

# Extending Reach – Increasing breast awareness among people with learning disabilities



Breast Cancer Care is committed to ensuring that everyone in the UK has access to high quality breast awareness and breast cancer information. We believe this is essential to increase early detection and lead to effective treatment.

The Extending Reach project was set up to improve breast awareness and promote the breast health of groups shown by existing research to be most at risk, present late and/or have low levels of breast awareness.

## OBJECTIVES

- ◆ To produce targeted community specific breast awareness and breast health resources.
- ◆ To increase breast awareness amongst under-represented groups with a long-term aim of reducing health inequalities.

## METHODS

**Baseline assessment:** In order to understand the breast awareness needs of people with learning disabilities we conducted a pilot project in Wales. Working with a group of women from the self-advocacy charity Cardiff People First and HiJinx Theatre, we held a drama-based workshop exploring how group members currently receive information about health matters and what formats and locations they thought would be most effective in the future.

**Outcome:** The workshop revealed group members were confused about possible breast cancer risk factors, and signs and symptoms to look and feel for. Those who had known people with cancer also expressed fear of the disease and a lack of knowledge of the improving survival rates following early detection. Everyone mentioned negative experiences of visiting their GPs, reflecting on the long time it took to see the doctor and then the frustration of not being listened to, with many doctors addressing the carer rather than the patient.

**Resource development:** In a series of follow-up sessions the group explored format options for the booklet, photographed group members in real-life settings for use in the resource and reviewed the draft booklet for comprehension, appropriateness of format, content, tone, language, colour and image use.

**Outcome:** Two breast awareness resources were developed; a booklet for people with learning disabilities and a supporting booklet for carers. Both resources were designed with the aim of enabling people to feel more empowered to take care of their bodies, and covered the key messages of breast awareness. The resource aimed at people with learning disabilities was designed so that women with learning disabilities can use the booklet independently or with support from their carer, and as such contains minimal text in large print with accompanying photo symbols to reinforce the messages. The carers' booklet was designed to provide support in aiding the person with learning disabilities to understand and practise breast awareness.



## EVALUATION

**Written evaluation:** Specially designed evaluation forms were included with all resources distributed, with a pictorial version for people with learning disabilities.

**Focus group:** An interactive theatre-based focus group was undertaken by Advocreate working with a group of 11 people (10 women and 1 man) with mild to moderate learning disabilities recruited by Vale People First. Using a variety of participatory methodologies the session explored what the group thought about the booklet and suggested modifications to be made before the booklet is launched nationally.

## KEY LEARNINGS AND NEXT STEPS

We have received a wealth of detailed feedback from health professionals, carers and people with learning disabilities. Based on these suggestions the resources will be redrafted before dissemination across the UK.

If you would like further details of the Extending Reach project please contact Miriam Light (Research & Evaluation Officer) on 020 7960 3566 or [miriam.light@breastcancercare.org.uk](mailto:miriam.light@breastcancercare.org.uk) or visit our website [www.breastcancercare.org.uk](http://www.breastcancercare.org.uk)

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