

Best practice case study:

Edinburgh Breast Unit, Western General Hospital

After noticing support for metastatic breast cancer patients was less systematic than that provided to patients presenting with primary breast cancer, the nursing team in the Edinburgh Breast Unit recognised the need for a service redesign that included the introduction of a secondary breast cancer CNS post.

To allow as much flexibility as possible in tailoring the service, the position was developed in the existing CNS team, with the new role originally constituting two experienced nurse specialists covering one full-time position.

This redesign was launched in March 2009, with NHS Lothian becoming the first health board in Scotland to support such a role. Key benefit areas to this service were seen as:

- Supporting self-management;
- Supporting development of practical and emotional coping skills;
- Enhancing patient's overall health and wellbeing.

The success of this service saw 97% of patients surveyed in a follow-up service evaluation finding the CNS service helpful.

"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"

- Secondary breast cancer patient, Edinburgh Breast Unit

Data

Understanding the importance of data collection for planning and developing services for those with secondary breast cancer, the team maintains its own nursing database that comprises new patients, ongoing caseload as well as patient deaths. This further provides justifications for the CNS role as increasing workload versus current resource is transparent through this data.

Key Considerations

Key factors considered to ensure the service was robust enough included:

- How the day to day operation would work?
- How referrals would be made?
- How ongoing support would be provided to patients?
- How the service would link in with other health and social care professionals in primary and secondary care?

Service

An open access policy was adopted for patients and their carers, with most of the work being outpatients seen either in a clinic situation or via telephone contact. First contact with patients is usually either at new diagnosis of SBC or progression of the disease, where all new patients have telephone or face-to-face contact within two weeks of referral. The initial meeting will assess people's individual needs, ensure they have a proper understanding of their diagnosis and treatment plan, and is an opportunity for the CNS to explain their role

and the support they can offer. Contact details and information sheets on the service are also provided.

This service remit reflects the top reasons for contact with the clinical nurse specialist listed in a patient satisfaction survey created by the team. These included:

- Provision of information on diagnosis and treatment options
- 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

Psychological Support

Recognising the psychological care needs of this patient group, access to clinical psychology services is available in the breast unit, using indirect (through joint working) and direct referral depending on patient need.

A more structured approach to assessing emotional distress and concerns for all new patients was piloted in April 2013 with the use of Macmillan's Concerns Checklist framework. The aim is to introduce this into everyday practice with a weekly nurse-led clinic for all new patients giving patients the opportunity to discuss their checklist.

An in-house course designed for CNSs and practitioners is also provided, which provides a 'toolkit' for psychological support strategies. Clinical psychologists also provide support for the CNS in terms of advice and support strategies for complex patient needs and providing a framework to support patients.

Breast Cancer Care's support group for patients Living with Secondary Breast Cancer was also launched for peer to peer support.

Links to Community

The service has worked hard to establish strong links with primary care, including local hospices and palliative care teams. Understanding that a secondary breast cancer diagnosis can affect numerous aspects of a patient's life including their financial situation, relationship with family and friends, employment status and lifestyle changes, the Breast Unit offers guidance to specialist advice in addition to direct referral if required. A key worker provides this individualised, coordinated care to meet the unique need of each patient.

Promoting Secondary Breast Cancer Nursing Skills and Expertise

Rotation opportunities are offered to CNSs from the early breast and adjuvant cancer service where they join the metastatic team for a fixed period or for one to two days a week with the aim of ongoing development of skills and competencies associated with caring for secondary breast cancer patients. Feedback from this programme has been extremely positive, with nurses reporting an increased knowledge base and the development of transferable skills.

In addition to rotations, an annual full day secondary breast cancer training event takes place which focuses on the patient experience and pathway from diagnosis of SBC to treatment options, side effects and ongoing symptoms control. The course is aimed at ward staff, community nurses, allied-health professionals, and anyone with an interest in understanding secondary breast cancer.