



# Living without reconstruction



**A practical guide to having a mastectomy and living positively without reconstruction**



# Contents

Introduction	4
Types of mastectomy	5
Surgical options and making an informed decision	6
Preparing for your mastectomy	7
After your mastectomy	8
Your new chest	9
Gallery of mastectomies	10
Lymphoedema and cording	12
Life after mastectomy	14
Post-surgery bras and breast forms	16
Dressing for your new body shape	18
Glossary and useful links	21
About Flat Friends UK	23

# Introduction

This booklet aims to help you understand what options there are when you have been told you need a mastectomy. Whether you are facing a mastectomy to treat breast cancer, or you are considering a risk-reducing mastectomy due to a strong family history or known inherited altered gene, the decision to have reconstruction or not after mastectomy is an extremely personal one. Whilst the views of your health care professionals, family, and friends are important, we think that it is more important that you have the surgery that you want, and which is right for you.

We have brought together patient-centred information and the real experiences of women to create a practical guide about having a mastectomy and living without reconstruction. Whether you are considering living flat, or are having delayed reconstruction, we hope this booklet will help you weigh up your options, prepare for your mastectomy, and provide advice to support you to live positively without reconstruction.

Gilly Cant

Founder and Trustee of Flat Friends UK



## Types of mastectomy

A **simple mastectomy** is an operation to remove all breast tissue, skin, areola and nipple, although a small amount of tissue often gets left behind – which cannot be avoided and is why it is important to continue self-examination after mastectomy. You may also have some lymph nodes from your armpit removed. A **radical mastectomy** is similar to a simple mastectomy; but, also involves removing lymph nodes from the breast and armpit, as well as some of the chest wall. You may be offered a **lumpectomy (wide local excision)** which removes the breast cancer and a margin of healthy tissue whilst keeping as much of your breast as possible. You can request a simple mastectomy instead of a lumpectomy if having breast-conserving surgery is not important to you.

### Single or Double?

If you are having a risk reducing mastectomy you will have both breasts removed – known as a **double or bilateral mastectomy**. If you have cancer in one breast you could have that affected breast removed only – known as a single or **unilateral mastectomy**.

I was relieved to be offered a single mastectomy instead of a lumpectomy. I started reading up about reconstruction and it was then I decided to go flat.

Nic

I was told I could have a bilateral mastectomy, or a series of operations which would have the same end result. It was therefore an easy decision for me: just one operation and one recovery.

Karen

Some women who need a single mastectomy may feel that they want their unaffected breast removed too. This is known as **contralateral prophylactic mastectomy (CPM)**. Research has shown that removing a healthy breast for women with no risk factors - such as no family history or inherited altered gene - does not reduce the risk of them developing primary breast cancer again. However, you have the right to request a CPM if you decide not to have reconstruction and want to achieve symmetry.

I knew it was my decision, not the consultant's. I felt it would be more distressing for me to look in the mirror at one large breast. CPM was purely my preference.

Cara

# Surgical Options and Making an Informed Decision

You should expect to be treated with dignity and respect by your breast care team. You should also be involved in making decisions about your care and treatment, including having time to ask questions and discuss the information that you are given. Your Breast Care Nurse (BCN) should support you with this. You can change your mind about any procedures at any time, and your choice should be respected by your team.

Your surgeon will discuss reconstruction options with you, but this does not mean that this is the surgery you must have. If you are unsure about whether you want to have reconstruction or not, then you can delay your decision until later. Your team may advise you to see a clinical psychologist to discuss your wishes and feelings to make sure that you are making the right decision for you.

## Things to consider:

- How you want to look and feel after surgery.
- The different ways breast shape can be created, including with reconstruction, or wearing **prostheses** under your clothes.
- How long the recovery time will be.
- Possible complications post-surgery.
- If you need to delay reconstruction.

My surgeon spoke to me about reconstruction. However, once I had the bilateral mastectomy and came to terms with my new body shape I began to like it. I didn't need breasts or unnecessary surgery.

Julie

I was told I was limited to the type of reconstruction I could have because of heart issues and I didn't want to risk losing the strength or movement in my back, so I opted to go flat after my prophylactic double mastectomy.

Sally

Ensure that your surgeon shows you photos of how they are expecting your chest to look so you have discussed your expectations.

Clare

# Preparing for your Mastectomy

## Questions you may want to ask your breast care team

- What scars will I have? Where will they be and what size?
- Will you make sure I am not left with excess skin or 'dog ears'?
- Can you show me photos of previous mastectomies done by my surgeon?
- Will my wounds be closed with stitches or glue? And, will I have drains?
- Could I wear a bra after the operation?

### My Questions

## Removal of lymph nodes

Breast cancer can spread to the lymph nodes in the armpit. Before your surgery, or as part of your mastectomy, you may have some of the lymph nodes in your armpit tested to see if they contain breast cancer cells. If you have been diagnosed with **invasive breast cancer** you will need to have your lymph nodes tested to help your team decide which treatments to offer you.

Lymph nodes may be checked using an ultrasound scan, a **fine needle biopsy (FNA)** which takes a sample of cells, or **sentinel lymph node biopsy** which uses radioactive dye injected into the breast to find the nodes closest to the lymph vessels connected to the breast. The closest node/s is then examined under a microscope to see if it contains breast cancer cells. If cancer cells are found in any of the lymph nodes you may need surgery to remove more nodes, or you may be recommended to have **radiotherapy** to the remaining lymph nodes.

## What to take to hospital

Your hospital will give you information about what preparations you need to make for your operation. However, you may find the following tips helpful.

- Front fastening tops, pull on bottoms, and slip on shoes.
- Soft, non-underwired, front-fastening bra if you wish to wear breast forms.
- Baby wipes and dry shampoo.
- Ear plugs, magazines, book, or a tablet.
- Pillows to prop you up whilst sleeping.
- Seat belt cover or small cushion to prevent rubbing.
- Mastectomy pillows and drain bags – some hospitals and charities provide these.

## After Your Mastectomy

Your wounds may be covered by a dressing, and your team will give you advice on whether you can shower, and when any dressings will be removed. If you are in pain, then tell your breast care team who can advise you on pain relief. It is normal for the area around your wound to be bruised. You may have wound drains put in place during your operation to help prevent fluid build up around the wound. These are usually kept in for around a week, your breast care team will advise you on the care and removal of your drains.

You may develop a **seroma** – a collection of fluid, or a **haematoma** – a collection of blood. This is usually reabsorbed by your body over time, or your breast care team may decide to draw it off using a needle and syringe.

I had a seroma after mastectomy. It became uncomfortable and looked like my boob had grown back! You could hear the fluid sloshing around. I had it drained three times, which was painless. It settled on its own after that.

Caroline

### Exercises

Your breast care team will give you advice on exercises to do after your mastectomy, these can help get your range of movement back, improve the symptoms of tight scars and **cording**, and reduce the risk of **lymphoedema**.

I was given a sheet of exercises to do twice a day. I think they were very important and helped me gain more or less full movement of my arm. I could barely lift my arm above a right angle at first but this gradually improved until I could lift it straight up.

Anne

### Radiotherapy

If you have breast cancer your team may advise you to have **radiotherapy** to shrink or kill any remaining cancer cells. Radiotherapy can affect the healing of your mastectomy wounds and can cause redness, so it is important to take care of the skin in the affected area.

I used aqueous cream as advised by my team and it worked for me. I was only really sore by my last session.

Karen



# Your New Chest

## Scars

You may feel anxious about looking at your new chest for the first time, and this is normal as you face the visible signs of the surgery you have had. It can help to speak to someone you are close to about how you are feeling, or you could speak to Flat Friends members who have been through similar experiences to you. It can also help to look at yourself in the mirror, building up to looking at your scar, to help you begin to accept the changes to your body.

I asked my surgeon before my surgery to make the scars symmetrical. So, when I first saw my scars and they were symmetrical I was very happy.

Angelika

Your scars should heal within six to eight weeks, although you may still have some swelling after this time. Mastectomy scars heal in either a half-moon or horizontal line, depending on which approach your surgeon uses. You can use moisturising creams, or scar oil to improve the look of your scars once the wounds are healed. Your surgeon should have made sure your scars are flat – if this is the result you have asked for. However, you may be left with excess tissue at the ends of your scars – known as ‘dog ears’; these can be removed with a minor operation later if they bother you.

I had revision work done about 1.5 years after my initial mastectomy. My first surgeon had left skin for recon and because I was so disappointed I found another surgeon who removed it for me.

Clare

## Numbness

The areas around your wound, armpit and shoulder blade can all feel numb after a mastectomy whether you have reconstruction or not. This may improve with time as your nerves repair themselves. As nerves repair they can cause shooting pains and cause an itchy sensation. You may also experience an itchy sensation where your nipple used to be – sometimes called ‘phantom nipple’.

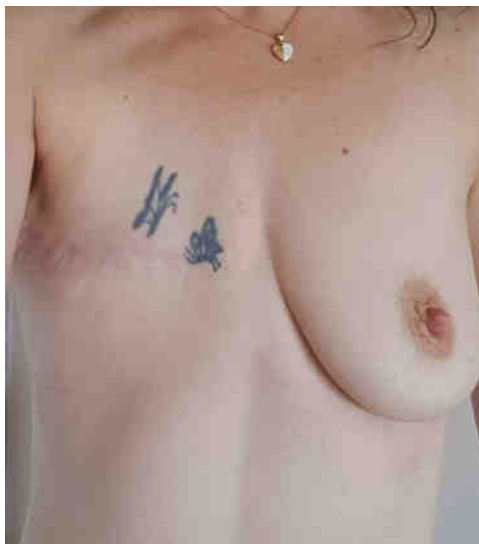
## Pathology Report

You can ask your medical team for a copy of the pathology reports from the test done on the breast tissue removed at your mastectomy. This report will contain information on whether the breast tissue contained cancer cells, and if these cancer cells are stimulated to grow by the hormones oestrogen or progesterone, or the protein HER2. This information helps your team consider which treatments would benefit you, such as chemotherapy or hormone therapy.

# Gallery of Double Mastectomy Results



## Gallery of Single Mastectomy Results



## Lymphoedema and Cording

Lymph nodes drain lymph fluid from the arm, so when these are removed it can cause a build up of fluid and swelling of the arm, shoulder, chest, or hand on the side you have had surgery on. When this swelling becomes long-term it is known as **lymphoedema**. Some women experience a feeling of heaviness, aching, or pins and needles in these areas.

Lymphoedema is a long-term condition which can develop soon after surgery, or weeks, months or years afterwards. It is not known why some women develop lymphoedema and others do not, but there are ways you may be able to reduce your risk such as:

- Taking gentle exercise such as swimming, but avoid over-tiring your muscles.
- Avoiding putting strain on your muscles such as heavy lifting or strenuous activities.
- Keeping the skin hydrated with cream.
- Avoiding injury such as cuts, scratches or burns by wearing gloves when gardening, washing up, or cooking, and avoiding using razors or wax to remove unwanted hair.
- If you damage your skin treat the injury promptly by cleaning and dressing the area to help prevent infection.
- It is not known if having blood pressure checks or blood samples taken on the mastectomy side are risks to developing lymphoedema, but you could try avoiding these where possible.

Although it cannot be cured, it can be managed with exercises and wearing compression sleeves.

Some women who have had lymph nodes removed may develop **cording**, which is when it feels like a tight cord in your armpit and down your arm. Stretching and physiotherapy can help reduce this.

I had cording in one arm from my wrist to my elbow. It was quite painful and looked weird. My BCN referred me for physio and it took about three sessions to sort it out.

Julie

I have lymphoedema in my hand, arm and chest. I was in shock when they told me I would need to wear a sleeve, glove and corset for life, but I have come to terms with it and manage sometimes without them.

Linda

*My Notes...*

## Life after Mastectomy

I'm very comfortable being a Unibooper. I can't think of anything it has stopped me doing.

Alison

I had a bilateral mastectomy and only occasionally wear prostheses. I sometimes notice people looking, but mostly I don't give a hoot. I feel confident and very happy. I love that I don't have to wear a bra.

Julie

I'm a happy Unibooper. I had a breast reduction after my mastectomy which was the right decision for me.

Sally

If you have had a single mastectomy you may feel that you would like surgery to your remaining breast in the future. You have the right to surgery to improve symmetry on the NHS. This could include a reduction – making your remaining breast smaller, or a **Contralateral Prophylactic Mastectomy** – the removal of your remaining breast.

If your surgeon will not agree to perform surgery to your remaining breast, you have the right to be referred to a different surgeon, or different hospital on the NHS. Your hospital's Patient Advice and Liaison Service (PALS) can offer further information, or help to resolve problems you have using the NHS.

I had my healthy breast removed one year after my single mastectomy. It was purely a personal choice as I did not like feeling lopsided. I'm happier now and glad I made the decision.

Jackie

### Check Yourself

It is important that you check yourself regularly, even after mastectomy. Once your scar/s settle, get to know how your chest now looks and feels. You should look for changes such as a lump, swelling or change in skin appearance from your collar bone all the way across your chest, into the armpit itself. If you notice any changes you should tell a member of your hospital team or your GP. If they are concerned they will arrange further tests. You will still be offered regular mammograms if you have a remaining breast.

## Personal relationships

You may be worried about how your partner will feel about you not having two breasts after your surgery, but they are likely to be relieved that you have had the surgery you need, rather than worrying about what you look like. Finding ways for both of you to talk about your feelings will help you identify changes in your relationship and support each other as you both adjust to life after breast surgery. There are also support groups for partners.

My husband was shocked about my decision but incredibly supportive all the way through. It doesn't bother him that I have one breast and he supports my decision to have my healthy breast removed.

Lisa

I have a lovely partner who kisses my scars and we have as good a sex life as before. Maybe that's a bit about my own confidence and how he makes me feel.

Viv

## Children

If you have children – of any age – you know them best. Decide how much they need to know, and be as honest as possible. It may help to show younger children your scars once they have begun to heal, to show them that you are feeling better.

My son was 14 when I was diagnosed. He was very supportive, and I even showed him my scar. He was completely unfazed by it.

Jane

My son was 2 when I had a single mastectomy, I never hid my scars. When he was 4 he asked why I had one boob so I told him it made me poorly and a doctor got rid of it for me. He understands this and is happy with it.

Sally

## Breastfeeding

When you have a mastectomy, your surgeon will remove as much breast tissue as possible, including milk ducts and usually the nipple. If you have a single mastectomy you could breastfeed using your remaining breast. If you have a double mastectomy you would need to bottle feed. But, whether you breast feed or bottle feed, feeding is a time to bond with your baby through skin-to-skin contact and eye contact. Your Midwife or Health Visitor will be able to support you with this.

## Post-Surgery Bras

Having the correct bra and prosthesis can make all the difference to your outline and your outlook, and mean others will not be able to tell that you have had breast surgery. Choosing the right bra after breast surgery can be daunting but with a professional fitting it can be an enjoyable experience. It is not necessary to spend lots of money initially as many high street brands and supermarkets now stock post-surgery bras, crop tops and swimsuits.



It is important to choose a comfortable bra which is soft cotton, front fasten initially; with or without pockets. As you progress through your healing stages, go for a good fitting bra that will support the weight of your existing breast or prosthesis. Some women have found that it is better to wait until your mastectomy site has settled.

The straps should feel snug, not too tight, and if you have a heavy breast or prosthesis and find your bra digging into your shoulders, choose wider or padded shoulder straps. There are silicone shoulder pads available which your bra straps fit into, these also stop your straps slipping off your shoulders.

Your bra size can change due to weight gain or loss, age or exercise, so it's important to get measured regularly. There are a couple of ways to find your bra size if you cannot arrange a professional bra and prosthesis fitting:

### Band size

Measure around your body underneath your bust in inches; if it's an even number add 4", if it's an odd number add 5". For example, 30" + 4" = 34 band

### Cup size

Measure over the fullest part of the remaining breast from the centre of the spine to the centre of the sternum, multiply this number by two, for example, 18" x 2 = 36. The difference between this measurement and your band size gives you the cup size. For example, 29" under bust and 35" over bust will give you bra size 34B. If you have a bilateral mastectomy, measure your band size and just try different cup sizes and prosthesis until you are happy with your size.

It is possible to find good fitting post-op bras and accessories. Your new bra should be comfortable but snug, and not ride up when you raise your arms. It should have generous underarm support to cover scar tissue - there is nothing more uncomfortable than having scar tissue or dog ears hanging over the side of the bra.

Joyce



## Breast Forms

Your breast care nurse will offer you an appointment to be fitted for a prosthesis. NHS patients do not have to pay for their prosthesis. Your prosthesis can be made of silicon, or you could choose a fabric one – known as a ‘comfy’ or ‘softy’. The NHS will replace your prosthesis when it is damaged or worn out. However, you can ask for a reassessment if your prosthesis is no longer the correct size or a good fit.



There are many prostheses to choose from: micro bead ones which are very light and ideal for swimming; foam ones which come with a removable cover, or silicone ones which are much like a natural breast and are available in different shapes, weights or stick on. It is a matter of finding what feels right for you.



You could also try knitted breast forms. These are lightweight, knitted, or crocheted cotton that are soft against scars and breathable. They can be requested in different colours, with or without a nipple. There are also breast forms designed for swimming which can be filled with shower scrunchies.

If you prefer not to wear prostheses, you could choose a stretch crop top or camisole vest top, some of these have shaped cups which are good if you have concave areas. Some are pocketed for you to wear with breast forms.

Some women wear stick-on nipples; there is a range of silicone, flat or projected nipples available which come in a variety of skin shades.

I'm a happy Unibooper, it has taken me a while to find my norm. I have an array of prostheses, a different one for each occasion.

Mary Anne

I always wear prosthetic boobs during the day, but am always glad to take them off at the end of the day.

Tina

## Dressing for your new body shape

You have spent most of your life a certain shape. As a teenager, you began experimenting with clothes; finding styles that suited you, following trends, and reflecting your personality through what you wore. Now you suddenly have fewer breasts, and possibly a new outlook on life. You are faced with a wardrobe of clothes accumulated over many seasons, even years, which no longer feel like they belong to you.

Shopping for a single or double flat chest is not that difficult; but, it is daunting to suddenly not know who you are, or what to wear. As you develop your style, focus on finding clothes that make you feel confident and comfortable in your own skin. Be true to your own taste, but try experimenting with styles you would not have worn pre-mastectomy. Be creative with different patterns, textures, styles, and accessories until you find the look that reflects your personality, celebrates who you are now and expresses who you want to be.

And finally, be prepared to try things on that do not suit you or that you don't like, this is something everyone experiences, whether they have breasts or not and is what makes finding the perfect item so special!

Finding clothes that you feel confident in can play a huge part in helping you accept your new body. I love experimenting with different styles I would never have worn before my mastectomy.

Sarah

When I put my prostheses on I decided I would rather be comfy and rock a frill-front top instead.

Lynn

I am very happy to flaunt my flatness in strappy tops and feel more feminine now than I ever have.

Caroline

### Body Shapes

One woman who has a mastectomy will have a different body shape to the next, and some may find that their body shape has not changed post-mastectomy. Body shape is about your proportions, rather than your dress size; someone who is a size 10 can have an 'apple' shape and someone who is a size 18 can have a 'banana' shape. Be ready to take a few sizes in to the changing rooms as you get used to what size you need in different style tops and dresses.



**If your shoulders, waist, and hips are around the same size, then you have a banana body shape** (also known as rectangle, athletic, and straight). Highlight your waist, and add movement.

**Try:** Gathered waistbands, frills, layering and patterns.



**If your hips appear wider than your shoulders, then you have a pear body shape.** Draw attention to your waist, and balance your figure by adding decoration and volume across your chest and shoulders.

**Try:** Off-the-shoulder and wide necks, Bardot frills, and bright or patterned tops with plain bottoms.



**If your shoulders appear wider than your waist and hips then you have a strawberry body shape** (also known as wedge). Highlight your waist, and add decoration down your centre and your bottom half.

**Try:** A-line or full skirts, and bright or patterned tops with plain layering.



**If your waist appears wider than your shoulder and hips, then you have an Apple body shape.** Show off your shoulders and legs, and add volume across your chest to balance your tummy.

**Try:** Swing and A-Line dresses and tops, and halter neck, strapless and cold-shoulder styles.



## **Basic tips on how to flatter and decorate single-flat and double-flat chests.**

### **Shape**

To add movement and volume look for:

- A-Line tops and swing dresses which flare gently from the chest
- Bubble hem tops, or dresses with elasticated waistbands
- Off-the-shoulder, halter-necks and boat-necks can all add width across the chest
- Avoid darts and princess seams where you are flat as they may not hang properly.

### **Fabrics**

Floaty fabrics such as crepe, chiffon and light cotton create movement; jersey drapes and gathers to create shape; lace and embroidered layers add interest, and textured knits add depth. Layer contrasting textures and colours to add depth and shape.

### **Detailing**

Extra features which suit a flat chest include:

- Double breast pockets (or single on your flat side)
- Gathered or cowl necklines
- Frills and pussy bows
- Pleats and pin tucks
- Contrasting sleeves

### **Decoration**

Be proud of your chest: Decorate it! Look for:

- Patterns to draw the eye around your outfit
- Contrasting patterns on the bib or yoke
- Appliquéd designs such as sequins, gems and beading
- Statement necklaces or long pendants

### **Asymmetrical Designs**

If you have had a single mastectomy also look out for:

- Pleats, draping or frills from one shoulder
- Contrasting panels or bold patterns to decorate your flat side

### **Accessories**

Scarves worn in various ways are also a quick way to do all the above. So, if you do not feel ready to splash out on a bold gingham cold shoulder blouse, or bright floral maxi dress, then build your confidence with your new style by decorating plainer outfits with bold accessories! Try patterned scarves, statement necklaces, and bold jackets instead.

## Glossary

<b>Bilateral Mastectomy</b>	Both breasts removed (also known as being double-flat, or a flattie).
<b>Contralateral Prophylactic Mastectomy</b>	Having an unaffected breast removed.
<b>Cording</b>	The feeling of a tight cord in your armpit and down your arm.
<b>Dog ears</b>	Excess tissue, fat, and skin at the edge of mastectomy scars.
<b>Fine needle aspiration/ biopsy</b>	A sample of cells are taken using a needle and syringe.
<b>Haematoma</b>	A collection of blood around a wound
<b>Invasive breast cancer</b>	Cancer that shows the potential to spread to other areas of the body.
<b>Lumpectomy</b>	Breast-conserving surgery to remove breast cancer along with a margin of healthy tissue.
<b>Lymphoedema</b>	A build up of fluid causing long-term swelling of the arm.
<b>Phantom nipple</b>	The sensation that the nipple that has been removed is still there – often feeling itchy.
<b>Prostheses</b>	Breast forms worn inside bra cups or bra tops to give the illusion of a breast or breasts.
<b>Radical mastectomy</b>	An operation to remove all breast tissue, skin, areola and nipple, as well as lymph nodes in the breast and armpit and some of the chest wall.
<b>Radiotherapy</b>	A precise dose of radiation – like an x-ray – given to the breast area after mastectomy to kill any remaining cancer cells.
<b>Sentinel lymph node biopsy</b>	A surgical biopsy using radioactive dye injected into the breast to identify the node closest to the lymph vessels connected to the breast. This sentinel node is then tested to see if it contains cancer cells.
<b>Seroma</b>	A collection of fluid around a wound.
<b>Simple Mastectomy</b>	An operation to remove all breast tissue, skin, areola and nipple.
<b>Unilateral Mastectomy</b>	Single breast surgically removed (also known as being single-flat, or being a Unibooper).
<b>Wide Local Excision</b>	Breast-conserving surgery to remove breast cancer along with a margin of healthy tissue.

*My Notes...*

## *My Contacts*

<i>Name</i>	<i>Tel/Email</i>

## About Flat Friends UK

Flat Friends UK (Registered Charity Number 1168730) became a registered charity in 2016 to promote living without reconstruction as an equal treatment option to reconstruction. We believe in a more balanced discussion that treats every surgical option equally, and every woman's choice with respect.

Our charitable purpose is the relief of women in the UK who have had or may face mastectomy and who live or are considering living without breast reconstruction; in particular (but not exclusively) by providing information, advice, and raising awareness among healthcare professionals and the wider public.

### How Flat Friends can support you

We create safe, friendly environments for women to share experiences, ask advice, and offer support to each other. You can ask to join our private Facebook groups, or you can use our public online forum via our website. Please contact us for information on regional support meetings.



### Contact details

Website: [www.flatfriends.org.uk](http://www.flatfriends.org.uk)  
Email: [support@flatfriends.org.uk](mailto:support@flatfriends.org.uk)  
Twitter: [twitter.com/flatfriends\\_uk](https://twitter.com/flatfriends_uk)  
Facebook: [facebook.com/flatfriendsuk](https://facebook.com/flatfriendsuk)  
Instagram: [Instagram.com/flatfriendsuk](https://Instagram.com/flatfriendsuk)



Flat Friends UK is here for women in the UK who have had or may face mastectomy and who live or are considering living without breast reconstruction. We provide information, advice, and raise awareness. We view living flat after a single or double mastectomy, with or without prostheses, as a positive outcome.

Visit [www.flatfriends.org.uk](http://www.flatfriends.org.uk) for further advice and support.

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