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*Aftercare Booklet*

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## Aftercare Booklet

This booklet has been put together with the hope it will help you in a practical way.

It contains aftercare information written by myself, recently a few more ladies have added to this hoping that what worked for all of us, will also help you.

Please remember that not everything works for us all. It is all the small things that make a difference when you are recovering from the vulval surgery, knowing what to use and reading what has helped other ladies after their surgery. I hope you can find plenty of answers in this booklet. It contains many tips for you, just basic simple tips, which will make a huge difference to your recovery.

Going through treatment for vulval cancer can be very frustrating and extremely stressful and I do hope this information will be of some use to you and help you feel more comfy after your surgery.

Please ask if there is a Macmillan Nurse available to talk to you in the hospital, or a Gynaecological, Clinical Nurse Specialist. These nurses are often looked upon as the nurses we all see when we are terminally ill. This is not the case, not only will they support you, but also your family too. If your hospital does not have one ask for the number of your nearest Macmillan centre and give them a call when you get home. These nurses will always be there for you if and when you need them. They will also help you to sort anything that is worrying you. Please make sure you make this valuable contact.

When you are feeling well enough, you may feel like going to the Macmillan Centre for a chat, coffee mornings and most Macmillan centres now have a variety of alternative therapies which you may like to try.

The Macmillan cancerline is a wonderful service to access. The nurses who take your calls are there to support, listen, help and advise you. The number is listed with some other useful telephone numbers on the list in this booklet..

Cancer Bacup do a wide range of booklets, which are a valuable source of accurate information, and you can order any as many booklets as you think will be useful to you and your needs. They are free to patients. The number is listed in this booklet.

All the nurses who take your call on the Cancer Bacup helpline are qualified cancer specialist nurses, and will be help and advise you whatever your need is.

I hope this booklet will help you to cope with any problems you may experience after your surgery.

If you should need any further support please do not hesitate to contact me on 0161 747 5911 and I will be happy to speak with you.

Best Wishes for a speedy recovery

Many thanks, to Sheila, Jean, Jeanie, Kym and Elise and Jo for their input into this new aftercare booklet.

**PLEASE NOTE** \* Some of the creams and ointments have a \* next to them, this is to remind you when you try a new cream or lotion, please make sure you do a sensitivity test before you apply this to the whole area, just in case you have a reaction to any of them.

The information in this booklet is based on our own experiences. It has been written for patients, by patients and is here to help you feel more comfortable. It is not offered as substitute for any medical problems. If you have a health issue or problem, please speak to your GP, Specialist nurse or Consultant about it.

**Note:** Please do not reproduce this information in any way, without prior permission from the owner. This information is printed off and placed inside a binder for any Lady who is in need of this information.

If you have any queries, please contact me at VACO Email: [vacouk@yahoo.com](mailto:vacouk@yahoo.com)

Thank you

Carol

List of items to purchase, depending on your own personal choice. Please note you will not have to purchase all of these items.

- ❖ Topper 8 Swabs
- ❖ Micropore
- ❖ Aveeno Bath Oil
- ❖ Aveeno cream
- ❖ Liquid Paraffin 50% & White Soft Paraffin 50%
- ❖ Propolis gel
- ❖ Feme Pads
- ❖ Dermol 500
- ❖ Honey Tulle Dressing's
- ❖ Aqueous Cream
- ❖ Emulsifying Ointment
- ❖ Boots Maternity pads
- ❖ Heat Pads
- ❖ Vitamins 3 for 2 (Boots always have these on offer)
- ❖ Boots Honey chamomile Lavender Muscle Soothing Bath Essence, (this has been dermatologically tested and is safe to use).
- ❖ Anthisan Bite & Sting cream
- ❖ Moisturising Cream
- ❖ Hold up Stockings

Some of the above items are also available on prescription from your GP if you do not pay, or have an exempt certificate.

## Hospital List

- ❖ Brush and Comb
- ❖ A Hot brush. The butane ones are a lot quicker and easier to use, and you can give yourself a treat, or let one of you family members do your hair for you, it will make you feel so much better.
- ❖ Shampoo and Conditioner. The travel size ones are much easier to take into the hospital with you.
- ❖ Nightdresses as opposed to pyjamas.
- ❖ Wet wipes.
- ❖ Dressing gown, one which will be warm enough for you in case you feel like going to sit outside for a little while.
- ❖ Make sure your dressing gown is not too long, and is not a zip up one.
- ❖ Non Slip, slip on slippers.
- ❖ Nail file.
- ❖ Make up bag, and small mirror. This will help you to feel so much better by making the effort to make yourself look nice.
- ❖ Cotton underwear.
- ❖ A diary may prove useful to write all of your feelings down, as sometimes it can be very distressing for you to talk to your family about how you are really feeling. We Ladies do not like to see our family upset so putting all this down may be beneficial to you, it was for me.
- ❖ Magazines.
- ❖ Small change for the trolley.
- ❖ Try not to eat too many chocolates as this will not do your figure any good in the long run, and you will regret this later. A good idea maybe to ask your relatives and friends to bring you fruit and maybe something off your list which will make you life a lot easier in the hospital.

**You own Personal list for the hospital**

### **Topper 8 Swabs**

I discovered these whilst in the hospital and they were not given to me for bathing myself with, but to put over my groin area. I discovered they were very good for bathing yourself with.

I asked my GP for them and he was able to put them on prescription for me.

These can also be purchased from Boots and they come in a pack of a 100 and well worth the money for the comfort.

They are also very useful for padding up you groins where you had your nodes removed as they cushion the area, especially if you have to wear underwear, which may irritate your groin area for a little while after your surgery.

### **Micropore**

This is ideal to hold the gauze swabs in place and easy to remove.

### **Aveeno Bath Oil\***

This is a very soothing, safe and is also dermatological tested bath oil, which is very soothing to add to your bath and also to bathe yourself with throughout the day. Add a small amount on a warm damp gauze swab to bathe with then lightly pat your self dry with the gauze which will make you feel a lot more comfortable.

It contains Collodial Oatmeal, which is recommended by Dermatologists for many skin disorders. It is safe to use in the bath after your surgery. It is very soothing and will not make the bath slippery. This can be purchased from Boots.

Another alternative for drying your vulva is a hairdryer, make sure this is set on the **COOL** setting and always test this on the back of your wrist before you use this on your vulva, this will only take a few seconds to dry yourself. Hold the dryer at knee level, any closer and it will aggravate you.

### **Aveeno Cream\***

Again this is a very soothing cream and safe to use on the vulva area. It can be purchased from Boots.

### **Liquid Paraffin 50% & White Soft Paraffin 50% \***

This is a very soft cream, acting as a good barrier cream when you go swimming. It can be used after surgery to protect your skin. It is similar to Vaseline but a lot easier to apply, much softer and lighter, it is also easy to remove.

### **Propolis Gel\***

This is a natural antibiotic, available from QVC shopping channel and cost £20-00 to buy. It is expensive but is well worth buying some of this especially if you are suffering with an infection on your vulva after surgery.

A few ladies have tried this and have all been ok with this, it has helped us all and so far no one has had a reaction to it.

It is also very good for eczema, dermatitis and most skin complaints. It can also be used for bites and stings.

### **Femme Pads**

Femme Pads were a wonderful discovery by one of the ladies, they look like a sanitary towel but are a lot thinner and slightly longer, and are filled with a special gel and the covering is a very soft pliable plastic. When they are frozen they are very soft and flexible and will fit easily and they are very comfortable to wear. These can be purchased from Boots or Mothercare and both sell the extra gauze sleeves, which you will also need a good supply of.

Put the pad in the freezer for approx 45 minutes, then you place this in one of the gauze sleeves which comes with them, then just place them in your panties and they will actually numb the vulva area and make you pain free.

After use you dispose of the gauze sleeve and then just wash the pad with warm soapy water ready then it is ready to freeze again.

Do not put the pad next to your vulva without the gauze sleeve or you will get an ice burn. Extra gauze sleeves can be purchased from Boots.

### **Honey Tulle\***

If you find after your surgery you have a small area which is taking longer to heal than the rest. These can help the healing and these tulle dressings contain only natural ingredients, which are very effective and you are highly unlikely to have a reaction to this. They can be a little awkward to keep on during the day, and are best used when you are lay down on the couch or the bed. They are also very good for vulval eczema and may other vulval disorders.

Just place the swab in place and because it is a little sticky it will stay in place for you. Some hospitals in the UK do have them so ask your Specialist Nurse or Macmillan nurse to see if they can get you some. If you cannot get these from the hospital you can actually order these from your pharmacist, but they do cost approx £12-00 a box, this may vary a little. I bartered with my pharmacist and he did reduce the price a little for me.

If you give the pharmacist the following details they will be able to order them for you. The details are: Malam Laboratories, Ltd. Oakwood Drive, Bolton BI1 5EE

### **Dermol \***

This cream can be used for bathing and also applied afterwards as a moisturiser. It is very soothing and makes you feel comfy as soon as you have used this. It is also very good for vulval eczema and many other vulval disorders. It can be obtained from Boots and is also available on prescription. It comes in a pump container which is easy to use.

### **Aqueous Cream\***

Aqueous cream is a very soft, high oil content cream, which is ideal for using to bathe your self. It helps to keep your skin very supple and more comfy. If you do use the aqueous cream in the bath, take extra care as it can make the bath a little slippery so be sure to have a towelling bath mat in for added safety and take extra care when you get out of the bath.

It is also good for moisturising your legs, which are now prone to dryness if you have had your nodes removed. You should be moisturising your legs daily to help to avoid any cracks in your skin, making sure you apply more to your feet which are more prone to cracking than the skin on your legs. It can be purchased at Boots and a large tub is quite cheap to buy.

If you do not like the aqueous cream as a general moisturiser for your legs and feet, there are plenty out there to choose from. If you have cellulitis please check before you use any perfumed cream on your legs. A nice cooling one to use is the Olive and Lavender wheat germ Cooling Massage Lotion. This can be purchased at Boots.

## **Emulsifying Ointment\***

Don't be put off by the appearance and texture of the emulsifying ointment. It looks very hard and like wax, but when applied to a warm damp gauze swab it goes very soft and has a very soothing affect and makes your skin feel a lot more supple after using it for a couple of weeks on a regular basis.

## **Sanitary Protection**

After surgery you will need some sanitary protection for 2-4 weeks. After trying quite a few brands and getting rashes and irritations through these, I tried the Boots maternity pads, which proved to be the best ones and caused me no irritation at all. Also, because there is a maternity pad, they are a lot thicker than the usual pads, which gives you added protection and comfort when you sit down.

## **Heat Pads**

Lots of ladies have mentioned they have suffered some back pain for a short time after the surgery, and we have found an extremely useful heat pad, which has so far worked for all the ladies who have tried them. The pads are very easy to apply and last for up to 8 hours. They start to work as soon as they are applied.

They have a sticky gel on the back of them which will stick to your skin and once in place the pads start to heat up pretty quickly, and will last for up to 8 hours, giving comfort and easing the back pain for you.

These come in a pack of two and could work out quite expensive. A good idea would be to ask your family and friends not to all bring you flowers and chocolates, but to buy you a box of the heat pads which will be much more beneficial for you. These can be bought from Boots.

## **Vitamins**

My Macmillan nurse suggested I take some immune boosting Vitamins. I did go and ask the pharmacist which to take as there were so many on the shelves and he suggested the ones I am still taking today.

Remember to tell the pharmacist about any medication you are taking be it from your GP or any health products so he they can be sure all your medication is ok to take together. I usually go to Boots for mine and always get them when they are on offer, 3 for 2 so you can usually make a saving on these.

### **Honey, Camomile & Lavendar Bath Essence**

This should only be used once healing is complete.

After having vulval surgery it is important that you do not use any kind of perfumed bath oil or soap as this may well cause you an irritation. I always loved my bubble bath and this was something I did miss. I was thrilled when one of the ladies suggested this to me as it is natural product and can be purchased at Boot's from the Maternity section.

When I did use this I found I had no reaction to it at all, and I finally got my bubbles back. A little bit of something you really enjoy is good for your self esteem.

### **Anthisan Bite & Sting Cream\***

This is useful to keep in, just in case you get bitten on your legs. It can be applied immediately and after keep an eye on the bite and if it starts to go red or warm to touch and swells you will need to let you GP take a look at it to check you are not developing an infection.

### **Tights or Hold up Stockings**

If you do feel you have to wear some tights after you surgery, they will most likely irritate you. We all know they make you very warm and just encourage problems because of sweating with them being nylon.

You could try wearing the hold up stocking they will not cause any problems and will let your skin breathe.

If you do decided to wear these make sure you have not moisturised the tops of your legs as any oil left on your skin, will not allow the rubber to stick to you as they should do and they will, after a short time fall down as I found out 😊

You could also try stockings and suspenders. You can also purchase crotchless tights from some of the high street shops.

If you do not like the stockings or the crotchless tights try buying a pair of tights from M & S as they have a very strong gusset which is stitched in, cut the **inner** part of the gusset and remove it from the tights and this will let you wear the stocking with no risk of any problems because you will not have the thick nylon gusset next to your panties.

### Some useful tips

Have your hair cut/streaked and styled just prior to you being admitted as it may be a while before you feel able to sit in a chair long enough to have your hair done.

When you purchase your slippers for the hospital, it is far easier and safer to buy a pair that you can slip on as bending down does not come to easy immediately after surgery, so this does make life a lot easier for you and make sure that they have nonslip soles.

When you are due to go home ask whoever is picking you up to bring you 2 pillows, 1 to sit on and 1 to put over your groin area this will make your journey home a lot more comfortable.

Ask your specialist nurse if there is a McMillan nurse available in the hospital to come and visit you. These nurses are wonderful and so supportive and they will also be able to put you in touch with your local McMillan Centre before you go home.

Write down all questions that come into your head about your operation and recovery as soon as they come into your mind. Also the same if you are due a follow up appointment, 3 months is a long time to wait if you forget to ask a question.

Inquire about counselling, you may need this at a later date, so it would be better to have it in place ready to use if and when you need it.

Whilst you are in the hospital ask your nurse for an extra pillow, use this to put in between your legs, this takes the pressure off your legs, and especially helps relieve the pressure on your knees. It makes resting a lot more comfortable.

When using any creams, do not put your hands in the pot, find something clean for dipping in and getting some out to place in your hand, as it will only encourage bacteria if you put your hands into it. As soon as you have finished with the ointment replace the top immediately, again it will stop any bacteria getting into the pot and contaminating the cream.

Sitting in the bath can be very uncomfortable too, so fold a bath towel or bath sheet up into a cushion size, place in the bath push it down and sit on that, so much more comfortable for you and more relaxing too.

Getting into the bath, especially if you have had your nodes removed can be some what of a challenge, and a painful one too if your legs just won't reach.

Alan made me a sturdy wooden box, I placed a rubber bath mat over this then a towelling bath mat, so it was safe to tread on, also make sure whilst you are getting in the bath like this that you are not alone, and that someone is around to check that you are safely in and out of the bath, you may well need some help for a while.

You can also buy a stool especially for the getting in the bath, so this is another option for you. This really will make your life so much easier getting in and out. Make sure you get someone else to test this out for you. If it does not hold your weight they will fall over, not you 😊

If you decide to use the shower to rinse your vulva, make sure you check the temperature as you will be numb underneath for quite some time and so you need to make sure that the water is not too hot, test it on the back of your wrist first. It is better to check this out than be sorry after.

Make sure before you get into the bath that everything is at arms reach for you and you do not have to stretch. It saves you a lot of hassle if all your needs are at hand.

If you are safe to have a bath alone and are in the house alone make sure you take the portable phone with you as it is the always the way when you immerse your body in water, the phone rings!!! Or better still put the answering machine on.

No leg shaving after you have had your nodes removed. This can cause you many problems. Buy yourself a proper lady shave, you will not, if used correctly get a cut from one of these. Waxing is also not recommended on the legs and the bikini line.

We now have to take better care of our feet, legs and especially our skin. Make sure that you moisturise your legs twice a day as they will have a tendency now to dry up, get someone to help you do this, or better still get someone else to do it all for you.

If you do develop Lymphoedema moisturising is more important now and also you need to see a Lymphoedema Physiotherapist who will teach you how to do your own Lymphatic massage at home.

It is a good idea to enquire whilst you are in hospital about the Lymphoedema Physiotherapist as sometimes they do have a long waiting list so it may be a good idea to ask either your Clinical Nurse Specialist or McMillan nurse, one of whom should be able to refer you before you go home.

It is a good to idea to get into the habit of elevating your feet when you sit down, this will help to keep the Lymphoedema down, and will also help to reduce any swelling that you already have.

You can also buy support tights from the high street shops, which will help with the Lymphoedema.

If you have to wear the support tights supplied by the hospital they can be quite difficult to pull on, put some talcum powder on your legs just before you put the tights on and wear a pair of rubber gloves which will help you grip the tights a lot better, making it a lot easier to pull them up.

If you are not going out anywhere, keep the underwear off, you will get used to this and it is much healthier for you anyway. It will be much healthier for you not to wear nylon underwear any more keep to the cotton and you will be less likely to have any problems.

A diary may prove to be a useful item to have. I found writing down each day all my inner feeling always made me feel better, as there may be things which you may not want to discuss or share with a loved one. An ordinary blank book will suffice, and even now after nearly 5 years I still keep my diary. It is also encouraging to read when you are having a bad day, and as time goes on you will realise the bad days get less and the good days get more which is also encouraging.

I hope that these simple suggestions have been of some use to you, if you think of anything else please let me know, then it can be added to this list and then everyone will benefit.

## **Aftercare for Radiotherapy**

### **Pelvic Radiotherapy**

Do not take anti-oxidants as a food supplement during treatment, as it may reduce the efficiency of the treatment.

Any side effects will probably not appear until 3 weeks into treatment, so even at the beginning conserve energy and try to keep legs elevated while sitting as swelling must be kept to a minimum.

### **Washing**

Use aqueous cream to wash with and also as a moisturiser every day.

It is not wise to bath as soaking in water only makes the skin mushy. Shower and if your shower is in the bath put the plug in so it fills with water and then you can sit in the water for a short time to give yourself a douche. I used to put lavender oil in the water as that is quite soothing and the smell is relaxing.

### **Toilet**

Radiotherapy can give you cystitis so drink plenty of water and cranberry juice. If your urine does start to sting take a herbal supplement called CANTHARIS, this is a miracle cure for cystitis, It can be bought in most good health food shops.

Use cotton wool dampened with water to wipe your self as any trauma to delicate parts is best avoided.

If you have a b day use it, especially if you become sore around your bottom.

### **Bowels**

As your bottom can become very sore it is best to keep stools soft.

Drink plenty of water.

Avoid foods like muesli and pulses.

Ensure you have a supply of Fybogel or senokot tablets.

### **Skin Breakdown**

Moisturise often with aqueous cream.

Avoid trauma to the area.

Radiotherapy departments advice the use of Aloe vera gel, however I found that it was of no help to me, but this was my personal experience of gel.

.  
If you do burn it is hard to dress as many creams are not to be used while being treated. I applied jelonet gauze and gauze pads which I kept in place with mens tight boxer shorts! Very attractive. I sadly became very burnt and the best dressing that I

used was Sorbsan sheets. These are an alginate gel dressing which acts as a barrier between the burn and any exudate which leaks out. Another advantage is that any fibres left in place when dressings are replaced simply become absorbed into the fluids so you do not have to cause further trauma trying to remove all of the dressing.

Please ask your nurse about the above dressings.

## **Aftercare for Chemotherapy**

To be added shortly

## **Questions to ask your Consultant**

## **Questions to ask your Specialist Nurse**



## **Notes**

## **Notes**

## Notes



If you have any queries, please feel free to contact me at VACO

Email: [vacouk@yahoo.com](mailto:vacouk@yahoo.com) or call me on 0161 747 5911 and I will be happy to help you in any way I can.

### **Legal disclaimer**

**We do not encourage you to self-diagnose your symptoms and would encourage you to work with your doctor (GP or specialist) to find the best treatment for you. All content within this booklet is provided for general information only, and should not be treated as a substitute for the medical advice of your own doctor or any other health care professional.**

**Always consult your own GP if you're in any way concerned about your health.**

