

Ensuring nursing provision for people with metastatic breast cancer

A toolkit for healthcare professionals



Introduction

We are delighted to welcome you to our new toolkit. This has been developed in response to requests from members of our Nursing Network* who increasingly contact us for advice and support around developing and improving the nursing service they offer to their patients with metastatic breast cancer.

This toolkit contains different modules covering a range of issues; from developing your nursing service to reflect current policy and national guidelines to suggestions about changing your service. It also includes case studies from nurses in practice so you can see what others have achieved.

We really hope this toolkit helps you develop the best nursing service you can for your patients with metastatic breast cancer. We envisage it as a dynamic item which will evolve over time. So it's vital you tell us what you think – please use the evaluation form (Appendix 2) so we can ensure the content of the toolkit always reflects your needs.

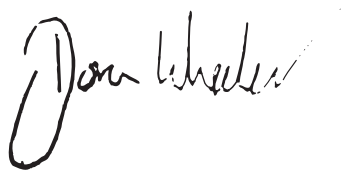
Finally, don't forget to tell us if you do adapt or change your service so we can share your experience with other Nursing Network members. By working together we can ensure everyone affected by metastatic breast cancer receives the highest standards of specialist nursing care.

Best wishes



Dr Emma Pennery

Clinical Director, Breast Cancer Care and
Head of the Nursing Network



Dora Wheeler

Policy Officer, Breast Cancer Care

You will see the terms 'metastatic' and 'secondary breast cancer' both used in this document. In many of our patient-facing materials we use the term secondary as patients are often more familiar with it.

* The Nursing Network has been created so you can come together with colleagues to share best practice, develop your skills and knowledge, and work more closely with Breast Cancer Care. If you spend more than 50% of your time with breast cancer patients, membership is free and essential for you and your team.

Overview

Module 1 – The case for change

- 1.1 Standards of care for people with secondary breast cancer
- 1.2 Benefits of specialist nursing provision
- 1.3 National guidance, targets and standards

Module 2 – Excellence in practice

- 2.1 Core competencies
- 2.2 A diagram showing the attributes of specialist nurses in metastatic breast cancer
- 2.3 The benefits of specialist nurses in metastatic breast cancer
- 2.4 Coordinating and providing continuity of care
- 2.5 Applying specialist knowledge and skills
- 2.6 Coordinating complex care
- 2.7 Meeting information needs and empowering patients
- 2.8 Preventing unscheduled hospital admissions
- 2.9 Supporting patients in clinical decision-making

Module 3 – Making the change

- 3.1 Identifying the number of patients diagnosed with metastatic breast cancer in your place of work
- 3.2 Gathering evidence of need
- 3.3 Harnessing support from multidisciplinary team (MDT) colleagues
- 3.4 Learning from others
- 3.5 Identifying what is needed in your place of work
- 3.6 Carrying out patient focus groups

Module 4 – Promoting the change in your nursing service

- 4.1 Communicating your existence
- 4.2 Proving your worth
- 4.3 Saving time and money

Module 5 – Case studies

Module 6 – Useful reading

This section contains descriptions of/abstracts of articles we think you may find interesting.

Appendices

- Appendix 1 – Template patient experience survey and letter
- Appendix 2 – Evaluation form
- Appendix 3 - References and reading list

Module 1 –The case for change

This module explores why you might consider altering the specialist nursing service currently offered to your patients with metastatic breast cancer.

It includes:

- Breast Cancer Care's **Standards of care for people with secondary breast cancer**
- a brief overview of the evidence supporting change
- relevant health policy.

1.1 Standards of care for people with secondary breast cancer

Breast Cancer Care's vision is that everyone affected by breast cancer receives the highest quality treatment, information and support. However, we know from studies and by talking to many people diagnosed with metastatic breast cancer, that this is not always achieved.

These standards were developed by Breast Cancer Care in conjunction with people diagnosed with metastatic breast cancer and healthcare professionals with expertise in the field. They are designed to form the basis of care that people with metastatic breast cancer should expect. We suggest the standards may be used to benchmark the care offered to your patients with metastatic breast cancer. Our Spotlight on Secondary Breast Cancer campaign asks all Cancer Networks to sign up to support our standards.

If your Cancer Network wants to **sign up**, visit our web pages to find out how www.breastcancercare.org.uk/spotlight

A person with secondary breast cancer should:

1. have access to a clinical nurse specialist, at and from the point of your secondary breast cancer diagnosis onwards. They will be knowledgeable about the disease, treatment and support needs for people with secondary breast cancer. This person will coordinate your care, act as your advocate and provide/signpost you to ongoing support and information
2. receive a multidisciplinary team (MDT) approach to your care. All healthcare professionals who contribute to the management of your care should meet regularly to discuss your case, so that you receive the best care for you. Your team should include members of the oncology and palliative care teams

3. experience continuity of care between the hospital and community services. Communication between the hospital-based team and your GP should be as efficient as possible using different methods of communication to ensure your GP is kept informed of your treatment and care. Your GP should be informed and kept up to date about your condition, and be able to provide support and care when appropriate
4. be given timely information, including a care plan, on all aspects of your treatment and care both verbally and in writing, and be clear on the purpose of your treatment, the side effects and potential impact on wellbeing. Your information needs should be assessed regularly and support should be provided alongside all information given
5. have your emotional wellbeing assessed regularly and have access to the appropriate level of psychological support. This should be when you need it, but particularly at diagnosis, when the cancer progresses and when treatment changes
6. have access to information on support services both nationally and locally. This should include the opportunity to meet/talk to others with secondary breast cancer. This could be online, on the telephone or face to face
7. have access to expertise in palliative care, and ongoing management of symptoms. You should be provided with information about end-of-life care when appropriate
8. have access to support and guidance on talking to partners, family, friends and children about the experience of living with secondary breast cancer and the impact it has on others. Your partner and family support and information needs should be assessed separately to your own by a healthcare professional involved in your care. They should be offered/signposted to information/support services specifically for them
9. have access to expert financial and employment advice. This should include information on your eligibility for relevant benefits and your rights at work under disability discrimination legislation

10. have access to appropriate treatments and be made aware of the availability of clinical trials for which you may be eligible before treatment is started or changed.

1.2 Benefits of specialist nursing provision

One of the most encouraging findings of the cancer patient experience survey carried out by the Department of Health was the positive impact of clinical nurse specialists (CNS) on patient-reported satisfaction (DH 2012). The findings revealed significant differences between those cancer patients who had access to a clinical nurse specialist and those who did not. Cancer patients with a CNS were significantly more likely to be positive about multiple aspects of their care and treatment. Although the survey does not classify responses by those with primary cancer and metastatic cancer, the findings are likely to be applicable to both.

Specialist breast care nursing in primary breast cancer is an established discipline in breast oncology and has been found to reduce levels of uncertainty for women newly diagnosed with breast cancer (Ritz et al, 2000) as well as significantly reduce morbidity in women undergoing breast surgery (Halkett et al 2006, Liebert et al 2003, Campbell et al 2006) However, the provision of breast care nursing for those with metastatic disease has been found to be inadequate (Reed et al, 2010) with little evidence that patients are routinely allocated a specialist nurse.

A UK-wide, cross-sectional survey representing 276 breast care nurses carried out by Breast Cancer Care in 2009 revealed that 19 of the trusts questioned had a dedicated metastatic breast cancer nurse specialist and 25 had a named nurse within the team for patients with metastatic breast cancer. However, just over half (57%) of the 276 participants believed specialist nursing care provided to patients with metastatic breast cancer was inadequate in their workplace. Many of the participants expressed a need for a designated metastatic breast care nurse, and some were working towards this within their NHS trust or private hospital.

Breast Cancer Care's aspiration of increasing the number of specialist nurses for patients with metastatic breast cancer is difficult to realise in the current economic climate. However, it may be possible for breast care nursing teams to review their service provision for people with metastatic breast cancer with a view to recommending and implementing changes

based on their findings. This toolkit provides guidance on how to go about this.

1.3 National guidance, targets and standards

The following table highlights key policy documents specifically relevant for clinical nurse specialists who care for metastatic breast cancer patients.

Policy Document/ web link	Author/Led by	Relevant UK nation and date published	Overview of document	Specific reference to nursing
<p>NICE clinical guideline 81. Advanced breast cancer. Diagnosis and treatment</p> <p>www.nice.org.uk/nicemedia/live/11778/43305/43305.pdf</p>	<p>National Institute for Health and Clinical Excellence (NICE)</p>	<p>England and Wales, 2009</p>	<p>The advice in the NICE guideline describes the tests, treatment, care and support that patients with advanced breast cancer should be offered.</p>	<p>Chapter 5, Community-based treatment and supportive care includes recommendations on psychosocial assessment and access to a key worker.</p>
<p>UK Guidance Document: Treatment of Metastatic Breast Cancer</p> <p>www.science-direct.com/science/article/pii/S093665511008831</p>	<p>Coleman, R.E. et al. Includes Tara Beaumont, Clinical Nurse Specialist (CNS), Breast Cancer Care</p>	<p>England, Scotland and Wales, 2011</p>	<p>This guidance document aims to provide succinct practical advice on the treatment of metastatic breast cancer, highlighting some limitations in the NICE guidelines and providing suggestions for management where data are limited.</p>	<p>The guidance supports the need for all metastatic breast cancer patients to have access to a clinical nurse specialist.</p>
<p>1st international consensus guidelines for advanced breast cancer (ABC1). <i>The Breast</i> 21 (3), 242-525 (2012)</p>	<p>Cordosa, F., Costa, S., Norton, L., Cameron, D., Cufer, T., Fallowfield, L.</p>	<p>England, Scotland and Wales, 2012</p>	<p>The European School of Oncology created an Advanced Breast Cancer (ABC) Taskforce in 2005 due to a lack of international consensus on managing this patient group. This led to the first international consensus guidelines conference on advanced breast cancer in Nov 2011. This paper summarises the guidelines developed.</p> <p>They are intended to be management recommendations that can be applied internationally, albeit with the necessary adjustments for each country.</p>	<p>Supportive care recommendation – every patient with metastatic breast cancer should have access to a clinical nurse specialist with the appropriate skill set.</p>

Policy Document/ web link	Author/Led by	Relevant UK nation and date published	Overview of document	Specific reference to nursing
<p>End of Life Care Strategy - promoting high quality care for all adults at the end of life</p> <p>www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277</p>	<p>Department of Health</p>	<p>England, 2008</p>	<p>The End of Life Care Strategy promotes high-quality care for all adults at the end of life. Its aim is to provide people approaching the end of life with more choice about where they would like to live and die. It encompasses all adults with advanced, progressive illness and care given in all settings.</p>	
<p>Quality standard for breast cancer</p> <p>www.nice.org.uk/media/F66/90/BreastCancerQualityStandardFinal.pdf</p>	<p>National Institute for Health and Clinical Excellence (NICE)</p>	<p>England, 2011</p>	<p>Contains 13 quality statements covering different aspects of diagnosis and treatment</p> <p>Statements 11, 12 and 13 are secondary breast cancer specific.</p>	<p>Statement 11 'People with secondary breast cancer have access to a key worker, who is a clinical nurse specialist whose role is to provide continuity of care and support, offer referral to psychological services if required and liaise with other healthcare professionals, including the GP and specialist palliative care services.'</p>

Policy Document/ web link	Author/Led by	Relevant UK nation and date published	Overview of document	Specific reference to nursing
<p>Quality in Nursing Excellence in Cancer Care: The Contribution of the Clinical Nurse Specialist</p> <p>ncat.nhs.uk/sites/default/files/Excellence in Cancer Care.pdf</p>	<p>National Cancer Action Team, NHS and Macmillan Cancer Support</p>	<p>England, 2010</p>	<p>This short guide is designed to support clinical teams, commissioners, employers and managers to understand and evaluate the contribution of CNSs in cancer as they plan their local workforce and service improvement strategies.</p>	<p>Defines the four main functions of CNSs working in cancer care as:</p> <ul style="list-style-type: none"> • using and applying technical knowledge of cancer and treatment to oversee and coordinate services, personalise 'the cancer pathway' for individual patients and to meet the complex information needs of patients and their families • acting as the key accessible professional for the multidisciplinary team, undertaking proactive case management and using clinical acumen to reduce the risk to patients from disease or treatments • using empathy, knowledge and experience to assess and alleviate the psychosocial suffering of cancer including referring to other agencies or disciplines as appropriate • using technical knowledge and insight from patient experience to lead service redesign in order to implement improvements and make services responsive to patient need.

Policy Document/ web link	Author/Led by	Relevant UK nation and date published	Overview of document	Specific reference to nursing
<p>Management of breast cancer in women. A national clinical guideline 84</p> <p>www.sign.ac.uk/pdf/sign84.pdf</p>	<p>Scottish Intercollegiate Guidelines Network (SIGN)</p>	<p>Scotland, 2005</p>	<p>Most of the clinical guidance refers to primary disease but issues around supportive care, for example, are relevant to those with secondary disease.</p> <p>Section 7.3 directly refers to metastatic disease</p>	<p>All women with a potential or known diagnosis of breast cancer should have access to a breast care nurse specialist for information and support at every stage of diagnosis and treatment. Contact details and information about the role of the breast care nurse should be available to the patients, their families and all members of the multidisciplinary team.</p>
<p>Better Cancer Care, an Action Plan</p> <p>www.scotland.gov.uk/Resource/Doc/242498/0067458.pdf</p>	<p>The Scottish government</p>	<p>Scotland, 2008</p>	<p>Pan-cancer document.</p> <p>Section 7 – Living with Cancer</p> <p>See also Better Cancer Care, an Action Plan Progress Report December 2010 www.scotland.gov.uk/Topics/Health/health/cancer/progressreport</p>	
<p>Management of Breast Cancer Services Standards</p> <p>www.healthcareimprovement.scotland.org/programmes/cancer/standards_for_cancer_services.aspx</p>	<p>NHS Quality Improvement Scotland</p>	<p>Scotland, 2008</p>	<p>Contains clinical standards for breast cancer services. Specific to secondary breast cancer, p.11</p> <p><i>'There is discussion of patients with new recurrence or metastatic disease by the core breast cancer MDT.'</i></p>	<p>Patients with a suspected or known diagnosis of metastatic breast cancer have access to a named breast CNS, or alternative in rural units, for information and support throughout treatment.</p>
<p>Living and Dying Well: A national action plan for palliative and end of life care in Scotland</p> <p>www.scotland.gov.uk/Publications/2008/10/01091608/0</p>	<p>The Scottish Government</p>	<p>Scotland, 2008</p>	<p>Living and Dying Well uses the concepts of planning and delivery of care, and of communication and information sharing, as a framework to support a person-centred approach to delivering consistent palliative and end-of-life care in Scotland.</p>	

Policy Document/ web link	Author/Led by	Relevant UK nation and date published	Overview of document	Specific reference to nursing
<p>National Standards for Breast Cancer Services</p> <p>www.wales.nhs.uk/sites3/Documents/983/Breast_Cancer_Eng.pdf</p>	<p>Welsh Assembly Government</p>	<p>Wales, 2005</p>	<p>Standards on Palliative care page 33</p>	
<p>National Standards for Rehabilitation of Adult Cancer Patients</p> <p>http://wales.gov.uk/docs/dhss/publications/100816nationalrehabstandardsen.pdf</p>	<p>Welsh Assembly Government</p>	<p>Wales, 2010</p>	<p>The standards detail the key elements of the diagnostic and treatment process that patients should expect to receive. These include requirements for patient-centred care, the formation and work of local, network and supra-network level multidisciplinary teams (MDTs), adherence to and audit against nationally agreed clinical guidelines, and waiting times from referral or diagnosis to start of definitive treatment.</p>	
<p>Improving Supportive and Palliative Care for Adults with Cancer</p> <p>www.nice.org.uk/nicemedia/live/10893/28816/28816.pdf</p>	<p>NICE, 2004</p>	<p>England and Wales, 2004</p>	<p>The guidelines advise those who develop and deliver cancer services for adults with cancer about what is needed to make sure that patients, and their families and carers, are well informed, cared for and supported. Guidelines contain recommendations about needs assessment, information provision, and access to support services including specialist psychological support, and communication guidelines. Widespread implementation of these guidelines should significantly improve the support and care of people with metastatic breast cancer.</p>	<p>All patients allocated a key worker who can coordinate the patient's care and whom they could contact at any time.</p>

Policy Document/ web link	Author/Led by	Relevant UK nation and date published	Overview of document	Specific reference to nursing
National Standards for Specialist Palliative Care Cancer Services http://wales.gov.uk/docrepos/40382/dhss/nationalstandardscancer/english/specialist-pallcare-e.pdf?lang=en	Welsh Assembly Government Cancer Services Co-ordinating Group	Wales, 2005	Cancer Standards define the core aspects of the service that should be provided for cancer patients throughout Wales.	
National Cancer Survivorship Initiative Vision Document www.ncsi.org.uk/wp-content/uploads/NCSI-Vision-Document.pdf	NHS Improvement	England, 2010	6. p.48 includes those with advanced disease	
Active and Advanced Disease (NCSI) www.ncsi.org.uk/what-we-are-doing/active-advanced-disease	Department of Health, Macmillan Cancer Support, NHS Improvement	England, 2012	This project looks at issues faced by cancer survivors with active and advanced disease.	

Policy Document and web link	Author/Led by	Relevant UK nation and date published	Overview of document	Specific reference to nursing
<p>Together For Health – Cancer Delivery Plan</p> <p>http://wales.gov.uk/docs/dhss/publications/120613cancerplanen.pdf</p>	<p>Welsh Assembly Government</p>	<p>Wales, 2012</p>	<p>A Delivery Plan for NHS Wales up to 2016. Pan-cancer document</p>	<p>Particularly relevant to secondary breast cancer is P12.</p>
<p>Improving Outcomes: A Strategy for Cancer</p> <p>www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123394.pdf</p>	<p>Department of Health</p>	<p>England, 2011</p>		<p>1.25, Pg. 11 Metastatic breast cancer data collection</p>
<p>Spotlight on secondary breast cancer: a policy initiative to influence the care of women with metastatic breast cancer. Breast Cancer Management (Sept 2012), 1 (3), 201-207</p>	<p>Reed, E., Wheeler, D., Scanlon, K.</p>	<p>UK, 2012</p>		

Module 2 – Excellence in practice

This module sets out the key skills required by specialist nurses caring for patients with metastatic breast cancer. It also examines key interventions undertaken by nurses who carry out this role.

2.1 Core competencies

From the work undertaken by the Secondary Breast Cancer Taskforce (2008) the core competencies needed for a CNS caring for patients with metastatic breast cancer were defined.

Knowledge

- Specialist knowledge of metastatic breast cancer, treatment and the illness trajectory.*
- Specialist oncology knowledge.
- Understanding of the implications of living with a chronic illness.
- Understanding of the psychosocial, spiritual/existential impact of metastatic breast cancer on the patient and their family.*
- Palliative care knowledge.*
- Knowledge of local and national support services for metastatic breast cancer patients.*
- Knowledge of current clinical research and trials.
- Knowledge of end-of-life care guidance.
- Knowledge of national and local information and support to patients' families.

Skills

- Ability to support patients in decision making.
- Ability to case-manage complex care, acting as a coordinator for patient care and liaising with all health/social care and other professionals involved in patient care.
- Advanced communication skills.
- Advanced assessment skills.
- Ability to discuss long-term illness issues, palliative care and end-of-life issues.*
- Ability to provide information to the patient using a number of different models and tools.
- Ability to identify patients who may require individual counselling.
- Ability to be the patient's advocate.
- Ability to support patients with a self-management approach to their care.

The CNS must also:

- ensure patients are given their contact details at diagnosis
- have access to relevant information about the patient
- be available to talk with the patient as soon as possible after a diagnosis of metastatic breast cancer*
- have access to clinical supervision.

Supporting guidelines

- In addition to these core competencies Breast Cancer Care fully supports the RCN guidance for nursing staff *Clinical standards for working in a breast specialty* (2007). The standards contain essential knowledge and skills which are the prerequisites for competent nursing practice.
- Breast Cancer Care also recommends that a CNS must be competent at levels 3 or 4 within the NHS Knowledge and Skills Framework.

* Breast Cancer Care recognises that taking on this role may mean some healthcare professionals will need additional training.

2.2 A diagram showing the attributes of specialist nurses in metastatic breast cancer

Breast Cancer Care commissioned research to explore the complexity and value of the metastatic breast care specialist nursing role. This examined the clinical, emotional and financial benefits of the role.

Using a combination of qualitative and quantitative research, a focus group was held with 12 nurses who predominantly cared for metastatic breast cancer patients. Here the nurses articulated the attributes of nursing required to manage these patients.

See diagram overleaf.

Attributes of secondary breast care nursing

Oncology knowledge and skill

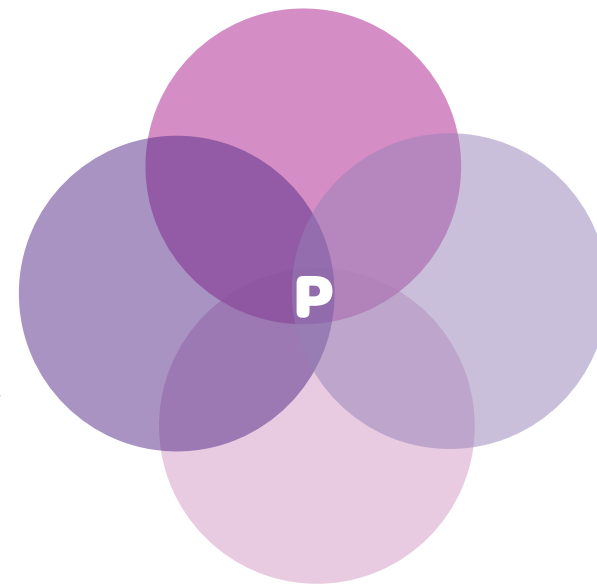
Cancer trajectory/pathway/complex care management/assessment
 Understanding of cancer/metastatic disease
 Pathology, treatment, psychosocial issues/long-term conditions

Personal attributes

Education
 Flexible
 Diplomatic
 Experience
 Autonomous
 Communication skills
 Life experience/empathy
 Coping strategies

Palliative care knowledge and skill

Symptom management
 Psychosocial care
 Dealing with death and dying



Breast care knowledge and skill

Understanding of breast cancer/treatments
 Assessment
 Psychosocial issues

P= Specialist metastatic breast care nursing

2.3 The benefits of specialist nurses in metastatic breast cancer

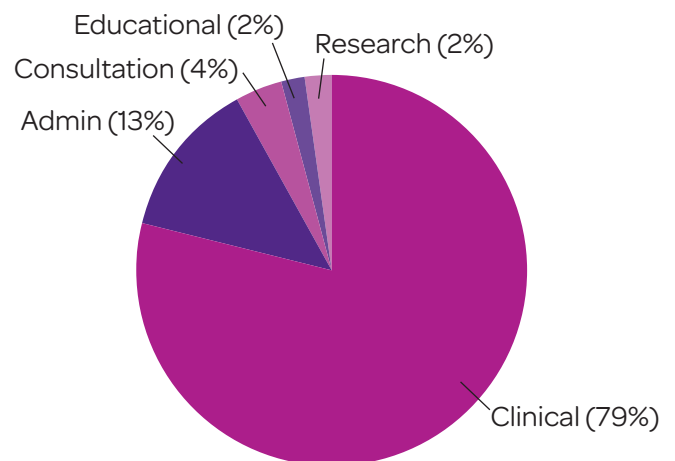
Following the research (2.2) the nurses entered data into the Pandora inter-relational database, developed by University College London Hospital NHS Foundation Trust and NHS Innovations, which articulates the work of the CNS.

Data from this research is used here to demonstrate the benefits of metastatic breast cancer nursing.

2.4 Coordinating and providing continuity of care

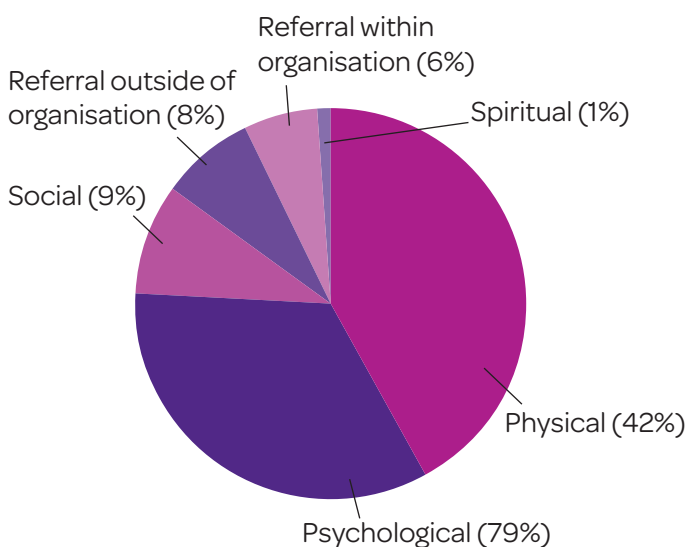
CNSs working with patients with metastatic breast cancer spend almost 80% of their time engaged in clinical work (see figure 1). This involves: providing direct clinical care to patients, meeting clinical needs such as symptom control or supporting patients in clinical choices, using professional judgement to coordinate care or providing other clinical staff such as GPs and hospital staff with expert clinical advice in this area of care. The range of work undertaken highlights the breadth of skills needed to undertake this role.

Figure 1 Type of intervention



Clinical work is varied with a large proportion (43%) consisting of providing psychological and social interventions. Forty-two per cent are physical interventions for patients and 14% are referrals. This can be seen in Figure 2.

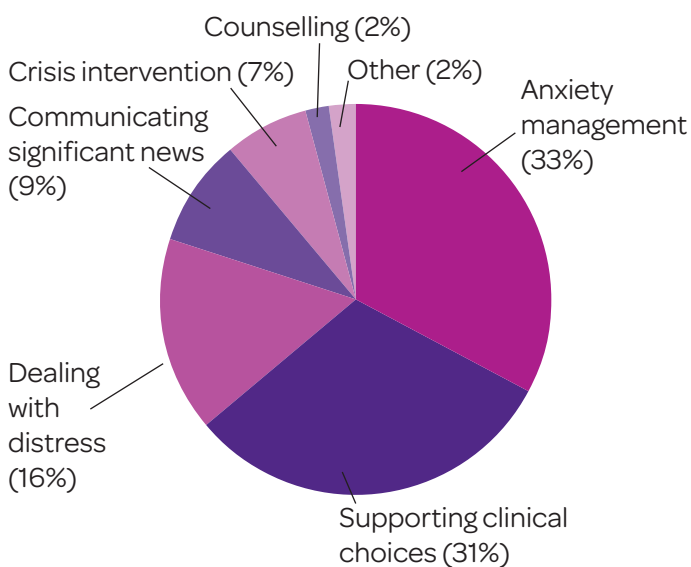
Figure 2 Breakdown of clinical work



2.5 Applying specialist knowledge and skills

Metastatic breast cancer carries a considerable psychosocial morbidity (Grabasch et al, 2006). CNSs working with patients with metastatic breast cancer focus much of their clinical work on providing specialist psychosocial support. The types of psychological care/interventions can be seen in Figure 3. This support is primarily in the form of anxiety management around disease progression/prognosis and supporting clinical choices. The poorer prognosis of metastatic breast cancer patients can mean higher risk of psychosocial distress (Svensson et al, 2009). This may also mean that the pattern and natural course of distress is different from those diagnosed with early stage disease. This has implications for the management of care and the differences in support required by this group of patients.

Figure 3 Psychological care interventions



0% responded to *Managing iatrogenic distress or anxiety*

Assessment of need is a core recommendation in *Supportive and Palliative Care for Adults with Cancer* (NICE, 2004) and is also recommended in the NICE guidance *Advanced breast cancer: Diagnosis and treatment* (NICE, 2009). Nurse specialists who have an understanding of the emotional impact of metastatic breast cancer are better placed to be able to assess the needs of this patient group and provide them with, or refer them to, appropriate support services. Providing such specialist and specific advice means that patients and families can enjoy a better quality of life.

'She (CNS) referred my son to counselling, which has really helped him. She also arranged counselling for me, but she will also sit and listen when I'm bawling my eyes out. She also told me about the local support group in my hospice. Without her I don't think I would be able to cope – she's taken stress off me. Without her I think I would have been a nervous wreck.' Patient

2.6 Coordinating complex care

A unique understanding of the patient experience, clinical knowledge and professional experience in metastatic breast cancer means that CNSs are able to negotiate on behalf of patients. They use highly developed coordination strategies to make pathways more efficient, applying local knowledge to speed up referrals and improve patient experience.

CNSs caring for patients with metastatic breast cancer patients are often responsible for developing and leading services in providing care for this patient group. The range of clinical and physical work they undertake can be seen in Figure 4.

Patients with metastatic breast cancer experience a range of symptoms relating to their disease and treatment such as pain, fatigue and sleeplessness (Aranda et al, 2005; Reed et al, 2012). CNSs working with these patients spend 46% of their clinical time directly managing patients' symptoms. Almost a quarter of their time is spent offering specialist symptom management and a further 15% recommending specialist and specific care to the multi-professional team. Yet research has shown that many patients with metastatic breast cancer do not receive adequate symptom relief, particularly in alleviating pain (Lebel et al, 2007). This highlights the importance of CNSs having expert knowledge of metastatic breast cancer being able to provide adequate symptom relief for patients.

'When I was diagnosed with secondaries my GP tried to help with my pain but it was like, try this, try that, try the other, then I was allocated a specialist nurse and she is right on the ball. Twice now when my pain has become

more severe she has assessed my needs at home and changed my pain control and I haven't needed to go into the hospice.' Patient

CNSs working with patients with metastatic breast cancer also apply their unique understanding of the disease to manage complex pathways and ensure continuity of care. Their knowledge includes recognising signs and symptoms of oncological emergencies, which are a risk for patients with metastatic breast cancer. They can ensure that the patients see the most appropriate members of the multi-professional team at the right time. This can be of particular importance in the management of comorbidities:

'I was concerned about symptoms described by a patient on the telephone – I arranged immediate review and MRI as the patient had the symptoms of spinal cord compression.' CNS narrative

An in-depth knowledge of services allows CNSs to play a strategic part in evaluation. They are exposed to patient opinion and perception every day and are able to inform tools such as patient satisfaction questionnaires or support patients in partnership working. CNSs regularly caring for patients with metastatic breast cancer (at least weekly) resolve unsatisfactory patient experiences before the formal complaints process is used; they use local knowledge to achieve the best outcome, which is often in the sphere of enhancing communication or mediation.

'The PALS office say they always know when I am away.' CNS narrative

2.7 Meeting information needs and empowering patients

It has been recognised that there are gaps in the information provided to those with advanced cancer (DH, 2007). Information needs are high in patients with metastatic breast cancer and it is essential that these are addressed (Sanson-Fisher et al 2000, Aranda 2005, 2006). Previously a strong reliance on doctors for information had been noted. However, more recent evidence shows patient preference for nurse information providers in contrast to other healthcare professionals, including doctors, particularly in terms of symptom control (Koutsopoulou et al 2010).

Research has shown that patients with metastatic breast cancer who have their information needs met have reduced feelings of anxiety and are less likely to be depressed (Mayer, 2006).

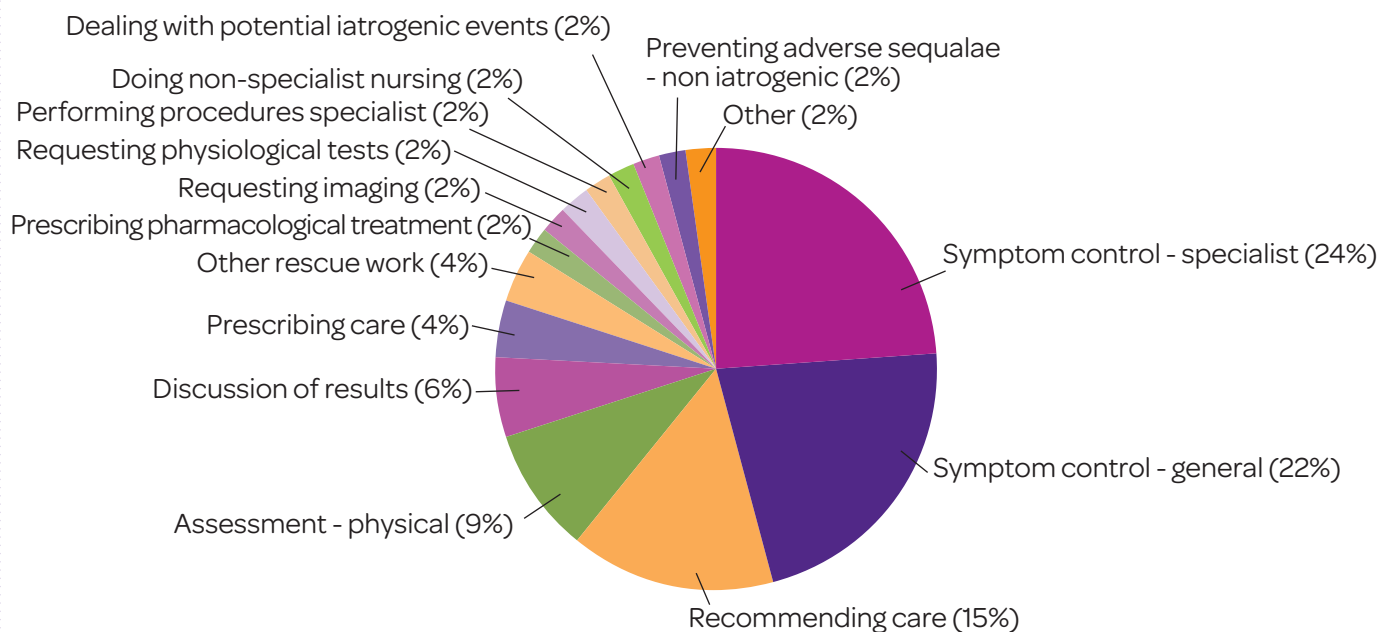
'The questions about my treatment, my doctor [GP] wouldn't have been able to answer those and my consultant doesn't give you enough time to ask those questions, so I wouldn't have had anyone to go and talk to had it not been for my nurse.' Patient

It is vital that support is provided alongside information given to patients to ensure the patient fully understands about their cancer and its management.

'I spent time discussing secondary breast cancer and the aims of treatment with a new inpatient.' CNS narrative

Nurse specialists with expertise in metastatic breast cancer are able to assess the information needs of patients and their families, and provide timely and accurate information.

Figure 4 The physical dimension of clinical care by CNSs working with patients with metastatic breast cancer



'Sometimes you need to have several conversations about recurrence with patients and families – they sometimes just don't take it in the first time.'

CNS narrative

Assessment of information needs is a key recommendation in the NICE advanced breast cancer guidelines (2009) and the ABC1 guidelines (Cardoso, et al 2012) – CNSs with skills and knowledge of metastatic breast cancer are essential to achieve this.

The expertise of CNSs caring for this patient group means they are aware of the range of issues people face and can provide information and continuing support. This experience also allows CNSs to assess the need for information where there may be gaps in provision and be at the forefront of information development.

'My nurse has helped sort out the benefits I am entitled to and got me a grant via Macmillan.' Patient

'The nurse sorted me out with a disabled badge.' Patient

Not having access to a CNS in metastatic breast cancer means that supportive, tailored information is difficult to access resulting in the cancer experience being even more challenging for patients.

'The only advice we get, or the chance to ask questions, is when something is wrong, and then when we do ask we're not always given the explanation of what to expect or how it's going to affect us. There are times you want to know something and there is no-one there to ask – we can cope at the hospital, but when we come away we've got nothing.' Husband of patient

2.8 Preventing unscheduled hospital admissions

CNSs working in metastatic breast cancer use their expertise to facilitate appropriate admission, discharge and referral to other members of the multidisciplinary team.

'The patient was due to go to a hospice but was in hospital as a brace had not been fitted. I arranged for the local clinicians to be involved and the brace to be delivered to the hospice where a local clinician agreed to fit it; the patient was able to go to the hospice and did not have to stay in hospital.' CNS narrative

CNSs working with metastatic breast cancer patients prevent emergency admissions to hospital. They provide an alternative to unscheduled care by helping keep patients in the community. They do this by working with community teams and GPs to provide clinical solutions to complex problems. Sixty per cent of the CNSs' work is dealing with community-based issues. According to the NHS Information Centre,

specialised nurses prevent an unscheduled care episode approximately 26 times a year.

CNSs caring for patients with metastatic breast cancer reduce new to follow-up ratios in cancer units, releasing clinic and outpatient time for new patients. A CNS specialising in metastatic breast cancer will see an average of 13 follow-up patients per week in an outpatient setting. Matched against the DH tariff this represents £53,040 in income and the potential release of 13 slots to new patients (new medical oncology £159,120 per 48 week year). This means CNSs working with metastatic breast cancer patients can speed up pathways, helping trusts meet targets and allowing new patients to be seen which allows for generation of income.

2.9 Supporting patients in clinical decision-making

People with metastatic breast cancer can face many difficult decisions around treatment, such as which treatment to have or whether to discontinue treatment. CNSs in metastatic breast cancer provide expert information at the appropriate level and time to assist with these decisions. Having a trusted relationship with the patient also ensures they and their family can make these difficult decisions in a supportive environment. The CNS can facilitate choice, particularly where patients are facing difficult decisions, for example about whether to continue with treatment:

'I might need to have chemo again. If I said I didn't want it, I think she [CNS] would support me and listen.' Patient

Supporting patients with metastatic disease through choice and decision making is a key component of the role of the CNS in metastatic breast cancer. This is emphasised by the Cancer Reform Strategy (DH, 2007) which recommends patient involvement in decision making. The experience and expertise of this group of nurses can ensure that partnership working becomes a reality. A third of psychosocial support interventions given by the CNS are around supporting patients to make these clinical choices. To make informed choices, patients with metastatic breast cancer need access to knowledgeable, professional and accessible support.

'I spent time with a patient advising on possible treatment options if current treatment is failing, and how to cope with this, that is, side effects of treatment on a daily basis and how to cope with family life.' CNS narrative

Module 3 – Making the change

This module sets out the steps you can take to make changes to your specialist nursing service. We recommend you read the article ‘Proving your worth’ by Alison Leary (2011) in addition to this module.

3.1 Identifying the number of patients diagnosed with metastatic breast cancer at your place of work

Identifying the number of patients with metastatic breast cancer within your place of work, including those who are living with the disease and the number newly diagnosed each year, can be tricky. The following may help capture this information.

- Consider consulting oncology clinics and Accident and Emergency department.
- Use past audit or local statistics, if available, or consider speaking to your local cancer registry about what is recorded in your area.
- Check with your MDT meeting coordinator if any records are kept of patients with metastatic breast cancer discussed at the breast MDT meeting.
- If possible carry out a short audit of the number of patients with metastatic breast cancer seen by a specialist nurse and also the number of patients ‘missed’.

3.2 Gathering evidence of need

- Consider carrying out a patient experience survey. This can provide vital pointers for improving the service and will also be an essential benchmark for auditing against any changes you make. Breast Cancer Care has developed a template survey you can adapt and use – see Appendix 1.
- Identify possible patient representatives/case studies whose accounts will highlight gaps in care. Evidence from patients will strengthen your case for making changes to your service – this can be anecdotal evidence from patient caseload, local user groups, Patient Advice and Liaison Service (PALS), and so on.
- Patient reports of how contact with a specialist nurse significantly contributed to care or, conversely, how the absence of a clinical nurse specialist resulted in gaps in care are valuable evidence.
- You could also seek opinion from local patient groups. You could suggest they attend Cancer Network meetings to highlight the issue. Breast Cancer Care has developed a short guide for people who want to campaign for improved standard of

care for people with metastatic breast cancer called **Taking action together.**

3.3 Harnessing support from MDT colleagues

- If you are going to submit a bid for increased specialist nursing time or a dedicated post for metastatic breast cancer, consider doing it with oncologists and other relevant colleagues.
- Look at arranging meetings with the senior management team/Cancer Network managers/lead cancer nurses to present the key issues and gaps in care that can be met by specialist nurses.
- Try to identify champions/allies for your cause and nurture them.
- Consider taking a user representative to meetings. Try to identify benefits to the other MDT members – saving their time, streamlining care, reducing admissions and enhancing adherence to treatment.
- If possible, show cost-savings as commissioners notice these. See our case studies section in Module 5 for some examples of how this has been done. See also Module 4, section 4.2 for more suggestions about this.

3.4 Learning from others

- Join Breast Cancer Care’s **Nursing Network** to support your professional development. The Network keeps you up to date with the latest developments in breast cancer.
- Make contact and visit existing teams who have changed their service to meet the needs of patients with secondary breast cancer.
- Get in touch with your Cancer Network service development managers for advice.
- Contact Breast Cancer Care (**secondarycampaigning@breastcancercare.org.uk**) for a contact list of nurses who provide specialist care to patients with metastatic breast cancer.
- Consider contacting Macmillan Cancer Support – it offers funding for three years towards specialist nursing posts. There should be a Macmillan development manager for your area who can offer advice.
- Use the NICE *Advanced breast cancer: Guide to resources* for implementing their advanced breast cancer guidance (NICE, 2009a). It contains a series of case studies of nurses who are in post as specialist breast care nurses for secondary breast cancer, how their roles work and their remit.

- Gather national documents that recommend specialist nursing input for patients with metastatic breast cancer, such as the NICE *Quality Standards for Breast Cancer* (NICE, 2011). See Module 1.3 for more information on meeting healthcare policy and standards.
- Identify local cancer charities who may consider funding/part funding. The National Cancer Research Institute (NCRI) could be an option if there is a commitment to increase the number of patients with metastatic breast cancer into clinical trials locally. Your local cancer clinical trials coordinator should have more information.

3.5 Identifying what is needed in your place of work

Each hospital will have different needs based on existing services. Plan the ideal model for a specialist nursing service in your unit. Think about:

- your existing breast care nursing team
- using administrative support to free nursing time
- other ways your role could be streamlined
- whether proposed role changes/additions will be a dedicated post holder or shared within the team (see the case studies included in this toolkit)
- talking to other cancer nurse specialists and other nurse specialists about the development to their teams – they may have made changes you can learn from
- exploring different ways of communicating with patients, for example, use of email, nurse-led clinics and support groups
- your resources – you may have to consider if you are taking on some new aspects of care what impact this will have elsewhere.

3.6 Carrying out patient focus groups

Focus groups are a good way to explore your patients' problems and needs to help you develop your service. This approach allows you to gather information from different patients with different experiences. As the group explores through discussion, patients share, discuss and challenge different viewpoints. This is a quick guide to what you need to consider if you want to run focus groups.

1. Purpose: be clear about what your aims and objectives are and what you want to learn from running a focus group. This is the first step before you begin to plan the process.
2. Planning: you will need to have a safe, quiet area where you run the group that can be easily accessed by your patients. Consider disabled access for those with limited mobility. You will also need to consider ways you will facilitate the group so that everyone is able to contribute; how you may deal with someone who dominates the group and those who are quiet.
3. Data collection: consider what equipment you will need. Some focus group facilitators use flip charts, while others find that taping the group is useful.

Either way you will need an effective means of gathering the data from the group.

4. The group: consider how many patients you will have in the group. On average six-eight group participants are a reasonable number – enough to allow group discussion and small enough to be able to facilitate the group effectively. To begin the group you may want to use an 'ice breaker' to help the patients relax a little.
5. Data analysis: try to ensure that two people listen to the tapes or read the transcripts and independently identify the key issues and themes. Then they should meet to discuss each other's impression of the data and what it reveals.
6. Report writing: your final report needs to convey to others the key issues in a concise and effective way. While it is important to keep it succinct and brief it is imperative that the reader understands what you found and the action plan you have for developing your service based on the findings.

Module 4 - Promoting the change in your nursing service

This module highlights ways of promoting the change in your nursing service for your metastatic breast cancer patients.

4.1 Communicating your existence

- Be sure to communicate the altered or extended service at every level so that everyone knows to refer patients to you, particularly if your team has not previously been involved in supporting patients with metastatic breast cancer.
- Tell patients you exist; including support groups and user groups. Inform relevant colleagues such as community palliative care teams, local hospices, GPs and cancer information centres.
- Use local media to publicise the service if appropriate (you will need to speak to your hospital press office beforehand).
- Be clear what the remit of the service is when you describe it to others.
- Ask your Cancer Network to put the issue on the agenda of the Network breast cancer site specific meeting.
- Tell us! We want to promote best practice examples, through our website and through our Nursing Network (which has more than 730 members) learn more about our Nursing Network **on our website** www.breastcancercare.org.uk/nursing-network

4.2 Proving your worth

- It will be important to keep accurate and up-to-date data to inform an annual audit and review.
- Try and carry out regular reviews of the service and its impact on the specialist nursing team.
- Also remember the importance of gathering patient evaluations – see Appendix 1 for a template patient experience survey. Breast Cancer Care's **Standards of care for people with secondary breast cancer** could also be useful.
- Try and establish clear working protocols. One recommendation would be to ensure contact is made with every patient within two weeks of diagnosis of metastatic breast cancer.
- It is important to consider support for yourself in carrying out this role.
- Remember to consider support for the service, for example: clinical supervision; how the service will be covered for holidays/sick leave; training and

development.

- It may help when approaching commissioners, colleagues and managers to be able to demonstrate in a measurable way the value of the CNS role for patients with metastatic breast cancer.
- There are a number of ways you may choose to do this, but below are some tips on how you might approach collecting data. In Module 6 – Useful reading there are several articles that give a more in-depth insight into providing evidence of the value of the CNS role.

4.3 Saving time and money

- You may wish to consider how you can demonstrate the CNS role saves the hospital trust money.
 - Avoiding hospital admission; ward stay, A&E admission.
 - Telephone work, reducing outpatient appointments, working with community colleagues to provide care in the community.
 - Nurse-led clinics.
 - Nurse prescribing and symptom control.
 - You may also be able to show how the same CNS interventions also benefit the patient and families.
 - Time/money saved by not needing to attend the hospital.
 - Preferred place of care considered.
 - Timely symptom control intervention; detailing how this would have been addressed if not done by CNS.
 - Coordination of care, demonstrating impact on patient if this is not carried out by a CNS.
 - See 2.8 for more tips.

Dr Alison Leary has developed a tool called Cassandra to help CNSs show how they spend their working time, which you may find helpful. The tool and information about how to use it can be found on Alison's website <http://alisonleary.co.uk/> under resources.

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 community services.
- 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

National Comprehensive Cancer Network (2007)
NCCN Clinical Practice Guidelines in Oncology:
Distress Management (version 1.2007). Available from
NCCN website (<http://www.nccn.org/index.asp>).

Joanne Beaumont

Macmillan Breast Care Clinical Nurse Specialist
Sheffield Teaching Hospitals NHS Foundation Trust,
Weston Park Hospital Cancer Services

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.

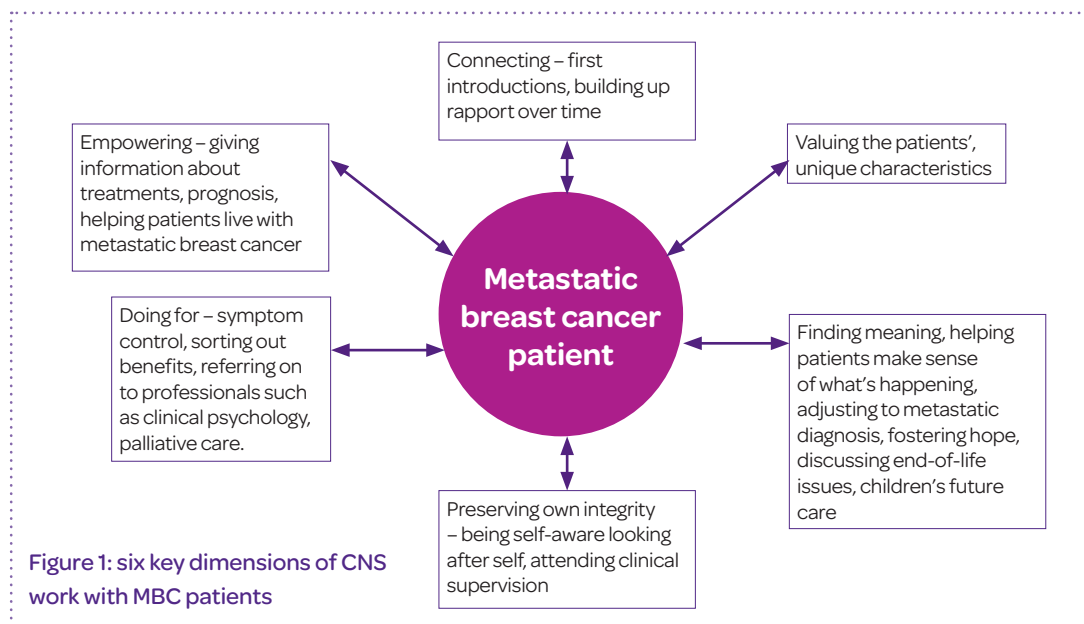
On initial presentation of metastatic disease, most patients require a lot of support while they adjust. Once they are stabilised and responding to treatment, less support is often required. Patients access the service according to their need. The most relevant times for them appear to be at initial 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.



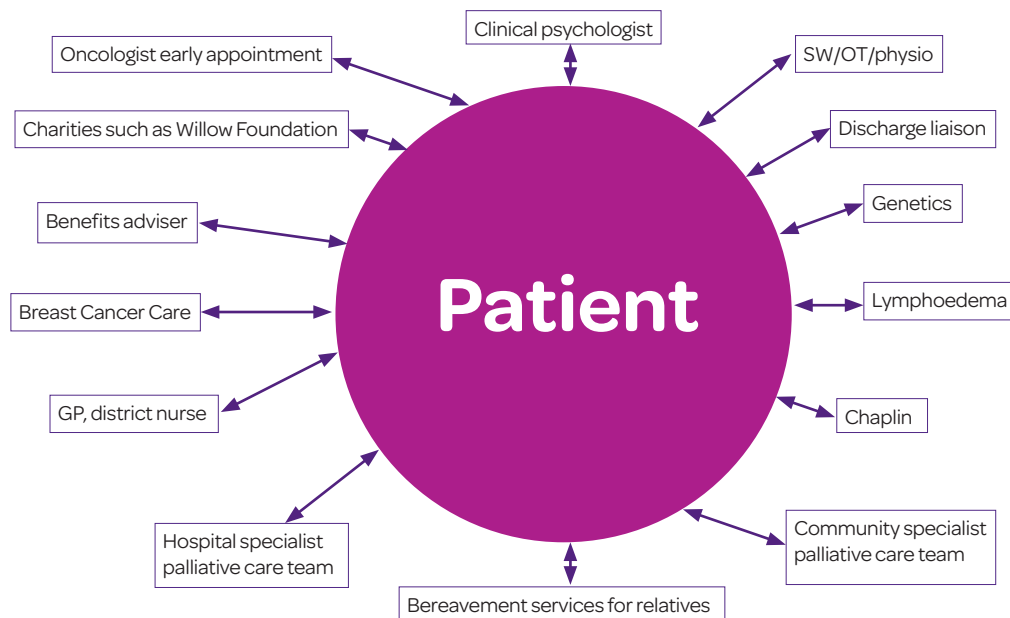


Figure 2: the breast CNS can link patients to appropriate services

- 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 emphasize 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

Davis, B., Oberle, K. (1990) ‘Dimensions of the supportive role of the nurse in palliative care.’ *Oncology Nursing Forum*, 17 (1), 87-94

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.

With approximately 550,000 people being diagnosed with breast cancer in the UK, breast care nurses have huge caseloads and unfortunately there are not the resources to cover metastatic clinics. Therefore we often do not know that these patients have been diagnosed with metastatic disease.

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 team 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.

Telephone contacts that can reduce unnecessary outpatient appointments (OPA)

- Coordinating investigations and OPA (results ready at OPA).
- Symptom control advice.
- Referral to palliative care.
- Reassurance.
- Explaining what was discussed in an OPA.
- Initiating investigations following discussion with medical team.

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)

Module 6 - Useful reading

This section includes a brief description or an abstract of articles you might find helpful. Full references are included.

Hardy, H. , Leary, A. (2010) 'Value to patients of a breast cancer clinical nurse specialist'. *Nursing Standard*, 24 (34), 42-47

Aim To compare patient experiences of the breast cancer nursing service before a CNS was established in post and then one year after their appointment. Method A questionnaire was handed out to 50 patients over a six-week period in May 2007 (pre-CNS survey) and one year later (post-CNS survey) to 32 of the original patients. Analysis was performed on the numerical data using Microsoft Excel. Content analysis was used to extract information from the free text.

Findings The evaluation showed that the CNS improved respondents' experiences and satisfaction with the breast cancer service. The pre-CNS survey highlighted that respondents wanted the CNS to be available after their consultation with the doctor to further explain information, and between clinic appointments to provide advice. Respondents also wanted the CNS to be a point of contact, to have specialist knowledge and to offer advice and support. The second survey showed that the CNS had improved the patient experience, and respondents were more satisfied with the service provided.

Conclusion This service evaluation supports the value of the CNS in improving patient experiences and developing services.

Leary, A. (2011) 'Proving your worth', *Nursing Standard*, 25 (31), 62-63

Alison Leary has tips on how nurse specialists can demonstrate added value.

[http://alisonleary.co.uk/docs/Proving your worth \(CNS all specialisms\).pdf](http://alisonleary.co.uk/docs/Proving_your_worth_(CNS_all_specialisms).pdf)

National Cancer Action Team, Macmillan Cancer Support (2010) *Quality in Nursing Excellence in Cancer Care: The Contribution of the Clinical Nurse Specialist*

This short guide is designed to support clinical teams, commissioners, employers and managers to understand and evaluate the contribution of CNSs in cancer as they plan their local workforce and service improvement strategies.

Oliver, S., Leary A. (2012) 'Return on investment: workload, complexity and value of the CNS'. *British Journal of Nursing*, 21 (1), 32, 34-7

The rheumatology nurse specialist (RNS) has become an integral and vital part of the multidisciplinary team and is valued by patients. Yet a number of challenges regularly face all CNS in the UK. The perception that CNSs are an expensive and poorly defined nursing resource results in regular threats to their sustainability, particularly that of the RNS. This study examined return on investment of the RNS.

Method An interrelational Structured Query Language database collected data on the day-to-day activities of the RNS based on previous models of CNS and RNS work, and qualitative narrative data were then subjected to data mining.

Results The RNS represented an excellent return on investment, in terms of income generation activity, patient safety and efficiency. These outcomes were achieved using key principles of proactive case management using vigilance, rescue work and brokering. The mean average per whole time equivalent RNS per annum represents £175,168 in terms of income/savings to an employing NHS Trust. This figure is likely to be an underestimation, as calculations on reduction in bed days in hospital have not been included.

Reed, E., Scanlon, K., Fenlon, D. (2010) 'A survey of provision of breast care nursing for patients with metastatic breast cancer – implications for the role'. *European Journal of Cancer Care*, 19 (5), 575–580

The role of the breast care nurse was developed in the UK and is now being adopted internationally. Although evidence is available to suggest that the role is beneficial in the care of people with primary breast cancer, it is emerging that people with metastatic breast cancer do not receive the same level of support. This study aimed to develop an understanding of the role of the breast care nurse in the provision of care for patients with metastatic breast cancer.

A cross-sectional survey of 276 breast care nurses in the UK found that 91% of breast care nurses stated that they provided care for patients with metastatic disease and 81% provided ongoing information and support. However, 57% of breast care nurses acknowledged that the provision of care for this population was inadequate and many reported feeling ill equipped to care for women with progressive disease. Care pathways for this patient group are unstructured and ill-defined, complicating the efforts of breast care nurses to identify and provide care for them. In conclusion, the current nursing service for women with metastatic breast cancer is inadequate but many breast care nurses are working to address this.

Reed, E., Simmonds, P., Haviland, J., Corner, J. (2012) 'Quality of life and experience of care in women with metastatic breast cancer: a cross-sectional survey', *Journal of Pain and Symptom Management*, 43 (4), 747-758

Context Despite developments in the medical management of metastatic breast cancer, little is known about the quality of life (QoL) and experience of care in women with it.

Objectives To explore QoL, experience of care, and support needs of women living with metastatic breast cancer in the UK.

Methods Questionnaire-based, cross-sectional study undertaken in two UK cancer centres and online via the Breast Cancer Care website, assessing QoL and experience of care in 235 women with metastatic breast cancer.

Results QoL was assessed using the Functional Assessment of Cancer Therapy-Breast QoL measure. Overall, QoL was low (mean 89.0, standard deviation 21.8) for total score. Low scores were seen uniformly in physical, social, emotional, and functional wellbeing domains. Symptom burden was a significant problem, with over one third of women (34%) reporting high levels of pain and other uncontrolled symptoms. In

multiple regression analysis, social wellbeing was significantly better for older women ($P < 0.001$) but was lower in those with bone metastases only ($P = 0.002$). Functional wellbeing was significantly higher in women without children ($P = 0.004$). Satisfaction with experience of care was low and appeared to be predominantly in the hospital setting, with little evidence of involvement of general practitioners and palliative care services.

Conclusion Despite improvements in treatment and survival of women with metastatic breast cancer, this group reports high symptom burden and dissatisfaction with elements of their care, indicating that alternative models of service delivery should be explored.

Warren, M., Mackie, D., Leary, A. (2011) 'The complexity of non face-to-face work with patients affected by metastatic breast cancer and their carers. The 'hidden consultations' of the clinical nurse specialist'. *European Journal of Oncology Nursing*, 7 Dec

Introduction Survival rates in breast cancer have risen in the past 30 years. Almost one third of those diagnosed will go on to developing metastatic breast cancer, which is becoming a long-term condition in cancer care. In 2006, there were 429,000 new cases of breast cancer were recorded across Europe. In recent years treatment for metastatic breast cancer in the UK has moved to the ambulatory setting meaning non face-to-face contact, for example through telephone consultation, has become a vital method of management.

Methods A prospective study conducted over a one-month period at a London trust. Data was collected by two CNSs on incoming calls using Excel and a bespoke interrelational structured query database. These data were then mined using standard data mining techniques.

Results The study collected 28 days of data. 229 patient and carer telephone contacts were recorded across the trust. Most calls were from patients (62.5%). Incoming calls resulted in the delivery of 1,282 interventions, a mean of six interventions per call (range 1-8) and clustered into four areas: meeting information needs (29%), symptom management (26%), psychological/social issues (33%) and other issues (12%). The incoming telephone work accounted for 63 hours which represented 30% of the total working time of the CNS. Calls primarily originated from patients who were in the follow-up phase (43% of calls), a group usually thought to prefer self management.

Appendices

Appendix 1 – Template patient experience survey and letter

As part of the review of your service you might want to carry out a survey of your patients with metastatic breast cancer. We have included a survey template. It can be adapted to your workplace, used to identify

any gaps in care and will provide evidence to support staffing proposals or reviews.

We have also created a draft letter you can adapt to send with the survey. Please check our website.

Template - Letter to patient

Dear *(insert name)*,

Patient satisfaction survey for patients diagnosed with secondary breast cancer

We would be grateful if you would consider taking part in a survey. This is to find out how you feel about the service we offer to you and ask how you think it could be improved. Your opinion would help us identify any gaps in the care we offer or where things need to be changed.

It will take about five minutes to complete and is completely anonymous; we will not be able to identify you in any way, so feel free to respond honestly.

You are under no obligation to complete this questionnaire, and choosing not to will not affect your care now or in the future.

If you have any queries about the questionnaire, please contact your nurse specialist.

There is a FREEPOST envelope attached for your reply. Please return the completed questionnaire by *(insert date)*.

Thank you for your time and valuable contribution to our nursing service.

Yours sincerely

TEMPLATE - Secondary breast cancer patient experience survey

For patients: thank you for reading this questionnaire, which reviews how well the needs of people diagnosed with secondary breast cancer are met by the breast care nursing service.

1 Were you given the name of and/or introduced to your breast care nurse/care coordinator at the time you were diagnosed with secondary breast cancer?

Yes No

2 How satisfied are you with the breast care nursing service since your diagnosis of secondary breast cancer?

Very satisfied
 Fairly satisfied
 Not satisfied

Comments _____

3 At the time of your diagnosis of secondary breast cancer were you given the information you wanted? Were you given the Breast Cancer Care **Secondary resource pack**?

Yes No

Comments _____

4 Do you feel the breast care nursing team give you sufficient information (both verbally and in writing) about your secondary breast cancer and treatment?

Yes No

Comments _____

5 Do you feel your emotional wellbeing is regularly assessed?

Yes No

Comments _____

6 Have you been informed about any counselling services, support groups or cancer centres in your area?

Yes No

Comments _____

7 Have you asked for advice about any symptoms, for example, pain, fatigue, breathlessness, coping with your diagnosis?

Yes No N/A

If 'Yes' please tick who you have discussed your symptoms with:

breast care nurse/key worker
 oncologist
 GP (local doctor)
 palliative care doctor
 palliative care nurse.

8 Have you been given sufficient information on financial (benefits, grants) and/or employment issues (working, stopping working, pension issues)?

Yes No N/A

Comments _____

9 Have you been made aware of any clinical trials you could take part in?

Yes No

Comments _____

10 Were you given a copy of the letter sent to your GP (local doctor) informing them of your diagnosis of secondary breast cancer?

Yes No

Comments _____

11 Do you feel your GP is kept informed about your condition and your treatment?

Yes No

Comments _____

12 Do you receive the care and support you want from your GP?

Yes No

Comments _____

Thank you for taking the time to give your views. Please return this questionnaire to your breast care team.

Appendix 2 - Evaluation form

We want to make sure the toolkit is as useful as possible. To help us improve and update the toolkit please to fill in this questionnaire.

1. How did you come across the toolkit?

- From Nursing Network
 - Browsing the web
 - Told about by a colleague
 - Told about by patient
 - Other, please state
-

2. Thinking about the different elements of the toolkit, please tell us what you think by ticking a box for each

	Excellent	Good	Not sure	Poor	Very Poor
Module 1					
Module 2					
Module 3					
Module 4					
Module 5					
Module 6					

Comment

3. Please indicate if you agree with the following statements.

The toolkit has helped me/my team to start developing the nursing service we offer our metastatic breast cancer patients

Yes No

I have signposted colleagues to the toolkit

Yes No

4. Was there anything missing from the toolkit that you think should be included in the future?

Yes (please say what) No

5. Do you have anything else to say about the toolkit?

We are very keen to hear about what action this toolkit may have prompted you to take.

We would like to promote examples of best practice. If you are interested in being a case study on our website please indicate here.

Yes No

If yes please include email address

We know that making changes can take time. We are keen to stay in touch with you to see what changes you make to your nursing service so we can learn from what you do and help share your experience with others.

Together we can improve the care of everyone living with metastatic breast cancer. If you would be happy for us to contact you in the future please tick here.

Yes No

Appendix 3 - References and reading list

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