Adopt a Change, Live Well

The RMH NHS Foundation Trust with thanks to Friends of The Royal Marsden Surrey and Macmillan Cancer Support
## Programme for the Day

<table>
<thead>
<tr>
<th>TIME</th>
<th>THEME</th>
<th>Presenter</th>
</tr>
</thead>
<tbody>
<tr>
<td>13:00-13:05</td>
<td>Welcome and introductions</td>
<td>Denise Flett, Clinical Nurse Specialist</td>
</tr>
<tr>
<td>13:05-13:35</td>
<td>Psychological adjustment after breast cancer</td>
<td>Lisa Dvorjetz, Counselling Psychologist</td>
</tr>
<tr>
<td>13:35-14:05</td>
<td>Managing menopausal symptoms</td>
<td>Denise Flett, Clinical Nurse Specialist</td>
</tr>
<tr>
<td>14:05-14:25</td>
<td>Work and cancer</td>
<td>Dr Priya Singh</td>
</tr>
<tr>
<td>14:25-14:50</td>
<td>Refreshments and visit stands</td>
<td>The opportunity to visit stands to find more information and support</td>
</tr>
<tr>
<td>15:50-16:00</td>
<td>Feedback / Finish</td>
<td>Nikki Snuggs, Clinical Nurse Specialist</td>
</tr>
</tbody>
</table>
Aims of today

- We know that many women struggle following treatment because of the changes that treatment causes or because of side effects of on-going drugs.
- By extension the family and friends of many women are also affected.
- The types of issues women report are often not single physical changes but clusters of changes.
- They often have knock on effects.
- We cannot take the problems away but, with you, can hopefully improve how you live with the changes.
Psychological Adjustment after Breast Cancer.

Lisa Dvorjetz
Counselling Psychologist
Overview

- Post treatment challenges.
- Helpful ways to promote adjustment.
- How our minds are designed to deal with stress.
- Anxiety and depression – what to look out for.
- Unhelpful ways of coping
- Helpful strategies
- When to seek help.
Diagnosis and Treatment

- Shock of the diagnosis.
- Getting through demands of acute treatment.
- Feeling out of control.
- Dealing with surgery.
- Disruption to life, and plans.
‘The psychological effects of a cancer diagnosis are often felt long after treatment has finished’
(Macmillan 2011)
After treatment ends...

- End of treatment can be an unexpected challenge.
- Physical health begins to improve but psychological health can take a while to catch up.
- An uncertain time with many adjustments to make and decisions about how to move forward.
- Balancing treatment related side effects.
- Doing a ‘new normal.’
- Managing fear of recurrence.
- Changes to relationships, body image and intimacy.
After treatment ends…

- Often there is some review of life and self.
- Most people respond by drawing on personal strengths and social support to help.
- There is a need for family, friends and professionals to understand the challenge.
Adjustment…

• A process and not an ‘event’.

• Different for each person.

• Involves finding reasons and confidence to do something.

• Overcoming any feelings of being ‘stuck.’

• Find a balance between your own and others expectations (it can be hard for others to understand emotional, physical and psychological barriers).

• They are adjusting too...Everyone can feel frustrated - wanting things to be ‘normal’.
Helping the process of Adjustment…

- ‘Downloading’ thoughts: write it/tell it.
- Expressing emotion – cry, angry walks.
- Keep socialising.
- Practice ways of relaxing/’unhooking’ from difficult thoughts.
- Recognise some difficult emotions are to be expected.
- Seek help for the things that are challenging.
How the brain (and body) deal with stress...
Short term stress response

- ‘Alarm centre’ starts a chain of rapidly occurring reactions > stress hormones released.
- Adrenaline is released in the body > physical and psychological effects: ‘fight’ or ‘flight’.
Experiencing ‘fight or flight’

• Racing thoughts
• Difficulty concentrating
• Dry mouth
• Racing heart
• Rapid breathing
• Feeling dizzy
• Blood diverted from digestive system.
• Cold hands.
• Muscles tensed ready for action.
• Feeling clammy/sweaty.
Over-riding ‘fight or flight’.

Focus on long breath out.

Check in body where muscles are tense and slowly stretch and allow them to loosen.

Find something to focus on in immediate environment and do ‘noticing’ – Describe what you see in as much detail as possible.

Respond to your experience with kindness.
Long term stress response

• In response to stress, messages are sent from brain to body to produce cortisol.

• Cortisol normally fluctuates in the body but constantly high levels interfere with some body systems.

• In the brain, high levels are thought to affect chemicals that support mood.
When stress goes on for a long time

- Stress responses may become stuck in ‘alarm mode’.
- Risk of tipping into levels of anxiety and depression.
- How to spot this...
Symptoms of Anxiety

• Above and beyond normal distress and worry.
• Symptoms most of the day, nearly every day and interfering with normal functioning.
• ‘Uncontrolled’ worry.
• Trouble problem solving/focusing thoughts.
• Muscle tension.
• Trembling/shaking.
• Restlessness.
• Dry mouth.
• Irritability.
Symptoms of Depression

- Above and beyond normal low mood
- Most of these, nearly every day..
- Feeling hopeless or empty most of the day.
- Loss of interest in things previously enjoyed.
- Feeling ‘slowed down’/without energy.
- Trouble sleeping (early waking or sleeping too much).
- Trouble thinking/concentrating.
- Thoughts of suicide.
Where to seek help

- Your GP.
- Your Breast CNS here at RMH
- The adult or family psychology service (Sutton or Chelsea).
- Mental health organisations.
- Private counselling.
- Cancer Support groups.
Unhelpful ways of coping

- Can offer a bit of relief in the short term but can make the problem worse over time...
- Keep us stuck in limiting cycles.
- Alcohol, smoking, comfort eating.
- Social withdrawal or bottling up feelings and thoughts.
- Avoidance - things around us, thoughts within us.
- Unhelpful thinking. When anxious, shown to have biases in thinking:
  - e.g. predicting the future, catastrophizing
  - Increases anxiety, affects mood → both makes us feel more psychical effects such as pain, hot flushes.
Helpful ways of coping

Relaxation Techniques:

- Sleeping
- Breathing
- Meditation
- Exercise
- Healthy Food
- Classes
Mindfulness

Promotes being present in the moment

In cancer patients has been shown to:
- Reduce the fear of recurrence
- Decrease stress, anxiety, and depression
- Promote higher energy
- Combat fatigue
- Decrease disturbed sleep
Brief CBT and Positive Framing

Thinking

• Acknowledge and check beliefs and expectations
• Identification of unhelpful or catastrophizing thoughts
• Develop an attitude of acceptance to change
• Recognise positive thoughts

Behaviour

• Manage negative reactions such as avoidance
• Refocusing behaviour ‘being in the moment’
Positive Framing and Brief CBT

Can aid in:

- Adjustment to living with cancer
- Anxiety management
- Depression
- Traumatic responses
- Self Esteem and Body Image
- Overcoming Avoidance
- Cognitive Restructuring of unhelpful thoughts
- Breaking Vicious Cycle of Thoughts, Emotions & Behaviours
Resilience Building

One person’s resilience is different to the next

- Resilience is made up of many factors, including personality, genetics, experiences, and how much support is available and provided.
- It is not static. Learning to adapt with change and understand changing levels of strength and resilience can bring a sense of peace and focus.
- Resilience isn’t about ‘being positive’; it is about coping, managing and maybe even thriving in the face of adversity.
- There are protective factors to resilience – these include having people around who recognise the persons personal qualities and abilities and provide support during stress and hardship.
5 Ways to Wellbeing

- New Economics Foundation (NEF) Evidence suggests that a small improvement in wellbeing can help to decrease some mental health problems and also help people to flourish.

The NEF document sets out 5 actions to improve personal wellbeing:
- **Connect**- connect with people around you, at home, at work or in the local community. Building connections will support and enrich you.
- **Be active**- discover a physical activity you enjoy and that suits your level of mobility and fitness
- **Take notice**- Reflecting on your experiences will help you appreciate what matters most
- **Keep learning**- Learning new things will make you more confident as well as being fun
- **Give**- Seeing your self, and your happiness, liked to the wider community can be rewarding and creates connections with people around you.
In conclusion

• Support your physical recovery by making healthy changes where necessary.
• Be mindful of your psychological needs at this stage.
• Review your coping strategies and make a change if necessary.
• Keep boosting your process of adjustment.
• Remember some stress is normal – but seek help if you feel unsure.
Any Questions?
Menopausal Symptoms & Breast Cancer Treatment

Denis Flett Clinical Nurse Specialist
What causes menopausal symptoms.

Menopause occurs as a result of:

- Natural failure of ovarian tissue - menopause
- Forced failure of ovarian tissue due to specific treatments such as chemotherapy, radiotherapy or hormone manipulation
- Removal of the ovaries

The resulting low and changing levels of hormones, particularly oestrogen, are thought to be the cause of menopausal symptoms in many women.

- Can also occur as direct result of endocrine treatment post menopause
- Out of all women who have had treatment for breast cancer the only group for whom menopausal symptoms may not be an issue are women with ER/PgR negative tumors who are settled into their post menopausal life before the cancer is diagnosed
Who is affected?

• Out of all women who have had treatment for invasive breast cancer the **only** group for whom menopausal symptoms may not be an issue are women with ER/PgR negative tumors who are settled into their post menopausal life before the cancer is diagnosed.

• ER negative pre menopausal likely to have chemotherapy which may bring about ovarian failure
• ER positive pre menopausal women will have treatment to stop ovarian production of oestrogen or block its activity
• ER positive post menopausal women may have to stop HRT
• AND start medication to further lower oestrogen levels
So what are the commonly reported menopausal symptoms
Many, varied and individual

- Hot flushes
- Night Sweats
- Anxiety
- Impaired sleep
- Vaginal symptoms
- Reduced libido/sex drive
- Hair thinning
- Unwanted body hair
- Mood changes
- Memory changes
- Relationship problems
- Loss of confidence
- Bone thinning/bone loss
- Fatigue
- Aching joints / arthralgia
Please indicate which is your MOST troubling menopausal symptom

1. Hot flushes/night sweats
2. Sexual difficulties (include vaginal health)
3. Thinning Hair
4. Aching joints
5. Mood changes
6. Cognitive abilities
7. Other
How affected are you by this symptom

1. I am aware of it but it does not affect day to day living

2. I have to make some changes or adjustments in order to live as I want to

3. I cannot live as I want to live no matter what I adjust or try
Managing symptoms – what can you do?
Vasomotor symptoms - the dreaded hot flushes and night sweats
Simple remedies
- Evening primrose Oil
- Chillow Pillow
- Cotton clothing
- Look for triggers

- Beware of over the counter remedies that rely on phytoestrogens
  - Red clover
  - Back Cohosh
  - Ginseng
  - Dong Quai
  - Soy (supplements)
- Also the so called non-oestrogenic herbs which act to encourage your own production of hormones
  - Macafem

Non drug:
- Acupuncture has shown a reduction in the frequency and intensity of hot flushes.
- Mindfulness and CBT can also be helpful for some women

Orthodox medications:
- Some anti-depressant drugs can help with hot flushes and night sweats.
  - Venlafaxine, Fluoxetine, and Paroxetine.
- They have been studied and widely used effectively for reducing flushes in women who have had breast cancer.
- **Some caution with Tamoxifen!!**
Sexual difficulties and vaginal health

- **Vaginal dryness** is common due to low oestrogen levels. This may result in discomfort during intercourse or prevent intercourse even if you want to

Remedies and solutions:
- Moisturisers and/or lubricants
- Lubricants are for use generally to help sexual intercourse. Yes, Sylk, Pjurmed
- Moisturisers are designed to help reline and improve vaginal wall lining and need to be used regularly.
  - Hyalofemme (non-hormonal)
  - Replens MD (non-hormonal)
  - Vagifem (oestrogen based)
- Hormonal and non hormonal
Other reasons for sexual difficulties

Desire = your interest in sex and being sexual
   Drive - biological basis
   Beliefs – cultural/personal learning
   Motivation – emotions

All of these can be affected as a result of being diagnosed, going through treatment and altered hormone levels

Affected by other common side effects – fatigue, interrupted sleep, body image,

Low hormone levels can reduce sensation and enjoyment even if you manage to want to have sex

Is only a problem if you say it is a problem – but if it is – SAY SO!
Arthralgias

- Reported by more than half of women going through a natural menopause
- Not fully understood
- Lowered oestrogen some interplay with pain processing pathways
- Abrupt loss of oestrogen may induce an inflammatory response

- More severe arthralgia if abrupt menopause, recently menopausal, obese

Advice

Simple analgesia
NSAID’s
Exercise
Weight loss
Osteoporosis - loss of bone density

- Bones tissue needs oestrogen to help it keep hold of calcium
- Loss of calcium from bones – thinning and weakening of bones
- Calcium and Vit D supplementation
- Role of Vit D
- Dexa Scans
  - Osteopenia
  - Osteoporosis
- Bisphosphonates
- Avoid being underweight
- Smoking
Mood changes/Irritability

- Oestrogen levels are linked to serotonin levels – chemical which has a significant role in determining mood.

- Varying levels will mean moods change

- Huge variety of emotions and effects from this emotional lability
  - Irritation, anger, argumentative, depressed, suicidal,
A word about symptom clusters

– Fatigue
– Lack of motivation
– Feelings of loss of self and role or inability to do as well as before
– Weight gain
– Hair thinning
– Body image
– Sense of self – ‘this is not me’
– Anger
What can you do as a whole person

Overall

Evaluate lifestyle – diet / weight/ exercise

Varied diet

Look for triggers and reduce

Reduce stress – mindfulness/time out/CBT/hypnotherapy

Use orthodox medication when you need

Give it time

Talk about it – there is no way you are alone!
Specialist Menopause clinics

- Some centres have specialist menopause services which often include clinics for women who have had breast cancer.

- You can ask your GP to refer you for a consultation if your symptoms are severe and not manageable.  
  [www.menopausematters.co.uk/clinicfinder.php](http://www.menopausematters.co.uk/clinicfinder.php)

- Speak to your clinical team if your cancer treatment is causing side effects that are affecting your quality of life.
Work and Cancer

Dr Priya Singh
Managing your fatigue

Tamslin Longley Senior Occupational Therapist
Jane Murphy Senior Occupational Therapist
It’s complicated!

- It’s not just tiredness
- It’s personal.
- Can also be linked to other symptoms.
- You need a toolkit to manage fatigue
**Acknowledge it**

**Fatigue**
- It’s persistent
- Tiredness out of proportion to what you’ve been doing.

- Physical
- Emotional
- Cognitive
Energy levels

- You only have so much energy.
- Think about how you are going to use it.
- Make sure you don’t use it all up at once.

- It’s going to take time to learn to manage it
Triggers

- Identify your triggers
  - When do you feel more tired?
  - Certain situations?
  - Is it associated with getting upset or anxious?
Vicious cycle of symptoms

- You get tired
- You do less
- You feel even more tired

- So......
Energy Conservation

- The 5 P’s
- Prioritize
- Pace
- Plan
- Position
- Permission
Pacing

Good day → Over activity

Prolonged rest → Increased fatigue

Bad day
Exercise

- Gentle exercise reduces fatigue
- Slowly increase your activity frequency and length
- Aiming for 30 minutes 5 x a week
- May start with 10 mins a day
Relaxation and Anxiety Management

- Relaxation is an active process
- Encourage the mind and body to work together
- Break the cycle
- Create a more calm and relaxed state
- Promotes rest
Simple relaxation exercise

Control breathing
Imagine you’re trying to make a birthday candle flicker
Not trying to blow it out
Let shoulders and neck relax
Hands relax
Jaws relax
Teamwork
Managing the risk of lymphoedema

Shannon Ruddell Lymphedema Therapist
Introduction

This session is about managing the risk of cancer related lymphoedema.

We will talk about:

- What lymphoedema is
- Why you are at risk
- Where you are at risk
- How to minimise the risk
- What to do if you are worried that you may have lymphoedema
The lymphatic system

– The lymphatic system is made up of groups of lymph nodes throughout the body which are connected by a network of lymph vessels
The lymphatic system

- Lymphatic vessels are thin walled tubes that drain fluid from the tissues and carry it to lymph nodes and eventually back into the blood system.

- It is a one-way system.

- Lymph nodes act as filters and play an important role in fighting infection.

- Lymphatic fluid is not pumped by the heart like blood, but depends on muscle movement to keep it flowing.
What is lymphoedema?

- Lymphoedema is chronic swelling which occurs when lymph cannot drain through the lymph channels or nodes.

- Cancer related lymphoedema can develop when the lymphatic system is damaged due to surgery or radiotherapy.

- It can occur anywhere in the body where lymph drainage is compromised.
Why are you at risk of developing lymphoedema?

- Lymph nodes may have been surgically removed or damaged by radiotherapy as part of your cancer treatment.

- Radiotherapy may cause scarring to the vessels lymph travels along.

- This can interrupt the drainage of lymph fluid.

- The swelling can develop at any time once normal post treatment swelling has settled.
Where are you at risk of lymphoedema?

- Treatment for breast cancer may involve the removal of lymph nodes in the armpit or radiotherapy to the breast or armpit
- At risk in the hand/arm
- as well as the **breast** and the front and back of the chest wall on the same side
How do I minimise the risk of developing lymphoedema?

Skin Care

– To minimise the risk of infection, keep skin and nails intact and meticulously clean
  
  – Use an unperfumed moisturiser daily
  – Try to avoid cuts/scratches/insect bites/blood tests
  – Wear long sleeves/gloves to protect skin e.g. when gardening
  – Use high factor sun cream, avoid sunburn
  – Be aware of signs of skin infection (cellulitis): redness/warmth/pain/flu like symptoms
  – Seek prompt attention for any infection
Minimising risk: **Physical activity**

– Staying fit and exercising regularly

  – Lymphatic drainage is improved with muscle activity
  – Return to previously enjoyed activities gradually
  – Avoid strenuous activities for too long – pacing
  – Avoid repetitive activities for too long – vary activity
  – Avoid extremes of temperature
Minimising risk: **Physical activity**

– Try to keep your weight within normal limits
– The risk of developing lymphoedema increases if you are overweight
Other ways to reduce the risk

– Avoid restricting lymph drainage- no tight clothing, jewellery

– Keep well hydrated and rested

– Long haul flights- avoid standing or sitting for long periods, move your arms, keep well hydrated, wear comfortable clothing

– Try to keep your weight within normal limits
In Summary- minimising the risk of developing lymphoedema

- Minimise the risk of infection
- Minimise the risk of inflammation
- Staying fit and regular exercise to promote lymph drainage
- Try to keep your weight within normal limits
What do I do if I am worried I may have lymphoedema?

- First signs: an ache or heaviness throughout the arm (No swelling)
- Occasional, mild swelling on the treated side (fingers, hand, arm, breast). Clothing may feel tighter
- Swelling that does not go away overnight and is there all the time
- Lymphoedema is not normally painful or cause a change in sensation or function.

- Contact your key worker, medical team, lymphoedema service or GP
How is lymphoedema treated?

Education and advice

Skin care;
To promote skin integrity

Exercise;
To maintain limb function

External support/compression;
To promote lymph drainage

Manual lymph drainage/ simple lymph drainage;
To stimulate lymph drainage
Further information and support

Lymphoedema Support Network (LSN)
www.lymphoedema.org/lsn

Breast Cancer Care
www.breastcancercare.org.uk

Macmillan
www.macmillan.org.uk/information-and-support/breast-cancer
Thank you for listening

Any questions?

Presentation acknowledgements:

Mary Woods, Nurse Consultant Lymphoedema
Rachel Day, Macmillan Specialist Lymphoedema Practitioner
Thank you for listening
Five evaluation questions
Q1. How helpful have you found today?

1. Not at all helpful
2. A little bit helpful
3. Neither helpful nor unhelpful
4. Quite helpful
5. Very helpful
Q2. Did you learn any new information today?

1. I’ve learned no new information
2. I’ve learned some new information
3. No opinion/not sure
4. I’ve learned quite a bit of new information
5. I’ve learned a lot of new information
Q3  Do you feel hopeful that you will be able to improve any side effects you have

1. I don’t believe anything will help

2. I am doubtful but am willing to try some of what I have heard today

3. Uncertain

4. Yes – a little hopeful

5. Yes – very hopeful
Q4. How helpful was it to talk to other people attending

1. I found this was not helpful at all
2. Neither helpful nor unhelpful
3. Quite helpful
4. Very helpful
5. This was the most helpful part of the day
Would you recommend that other people attend this type of event?

1. Yes

2. No