

Good Practice Guidelines for Breast Screening in Women with Learning Disabilities

Definition and Facts

A person with a learning disability has:

- a reduced ability to understand new or complex information

and

- difficulty in learning new skills and coping independently.

These disabilities must have started before adulthood (aged 18) and have a lasting effect on development.

A learning disability may be mild, moderate, severe or profound and IQ is generally below 70. People with learning disabilities have many different talents, qualities, strengths and support needs.

Some will have difficulties communicating their ideas and preferences, but most struggle with abstract concepts or complex ideas.

Women with learning disabilities are living longer and fuller lives and should have access to breast screening on the same basis as other women.

The purpose of this paper is to describe good practice for health professionals to ensure that women with a learning disability have the same rights of access as all other women to the NHS Breast Screening Programme (NHS BSP).

It highlights good practice, before, during and after a mammogram and includes guidance on assessing consent, providing accessible information and preparing for further investigations.

Disability Discrimination Act

As of October 2004, service providers now have a duty to make reasonable adjustments to ensure that disabled people do not find it impossible or unreasonably difficult to access that service. This may include changes such as:

- Altering policies, procedures, practices which make it impossible for a disabled person to access a service.
- Removing, altering or avoiding physical obstacles to access.
- Providing alternative solutions to problems of access.

Best Practice Suggestions for Breast Screening Units

- Breast screening units should investigate opportunities for training staff about disabilities, equality issues and consent.
- Learn about basic sign language (see attached picture board).
- Develop systems for 'flagging up' a learning disability by checking previous notes, liaising with GP practices/CLDTs for lists of woman 50+ with a Learning Disability.
- Encourage individuals and carers to contact the unit before the appointment to discuss any needs or anxieties.
- Ensure picture leaflets explaining the screening process are available.
- Provide invitation letter in large print and an easy to read format.
- Offer preliminary visits to the unit to allow the woman to become familiar with the surroundings and meet the radiographer.
- Arrange a longer appointment time. (minimum 20 minutes).
- People in wheelchairs should be offered appointments in static units.
- If possible arrange appointment when the unit is less busy (either first or last appointment or weekends?)
- Ensure that the supporter accompanying the woman understands the screening process.

A

Before Appointment

- Discuss issues of consent with carer and individual.
 - Establish communication methods of each individual before procedure i.e. how she indicates yes and no.
 - Discuss procedure with individual using picture leaflets.
 - Make woman familiar with the machine and how it works.
 - Explain any noises or flashing lights which may occur.
 - Use role play and lots of physical gestures to explain procedure.
 - Confirm with carer that breast screening has been explained to her.
- Assess the woman's suitability for mammography using the following guidelines:

Is woman able to:

- Hold head up unaided.
- Flexibility to hold arms clear of chest and equipment.
- Support body upright if in a wheel chair.
- Sufficient muscle control to remain still and maintain one position (for up to 5 minutes).
- Tolerate some discomfort.
- Comprehend and co-operate to simple requests.
- Cope in unfamiliar situations and environments.

B

During Appointment - Taking the mammogram

- Continue to explain in clear, simple language every stage of the procedure.
- Allow extra time intervals for the woman to respond to questioning.
- Use plenty of eye contact to check understanding.
- Check with supporter that woman is complying with procedure.
- A gentle hand on the woman's back may help the woman to keep still during compression.
- Advise supporter to stay close to the woman (with correct protection against radiation).
- Encourage supporter to calm and reassure woman throughout.
- Remind woman of any noises of the mammogram just before they occur.

Consent to screening

For disabled women, as with other women, the issue of valid consent is crucial.

Consent is only valid if:

- Woman understands
- Woman can communicate
- All woman invited must be given enough information to enable them to make an informed choice about whether to attend the appointment.

But remember:

- Have you spent sufficient time talking and listening and determining level of understanding?
- Communication effective.
- Explained using persons preferred method of communication.
- Involved supporter/carers interpretation input.

Having established that the woman has an understanding of breast screening, the radiographer should then proceed on the basis of behavioural consent.

Behavioural withdrawal or undue distress during the procedure should be seen positively as the woman's choice on that occasion.

It does not mean removal from the screening programme. Withholding or withdrawal of behavioural consent during screening should be documented in the woman's notes and another screening appointment arranged at the usual 3 yearly interval.

This can apply some time before screening, immediately before or during the appointment.

Examples of withholding consent may include:

- Refusal to accompany carer to appointment.
- Refusal to enter screening unit.
- Refusal to comply with requests such as undressing.
- Becoming unduly distressed or agitated.
- Not co-operating with radiographers instruction.
- Shying away from staff or equipment.

C

After appointment

- Make sure support staff are aware of the possible results of breast screening and how to prepare the woman if she is referred for assessment.
- Inform woman and support staff/relatives about breast awareness and visual signs of changes in between screening.

Look for:

- Changes in shape, size , symmetry.
- Puckering, dimpling or 'Orange peel' appearance of skin.
- Veins which stand out more than normal.
- Rashes.
- Discharge from nipple.
- Change in position of nipple (pulled in, inverted, pointing in different direction)
- Unusual smell or sticky sore on breast.
- **ANYTHING THAT IS DIFFERENT FROM NORMAL.**

Next steps:

Questions to ask:

- Could patient be better prepared before next session?
- Could mammogram be carried out in a different environment?
- Are more (or different) supporters required i.e. a family relative, best friend etc.
- If woman is high risk, could a less invasive method of screening be offered?

(eg. ultrasound, physical examination?)

- Ensure that woman and support workers are given information on general breast care and breast awareness.

Tips/Best Practice

- Have information about breast screening, breast awareness and cancer in an accessible format.
- Compile a folder or box with appropriate resources and information.
- Be aware of the CLDTs, PALS, HFT.
- List of useful websites.
- List of resources available.
- Learning the basic MAKATON sign language.

Resource List

Materials for people with learning disabilities

Having a mammogram. A booklet for women with a learning disability.

Women's Health Information and Support Centre 120 Bold Street, Liverpool, L1 4AJ
Tel. 0151 707 1826 email: women@whisc.org.uk £2.50

A visit to the Breast Assessment Unit

A book for women with a learning disability Women's Health Information and Support Centre 120 Bold Street, Liverpool, L1 4AJ Tel. 0151 707 1826 email: women@whisc.org.uk £2.50

Be breast aware A teaching pack for women with learning disabilities and those who work with them Lisa Poynor, CLDN, Surrey Oaklands NHS Mental Health and learning disabilities trust, Langley House, Church Lane, Oxted, Surrey, RH8 9LH

Breast Screening A pack for women with learning disability to use with a carer to attend for breast screening Diane Mc Cormack, Health Promotion Service, Jarvis Centre, 60 Stoughton Road, Guildford, Surrey, GU1 1LJ Tel: 01483 532 828 dianemaccormack@gwpct.nhs.uk free

Looking after my breasts A book beyond words Book Sales, Royal College of Psychiatrists, 17 Belgrave Square, London SW1X 8PG Tel: 020 7235 2351 www.rpspsych.ac.uk £10.00

Keep yourself Healthy: a multimedia guide to examining breasts

A CD ROM FAIR (Family Advice and Information Resource) 25 – 27 West Nicoloson Street, Edinburgh, EH8 9DB Tel 0131 662 19625 e-mail: fair@btconnect.com £3.50

Keeping yourself healthy – a guide to examining your breasts

A booklet guide to breast examination using simple text and illustrations

FAIR (Family Advice and Information Resource) 25 – 27 West Nicoloson Street, Edinburgh, EH8 9DB Tel 0131 662 1962 e-mail: fair@btconnect.com 50p each

Breast Awareness - A booklet for women with a learning disability. Women's Health Information & Support Centre. 120 Bold Street, Liverpool, L1 4AJ. Tel. 0151 707 1826 e-mail: women@whisc.org.uk £2.50

Leaflet - An easy guide to breast screening

Leaflet – Consent, a guide for people with learning disabilities

Materials for carers/relatives

Brochure - Consent – what you have a right to expect, a guide for relatives and carers