Free business cards for breast care nurses
Royal Marsden Hot Topics Meeting
Persistent pain after breast surgery
DO I NEED CHEMOTHERAPY?

An individual question...  ...An individual answer

- The ONLY multi-gene assay that helps to identify patients at risk of distant recurrence\(^1,2\) and patients who are likely, or unlikely, to benefit from chemotherapy\(^3,4\).
- Intended for newly diagnosed patients with early-stage, ER-positive, HER2-negative invasive breast cancer that is node negative or with 1-3 positive nodes\(^1,2\).

Visit us at www.oncotypeDX.com

References

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Calls may be monitored for training purposes. Confidentiality is maintained between callers and Breast Cancer Care.
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A view from...

Vicky, who is involved with Breast Cancer Care’s ‘Secondary. Not second rate.’ campaign to improve standards of care for people with secondary breast cancer.

I was first diagnosed in 2009 with breast cancer on my left side, followed by my right side in 2011 while undergoing investigations for possible metastases. Things then went fairly quiet barring reconstructive surgery until I started suffering with leg weakness and difficulty walking at the start of 2015. This progressively worsened.

On a second visit to the GP and a following a blood test I was summoned to A&E as an emergency with my calcium levels through the roof, and diagnosed with secondary breast cancer in my bones. The spinal issues left me with a permanent disability, and I have pretty much had to learn to walk again. After some chemotherapy and radiotherapy, I was in remission until this year when it progressed to my lungs and liver.

From my own experience I feel a lot more ‘left to it’ with my secondary breast cancer, which can feel isolating. The hospital I am treated at is excellent clinically. I have been with my oncologist for many years now and trust him and his team, but the holistic care is where I feel there could be more emphasis. Even just a word from the nursing team, asking how I am. They are busy, but that little ‘how are you’ when they see me would make so much difference. I have been referred to my local hospice and get my counselling and general holistic care from there, but still feel the NHS should offer this as well as treating you medically.

I think the campaign being undertaken by Breast Cancer Care is a vitally important one. As a former clinical audit officer working in the NHS until my forced ill-health retirement last year, I was shocked to hear that two thirds of Hospital Trusts don’t know how many of their patients have secondary breast cancer. This surely makes it more difficult for them to plan and provide the right care.

I contacted my own Trust where I am treated and, after two messages being ignored, got a vague answer via the Freedom Of Information service. I was quite shocked at this. We secondary patients do not deserve to get second-rate care. Statistics and outcomes are essential to know what treatments are doing and how they are working.

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Policy and campaigns news

The Cancer Drugs Fund
The new Cancer Drugs Fund (CDF) came into effect on 29 July. At the time of printing, the following breast cancer drugs are available via the CDF*:
• pertuzumab (Perjeta)
• everolimus (Afinitor)
• trastuzumab emtansine (Kadcyla or TDM-1).

Under the updated system, these drugs will be reassessed by NICE over the coming months. The outcome for patients in England will be one of the following:
• The drug is approved for routine use on the NHS and is available to patients.
• The drug remains on the CDF and is available to patients. The drug will be available for a limited time of up to around two years. During this time, further evidence is collected to enable NICE to make a final decision.
• The drug is removed from the CDF and is only available to patients through a successful Individual Funding Request (IFR).

Until these drugs have been reassessed, they will remain available to patients. If these drugs become unavailable in the future, patients already receiving them will continue to have access.

We’re continuing to monitor the progress of these re-appraisals and the impact of these changes for breast cancer patients in England. For more information about the changes, or if patients have come to you with any concerns, email campaigns@breastcancercare.org.uk

*Note on eribulin: following a recent positive re-appraisal by NICE, eribulin will be moving from the CDF into routine NHS use.

Updated Breast Cancer Quality Standard
In June, NICE published an updated version of their Breast Cancer Quality Standard. The updated Standard is a set of six statements, which set out priority areas for quality improvement and is available at www.nice.org.uk/guidance/qs12

Secondary. Not Second Rate.
For many years, Breast Cancer Care has pushed for significant improvements in care for those living with and affected by breast cancer, including secondary (metastatic) breast cancer. In July, we launched our campaign on secondary breast cancer called ‘Secondary. Not Second Rate.’ (see ‘A view from...’ opposite), which aims to provide an up-to-date picture of the range of issues affecting people living with secondary breast cancer today.

Diagnosis
Our first report focused on diagnosis and the support and information people need. Future reports will be published in the coming months exploring secondary breast cancer patients’ experiences of treatment and care, and the broader impact of living with secondary breast cancer.

From a sample of 841 people, our findings at diagnosis include:
• Only 22% of respondents were aware of the possible signs and symptoms of secondary breast cancer.
• 21% of people who’d had a previous primary breast cancer diagnosis were treated for another condition by their GP, before their secondary breast cancer was diagnosed.
• Almost half (49%) were not advised that they could bring someone with them when they were diagnosed.
Less than half (48%) felt equipped to manage their symptoms and pain, post diagnosis.

We want to see better care and support for people living with secondary breast cancer from before diagnosis onwards. Specifically, we want to see improved awareness of the possible signs and symptoms of secondary breast cancer; increased support for GPs in identifying possible cases of secondary breast cancer; increased information for patients about local and national support services specifically for secondary breast cancer; and early referrals to palliative care teams, preferably near the point of diagnosis.

Data
We’ve long been calling for data on diagnosis and treatment of secondary breast cancer to be routinely collected by hospitals and shared publicly, so that commissioners and healthcare providers are able to identify their local patient population’s needs and plan services effectively to meet them. Many of the ongoing problems in care and support for those living with secondary breast cancer can be traced back, at least in part, to the lack of available data on the disease. We know that improved data is something that many members of the Nursing Network have also been striving for, to help their own patients.

There is no accurate, up-to-date figure on the number of people diagnosed or living with secondary breast cancer in the UK. In January 2013, it was mandated for data on secondary breast cancer to be collected by NHS Hospital Trusts in England. However, to date, no such figures have been published. In Scotland, although data collection is not mandatory, progress is being made, with the Scottish Cancer Registry identifying an estimated 4,090 patients living with secondary breast cancer in 2013. In Wales, there has been a commitment to collecting data on the disease since 2013. However, little progress has been made and there is still no single dataset available.

Our second report therefore focused on gaining a national picture of which NHS Trusts in England were collecting data on patients diagnosed with secondary breast cancer. We published the findings of our Who’s Counting? campaign in England, which aimed to identify the barriers that are preventing the routine collection and publication of this data. Below is a summary of our findings; the full report, which includes more detail on our methodology and findings is available at breastcancercare.org.uk/secondary

Findings
• 125 Hospital Trusts (93% of applicable Trusts) responded to our request for information, enabling us to capture a comprehensive picture of data collection across England.
• We found that only a third (33.6%) of Trusts are meeting their requirement to collect data on secondary breast cancer in full i.e. they have systems and processes in place to collect data and are then submitting this to
the national Cancer Outcomes and Services Dataset (COSD).

- Nearly one in five Hospital Trusts (19.2%) are not collecting any data on their secondary breast cancer patients.
- The remaining Trusts (47.2%) are collecting some data but do not appear to be meeting their requirement in full. In some cases, new processes have been set up and we were pleased to see that our campaign acted as a catalyst for some Trusts, including in a few cases, the establishment of a new multidisciplinary team (MDT) for secondary breast cancer patients or a dedicated slot at an existing MDT meeting.

From the responses we received and the in-depth case studies we sought, we identified a number of barriers to full data collection being achieved, as well as examples of best practice.

Barriers to data collection include:

- lack of available resources to collect data
- lack of awareness of the need to collect data and/or how to collect data
- confusion over the definition of secondary breast cancer
- lack of buy-in and leadership.

Conversely, there are a number of themes that come out of those hospital Trusts collecting data in full:

- Trusts doing well appeared to have some infrastructure behind their collection, analysis and use of data.
- A dedicated secondary breast cancer MDT represents one of the most obvious opportunities for data on that patient to be collected and collated.
- Buy-in. Trusts that are collecting data often have a culture that data collection is the responsibility of more than just one person.

Next steps
Both our reports make a number of recommendations to improve how and when patients are diagnosed with secondary breast cancer and data collection on secondary breast cancer in England. We will monitor progress in this area and work with Hospital Trusts to share best practice, including disseminating our findings. We will also continue to lobby on the specific needs of those living with and affected by secondary breast cancer.

Visit our campaign page to find both reports: breastcancercare.org.uk/secondary

For more information, contact the Policy and Campaigns team at campaigns@breastcancercare.org.uk

You can download our quick guide to the Signs and symptoms of secondary breast cancer from our website: breastcancercare.org.uk/secondary-quick-guide

References
2 Figures provided to Breast Cancer Care by the Scottish Cancer Registry in 2015. However, the Scottish Cancer Registry issued some caveats with this figure that it may be an over- or underestimation.

Information correct at time of press
Breast Cancer Care’s exciting new support app

Breast Cancer Care is making a support app for people with breast cancer, and we’re eager for you to be involved.

We know that our user base is technically savvy, with the majority using mobile devices to access our website and the Forum.

We also know that one of the most difficult times for women emotionally is when they finish hospital-based treatment and are suddenly facing the reality of life after breast cancer.

There is evidence of an increasing appetite among the public to use health apps and go online for information, help and support about health conditions. Even the government are utilising this; as set out in ‘Personalised Health and Care 2020’ where a key aim is to enable people to make the right health and care choices through access to accredited apps and digital information.

Breast Cancer Care is working closely with people who have had breast cancer to create an app that supports them to move forward after treatment. Women have begun testing the tool already.

We’re calling it BECCA, the Breast Cancer Care App, and it gives users day-to-day strategies and bite-size pieces of information about coping and living well after breast cancer. This includes information on healthy eating, exercise and mindfulness, as well as peer-led advice that enables users to feel they are not alone in their experience.

How you can help

You can register to test the app at breastcancercare.org.uk/becca

We hope you can also support this work by submitting content to feature in the app.

Currently BECCA features digital support flashcards for women to interact with. The cards are created by teams at Breast Cancer Care and our users themselves. They deliver strategies for coping, maintaining a positive outlook, self care, and information about the longer term impact of the disease.

We have created a simple online form that enables you to submit copy to make your own support cards, which we will review and upload into the app. You can access the form at https://becca106.typeform.com/to/GkgWU6

We hope that together we can build a really effective app that can help women move forward after breast cancer.

For any queries about the app, contact becca@breastcancercare.org.uk
Free business cards for breast care nurses

As part of our commitment to supporting Nursing Network members to enhance and inform their clinical practice, we’re really excited to introduce a new benefit to our members.

Breast care nurses and clinical nurse specialists can now order free personalised business cards from Breast Cancer Care. The front of the card has a clear and simple design with space for your name, job title and contact details. There is also a space to include your NHS Trust’s logo. The design on the reverse provides details for Breast Cancer Care – our free helpline and website.

Having the cards available in your clinics will ensure that your patients know who to contact in the breast unit should the need arise, and at the same time raises awareness of Breast Cancer Care.

Nursing Network members often tell us that our wide range of patient information resources are of great benefit to their patients. The business cards complement our information resources by signposting patients to our website where they can access the full range of patient information, read guest blogs from women and men who are living with and beyond breast cancer, find out about the support services we offer and engage with others through our online community.

Ordering the business cards

Ordering the cards couldn’t be easier. You provide us with the details, and we’ll print the cards and have a set of 200 delivered to you.

To place an order, simply fill in the order form by visiting breastcancercare.org.uk/business-cards. If you’re keen to include your Trust logo you’ll need to have a high resolution version of the image to hand when you fill in the form.

The business card offer is available exclusively to breast care nurses and clinical nurse specialists in breast care.

If you have any questions, contact Nik Thoren, Clinical and Information Services Manager at nursingnetwork@breastcancercare.org.uk or on 0345 092 0802.
Award-winning information

We’re thrilled that the Secondary breast cancer resource pack won the long-term conditions category at the BMA Patient Information Awards.

The BMA presenting the award to participants from the Christie Secondary Breast Cancer Focus Group, Macmillian Secondary Breast Cancer Nurse Specialists at the Christie Hospital and Breast Cancer Care staff

The awards celebrate accessibility, design and balance in the production of information for patients. Any organisation producing information aimed at patients from the private, public or voluntary sector are welcome to submit resources for the awards. All resources are then looked at by volunteer reviewers who are experts in health information.

It was especially gratifying to win as we’d worked hard to update and produce the pack with the help of secondary breast cancer clinical nurse specialists and secondary breast cancer patients at the Christie Hospital.

Lead Macmillan Secondary Breast Cancer Nurse Specialist, Sharon Foy and Macmillan Secondary Breast Cancer Nurse Specialist, Claire Gaskell were able to come to the awards ceremony along with two patients from their Secondary Breast Cancer Focus Group. Claire said:

‘We are so happy that the hard work of our patient group has been rewarded in this way. They are an inspirational group working hard in often difficult circumstances and whilst on active treatment, to make a difference for other patients in a similar position and we feel very privileged to be helping them to do this at the Christie.’
Working together
The Secondary Breast Cancer Focus Group had originally come together to work towards the Service Pledge. This is a joint initiative between Breast Cancer Care and Breast Cancer Now to drive local improvements in care and support for people with secondary breast cancer. The Focus Group had suggestions for practical tools to help them monitor their condition and make notes on the results of tests and clinic discussions. The Christie team contacted Breast Cancer Care to see if the Focus Group’s work could be combined with our Secondary breast cancer resource pack.

Over a number of months we worked with the group developing their ideas, which included a ‘Questions you may want to ask’ prompt list and a patient record sheet for clinic appointments. The independent reviewer of the pack at the BMA said: ‘This is a lovely resource. It has clearly benefitted from some high quality user involvement which, given the subject matter, is an achievement in itself... All in all, a really empowering and sensitively done resource.’

Highly commended
We were also recognised with a highly commended award for our resource for schools – Breast mates. This pack provides information about breast health and breast awareness for girls aged 11 to 16. It features a workbook for a teacher/healthcare professional to enable them to run an information session, posters to prompt discussion and small take away leaflets covering breast development, bras and common myths about breast cancer.

The independent reviewer of this resource said:

“This is an excellent resource that will provide a very helpful opportunity for teenage girls to take part in a valuable information session with their peers... I'm glad to know this resource is out there and hope it gets used a lot.”

The Secondary breast cancer resource pack and Breast mates pack can be found at breastcancercare.org.uk/publications, along with our other information resources.
Highlights from the Royal Marsden Hot Topics meeting 2016

Senior Clinical Nurse Specialist, Rachel Rawson summarises the main points from the recent Royal Marsden conference.

Year on year, the Hot Topics breast cancer meeting provides multidisciplinary teams with an update on what is new, challenging and controversial in the management of patients with breast cancer.

This year, it addressed dilemmas related to neo-adjuvant therapy, including imaging techniques and surgical management of the axilla. It gave really clear guidance on some of the common questions that patients ask, namely who needs genetic testing and the burning question of dietary advice after breast cancer. Updates were also presented on molecular testing and emerging novel therapies in metastatic breast cancer.

Imaging assessment of the axilla following neo-adjuvant chemotherapy

Dr Romney Pope

Neo-adjuvant chemotherapy (NAC) is increasingly used to down stage breast and axillary disease and has demonstrated high rates of pathological complete response, especially in patients with triple negative and HER2 positive breast cancer.

Axillary nodal clearance is standard surgical treatment for node positive disease. But this is associated with morbidity and may not be necessary when replaced with sentinel lymph node biopsy in patients whose NAC results in nodal pathological complete response.

Findings from a short series looked at patients having an axillary ultrasound and image-guided clip insertion into a confirmed involved node prior to NAC.

This was found to improve the accuracy of axillary assessment and reduce unnecessary clearance in some patients with a nodal pathological complete response post NAC.

Further work is needed to identify the most appropriate patients for this approach.
Which patients need genetic testing?
Dr Zoe Kemp

This session was thought-provoking in terms of where genetic testing may be in the future and how the Royal Marsden is now categorising patients for testing. It reported on the merits of expanding testing beyond the traditional family history criteria and testing multiple cancer predisposition genes simultaneously.

It’s reasonable to offer testing to women 50 years and under with bilateral breast cancer and/or triple negative breast cancer and all women with breast and ovarian cancer, regardless of family history.

What dietary advice to give my patient?
Dr Clare Shaw

Questions from patients about diet and exercise feature commonly in both the primary and secondary setting. This session discussed the recommendations within the World Cancer Research Fund – Diet, nutrition, physical activity and breast cancer survivors report¹, and detailed some key information for patients.

Key points
Dairy intake is unrelated to breast cancer specific outcomes (recurrence and survival) however low fat options are prudent for weight loss.

• Soy foods may reduce mortality (consumption of 10mgs or more of isoflavones confers a benefit). But evidence is from epidemiological studies (not interventional) and the safety of supplements such as red clover remains unclear.

• Studies show varying degrees of weight gain during and after breast cancer treatment. It’s proposed that gaining weight can adversely influence prognosis but there are no RCTs demonstrating this. It is prudent to advise patients to try to be as lean as possible without being underweight and to be physically active for 30 minutes per day.

1 The full report can be found here:
Molecular Profiling – what do I need to know?

Professor Mitch Dowsett

Molecular profiling – for example Oncotype Dx and EndoPredict – has become part of the decision making around chemotherapy for a subset of women with ER positive breast cancer. The primary purpose of molecular profiling is to estimate residual risk of distant recurrence over 10 years. This then allows those who are at minimal risk to avoid chemotherapy.

However the estimates of risk by molecular profiles are independent of those from clinic-pathological features such as tumour size, grade and nodal status. Data is now emerging that integrating the two sets of features provides the most accurate estimate of risk. The San Antonio breast conference later this year will provide more insight into this with the publication of new data.

New drugs for metastatic breast cancer – hype or real progress?

Professor Stephen Johnston

This was a really interesting session that looked back at the last four years of new therapies in metastatic breast cancer and whether they were changing practice or just hype – many were just hype.

Key points

• Oestrogen receptor positive metastatic breast cancer first line fulvestrant (FALCON trial) indicates fulvestrant is superior to anastrozole.
• In those tumours that have become endocrine resistant, the Paloma 3 trial showed that fulvestrant plus palbociclib was associated with significant and consistent improvement in progression-free survival.

• As with other cancers, immunotherapy may be the way forward particularly in triple negative metastatic breast cancer.

The 10th Annual Royal Marsden Breast Cancer Meeting will take place on Friday 6 October 2017.
Persistent pain after breast surgery

A significant number of patients develop persistent pain after breast surgery. Dr John E Williams, Consultant in Pain Medicine at the Royal Marsden Hospital, London outlines the prevalence, risk factors, clinical presentation and treatment of this condition.

**Chronic pain after breast surgery**

There is an increasing awareness of the problem of chronic pain after breast surgery. More than 13 epidemiological surveys conducted in the past 20 years have indicated that as many as 50% of patients may develop persistent pain after breast surgery.

Many possible causes have been implicated and an understanding of these will help the clinician direct analgesic treatment and preventative strategies appropriately. Additionally, risk factors for developing chronic pain have been proposed and may indicate which patients are predisposed to developing this condition.

Patients need to be informed of the possibility of developing persistent pain after breast surgery.

**Prevalence of chronic pain after breast surgery**

The prevalence of chronic pain after breast surgery ranges from 8-75% (table 1). However, there is little uniformity in these studies, and variables include different patient populations, study methodology, type of surgery performed, and variations in the severity of the pain at differing time points.

Table 1. Epidemiological studies measuring the prevalence of pain after breast surgery

<table>
<thead>
<tr>
<th>Study author</th>
<th>Year</th>
<th>Prevalence of pain after breast surgery</th>
<th>Time after surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jamison</td>
<td>1979</td>
<td>44%</td>
<td>2 years</td>
</tr>
<tr>
<td>Kroner</td>
<td>1989</td>
<td>23%</td>
<td>1 year</td>
</tr>
<tr>
<td>Vecht</td>
<td>1990</td>
<td>18%</td>
<td>6 months</td>
</tr>
<tr>
<td>Kroner</td>
<td>1992</td>
<td>17-31%</td>
<td>6 years</td>
</tr>
<tr>
<td>Ivens</td>
<td>1992</td>
<td>20%</td>
<td>&gt; 4 years</td>
</tr>
<tr>
<td>Polinskey</td>
<td>1994</td>
<td>22-32%</td>
<td>Mean 8 years</td>
</tr>
<tr>
<td>Tasmuth</td>
<td>1995</td>
<td>&gt;50%</td>
<td>1 year</td>
</tr>
<tr>
<td>Wallace</td>
<td>1996</td>
<td>22-49%</td>
<td>1 year</td>
</tr>
<tr>
<td>Smith</td>
<td>1999</td>
<td>43%</td>
<td>3 years</td>
</tr>
<tr>
<td>Johansen</td>
<td>2000</td>
<td>15%</td>
<td>6 years</td>
</tr>
<tr>
<td>Fassoulaki</td>
<td>2002</td>
<td>33%</td>
<td>3 months</td>
</tr>
<tr>
<td>Fassoulaki</td>
<td>2005</td>
<td>57%</td>
<td>6 months</td>
</tr>
<tr>
<td>Kairaluoma</td>
<td>2006</td>
<td>8%</td>
<td>1 year</td>
</tr>
<tr>
<td>Mejdahl</td>
<td>2013</td>
<td>22-53%</td>
<td>Up to 6 years</td>
</tr>
</tbody>
</table>
Classification and nomenclature of chronic pain after breast surgery

Originally, pain after breast surgery was referred to as 'post mastectomy pain'. Recent studies have indicated that it is also prevalent after other types of breast surgery, such as breast conserving surgery and reconstructive surgery. Therefore, we should refer to this phenomenon as ‘pain after breast surgery’.

There are many different possible causes of pain after breast surgery. Making a correct diagnosis is important as this will direct the appropriate analgesic treatment or preventative strategy. Table 2 lists the aetiology of the different types of pain after breast surgery commonly seen in patients attending the pain clinic at The Royal Marsden Hospital.

It is important to recognise that pain may be due to recurrent breast disease, and that appropriate investigations should be performed to confirm or exclude this in the first instance. Some patients may have pain from a pre-existing condition, such as fibromyalgia or osteoarthritis.

Neuropathic pain following breast surgery has been classified into four different categories:

i. Intercostobrachial neuralgia, considered the commonest cause of neuropathic pain, caused by cutting, stretching or bruising of the nerve.

ii. Phantom breast pain.

iii. Micro and macro neuroma pain.

iv. Pain from any other nerve injury, such as damage to intercostal nerves.

Pain may also be due to implants and reconstructions. Different causes of this type of pain include capsulitis, implant migration and atypical chest pain due to silicone breast implants.

Pain may also be associated with the restriction of movement that lymphoedema causes, or may be due to muscle spasm. Chemotherapy and/or radiotherapy may also exacerbate or contribute to pain after surgery. Finally, psychological factors such as anxiety, stress and depression are important in all chronic pain states.

The intercostobrachial nerve running across the floor of the axilla. Damage to this nerve due to bruising, stretching or cutting can result in persistent pain.

Typical location of pain after breast surgery, due to damage of the intercostobrachial nerve.
Risk factors
Less invasive surgical procedures such as sentinel node biopsies reduce the number of patients who have axillary node clearance, thus decreasing the risk of damaging the intercostobrachial nerve.

Improved acute post-operative analgesia may also reduce the risk of developing chronic pain. A variety of perioperative and postoperative strategies have been proposed, including the use of paravertebral blocks. Acute pain management is best achieved by having a dedicated acute pain service, good staff, and patient education.

Natural history
Most patients with persistent pain after breast surgery improve within the first three months. It is likely that patients with pain beyond this time can expect further improvement in the ensuing three months to two years. Some patients will have pain beyond this time, with one study reporting pain in patients six years following surgery (Mejdahl et al 2013).

Classification of pain after breast surgery

<table>
<thead>
<tr>
<th>Classification of pain after breast surgery</th>
<th>Clinical examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-existing pain</td>
<td>• osteo/rheumatoid arthritis</td>
</tr>
<tr>
<td></td>
<td>• cervical radiculopathy</td>
</tr>
<tr>
<td></td>
<td>• costo chondritis</td>
</tr>
<tr>
<td></td>
<td>• fibromyalgia</td>
</tr>
<tr>
<td>Tumour-related pain</td>
<td>• recurrent disease in breast/axilla</td>
</tr>
<tr>
<td></td>
<td>• metastatic disease to cervical spine</td>
</tr>
<tr>
<td>Post-surgical neuropathic pain</td>
<td>• intercostobrachial neuralgia</td>
</tr>
<tr>
<td></td>
<td>• phantom breast</td>
</tr>
<tr>
<td></td>
<td>• neuralgia of other nerve in area</td>
</tr>
<tr>
<td></td>
<td>• neuromata</td>
</tr>
<tr>
<td>Other post-surgical pains</td>
<td>• scar pain</td>
</tr>
<tr>
<td></td>
<td>• carpal tunnel syndrome</td>
</tr>
<tr>
<td></td>
<td>• transient brachial neuritis</td>
</tr>
<tr>
<td></td>
<td>• complex regional pain syndrome</td>
</tr>
<tr>
<td>Pain due to implants and reconstruction (Wallace)</td>
<td>• capsulitis/foreign body reaction</td>
</tr>
<tr>
<td></td>
<td>• capsular contraction and hardening</td>
</tr>
<tr>
<td></td>
<td>• implant immigration</td>
</tr>
<tr>
<td></td>
<td>• pain in donor site after latissimus dorsi surgery</td>
</tr>
<tr>
<td>Other causes of pain after breast surgery</td>
<td>• psychological/emotional factors</td>
</tr>
<tr>
<td></td>
<td>• chemotherapy/radiotherapy</td>
</tr>
<tr>
<td></td>
<td>• lymphoedema causing restricted movement</td>
</tr>
<tr>
<td></td>
<td>• idiopathic</td>
</tr>
</tbody>
</table>
Learning together

Treatment

Treatment depends on the cause of the pain, according to the classification system described in Table 2.

Chronic neuropathic pain is treated with the use of anti-neuropathic agents such as antidepressants and anticonvulsants, in the first instance, and with short-term use of opioids in resistant cases. Amitriptyline, a tricyclic antidepressant, has proven efficacy but compliance may be limited by the adverse effects, especially drowsiness. Pregabalin can also be used and some clinicians are using pregabalin prior to breast surgery.

Topical treatments such as capsaicin cream and lidoderm 5% patch may also be beneficial.

Pain management programmes utilise a combination of psychological and physical interventions such as cognitive behavioural strategies and physical exercise, and can result in decreased pain as well as improved quality of life and mood.

Conclusions

Chronic pain after breast surgery is a growing public health problem affecting many thousands of patients in the UK and worldwide. It is important for healthcare professionals to understand this phenomenon and to inform patients about possible pain problems following breast surgery. However, it is a complex phenomenon, with many potential contributing factors, that requires a multidisciplinary treatment approach starting before surgery and continuing into the post-operative period and beyond.

References


Partial breast irradiation for early breast cancer

This is a summary of a Cochrane Review.

**Keywords:** Breast cancer, irradiation, treatment, early-stage breast cancer

**Review question**
To determine whether partial breast irradiation (PBI)/accelerated partial breast irradiation (APBI) is equivalent to or better than conventional or hypo-fractionated whole breast radiotherapy (WBRT) after breast-conserving therapy for early-stage breast cancer.

**Nursing implications**
Women with an early breast cancer diagnosis who choose to keep their breast are usually recommended to have radiotherapy as well as surgery. This is to make every attempt to ensure that the cancer does not re-grow in the breast. Providing the most effective form of treatment for women will then have a greater impact on their overall psychological health, and ensure they are happy with the outcome of choosing to keep their breast and the overall look of the breast after the radiotherapy.

**Study characteristics**
The review considered randomised controlled trials that evaluated conservative surgery plus PBI/APBI versus conservative surgery plus WBRT. The comparisons had to be unconfounded (i.e. treatments given to the randomised groups had to differ only in relation to the volume of the breast irradiated). Trials incorporating adjuvant treatments, such as chemotherapy, monoclonal antibodies or hormonal therapy, were eligible if the RCT applied these other treatments in exactly the same way to both groups.

Women with histologically confirmed early-stage breast cancer who had conservative surgery were included. Surgery could include lumpectomy and wide local excision or quadrantectomy, with or without axillary dissection, axillary sampling or sentinel node biopsy. Women with a previous diagnosis of breast cancer were not eligible for inclusion.

The primary outcomes included local recurrence-free survival in the ipsilateral breast and cosmetic outcome or breast appearance. The secondary outcomes were overall survival, toxicity (including acute and late effects of radiotherapy), new primary tumours in the ipsilateral breast, cause-specific survival, distant metastasis-free survival, relapse-free survival, loco-regional recurrence-free, subsequent mastectomy (ipsilateral partial mastectomy, modified radical mastectomy or radical mastectomy), compliance (defined as the number of women who commenced treatment with PBI/APBI or conventional external beam radiotherapy (EBRT) and completed the treatment course), quality of life, the effects of PBI/APBI and EBRT on global quality of life and the physical, emotional and psychological domains and patient preference – that is, did women prefer PBI/APBI or WBRT given the advantages and disadvantages of each approach?
Summary of key evidence

When you consider the quality of the evidence used it was evident that PBI did not give the same cancer control in the breast as treating the whole breast with WBRT. Although the difference was small and in some cases rare, side effects were generally worse in PBI.

When reviewing the seven studies (7,586 women studied of the 8,955 enrolled) local recurrence was rare but more commonly seen in PBI, along with changes in breast appearance including scarring. The women’s survival rate this did not differ between the treatments with the same number of women dying of breast cancer. The review of the evidence also demonstrated that the same number of women went on to develop metastasis with the same number of women requiring mastectomies at the end of the treatment.

Best practice recommendations

From the evidence reviewed it would appear that local recurrence and ‘elsewhere primaries’ (new primaries in the ipsilateral breast) are increased with PBI/APBI (the difference was small), but with no evidence of detriment to other oncological outcomes. It appeared that cosmetic outcomes and some late effects were worse with PBI/APBI but its use was associated with less acute skin toxicity. The limitations of the data currently available mean that there cannot be a definitive conclusion about the efficacy and safety of PBI/APBI or ways to deliver it. Ongoing trials will address relevant clinical outcomes. PBI/APBI is a highly technical intervention that is operator dependent and requires careful quality assurance and robust information given to potential clients.

Summary author: Nerys Bolton, Pathway Director IPL Adult Nursing Programme, Canterbury Christ Church University Canterbury, UK; member of the Cochrane Nursing Care Field

Reference

Why I recommend Breast Cancer Care’s Someone Like Me service

Angeline Macleod, Breast Care Nurse at the Highland Breast Centre, Raigmore Hospital, talks about the importance of providing support from people who have been there themselves.

As breast care nurses, we are very aware of the importance of people with a diagnosis of breast cancer having access to people who have been through similar experiences. We understand that this contact has a value that we cannot replicate, and actively encourage people to talk to others who have had breast cancer treatment. This is regularly enforced at the ‘moving on’ events we host, where feedback consistently highlights the benefit of this contact.

Many have said how free they felt talking to someone who seemed to “instantly understand”.

In the Highlands, we are fortunate to be able to recommend a number of local support groups – some specifically for breast cancer. We are also lucky to have a Maggie’s Centre in Inverness. We advise people to make full use of recommended internet resources, steering them to Breast Cancer Care and Macmillan – and including, where appropriate, the ‘Young Adults with Breast Cancer’ and ‘Flat Friends’ Facebook forums.

We routinely mention the Someone Like Me facility offered by Breast Cancer Care. Often we highlight this when people say they are not ‘group people’, or that they don’t want others ‘knowing their business’, or that they live too far away from Inverness where most support groups are held.

Generally, at the end of treatment people show signs of isolation and uncertainty, and we find that this is a particularly timely moment to tell them about Someone Like Me. Feedback from people who have used this service has shown that it helped to alleviate these feelings at this tender time of transition. Many have said how free they felt talking to someone who seemed to ‘instantly understand’.

Two specific but very different examples capture why we endorse the Someone Like Me service.

A patient with grade 3 invasive ductal cancer, all nodes positive following axillary node clearance, confided that she was struggling with a deep fear that she won’t live past five years. She said that if she could find someone else who had their entire nodes positive but was still alive it would help her. She scrolled through forums looking for someone who had all their nodes positive but couldn’t find anyone, which added to this fear that it was because they had died.
We talked her through the Someone Like Me service and what would be involved. It was very satisfying to hear from her a week later. She had contacted Someone Like Me and was impressed by the sensitivity of the staff member who took her call and promptly matched her with a woman who also had grade 3 and entirely node positive breast cancer, who is now seven years post treatment and living a full and healthy life. This gave hope and relief to her that was transformative.

Another patient expressed difficulty in making a decision regarding which type of reconstructive surgery to opt for. We suggested she use the service to contact people who have had different reconstructions such as DIEP, LD flap and implant only. She contacted Someone Like Me and again was promptly connected with three people, each of whom had different reconstructions previously and were able to give insights into how they had each experienced the particular surgery. Furthermore, each contact was able to identify with the burden of decision-making at a time of turmoil following a diagnosis of breast cancer.

Our nurses would like to thank Breast Cancer Care for this service – it is very satisfying to see its positive effects for the people we collectively seek to help.

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**About the Someone Like Me service**

**What is the Someone Like Me service?**

The Someone Like Me service matches people with a primary breast cancer diagnosis, or who are at risk of developing breast cancer, with a volunteer who shares similar diagnosis type, treatment pathway and personal circumstances and has been trained to help. Users of the service are able to ask questions and talk openly without worrying about causing distress to the person listening.

**Who is the Someone Like Me service for?**

Anyone affected by breast cancer, including partners and family members, who wants to speak to someone who understands and is further on from their breast cancer experience. Our volunteers can support around all aspects of breast cancer, from diagnosis to survivorship. We also support those who are undergoing genetic testing or have a confirmed altered gene.

**How does the service work?**

1. Self or professional referral to the Someone Like Me service
2. User assessed by the Someone Like Me team and a suitable volunteer identified
3. Volunteer given brief and starts supporting the user
4. Report submitted by volunteer upon completion and evaluation form sent to the user
5. For the email support service, the user chooses who to email from the volunteer profiles on our website. Emails are monitored and evaluations sent at the end of the support.

**What topics are covered?**

The topics covered by the service are listed opposite.
### Topics covered by Someone Like Me

#### Diagnosis
- DCIS
- Invasive breast cancer – ductal and lobular
- Tubular breast cancer
- Paget’s disease
- Occult breast cancer
- Squamous cell carcinoma
- Inflammatory breast cancer
- Second primary
- Recurrence
- Triple negative diagnosis
- Triple positive diagnosis
- Bilateral breast cancer diagnosis
- BRCA 1 and 2 gene carriers with and without a diagnosis of breast cancer

#### Treatments
- PICC line and Hickman line
- Neo adjuvant chemotherapy
- Neo adjuvant hormone treatment
- Hormone therapy treatments
- Targeted therapy treatments
- Worn cold cap
- Volunteers that had to come off certain treatments

#### Surgery/reconstruction
- Skin sparing mastectomy
- Wide local excision/lumpectomy
- Immediate and delayed reconstruction
- DIEP, TRAM, LD flap, LICAP, IGAP, ADM, implant, tissue expander reconstruction
- Bilateral reconstruction
- Preventative surgery
- Mamnoplasty surgery
- Deconstruction (tissue expander)
- Reduction/augmentation to other breast
- Lipofilling
- Nipple tattoo and reconstruction
- Prosthesis use
- Volunteers that have made decisions regarding reconstruction/surgery types, including the decision not to have reconstruction

#### Fertility
- BC diagnosis while pregnant
- Had child/children following diagnosis
- Eggs harvested
- Eggs/embryos frozen

#### Other health conditions
- Hodgkins Lymphoma
- ME/Chronic Fatigue Syndrome
- Volunteers with a treatment path influenced by other health concerns
- Arthritis/osteoporosis/osteopenia
- Depression/anxiety
- Volunteers affected by other types of cancer

### How can patients access Someone Like Me?

The service can be accessed by calling **0345 077 1893**, emailing **someonelikeme@breastcancercare.org.uk** or texting SLM and their name to **07889 001289**.
Sharing practice

The challenges of supporting people with cancer and dementia

Lorraine Burgess, Macmillan Dementia Nurse Consultant, talks about her two-fold role in supporting people with cancer and dementia.

Cancer specialists are treating an increasing number of patients that present with both cancer and dementia. Both cancer and dementia are primarily diseases of older people with currently more than three out of five cancers being diagnosed in people aged 65 and over, and one in three people affected by dementia over the age of 65 years. The prevalence of co-existent diseases such as dementia in addition to breast cancer becomes increasingly important in an ageing population. However, the clinical implications are unclear.

In July 2013 I took up the post of Dementia Clinical Nurse Specialist, Christie NHS Foundation Trust in South Manchester. It was a new, innovative post supporting both people with dementia and their carers whilst having treatment for cancer at the Christie, and one that has created a lot of interest from people working within oncology services around the country. My post has since been part-funded by Macmillan and has developed into the first ever Macmillan Dementia Nurse Consultant.

With increasing numbers of older patients receiving cancer treatments, and using oncology services, the individual needs of patients are of paramount importance and the decision to offer and treat such patients can often present healthcare professionals and family carers with a number of ethical and practical challenges. Myself and another later life mental health nurse who I work with very closely aim to address this gap and explore ways in which the care of the person with cancer and a co-existing dementia may be improved, paying attention to the identification of factors that can often enhance (or compromise) patient experience. Our goal is to work alongside healthcare professionals and specialist teams at the Christie to invoke change and provide better support for the patient, carers and staff experiencing dementia and cancer.

A large element of my role includes the provision of education to enhance skills and knowledge of nursing staff in understanding the needs of those with dementia and co-existing cancer. Nurses often express to me that they find caring for people with a dementia particularly difficult especially when a delirium is also present. Having a dementia can increase the risk eight-fold of developing a delirium and this can be particularly problematic given the range of medicines used in oncology such as anti-emetics, steroids, opiates and agents used in the management of hypercalcaemia. Unrecognised pain, invasive treatments and an unfamiliar environment may also contribute to delirium. Caring for people who present with a combination of dementia, cancer and a delirium can be a frightening and difficult experience and many nurses often express to me that they lack confidence when this situation occurs.

Supporting both the person with dementia and/or their family is a key part of my role and may include one-to-one help as well as post-diagnostic education, advice on future planning and emotional support. It can be an extremely difficult time for both the
patient and carer if they are informed that they have a dementia as well as receiving a diagnosis of cancer. However, due to the nature of the cancer and treatments involved there are key areas that need to be addressed, not least the form of treatment and the impact it may have on the person such as confusion, memory loss, loss of nutritional status and potential pain.

Along with the importance of getting a timely diagnosis and improving access to the right care at the right time, there are a host of other areas where more can be done to help people who have dementia and a co-existing cancer. These include pain management, which can be harder where dementia makes someone less able to communicate; advance care planning; and support for carers.

Good quality dementia care is challenging. It takes time, planning, forethought and commitment. The challenge is about seeing people living with dementia as complete and whole beings, about training staff in person-centred care and the value of how understanding the person's life history may help make sense of their often misunderstood behaviour. The person-centred approach values people with dementia and treats them as individuals, and necessitates looking at the world from the 'reality of the person with dementia'. It recognises that people with dementia require an enriched social environment and stimulation to promote their wellbeing. It is about being prepared to take risks, and enabling the person rather than disabling them, and I see it is my responsibility to play a leading role to help optimise the outcomes for people with dementia and co-existing cancer.

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**Join our team**

Breast Cancer Care is the only specialist UK-wide charity providing support for anyone affected by breast cancer. We’ve been supporting them and campaigning on their behalf since 1973. Our team of 10 permanent nurses provides information and support to clients in so many different ways, from taking calls on the Helpline, to teaching patients about side effects on a Moving Forward course, and writing our award-winning print and online patient information.

If you have recent experience in breast cancer and are passionate about ensuring every person gets the best information and support, come and join our fabulous and friendly team. We have vacancies at Band 6 and 7, full/part time and sessional.

**Closing date 5 December, interviews 13 December.**

For more information visit breastcancercare.org.uk/about-us/jobs or email us at recruitment@breastcancercare.org.uk
New booklet
After breast cancer treatment: what now?

Breast Cancer Care has developed a new booklet to replace our Your follow-up after breast cancer: what’s next? publication.

After breast cancer treatment: what now? is aimed at people coming to the end of hospital-based breast cancer treatment and still focuses primarily on follow-up. With follow-up care becoming much more varied over the last few years and the Recovery Package becoming more widely used, we’ve updated this information to give a more accurate picture of follow-up care today and the terms people might hear.

Following feedback from healthcare professionals and people affected by breast cancer, we’ve also expanded the booklet to cover the wider aspects of treatment finishing. It now includes information on health and wellbeing, staying breast and body aware, and how people might feel at the end of treatment. The new title reflects this broader content.

Breast and body awareness ‘quick guides’

In particular it was strongly felt that there should be more information on the ways breast cancer can come back (recurrence) and how to stay breast aware after breast surgery. As a result we have expanded this information and emphasised the importance of checking for both recurrence and a new primary cancer.

Our ‘Secondary. Not second rate.’ campaign, launched in June 2016, highlighted the importance of raising awareness of secondary breast cancer among women who have been diagnosed with primary breast cancer.

Survey findings showed only 22% of women with secondary breast cancer knew the possible signs and symptoms of breast cancer spread and only 40% were told how to get back into hospital care if they had any of these. We know that prompt diagnosis may help women to live for longer, improve their quality of life and reduce the chances of serious complications.

We have created two ‘quick guide’ pages on ‘being breast aware’ and ‘being body aware’, listing the signs and symptoms of recurrence (or a new primary) and secondary breast cancer to look out for and who to contact with any concerns. These have been designed to stand out from the rest of the booklet for emphasis and easy reference.
Revised booklet
Your body, intimacy and sex

The latest edition of our Your body, intimacy and sex booklet is now available. This booklet was reviewed in June with the help of our clinical reviewers and people who have had breast cancer.

We know that for many women physical changes to their body and the impact on intimacy and sex can be one of the most upsetting side effects of breast cancer treatment. It can also be more difficult to talk about these issues, which is why it is so important to have accessible, high-quality written information on this topic.

This booklet is designed to help women feel more comfortable with these changes, identify their concerns and find support if they need it. Topics include:

- physical changes during and after treatment, including changes to the body after surgery, menopausal symptoms, hair loss and lymphoedema
- how the physical and emotional effects of breast cancer and its treatments can affect sex and intimacy, and tips on how to cope with this.

Talking about sex and intimacy
As this topic can be less openly discussed than other side effects of breast cancer, women often feel more isolated with these concerns. We include women who’ve had breast cancer in everything we do and know how valuable it can be to hear from people who have been through similar experiences. We asked volunteers about the effects breast cancer had on their body image and intimate relationships, and have included their quotes and stories throughout the booklet.

For many women, getting support to help cope with the changes to their body, intimacy and sex is an important part of their treatment and care. However, it can be difficult to ask for professional help with these issues. The booklet includes a prompt list, designed to make it easier for people to discuss these concerns with their healthcare professional or when calling the Breast Cancer Care Helpline. This is included as a pull-out page at the back of the booklet and can also be downloaded from breastcancercare.org.uk/patient-resources

The new booklets are available to order from breastcancercare.org.uk/publications or by calling our Helpline on 0808 800 6000.
CAROLS BY CANDLELIGHT

Monday 5 December 2016, 7pm
St Paul’s Church, Knightsbridge

An evening of traditional carols and seasonal readings, plus performances from two of London’s leading choirs that will put you in the Christmas spirit. Then continue the festivities, by joining us for an exclusive supper at the Jumeirah Carlton Tower Hotel. You’ll be treated to a delicious two-course meal with wine and live entertainment.

Tickets start from £32

For more information and to book
breastcancercare.org.uk/carolslondon