to hospice at appropriate time.

In conclusion, prior to the role of Oncology Breast CNS those patients diagnosed with MBC felt unsupported. If there was a breast CNS present in the clinic at the time of their diagnosis they may have seen them, but it was likely they were seen by the doctor with no nurse present and little or no supportive follow up.

The development of the Oncology Breast CNS post has meant that these patients are now supported by a nurse who is knowledgeable about their disease and subsequent treatment. They have direct contact with someone who has quick access to the MDT for action and advice. And, who can signpost them to appropriate services in a timely manner while providing continuity of care with someone with whom they have built up rapport and trust.

‘Six years ago I was told the cancer had spread to my bones, I was given a tablet and told to come back in three months. My husband and I felt hopelessly lost and vulnerable. Now the access we have to my specialist nurse is a tremendous help: I’m not alone, I can phone with any question however small. I can put the cancer away and if there is a problem I just phone.’

(Yvonne, 2012)