Too little, too late
Palliative care and secondary breast cancer in England

Summary

- Specialist palliative care services can have a profound impact on people living with secondary breast cancer, many of whom will be experiencing regular, debilitating pain and other symptoms, as well as coping with having an incurable disease.
- However, all too often, access to palliative care comes very late, or in the very worst cases, not at all. This means there are people living with unnecessary pain. Choices about end of life are also less likely to be made.
- Timely access to specialist palliative care services should be standard for all secondary breast cancer patients but more needs to be done before this can be achieved.

Key recommendations

1. All secondary breast cancer patients should be provided with information about what palliative care is, particularly in relation to how it can support them during treatment and before end of life.
2. Every secondary breast cancer patient should have a named specialist nurse as part of their care who, among other things, can refer to a palliative care team and provide emotional support.
3. Training must be provided to oncologists, GPs and nurses to be able to have difficult conversations with patients about palliative care.
4. In line with the new cancer strategy, multi-disciplinary teams must begin to routinely discuss secondary breast cancer patients and identify when a referral to a specialist palliative care team would be appropriate.
5. Following the recommendation of the cancer strategy, all secondary breast cancer patients should receive a holistic needs assessment in order to identify if they would benefit from early access to palliative care.
6. The Government and NHS England must commit sufficient funding for palliative care to ensure that every secondary breast cancer patient is able to get the support they need.
Secondary breast cancer

For those living with a diagnosis of secondary breast cancer, access to specialist palliative care services can make all the difference in maximising quality of life and having a good death. But for too many, this support is simply not available. In many cases, where the support does become accessible, it is a case of too little, too late.

Secondary breast cancer – also known as metastatic, advanced or stage four breast cancer – occurs when breast cancer cells have spread from the breast to other parts of the body, most commonly the bones, lungs, brain and liver. Unlike primary breast cancer, secondary breast cancer is not curable. It can be treated and on average, people can live with the disease for 2-3 years. However, the trajectory of the disease is known to vary significantly and some people may live for much longer, whilst others only have a matter of months following their diagnosis. It is estimated that there are 36,000 people living with secondary breast cancer in the UK and each year, around 12,000 people die from the disease.

Breast Cancer Care has found that in England, as in the rest of the UK, the needs of secondary breast cancer patients are too often not being met. The Secondary Breast Cancer Taskforce, led by Breast Cancer Care, reported in 2008 that people with secondary breast cancer were far less likely to have a clinical nurse specialist, who can help co-ordinate care and provide emotional support, as part of their care and treatment, in direct contrast to the experience of many primary breast cancer patients. There is also a continued dearth of data on secondary breast cancer, which is denying commissioners the information they need to plan services effectively to meet their patients’ needs. Ultimately, it is a disgrace that the UK is still unable to provide an accurate figure for the number of people diagnosed with the disease each year.

In those cases where a patient is diagnosed with metastases following a previous diagnosis and treatment for primary breast cancer, they soon discover that their needs in both situations are very different. With secondary breast cancer, on top of a gruelling treatment regime, they must come to terms and deal with the emotional issues of living with an incurable disease.

2 ibid
3 Reed, E., Corner, J., (2013), Defining the illness trajectory of metastatic breast cancer, BMJ Supportive and Palliative Care
5 Breast Cancer Care (2008), Secondary Breast Cancer Taskforce: Improving the care of people with metastatic breast cancer, Final report
"When the secondary diagnosis comes, people talk to you differently. They talk to you about extending your life, having a good quality of life. The reality is that there is no cure at the moment and that is the one thing that is so hard to get over." Heather

The vast majority are also living with pain caused by their cancer. Our research for Secondary Breast Cancer Awareness Day 2014 found that 90% of people experienced regular pain and for 78%, their pain affected their ability to undertake everyday activities.6

"The pain I had, from when I was diagnosed, basically it was excruciating. It was so bad that I couldn't hold a glass in my hand or put a handbag on my shoulder. I couldn't touch my head, I couldn't dress myself. I couldn't sleep. And I couldn't breathe properly." Rowena

The role of palliative care

For both of these reasons, palliative care is essential for secondary breast cancer. Hospices and community based services can provide symptom management and pain control so that no one need live with unnecessary pain. Furthermore, the emotional support, for both the patient and their family, can help people come to terms with having an incurable disease, as well as ensuring that decisions are taken and adhered to about choices at end of life.

"Going there to the hospice was a revelation to me. It was a happy, welcoming, light, airy, pleasant place to be, where they were able to alleviate some of the most distressing and troubling symptoms that I was suffering from." Eleanor

The National Institute of Health and Care Excellence (NICE) defines palliative care as:

"The active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments."7

The NICE guideline for Advanced Breast Cancer currently states that there should be a holistic assessment of a patient’s needs at diagnosis, during and after treatment, at relapse and when death is approaching. This assessment should cover physical as well as psychosocial and spiritual needs.8 Were such assessments taking place regularly for

---

6 Breast Cancer Care, 2014, ‘Share your Experiences’ survey with 204 secondary breast cancer patients between 19/08/2014 to 22/09/2014. For full findings please contact: andy.glyde@breastcancercare.org.uk
7 NICE. (2004) Improving Supportive and Palliative Care for Adults with Cancer
secondary breast cancer patients, it is expected that palliative care would be identified for many as an obvious benefit for their care and wellbeing.

However, we know that too many people are not able to access this support. When it is available, support often only comes in the final weeks or even days at end of life, despite the fact that palliative care services can help at any point from diagnosis of secondary breast cancer.

Breast Cancer Care calls for better access to specialist palliative care services for everyone living with secondary breast cancer. Palliative support should come at the point of diagnosis or at a timely point, such as when the patient becomes symptomatic. It should provide people with both the symptom control to help them live as well as they can for as long as possible, the emotional support to cope with having an incurable disease, and support to make choices about end of life.

Our Standards of care for people living with secondary breast cancer highlight what good care should look like for secondary breast cancer patients. These include that people should expect to have access to expertise in palliative care, symptom control and ongoing management of troublesome symptoms, including being provided with information about end of life care when appropriate.9

Recent reports have suggested that big improvements are being made in palliative and end of life care in the UK. The Economist Intelligence Unit has suggested that the UK has the best end of life care in the world10. The Care Quality Commission has found that 90% of inspected hospices are providing good or outstanding care11. The recent One Chance to Get it Right – One Year On has shown progress made following the decision to scrap the Liverpool Care Pathway.12 However, all of this risks muddying the waters and fails to recognise that palliative care and support services are not currently universally available to all.

Furthermore, the recent debate around palliative care has largely focused on the need to expand support beyond those living with cancer. However, it is important that this does not

---

11 Care Quality Commission (2015), http://www.cqc.org.uk/content/most-hospices-are-%E2%80%98good%E2%80%99-or-better-says-cqc, accessed October 2015
lead us into the trap of thinking that we have got it right for cancer patients. We know from our work with people living with secondary breast cancer that this is simply not the case.

The reasons why this is not currently happening in England are varied and this report examines these in a bit more detail. In each case, the problems are not insurmountable and it is critical that government, commissioners and healthcare professionals come together to help bring about the changes that secondary breast cancer patients so urgently need.

In this detailed briefing, we make a series of recommendations, which if implemented, would go a long way in ensuring that everyone living with secondary breast cancer has access to this vital support.

The case of Mrs A

Mrs A had been diagnosed with secondary breast cancer and lived with the disease for six years, receiving numerous treatments to prolong her life. Over the final year of her life, she was increasingly symptomatic and experienced pain which was not well controlled. She had no access to a palliative care team.

She was discharged from a large cancer centre one day after being told that her current treatment was stopping and there was nothing further to be done. She died three days later at home.

Her family were distressed that she had been given ongoing active treatment even though Mrs A had become so symptomatic and debilitated in her final months. They had never discussed a time when treatment would stop or acknowledged that she was dying, as they tried to remain positive.

Referrals to palliative care and barriers to access

At the point at which someone is diagnosed with secondary breast cancer, we know that people will have a lot of questions about what comes next: What are my options? How long do I have to live? What support is available?

“At first it is very scary. You don’t know where to learn the things that you need to know. What do you need to know? What’s going to happen to you? What treatments, pain management? So you have a whole load of questions and you’re scared because you always hoped it wouldn’t come back.” Letitia

13 Case study provided as part of entry to Breast Cancer Care’s Nursing Network Awards 2013
One important area of support is palliative care. Given that some people will be diagnosed following presentation of chronic pain, it can start to help immediately with symptom control for those experiencing pain and other symptoms. In other cases, making sure that patients are aware of how to access their local hospice or palliative care team means that they know where support services are available in future.

However, Breast Cancer Care has found that as many as four out of ten people living with secondary breast cancer have never been offered a referral to palliative care. A further 25% have never had a discussion about palliative care with their oncologist or a nurse. This is despite the vast majority (90%) of people experiencing regular pain as a result of their cancer.

We know that the trajectory of secondary breast cancer is far from simple and varies from person to person. It can often be described in cycles of decline and reprieve where one treatment fails and another is found, up until the point that treatment options run out and the end of life phase begins. This makes it difficult for healthcare professionals to accurately pinpoint the end of life phase when palliative care plays its most significant role. Furthermore, it means there is no a one-size-fits-all model for the right time for a referral to a palliative care team. However, for some, such conversations are not happening at all, in those cases, and it is difficult to see how those patients could possibly access such vital support.

**Patient awareness and understanding of palliative care**

Among patients, we know there is a common misunderstanding of what palliative care is and what it provides. This is acting as a significant barrier to the number of people who are then willing to access the support that might be available to them.

Breast Cancer Care has found that an overwhelming number of people, 70%, believe that palliative care is just about end of life when they were first told about it. For many, their focus will be on treatments that can continue to extend their life and maintain their quality of life.

---

14 Breast Cancer Care, 2014, ‘Share your Experiences’ survey with 204 secondary breast cancer patients between 19/08/2014 to 22/09/2014. For full findings please contact: andy.glyde@breastcancercare.org.uk
15 Reed, E., Corner, J., (2013), Defining the illness trajectory of metastatic breast cancer, BMJ Supportive and Palliative Care, available at: [http://spcare.bmj.com/content/early/2013/07/23/bmjspcare-2012-000415.abstract](http://spcare.bmj.com/content/early/2013/07/23/bmjspcare-2012-000415.abstract)
17 Breast Cancer Care, 2014, ‘Share your Experiences’ survey with 204 secondary breast cancer patients between 19/08/2014 to 22/09/2014. For full findings please contact: andy.glyde@breastcancercare.org.uk
To talk about palliative care is seen by many as entering the end of life phase and stopping treatment, when that is simply not true.

This goes a long way to explaining why some people are not taking up a referral for palliative care even if they are offered it. This means that they are likely to be living with pain unnecessarily, while there may be no discussions or decisions made about their choices at end of life when the time does come.

"When I was first diagnosed with secondary breast cancer, I had never heard of palliative care. I had no idea what it meant - it might have been of use to me but I didn't know because I didn't know what it meant. Certainly I was very afraid of the hospice. Literally, physically afraid, I would avoid it." Eleanor

In some cases, nurses are getting around this barrier by using different language to describe palliative care services. However, efforts should be made to ensure that patients understand what palliative care is and what it can offer them before they reach end of life.

**Recommendation 1:** All secondary breast cancer patients should be provided with information about what palliative care is, particularly in relation to how it can support them during treatment and before end of life.

As well as the multi-disciplinary team (MDT), one other way that a patient might be identified where palliative care could be beneficial is through a specialist nurse. A clinical nurse specialist (CNS) acts as a point of contact between the patient and the hospital. They can help to co-ordinate care and signpost to relevant services, as well as providing emotional support. Evidence shows that a CNS is the biggest driver to improving patient experience.

"I received really good care from a secondary breast cancer nurse. Having a secondary breast cancer nurse meant I could ask countless questions, phone any time I was worried about anything. She's my link between the consultants and me. So she makes a massive difference." Frances

Unlike the experience of many with primary breast cancer, it is far less likely for secondary breast cancer patients to have a CNS as part of their care. A recent study found that there were just 19 dedicated secondary breast cancer nurse post-holders across the UK in 2010.

---

19 Information provided as part of entry to Breast Cancer Care’s Nursing Network Awards 2013
Breast Cancer Care estimates that this will now be at approximately 15-25 posts. This is compared to around 600 conventional breast care nurse posts. This means that so many secondary breast cancer patients simply do not have this support.

“I was shocked when I found out that not everyone has a secondary breast cancer nurse. I can’t imagine what coping with my diagnosis would have been like without that support.” Emma

A lack of CNSs means that another possible avenue to palliative care is not available for many secondary breast cancer patients. Breast Cancer Care believes that everyone living with secondary breast cancer should have a CNS as part of their care. We are encouraged to see a similar recommendation included in the new cancer strategy.

**Recommendation 2: Every secondary breast cancer patient should have a named specialist nurse as part of their care who, among other things, can refer to a palliative care team and provide emotional support.**

**Other barriers to accessing palliative care services**

As well as patient misunderstanding of palliative care, there is also an apparent reticence among some healthcare professionals to speak about palliative care and end of life. This is understandable to a degree. Much like their patients, oncologists and nurses will want to discuss treatments that will extend life before considering what happens when treatment options are exhausted.

There is also anecdotal evidence to suggest that GPs, oncologists and nurses feel uncomfortable or unable to have difficult or potentially upsetting conversations with patients about death and palliative care. Much like patients, some professionals view palliative care and end of life as one and the same.  

**Recommendation 3: Training must be provided to oncologists, GPs and nurses to be able to have difficult conversations with patients about palliative care.**

A further issue is that services can feel more disjointed to patients with secondary breast cancer. For someone diagnosed with primary breast cancer, their case will be discussed by the MDT, consisting of a range of healthcare professionals involved in that person’s care. When this works well, it leads to a more seamless pathway to treatment for the patient.

Available at

22 Based on information provided as part of entry to Breast Cancer Care’s Nursing Network Awards 2013
However, we know that secondary breast cancer patients are not routinely being discussed at MDT meetings. This is largely due to the fact that patients with secondary breast cancer will be dealt with mostly by their oncologist, rather than a range of professionals. Ultimately, this means that care is not co-ordinated across services.

The new cancer strategy, *Achieving World-Class Cancer Outcomes: a strategy for England 2015-2020*, published in July 2015, includes a recommendation that MDTs routinely discuss metastatic cancer patients to ensure their care is joined up. If this is achieved, it is likely more patients will be referred to specialist palliative care services as the need arises.

**Recommendation 4:** In line with the new cancer strategy, MDTs must begin to routinely discuss secondary breast cancer patients and identify when a referral to a specialist palliative care team would be appropriate.

Moreover, the cancer strategy recognises the importance of early access to palliative care for patients with advanced cancers. It recommends new pilots involving holistic needs assessments in order to identify those patients who would benefit from earlier access to palliative care.

**Recommendation 5:** Following the recommendation of the cancer strategy, all secondary breast cancer patients should receive a holistic needs assessment in order to identify if they would benefit from early access to palliative care.

We know that there are some hospitals and palliative care services who are leading the way in ensuring that referrals to palliative care happen and that more secondary breast cancer patients access this support. The Ashgate Hospice has undertaken an audit of all secondary breast cancer patients to understand when they were referred for palliative care and for what reason in order to identify gaps in care. This work has helped to initiate discussions about referral pathways and the palliative care team saw a noticeable increase in referrals as a result.

The Christie NHS Foundation Trust was recently recognised in Breast Cancer Care’s Nursing Network Awards in 2013 for improving how it identifies secondary breast cancer patients who would benefit from earlier specialist palliative care support. Using the Sheffield Profile for Assessment and Referral for Care (SPARC) holistic needs model, patients were identified when they were still relatively symptom free. As well as improving access to

---

23 Breast Cancer Care (2008), Secondary Breast Cancer Taskforce: Improving the care of people with metastatic breast cancer, Final report
25 Ibid
26 Information provided as part of entry to Breast Cancer Care’s Nursing Network Awards 2013
palliative care, it has led to fewer emergency admissions, shorter lengths of stay in hospital, and fewer patients dying in hospital.\textsuperscript{27}

\textbf{Resources for palliative care}

Sooner or later, any discussion about extending a service within the NHS to more patients must examine the necessary resources required in an ever increasingly challenging financial environment. Compounding the issue for palliative care is an expected increase in demand as prevalence of breast cancer is set to increase, with the number of people living with a breast cancer diagnosis set to rise from 570,000 people to 840,000 in 2020.\textsuperscript{28} Without the resources required to meet this demand, patients will ultimately lose out.

There is anecdotal evidence that this is already having an impact on patients. Breast Cancer Care has heard of palliative care teams turning away patients who have been referred to them. This particularly seems to be the case where patients are not considered to be in their end of life phase or not overly symptomatic. Ultimately, this creates a perverse scenario which means that in some cases secondary breast cancer patients are expected to become more unwell before they are deemed eligible for support, despite the evidence showing that earlier access to support maximises quality of life.

Worryingly, there appears to be a growing postcode lottery, both within England and between different nations within the UK, of accessibility of palliative care support. While current structures of the NHS in England encourage services to meet local needs, there should be a basic minimum standard with regard to palliative care and what every secondary breast cancer patient can expect to receive.

While much of this might be explained by an NHS needing to make difficult choices about the financial resources it has, particularly in light of the £22 billion of efficiency savings highlighted in the \textit{Five Year Forward View}, under-resourced palliative care services are bad both for patients and the NHS as a whole.

\textbf{Wider benefits of good access to palliative care}

When considering that so many secondary breast cancer patients experience regular debilitating pain, it is absurd that regular access to palliative care is not available. Without it,

\begin{itemize}
\item\textsuperscript{27} Hunt, L., (2014), Rewarding innovation and best practice in breast cancer care, Cancer Nursing Practice, available at: \url{http://journals.rcni.com/doi/pdfplus/10.7748/cnp2014.03.13.2.16.s18}
\item\textsuperscript{28} Maddams J et al (2012) Projections of cancer prevalence in the United Kingdom, 2010–2040, British Journal of Cancer. 107, pp1195-1202
\end{itemize}
people are more likely to end up in accident and emergency services when self-management is no longer able to sufficiently relieve their pain. As a result, their hospital stay will be longer in duration than it otherwise needed to be. All of this adds unnecessary pressure on a health system that is well documented to be already struggling under the weight of emergency admissions and delayed discharges.

There is a growing body of evidence that palliative care can ease pressure on acute services on top of ensuring patients' wishes around end of life are met. Reductions in emergency admissions and length of hospital stays, particularly in the final weeks of life, can only be a good thing for all. Investment in palliative care should be increasing in order to maximise the potential to provide further efficiencies to the NHS in the long term.

The Government has committed to providing £8 billion of funding to deliver the Five Year Forward View and the new cancer strategy. While much of these efforts are based on prevention and early detection in order to save lives, there must also be sufficient funding available to palliative care services to provide the support that is necessary for people living with secondary breast cancer. As well as offering much needed care for patients, this is also likely to contribute to the efficiency savings needed to make the NHS sustainable in the long term.

**Recommendation 6: The Government and NHS England must commit sufficient funding for palliative care to ensure that every secondary breast cancer patient is able to get the support they need.**

Furthermore, there are many people caring for loved ones with secondary breast cancer. They will be providing support with everyday activities, helping with medication, and offering emotional support. Without these unpaid carers, our health and social care system simply would be unable to function.

It is vital that these carers, as well as other family and friends, also receive support as their loved ones living with secondary breast cancer. Palliative care services provide emotional support for family while the support for the patient, particularly at end of life, can take some of the burden from carers. This is only possible though where palliative care services are available at a timely point.

---

29 Murtagh, F., (2014), Can palliative care teams relieve some of the pressure on acute services?, BMJ 2014, 348
**Conclusion and final recommendations**

It is vital that there are sufficient specialist palliative care services accessible to people with secondary breast cancer. Only when that happens will people be able to live without unnecessary pain, maximise their quality of life and make decisions about end of life.

For this to happen, Breast Cancer Care makes six recommendations, which government, health bodies and professionals need to work together with the voluntary sector and patients to bring about the change so urgently needed:

1. All secondary breast cancer patients should be provided with information about what palliative care is, particularly in relation to how it can support them during treatment and before end of life.
2. Every secondary breast cancer patient should have a named specialist nurse as part of their care who, among other things, can refer to a palliative care team and provide emotional support.
3. Training must be provided to oncologists, GPs and nurses to be able to have difficult conversations with patients about palliative care.
4. In line with the new cancer strategy, MDTs must begin to routinely discuss secondary breast cancer patients and identify when a referral to a specialist palliative care team would be appropriate.
5. Following the recommendation of the cancer strategy, all secondary breast cancer patients should receive a holistic needs assessment in order to identify if they would benefit from early access to palliative care.
6. The Government and NHS England must commit sufficient funding for palliative care to ensure that every secondary breast cancer patient is able to get the support they need.

**About Breast Cancer Care**

Breast Cancer Care is the only UK-wide charity providing specialist support and tailored information for anyone affected by breast cancer. Our clinical expertise and emotional support network help many thousands of people find a way to live with, through and beyond breast cancer. We offer training for specialist breast cancer nurses and opportunities for them to share best practice. Our information is used in breast care units across the UK. We promote the importance of early detection, and campaign for better support and care, involving people with breast cancer in all that we do.