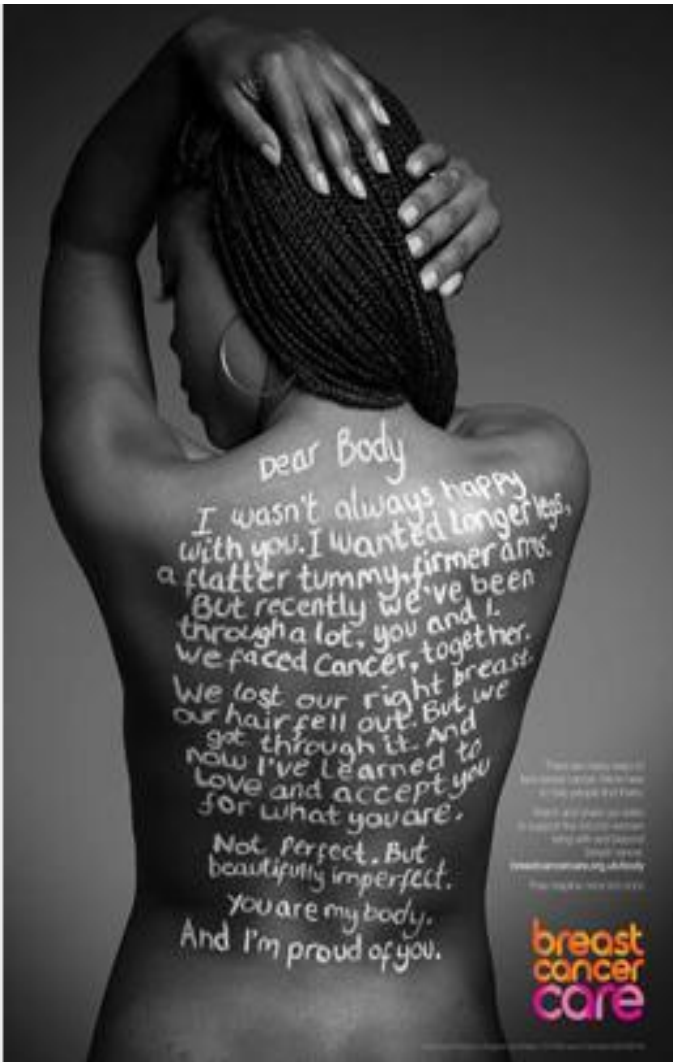


# Altered body image, intimacy and breast cancer

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Senior CNS



Dear Body

I wasn't always happy with you. I wanted longer legs, a flatter tummy, firmer arms. But recently we've been through a lot, you and I. We faced cancer, together. We lost our right breast. Our hair fell out. But we got through it. And now I've learned to love and accept you for what you are.

Not perfect. But beautifully imperfect. You are my body. And I'm proud of you.

These are real words from a real woman. She's here to help you find your own words. Visit [www.breastcancer.org/whofody](http://www.breastcancer.org/whofody) to learn more.

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# Is altered BI is an issue?

**Breast Cancer Care carried out a poll from 23/08 to 09/09 2013 via Facebook and 'Breast Cancer Voices,' - 603 people responded**

**72 per cent of respondents (437) said they feel less confident about their bodies. Many felt it had lowered their self esteem, that they had experienced a 'loss of self' compared to what they felt before breast cancer or felt a combination of the two.**

# My body, myself

## What do women want?

- treated as a whole person
- listened to as an individual
- access to specialist information
- referral to services that offer support
- talk to others about coping strategies
- involvement of partner

<http://www.breastcancer.org.uk/body-image/breast-cancer>

# Altered body image

- ★ What is body image?
- ★ Impact of surgery on body image
- ★ Impact of altered body image on relationships

# What body image is not

- Its not **self esteem** or **quality of life** because this involves one's relationships, career, values etc
- **BUT** both of these can be influenced by body image and changes in body image do not always reflect self esteem and quality of life
- **So what is it....**

# It's multifaceted

- Perceptions, thoughts and behaviours related to ones physical appearance, attractiveness and competence as well as ones perceived state of overall health, wholeness, functioning and sexuality
- **It's a highly subjective experience** Borquiren

# So what influences body image?

Before age 6 –awareness of societal bias

**Gender role  
socialisation** physical  
appearance and behaviour

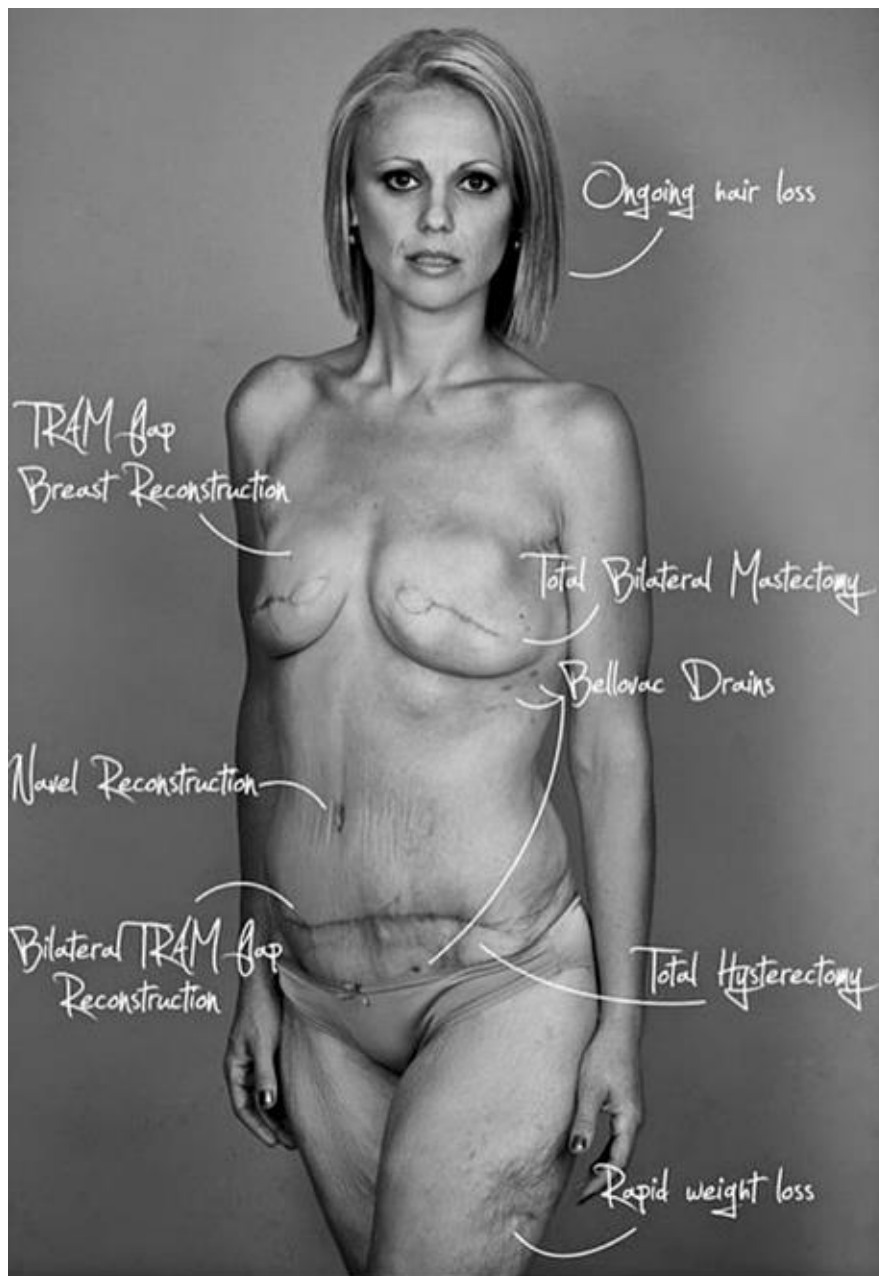
**Direct /indirect-** Media,  
family, friends peers all  
reinforce cultural ideas of  
attractiveness and the role of a  
woman -societal approval

**Self objectification** constant  
comparison and perceiving a  
discrepancy between actual and  
ideal self plays a pivotal role in  
poorer BI



# Beth Whaanga





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# The general body image literature suggests that :

Poor body image is associated with emotional distress

Cash et al 2004

Evidence suggests that there is an interaction between BI and age which predicts some aspects of emotional distress i.e. younger women more affected

Miller et al 2013

# Adjustment after breast cancer to BI changes

The evidence suggests that:

- Not all patients will manifest the same body image issues
- Changes to body image because of breast cancer not only affect the person but also affect how others behave towards them
- **Constant reminder of disease**
- **Change accommodation** -The speed with which these changes happen can also be a factor
- **Sensory perceptions**-phantom sensations
- External prosthesis

Bolton, Lobben and Stern 2010

# The potential to affect body image

- **Surgery**
- Weight gain
- Lymphoedema
- Menopause —trouble shooting BC survivorship
- Hair loss

# Body image disturbances are...

- ★ Consistently associated with mental distress, anxiety, reduced physical health, sexual dysfunction and impaired QOL
- ★ A significant subset continue to report BI difficulties years later

# Body image and surgery

Impact of  
mastectomy  
lumpectomy  
reconstruction



Young /Old

Choosing  
reconstruction-  
expectation and reality  
what influences choice?

# Young /Old

- Younger women had a poorer BI compared to older women
- More pronounced in single women regardless of surgery
- Negative impact was strongest among young married women

Helms et al 2008 literature review



lumpectomy  
mastectomy  
reconstruction

# The numbers (UK data)

**82% have surgery (90% under 50)**

- 57% breast conserving surgery
- The remainder undergoing mastectomy with or without reconstruction

- **21 % immediate reconstruction** National mastectomy and reconstruction audit 2009 (10% up)

- 11% opted for delayed reconstruction

# Breast conserving surgery and body image

BI only minimally disturbed by WLE

Incidental finding:

**Patient level of satisfaction was  
higher than that of the clinician**

Lyngholm et al 2013

# The psychological effect of mastectomy with or without BR

103 ♀ pre surgery, 6 and 12 months post

BI concerns across the study group improved significantly over the study

- 12 months post surgery younger women had less favourable BI (all surgery)
- Overall satisfaction scores  **delayed**  **mastectomy**

 **Immediate reconstruction**

Harcourt et al 2002

# Psychological functioning and mastectomy +/- BR

**Harcourt et al 2002**

**The psychological effect of mastectomy with or without breast reconstruction**

HCP should not assume that immediate reconstruction necessarily offers greater improvements in psychological functioning.

**Brunault et al 2013**

There is a strong association with depression in long term BC survivors and patient perception of cosmetic outcome (non reconstruction)

# Men's experience of their partners mastectomy

## Primary concern was their partners health BUT

- Described mourning the loss of their partners breast
- Questioned their ability to cope with altered BI
- Shift in level of intimacy-no longer seeing partner naked
- For some men very complex issues of not seeing the surgery/seeing the surgery/reaction to it/ partner not wanting to show. Men feeling distaste, unattractive, less feminine
- The majority of men reported that mastectomy had had a negative effect on their sexual relationship

• Rowland and Metcalfe 2014 systematic review

# Breast reconstruction who has it and why?



**Lots of studies spanning the last 20 years overwhelmingly they seem to say that the driver for BR is young age, lower feelings of attractiveness, and sexual interest**

- ★ **Mean age significantly lower (52vs 64)**
- ★ **Higher education**
- ★ **Employed**
- ★ **Influenced by physicians opinion**
- ★ **Sexually active**

Fallbjork et al 2010





# Fang, Shu and Chang 2013

## Meta analysis

Breast reconstruction can recreate physical appearance but is unable to resolve women's physical perception of feeling abnormal or different.

Whilst those women undergoing BR had a better body image than those who had a mastectomy alone it is not always the panacea.

Body image problems occur despite satisfaction with shape and appearance

**Offering accurate and realistic information for women ♀ during decision making is key**

# Motivations, influences, predictors and impact

# The motivation

155 ♀

63% 40-60, 54% African American

**Most likely to be motivated by body image concerns NOT sexuality or femininity**

♀ between 50-65 more likely to pursue BR

African American women were less likely to be offered/accept referrals

Women undergo reconstruction to 'feel whole again', get rid of external prosthesis, avoid mutilation and feel feminine again

Only 25% ♀ reported being concerned about partners satisfaction when making decisions

**Women who chose not to have BR often cite additional surgery and complications for not going ahead**

Duggal et al 2013

# The predictors

- **US SEER data base- over 52,000 cases**
- **The most likely predictors (immediate and delayed) are:**

Younger age  
White race  
Lower stage disease  
Urban living

SEER data base Agarwal et al 2011

# The influences

- Influenced by **clinician-** pre op discussion re reconstruction Duggal 2013
- The impact of age, phases of a woman's life, prior body image Fallbjork et al 2010

# The impact

**Pockai et al 2009**

**Meta analysis**

Findings- breast reconstruction may impair QOL  
**Need for HCP improved QOL through pre op counselling**

**Sheehan J et al 2008**

Looked at the occurrence of women experiencing regret associated with breast reconstruction.

**Prior negative BI is associated with decision regret**

# So what is really important for the patients adjustment?

## Immediate and delayed reconstruction

### Cosmesis

- Feeling normal and looking normal –confidence and femininity

### Relationship with surgeon

- Positive and negative feelings- difficulty telling surgeon of disappointment

### Reconstruction as completion of cancer journey

- Patients felt they had completed the cancer journey positive whether cosmesis was good or poor

Beesley 2012 (audit)

# In summary

## All women are individuals

- Surgery does impact on BI particularly in relation to immediate reconstruction
- Assessing patient expectation
- Younger age
- It's the patients view of the end result that is crucial – they maybe satisfied when the surgeon is not
- Importance for patients that the information given is realistic



# Stella Duffy

novelist and performer



Dear nice, young (usually), male (usually) breast cancer reconstruction surgeon,  
Thank you for your help in making me healthy. But we've come to a tricky  
discussion, about the difference between seeing and feeling.

I don't care what you can *see*; I care what I can *feel*. When I am dressed, and up  
and about and getting on with my life, the size and shape of my breast really  
isn't a big deal. I'm a woman, in my middle age. I have body issues. That's normal  
for me.

When you ask me to stand in front of you, both breasts bared, and compare my  
"new" breast to my "old" breast and ask if I want the old one reshaped, you are  
insulting me. You are insulting the part of me that has, brilliantly, not had cancer.  
I quite like the bit that's not had cancer. No, I don't want it cut up too. (I try to  
love the bit that has had cancer as well, because I figure that's more sane. It's  
tricky, but I try.)

<http://www.theguardian.com/commentisfree/2014/nov/14/breast-reconstruction-surgeon-cancer?commentpage=1>

# Is lymphoedema significant?

## Priorities for women with lymphoedema

Information and support around the condition featured highly

- **BUT issues around body image featured highly**

- accepting appearance
- hiding
- clothes
- self consciousness
- avoiding social situations

Girgis et al 2011BMJ

- lymphoedema altered relationship patterns and led to self isolation

Ridner et al 2013

# Is weight gain significant?

‘Losing my hair was a big worry for me, but within a few months I also started to put on weight, a lot of weight, and I didn’t feel myself. It was after my secondary diagnosis that it started to have an even bigger impact on my body image.’

# What causes weight gain?

Why women put on weight remains unclear **BUT**

- ➔ Imbalance between energy intake and energy expenditure
- ➔ Weight gain is common in all age groups  $\pm$  5kgs and has been rigorously researched across all treatment modalities
- ➔ Weight gain tends to be central and is associated with muscle loss –(sarcopenic obesity) potential reduction in muscular strength and mobility

**Women reported gaining between 1-5kgs on average**

**62% women were moderately to severely bothered by their weight gain**

Demark-Wahnefried et al 2012 Cancer Partridge et al 2004

# In terms of recurrence

Preliminary evidence suggests that lifestyle change may also improve prognosis in individuals with early-stage cancers **but** much work still needs to be done to validate this and to determine which types of lifestyle change are most important.

Chlebowski RT et al J Natl Cancer Inst. 2006;98(24):1767.

# Body image and intimacy



# So what does a woman think?

‘I had to lose my nipple after radiotherapy which I was ok with. What I didn’t realise was I wasn’t likely to be having sex again either. My husband had not wanted sex since my diagnosis. I cannot look at my body in the mirror and my husband stays ‘asleep’ while I get dressed and comes to bed after me.’

# What we know is

- Surgery
- Lymphoedema
- Weight gain
- Menopause

**And this affects intimacy**



# Intimacy is affected after breast cancer

1,011 women in the analyses, <70 years partnered

**70% experienced sexual function problems**

Panjari, Bell & Davis Jnl Sex Med 2011

**Women with body image issues were 2.5 times more likely to report sexual function problems**

Most of the sexual difficulties related to breast cancer can be managed-physical and psychological

# Physical changes that can impact on intimacy

**A lot of research around surgery and sexual function.  
Association with mastectomy BUT mixed results**

## **In addition**

Numbness in previously sensitive breasts/abdomen/loss of nipple

Chemotherapy associated with problems of arousal, lubrication, orgasm and sexual pain

Radiation associated with feeling medically 'invaded'

Weight gain, hair loss.....

# Validating altered BI and it affects

# Pre surgery-

**Whole MDT  
approach**

**How do we manage  
expectation?**

**patient  
partner  
surgery**

**partner**

Women need to know  
that their issues are  
not unique and that  
they are valid

**Assessment tool**

# Post surgery

## Immediate

Encourage patients to confront surgical scars ASAP

## Survivorship phase

Frame a question around hormone therapy... 'many women tell us.. Is this so for you?'

## Validity

Women need to know that their issues are not unique and that they are valid



# Signposting



**SexualAdvice**  
Association

**Intimacy & Sexuality For Cancer Patients and their Partners A  
Booklet of Tips & Ideas for your Journey of Recovery**

## **Encourage patients to confront surgical scars ASAP**

Reinforce that initially this will be difficult but lessens the more a person looks. This is a process called “habituation”.

Advising patients to use a full length mirror, fully clothed, then working towards undressed.

Encourage a patient to touch their scars so that they know what it feels like, if it is sensitive, numb, painful.

<http://www.sda.uk.net/index.php>



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# Know what's available

## Breast Cancer Care

- Someone like me
- Live chat
- Younger Women's Forum
- Forums

## Relate

- Singles, couples, sex relationships
- <http://www.relate.org.uk/userfiles/documents/GPsheetWebsiteVersion1.pdf>

## College of sexual and relationship therapists (COSRT)

- <http://www.cosrt.org.uk/tips.asp>

## Local

Set up pathways

Gynaecologist  
Psychologist/  
psychiatrist/  
counsellor

# Consider how a person wants to receive information on intimacy

## Ussher et al 2012 (review)

**Majority of respondents wanted to receive information about sexual well being nearly 2\3rds had not received it**

- Written, booklets, websites
- Levels of satisfaction with information where high from BCN, helplines, and psychologists
- **Talking to partners important coping strategy**



# It's evident from the literature that...

.... women who held greater investment in physical appearance exhibited greater difficulty post treatment and reported more body dissatisfaction and poorer mental health than those who held lower levels of investment

Petronis 2003

Boquiren et al 2013

# And finally

- Altered BI affects how a woman views herself, the relationships she has with others and her long term QOL
- We can't change a woman's original body image perception but maybe we can validate her concerns and signpost
- Sexuality and intimacy are central to psychological well being and QOL and they make the experience of cancer more manageable. Emilee et al 2010



**Thank you**  
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