

LIVING WITH SCI

FACTSHEETS

sia spinal
injuries
association
FOR LIFE AFTER SPINAL CORD INJURY



**BREAST AWARENESS
(FOR WOMEN WITH SPINAL CORD INJURY)**

Breast Awareness for Women with Spinal Cord Injury

Breast awareness means getting to know what is normal for you. Breast tissue varies from woman to woman. Some women have naturally 'lumpy' breasts often making self-examination confusing.

It is very easy to forget to carry out a monthly check for breast lumps but unfortunately having a spinal cord injury does not mean breast cancer will not occur.

The breast awareness five point code



1. Know what is normal for you
2. Look and feel
3. Know what changes to look and feel for
4. Report any changes without delay
5. Attend for routine screening if aged 50 and over

For women with paralysis, self examination can be more challenging. Sadly, women with disabilities often have less access to breast health services than any other groups of women. BUT: Disabled women have the same rights of access to breast screening as other women.

Screening

In the UK women are invited for breast screening from the age of 50 to 70 years of age every 3 years. You may not receive a letter immediately after your 50th birthday, in reality the first invitation letter can arrive any time between your 50th and 53rd birthday. If you have any worries you should contact your GP Surgery to make sure your name is on the appropriate mailing list. Of course you don't have to be restricted to the 50-70 years recall system. If you have concerns at any age you can ask your GP to refer you for mammography.

Self-help

Some studies suggest that SCI women don't present for health screening as often as non-SCI women. But don't let obstacles get in the way and in the process compromise your health. NHS Staff with little understanding of SCI can affect the way you view screening in the future. Comments from a health professional such as ***“OK, Elizabeth, we're going to go into the exam room now. Can you stand?”*** are very upsetting.

Monthly self examination

Many breast lumps are detected by women themselves. But feeling for lumps forms one part of breast examination, looking carefully at your breasts in a mirror is also vital. For SCI women poor posture may make this difficult and a mirror needs to be the correct height for you in your wheelchair. You are looking for any change in size, shape of the breasts, discharge from the nipple or puckering of the nipple. Also, skin changes e.g. rashes or orange peel appearance. Always check the armpit area for swelling or lumps.

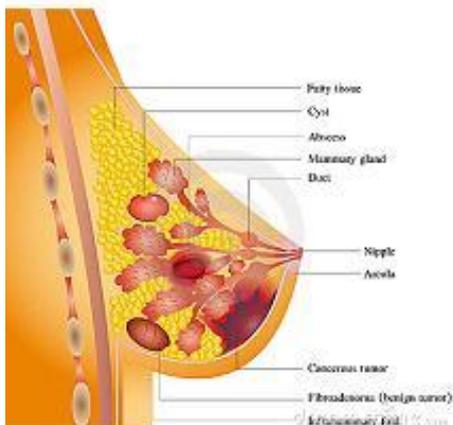
The best time to self-examine is between 4 to 7 days after your period, or on the same day each month if your periods have stopped.

If you are unable to self-examine because of limited movement or problems with spasms:

- Ask husbands / partners / PAs to help you
- Ask your GP when you go to the surgery / ask to see a female GP if you wish.

Normal Changes

Along with the rest of the body, your breasts change through the decades. Breast tissue is made up mainly of fibrous, fatty tissue plus tissue that makes up the milk-producing glands (glandular tissue). There is no muscle tissue in breasts.



During our 30's and 40', the hormone oestrogen helps keep breasts firm. Problems during these years tend to be of a benign (non-cancerous) nature. Cysts (fluid filled sacs) can occur and these may cause varying degrees of pain. If cysts reoccur regularly they can be drained or surgically removed.

Another painful condition is caused by rubbery benign lumps called fibroadenomas. They too can be surgically removed if troublesome.

Pain can also occur around the time of menstruation.

Some sagging may occur after pregnancy / breastfeeding as breasts shrink back to their normal size.

As we age, the fatty tissue reduces, this is a contributory factor to lack of firmness. Equally, ageing skin naturally loses its elasticity.

In your 30's and 40's the fatty tissue, which is dense, makes lumps / breast cancers more difficult to detect on mammogram. The risk of breast cancers during one's 30's is low, but any persistent problems, should be checked by your GP.

In your 40's, you are more likely to notice that the shape of your breast is changing.

In your 50's, breasts naturally shrink. Hormonal changes affect the glandular tissue – breasts also appear less firm.

In your 20's, 30's and 40's, you may experience lumps around the time of your period, which then go away. But feeling a new lump when you are post-menopausal, should alert you to seek a medical opinion.

Mammogram



Mammography is a procedure which is technically difficult and which requires a high degree of co-operation between the mammography practitioner and the woman. The woman has to be carefully positioned on the X-ray machine, and must be able to hold the position for several seconds. This may not be possible for women with limited mobility in their upper bodies or who are unable to support their upper bodies unaided.

If a woman has a physical disability, or is a wheelchair user, then the breast screening unit should advise on whether breast screening is technically possible and where would be the most appropriate place for her to be screened. This will usually be at a static unit. If a mammogram is not technically possible, the woman should still remain in the call and recall programme, as any increased mobility at a future date may make screening easier. There is no alternative to screening by mammography. If a woman cannot be screened she should be advised on breast awareness.

W: www.breastcancercare.org.uk

Helpline: 0808 800 6000

This information is taken from **Equal Access to Breast and Cervical Screening for Disabled Women – Cancer Screening Series No 2 – March 2006** which can be downloaded from the NHS Cancer Screening Programmes website at www.cancerscreening.nhs.uk/publications/cs2.pdf

Tip when attending for Mammogram

- Contact your local hospital to see what facilities are available and what, if any, specific arrangements they would like you to make
- Inform staff of your specific needs for example, assistance getting onto table, adjustable bed, staying in your wheelchair
- Find out the access to NHS buildings / screening unit
- Ask for a double appointment
- Take someone with you
- Ask for two radiographers to be present to assist with positioning if you are unable to take someone with you who could assist you
- Ask if a seated mammogram is possible – some departments offer this
- Ask if your mammogram can be performed lying down if that suits you best
- What about your Spinal Cord Injury Centre? Do they offer mammograms, or physical examination
- If you stay in your wheelchair, remove the footplates, as this will allow you to get close to the X-ray machine. You may also need to move forward for easy access and positioning.



One member reported that at her first mammogram, she was transferred on to a chair but felt that she was man-handled in the process

Some women will have problems with positioning and balancing and this is where expert assistance, from a PA, partner or professional will make a tremendous difference. The procedure may bring on spasms or pain in some women.

If you are concerned about side effects from a mammogram, to put it in perspective, a mammogram emits a very low dose of radiation, about the equivalent of flying from London to Australia and back.

Breast Cancer

Are you are at risk of Breast Cancer?

Having a SCI probably does not increase your risk of developing breast cancer but some of the consequences of SCI may delay or prevent early detection. But, bear in mind that 80% of breast lumps are benign (non cancerous).

What increases the risk of breast cancer?

- Close family member having breast cancer, mother, sister
- Obesity, particularly if you eat a diet high in fat
- High alcohol consumption
- Non-childbearing
- Age – the risk of breast cancer increases with age

Additional risk factors for SCI women:

- lack of sensation
- lack of dexterity making self examination difficult / impossible
- sedentary lifestyle
- posture changes
- not having access to mobile screening
- difficulty accessing buildings and x-ray machines
- lack of understanding of SCI by NHS staff.

“I think being a complete tetra has definitely meant that it has been detected quite late.” SIA member Liz

Investigations and treatment for breast cancer can be a positive experience

“...the treatment was very good, talking to staff to make them aware of my needs was no problem. The staff were approachable, kind and the care was excellent.”

Sources and Useful Website Links

This fact sheet was produced by the SIA Advice Line with information from the following sources:

www.cancerscreening.nhs.uk
www.breastcancercare.org.uk
www.cancerhelp.cancerresearchuk.org/
www.breastcancercare.org.uk

You may also find the following organisations helpful:

www.breakthrough.org.uk/
www.breastcanceruk.org.uk/
www.breastcancercampaign.org

NB This list is not exhaustive and you may find other sites and support organisations of use to you

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ABOUT SIA



The Spinal Injuries Association (SIA) is the leading national user-led charity for spinal cord injured (SCI) people. Being user led, we are well placed to understand the everyday needs of living with spinal cord injury and are here to meet those needs by providing key services to share information and experiences, and to campaign for change ensuring each person can lead a full and active life. We are here to support you from the moment your spinal cord injury happens, and for the rest of your life.

For more information contact us via the following:

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W: www.spinal.co.uk

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