

Supporting black, Asian and minority ethnic women following treatment for breast cancer



Summary

- Many people feel a sense of loss and isolation after completing their treatment for breast cancer. Black, Asian and minority ethnic (BAME) women have additional needs at this time, with increased isolation, communication issues, and services that currently do not always meet their needs.
- Breast Cancer Care believes that everyone should get the support they need after they have completed their hospital-based treatment so that they can live well and find their 'new normal'.
- The needs of BAME women must be addressed by all existing post-treatment services. Furthermore, health policy-makers throughout the UK must consider BAME breast cancer patients in the implementation of current cancer strategies and plans, as well as the development of new cancer policy.

Please note, this report is based on the initial findings of research undertaken by Breast Cancer Care, in collaboration with King's College London and funded by the Big Lottery Fund. Full results of our research are due to be published later this year.

Every year, around 58,000 people are diagnosed with breast cancer in the UK – the equivalent of 159 people every day, seven people every hour, or one person every 10 minutes. It remains the most common cancer in the UK, and makes up nearly a third of all new cancers diagnosed in women. One in eight women will develop breast cancer over their lifetime.

Survival rates continue to improve for breast cancer, meaning that more people than ever are living having had a diagnosis for the disease. There are currently an estimated 691,000 people in the UK who have been diagnosed with breast cancer. This is set to rise to 840,000 by 2020.

This presents a huge challenge to our society, as well as our health and social care services.

All of these people need to be given the help and support they need to be able to live well following their treatment for breast cancer. They need the right information to know how to manage side effects and spot a possible recurrence of the disease, as well as the support they may need to return to work and find their 'new normal' in life.

Breast Cancer Care is the only UK-wide charity providing specialist support and tailored information for anyone affected by breast cancer. One of the areas we particularly focus on is supporting people after their hospital-based treatment for breast cancer – that is, after they have completed any combination of chemotherapy, radiotherapy and surgery.

We know from listening to people with breast cancer that this period can be extremely difficult.

Many people can feel a sense of loss and abandonment when their treatment finishes. It may be the first time they have been able to think and process the emotional impact of their breast cancer. They may have questions about what's next and not know where to turn to.

Furthermore, they may be continuing to deal with the ongoing side effects of their diagnosis and treatment when trying to return to work or resume their usual roles and responsibilities. If they are on long-term hormone treatment, they may be experiencing menopausal symptoms. They may be coming to terms with having an altered body image, following the removal of part or all of one or both breasts. It may be difficult for them to return to 'normal' after their treatment.

Moving Forward

Breast Cancer Care supports many people following their hospital-based treatment through our 'Moving Forward' self-management courses. Run in partnership with NHS hospital trusts, these courses take place over half a day for three to four weeks. They provide information and support on a range of topics including healthy living, side effects of treatment, intimacy and relationships, and spotting the signs and symptoms of a possible recurrence.

In 2014/15, Breast Cancer Care worked with 22 NHS units across the UK to deliver Moving Forward courses to 1,050 people. By the end of each course, the participants reported:

- an enhanced understanding about how to manage their lives after treatment
- they were better informed about further sources of information and support
- they were empowered in making decisions that have a positive impact on their wellbeing
- they felt less isolated, and had increased self-confidence to move on with their lives.

Furthermore, by addressing the possible signs and symptoms of a recurrence, Moving Forward helps deal with the biggest anxiety that many people have after completing their treatment – that the disease will return.

The move away from traditional follow-up appointment models of care shows that self-management is the only sustainable model for the NHS in the future. For it to be a success, the right support needs to be available to help people self-manage after treatment.

The new Cancer Strategy for England, *Achieving World-Class Cancer Outcomes*, published in July 2015, placed a significant amount of attention on the need to support people living with and beyond cancer. The Strategy is clear that people must be supported after their cancer treatment has finished. One of the key recommendations, already accepted by government and health bodies, is that by 2020 all cancer patients will receive a 'recovery package' which will support them to live with and beyond cancer. It will include a holistic needs assessment and individualised care plan, information and support, and access to patient education (self-management) events. As the only patient education service at this stage specifically for breast cancer patients, Moving Forward plays a key role in helping people live well, manage the consequences of treatment and find their 'new normal' after breast cancer. Breast Cancer Care's ambition is that everyone diagnosed with breast cancer has access to a Moving Forward course following their treatment.

Black, Asian and minority ethnic women with breast cancer

There is less evidence available about the impact of breast cancer on different ethnicities. But we know that breast cancer does not discriminate; it affects people from all ethnic and social backgrounds. Anyone, regardless of ethnicity, may face the prospect of a diagnosis, the gruelling treatment regime and subsequent side effects, the emotional impact of altered body image, and the challenge of finding a 'new normal' after breast cancer.

While incidence rates of breast cancer among the largest ethnic groups in the UK (South Asian, black Caribbean and black African) are lower than the white population (NCIN, 2009, Ali et al, 2010; Downing,

2011), there tend to be poorer survival outcomes for women from these ethnic backgrounds (Jack, Davies and Moller, 2009). This has largely been attributed to later diagnosis of the disease, at which point it is often more difficult to treat. Evidence suggests late diagnosis is attributed to lower uptake of screening, fears and misconceptions about cancer, and poorer breast awareness knowledge and practices among these groups (Jack, Davies and Moller, 2009).

Furthermore, we know that the experience of BAME breast cancer patients tends to be poorer than those of white women. The Cancer Patient Experience Survey has shown that some ethnic groups are significantly less satisfied about the care they receive than others, in particular in some aspects of communication and the way they feel treated by staff (NHS England, 2013).

However, there has been far less attention given to the needs of BAME women after they have completed their treatment. With increasing importance being placed on 'survivorship', it is vital that the needs of these groups are understood and that adequate support is available to them.

The Cancer Strategy in England recognises that BAME cancer patients often experience poorer levels of support than other groups. However, the Strategy contains no specific recommendations for improving outcomes and experience, including post-treatment, for different ethnic groups. This risks BAME cancer patients being left with their needs still unmet, meaning that they are likely to continue to experience poorer recovery from cancer, and poorer self-management practices, making them at higher risk of requiring more intense intervention from health and social care services.

Over the past five years, Breast Cancer Care has undertaken a ground-breaking piece of research in this area. Funded by the Big Lottery Fund and in collaboration with King's College London, the project aimed to better understand what the needs of BAME women are after their breast cancer treatment and how supportive services could ensure that they are addressing these.

The full results of this research are due to be published later this year. Initial results have identified three key points that highlight the additional needs of BAME women:

- 1.** BAME women can find themselves more isolated than other groups after treatment. This can be because of the stigma of cancer, which still exists in some communities, meaning that people can feel less able to turn to others or seek help.
- 2.** Information and support may not be accessible due to language and communication issues. Even those who are English-speaking report difficulties and fears in both understanding the information they receive and being able to articulate their concerns.
- 3.** Existing services do not always address cultural differences of religious beliefs in the support they provide. In some cases lymphoedema sleeves and breast prostheses were not available in different skin tones. Information about healthy living and nutrition does not always take into account religious beliefs. Suggestions on issues such as skin care and hair care is not always suitable for South Asian or black women.

PROWESS

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In response to these findings, Breast Cancer Care developed a culturally inclusive pilot service to support the self-management of BAME women after their hospital-based treatment for breast cancer: 'Promoting Recovery, Wellbeing, Equality and Support in Survivorship' (PROWESS).

Using our Moving Forward service model as a starting point, groups of black African, black Caribbean and South Asian breast cancer patients, as well as hospital-based and community-based healthcare professionals, worked with us to co-design this new service. Crucially, it was decided at an early stage that PROWESS would not be targeted solely at one or more ethnic or social community. Instead, it would be culturally adapted so that it could be inclusive for all.

The key components of PROWESS that can be different from existing services were:

- it was based in a local community setting
- it was facilitated by trained patient volunteers from target communities, with a personal experience of cancer
- it allowed extra time for social support – during group discussions, coffee and lunch breaks, etc.

Other features included:

- some sessions were open to family members and carers to attend along with the participants
- it consisted of five half-day sessions, which might be run on a weekday morning or over a series of weekends
- it was delivered as discussion-based information sharing, using case studies, storytelling and practical skill development
- it incorporated goal-setting.

Between January and July 2015, 31 women from South London attended one of the five PROWESS services run in local community settings. Initial results show improvement in the women's physical and emotional wellbeing, and their self-confidence to manage their wellbeing three months after attending PROWESS.

We are now evaluating the findings of this pilot to identify how we can ensure that all of our services for people with breast cancer are culturally adaptable and inclusive.

Conclusion

With more and more people surviving breast cancer for longer, it is vital that those living with a breast cancer diagnosis are given the support they need to self-manage and live well after their treatment has finished. There must be information about signs and symptoms of possible recurrence to reduce women's anxiety and enable them to feel more confident in being able to spot a possible recurrence early and report their concerns.

This is important not just for an individual's ongoing health and wellbeing but for us as a society.

Supporting people to adjust to their 'new normal' means that more people will be able to go back to work and contribute to society in different ways.

Post-treatment support is also crucial to the future sustainability of the NHS. Unnecessary follow-up appointments with clinicians are no longer required, freeing up healthcare professionals' time. Better support can also reduce the number of emergency admissions and ongoing costs of treating later stage disease.

Breast cancer does not discriminate. This means that support post-treatment must be available for people from all ethnic and social backgrounds. But our research has highlighted that BAME women are not always getting the support they need. It is not that specific services are required that are targeted solely to BAME women. Instead, all services that look to encourage self-management should be made culturally accessible and appropriate to the needs of local populations, so that they can be inclusive to all. From our pilot PROWESS service we have developed a model of culturally-appropriate, supportive self-management care, which can be applied across the different cancer types.

Breast Cancer Care calls for all women, regardless of ethnic and social background, to have the information and support they need to live well after their breast cancer treatment.

Furthermore, health policy-makers in each nation of the UK must take into account meeting the needs of people affected by breast cancer from different ethnic and social backgrounds in future cancer policy. In England, this means that the implementation of the Cancer Strategy must consider how best to support BAME women after breast cancer treatment. In Scotland, Wales and Northern Ireland, these factors must be considered as and when new strategies and plans are developed.

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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 have helped thousands of women and their families every year through our face-to-face, phone and online services. 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.

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