



*An information guide about*  
**Scalp Cooling**

**2020**





## **Note to the reader**

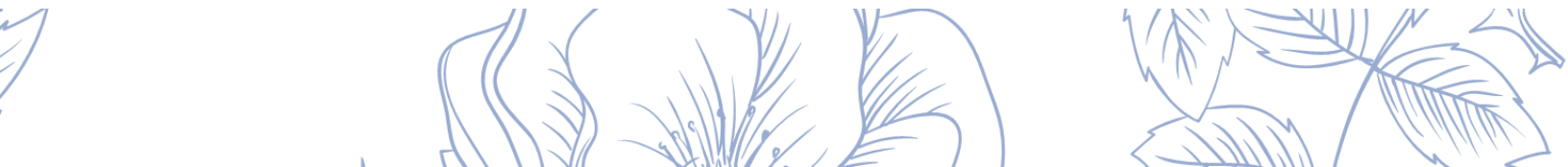
This booklet was designed in partnership with women with breast cancer, their family members and health professionals. However, if you are male and/or have a different tumour type, there will still be many areas of information in this booklet that are relevant to you.

This guide is not a substitute for professional medical advice. It is always best to ask a member of your treating team for advice specific to your individual situation.

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*Not everyone wants to try scalp cooling. It is a personal decision. Scalp cooling has no impact on how your chemotherapy treatment works.*

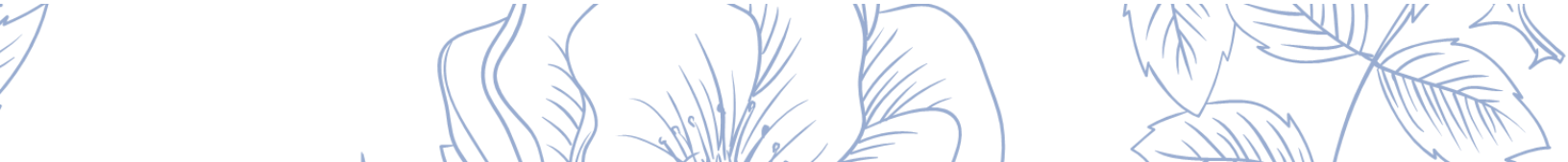
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# Contents

<b>Welcome .....</b>	<b>1</b>
<b>How does scalp cooling work? .....</b>	<b>2</b>
How the cap should fit.....	3
<b>Side effects and expectations.....</b>	<b>4</b>
Coldness .....	4
Discomfort.....	5
Treatment time .....	6
Hair loss.....	7
<b>Stopping scalp cooling.....</b>	<b>9</b>
<b>Advice from the experts.....</b>	<b>10</b>
To cut or not cut your hair... ..	12
Packing your scalp cooling bag .....	13
<b>Caring for your hair .....</b>	<b>14</b>
<b>Shared experiences .....</b>	<b>15</b>
<b>Further information .....</b>	<b>21</b>
<b>References .....</b>	<b>21</b>





## Welcome

This booklet has been developed for people who are thinking about, or have decided to try scalp cooling, during their chemotherapy treatment.

Scalp cooling is a technique that was developed to help reduce the hair loss caused by some chemotherapy drugs. Your medical team will explain whether your chemotherapy is likely to result in hair loss.

This booklet explains how scalp cooling works, how it feels, its potential side effects and, offers practical help and advice about how to care for your hair from women who have had scalp cooling. It also draws on the research evidence that is available. Useful websites are listed at the end of the booklet if you would like further information.

*“I am glad I tried scalp cooling. It was never for vanity reasons, it was for privacy, no one needs to know what’s going on in my life.”*

Fatemeh, 48 years old

*“Initially, I felt like the definition of scalp cooling success was how much hair you had at the end of treatment. What I discovered was that it gave me extra time to mentally prepare for losing my hair. In the end, I lost a lot of hair, but I think I was ready at that point, I was four months in. That extra time to adjust was the value in scalp cooling...”*

Alanna, 30 years old

## How does scalp cooling work?

Scalp cooling works by lowering the temperature of the scalp (the skin covering your head) before, during and after each chemotherapy treatment. Generally, the scalp skin temperature is around 32°C. With scalp cooling, the temperature of the scalp drops to between 15 to 20°C.

The scalp cooling machine (shown in the picture below) circulates a cold gel around a tight-fitting cap that is worn during each chemotherapy treatment. The cold gel makes the blood vessels of the scalp smaller so that less blood flows through them. As a result, less hair is exposed to the chemotherapy drug.



Susan during a scalp cooling session



The Paxman scalp cooling system

Scalp cooling will only reduce hair loss from your head. Body hair, such as eyelashes, eyebrows and pubic hair, may still fall out with chemotherapy treatment.

## ***How the cap should fit***

The cap must fit tightly all over your head. Making sure that the cap fits along the hair line and that there are no gaps between the cap and the scalp is essential. If your cap does not fit well the cap size may need to be changed.

*“In my first session I felt a gap, not much, probably half a centimeter, I didn’t realise that was enough to prevent it working there.”*

Namka, 47 years old

Cooling caps that are not fitted tightly have been linked with more hair loss, often in patches where contact with the scalp is poor. If you do not feel your cap is fitted properly, tell your nurse. The nurse won’t mind at all. You are the one wearing it, so you are the expert!

*“I had lost a lot of hair and I had the confidence to say, hey it’s not fitting like it did last time. I am so glad I did. The nurse was grateful too.”*

Lara, 48 years old





## Side effects and expectations

### Coldness

The scalp cooling cap will feel very cold when it is first put on. Most women who helped us write this booklet, told us that it takes between 5 - 15 minutes for your body and scalp to get used to the level of coldness, but it may take longer for some people. Some women remain cold for the entire treatment session. Ways to manage this are outlined later in this booklet.

*“It’s pretty unbearable for the first fifteen minutes and then it’s okay.”*

Helen, 36 years old

*“It’s like you have an ice bucket on your head and it’s sort of like brain freeze but a hundred times worse.”*

Anne, 63 years old

*“I only really struggled with the cold the first time, the second time I knew what to expect. It got easier each session, in the last sessions after a minute or so I was fine.”*

Terry, 48 years old

If possible, during your pre-chemotherapy education session in the Day Therapy Unit, ask the nurse if you can feel the cooling cap so that you have a good idea of how cold it will feel on your head.

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*If you start scalp cooling and want to stop because you find it’s not for you, you are free to do this at any time. Please let one of the Day Therapy Unit nurses know.*

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## Discomfort

The cooling cap is cold and tight, this can cause discomfort during and after treatment. The other discomforts some people experience include:

- Headaches/migraines
- Feeling faint, dizzy and nauseous
- Discomfort from the chin strap and forehead pain from the pressure of the cap

Remember, if scalp cooling becomes too uncomfortable it can be stopped immediately.

*“The big thing for me was the headaches from the pressure of wearing the headgear, it got very heavy.”*

Steffi, 42 years old

*“I found it very difficult to have a conversation while wearing the cap because my jaw was constricted from the chin strap”*

Megan, 28 years old

## Using the bathroom during scalp cooling

Because you are connected to the scalp cooling machine (which can't be moved about like your chemotherapy infusion stand) you are restricted from moving around.

If you need to go to the toilet, the cooling cap will be disconnected from the cooling machine. When you stand up, you may feel dizzy, so it is good to have a friend, or a nurse walk to the bathroom with you. While you are not connected to the machine, the cooling cap will warm up. If this is less than 15 minutes, it shouldn't affect hair loss.



## Treatment time

The time of your treatment will increase when you have scalp cooling. Scalp cooling starts 30-minutes before the chemotherapy infusion, stays on during chemotherapy and for 30- to 90-minutes after chemotherapy ends. The additional scalp cooling time depends on the type of chemotherapy drug and how long it takes to fit the cap correctly, but it can add up to two and a half hours.

*“It was really time consuming. I’m always the first one there and the last one to leave so that was kind of depressing...”*

Sandra, 45 years old

*“Scalp cooling only added an extra hour to my treatment and that didn’t bother me. Plus, it meant I got the morning slot which was great.”*

Ayfer, 48 years old

*“I had headaches and it extended my treatment time by hours... you’re there virtually the whole day and you’ve got this blasted thing giving you a headache.”*

Catherine, 63 years old





## Hair loss

Many people who use scalp cooling still experience total or some hair loss or hair thinning. There are different reasons for this, including the type and dose of chemotherapy treatment and hair type.

Some research has suggested that people with thick hair are more likely to lose hair compared to those with thin hair.<sup>1</sup> This is because thick hair insulates the head, so the cap cannot make close enough contact with the scalp.

### *Scalp cooling success rate*

The success rate of scalp cooling is unclear because studies to test how effective it is have included people having different chemotherapy, with different hair types, and have used different cooling machines. But there is some evidence<sup>2</sup> that scalp cooling can lower the risk of significant hair loss by 43%, leaving people feeling that they had enough remaining hair so they did not need to use a wig or hair covering.

Hair loss can happen as thinning or it may come out in patches. Most hair loss occurs after the first two sessions of chemotherapy. If you lose a lot of hair, your nurse may talk to you about stopping scalp cooling. This is to protect your scalp from **cold burn**, an injury that can occur when something very cold, like the cold cap, is in contact with the skin.

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*Some people find that gradually losing their hair while using scalp cooling is harder to cope with than a quicker hair loss without scalp cooling*

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## ***Being as prepared as possible***

Seeing your hair come out can be confronting and upsetting. We have included some photographs below and hope that these help prepare you for what hair loss may look like.



### **Grade 1**

0 – 25% hair loss



### **Grade 2**

25% - 50% hair loss



### **Grade 3**

50 – 75% hair loss

It is important to keep in mind, that two people with the same grade of hair loss can look very different; hair can fall out in patches or it can present as overall thinning.

## Stopping scalp cooling

It is okay to stop scalp cooling at any time. The most common reasons people stop are; the coldness causes too much discomfort, headaches, or not being able to, or wanting to spend the extra time in hospital that scalp cooling requires.

It is important to remember, once you stop scalp cooling you cannot start it again at your next chemotherapy session.

*“When I was going to have my third session my hair was falling out and the nurse said I don’t think you should have it... But it was up to me, and I thought, I don’t need any more problems, so I finished. But I was glad I gave it a shot.”*

Anita, 73 years old

*“I had scalp cooling all the way through except for the last one... I had eight rounds of chemo, and then on my seventh round the migraine it was ... it was unbearable, and the cap was so tight ... I just couldn’t anymore. So, I said I wanted to stop, and everyone was fine with that.”*

Sonja, 49 years old





## Advice from the experts

The advice below was shared with us by women who have experienced scalp cooling. These are the things they wished they'd known before they started:

- Take pain relief (e.g. Panadol) about 30 minutes before scalp cooling starts
- Go to the bathroom before you get connected to the scalp cooling machine
- Ask the nurse to show you how to disconnect and connect the cap from the tubing
- Use hair conditioner to help with cap application and removal
- Use a soft headband underneath the scalp cooling cap to cushion your forehead and ears
- Bring a hat or head scarf with you to the hospital, ready to wear when you go home
- You are likely to feel cold during scalp cooling so you may need to wear a cozy jumper or jacket
- You can also ask your nurse for a blanket or bring your own. Some women said that having their own blanket or cozy wrap made the environment feel more comforting
- Several women found that their support person, such as a friend or family member who came with them to chemotherapy sessions, was the best person to ensure the cooling cap fitted correctly

*“Particularly for the first chemotherapy session, bring a bossy friend, someone that will take the time to make sure it’s fitting well, who will speak up for you and who isn’t afraid to handle your head a bit rough.”*

Nicole, 48 years old

*“When trying to put the cap on the nurse said she was worried about hurting me, and my friend, who was doing the chemo with me, she said I’m prepared to hurt her, and she proceeded to put the cap on perfectly.”*

Kerry, 54 years old

Some women explained that distraction, through conversation with others or meditation, was helpful during the initial cold period, while others talked about the benefit of being left alone.

*“I was like this is the point you need to distract me, I need you to talk to me now. We did the Herald Sun quiz every chemo at the freeze time, cause, don’t leave me to my thoughts, all I’ll be thinking about is the cold.”*

Paula, 49 years old



## ***To cut or not cut your hair...***

Some women suggest cutting your hair short before treatment to minimise the quantity of hair loss, because it can be distressing to lose large amounts of hair. Many women with thick hair also felt shorter hair might help with getting tight fit of the cap. There is no evidence that the results of scalp cooling are better if the hair is short.

Other women felt having longer hair was an advantage as it helped with covering bald patches and giving the illusion of more hair (especially when wearing head scarfs).

*“I think to help eliminate any trauma you should get your hair cut short. I kept mine long... I had a shower one morning and it was like in a horror movie, it was coming out in clumps...”*

Millicent, 49 years old

*“I would wear a scarf or a thick headband and leave the long hair I still had falling out, it gave the impression I still had my hair”*

Naveetha, 48 years old





## ***Packing your scalp cooling bag***

Below are some suggestions from women who have been through scalp cooling, for things you may want to bring with you on the day:

- Panadol
- Warm clothes (including socks) and a blanket
- A hot water bottle/ heat pack
- A hot thermos of tea/soup
- Your preferred conditioner/hair treatment - Some women experience an altered/heightened sense of smell during treatment and recommend a neutral smelling conditioner
- A soft headband to help with forehead pressure and coldness
- A small amount of padding to go under the chin strap (or ask the nurse to use a soft dressing)
- Entertainment e.g. music, book, podcast
- Contact lenses if you normally wear glasses
- A hair wrap or hat for the journey home after treatment



## Caring for your hair

Here are some pointers women recommend for looking after and managing your hair whilst having scalp cooling:

- ✓ Be gentle with your hair at all times
- ✓ Don't wash your hair immediately after scalp cooling, instead wait 24-48 hours (if you need to wash your hair immediately use cool water)
- ✓ Aim to wash your hair once a week or less
- ✓ Use gentle shampoo that is sulfate and paraben free (you can ask one of the nursing team for recommendations)
- ✓ Don't use a hair dryer or straightener
- ✓ Don't colour or perm your hair
- ✓ Use a wide tooth comb and don't over brush
- ✓ To help with tangles, use your fingers to comb conditioner through your hair. With dry hair, it helps to hold the hair above the tangles, so you don't pull on the hair roots
- ✓ Use scrunchies instead of hair ties
- ✓ Use a satin/silk pillow case





## Shared experiences

Here are some useful tips and words of encouragement from women who helped us develop this information resource

### Irene:

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*When I found out I had breast cancer, my first thought was ‘I’m going to lose my hair!’ At the time, this seemed scarier than the notion of treatment and a life of monitoring.*

*Through my research I discovered scalp cooling. A chemotherapy nurse told me that there was a chance scalp cooling wouldn’t work and that even if it did, my hair would be significantly thinner – it was a chance I was willing to take. I also obtained a wig ‘just in case’ it didn’t work.*

*Scalp cooling made my chemo much harder than it could have been, despite this, it was worth it, and I would do it all again.*

*During treatment, I felt like I was choking with the tightness of the chin strap, I couldn’t talk or eat. For the first 10 – 15 minutes, my head felt like it would explode, but then the pain eased. After each treatment I worried daily about; ‘is it working?’, ‘will I find hair on my pillow?’, ‘why is so much hair falling out when I shower?’*

*I got through 16 scalp cooling sessions and shocked everyone with how much hair I retained (see photo). My Radiation Oncologist couldn’t believe I had just completed chemo. I did lose some hair at the crown and nape of my neck and it was much thinner, however, I got through cancer treatment with the anonymity I so desperately wanted. Plus, I continued to look ‘normal’ for my two small children.*

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*Irene's top scalp cooling tips:*

- *Take strong paracetamol an hour before scalp cooling starts.*
- *For the first 10 – 15 minutes of scalp cooling, shut your eyes, don't talk and focus on your breathing. The cold and pain will pass as you get used to it.*
- *Pack a scalp cooling bag for each treatment including your own blanket, conditioner and beanie.*
- *Only wash your hair once a week and use a gentle shampoo. Wait two days after each chemotherapy session before washing your hair. No blow-drying, straightening or colouring.*
- *Sleep on a silk pillow case and use scrunchies to tie up your hair. I continued this hair care ritual months after chemo finished.*
- *Don't be scared to ask your chemo nurse about their experience with fitting scalp cooling. If in doubt, get a second opinion from another nurse to ensure your cap it fitted correctly*



**Irene, 43 years old**



## Susan:

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*A friend mentioned scalp cooling to me, so I brought up the topic with the Breast Care Nurse. I was told it was very uncomfortable and advised to take a Panadol before each session, I did this religiously. I'm not sure if the Panadol actually helped or whether it was a placebo effect... I also tried the mind over matter principle, by repeating to myself 'it's okay, it doesn't hurt'. The discomfort lasted a few minutes, then I was able to relax.*

*The process of putting the cap on is cumbersome... I also needed three blankets to keep warm. The tube which attached the cap to the machine uncomfortably rested at the back of my neck, this meant I had to turn my head to the side for the duration of the treatment. Using the bathroom was a bit of an effort as I had to wait for the nurse to disconnect/reconnect me to the machine and take off/put on the layers of blanket.*

*Scalp cooling did not stop my hair loss, but I believe it slowed down the process. The hair loss began after my second chemo session. I have a lot of hair, so initially the loss was not too noticeable. I lost hair mainly from the top of my head. I went to a concert after my second chemo session and to a family dinner after my third, no one could tell I was losing hair. However, as I progressed through the eight chemo cycles, the accumulative loss made me question the benefit of sticking with the scalp cooling.*

*Scalp cooling extended the treatment sessions and I found this the hardest to deal with. I was always the first one in and usually the last to leave. In the end, I stopped the scalp cooling for my final chemo session. By this stage, I had lost what I thought was a lot of hair and had decided that I wanted to shave my head. I felt so relieved during that last session.*

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Susan, 45 years old

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*Do I regret doing scalp cooling? No. However, if I did it again, I would probably stop as soon as I started to question the benefits.*

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## Debbie:

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*I had a friend who had gone through chemo about a year before me. She was invaluable to me through my cancer journey. It was from her I learnt about scalp cooling. At this stage, my hair was thick, wavy and medium length. I don't do cold, but I'd try anything to keep my hair. Tips I got from her were to make every effort to keep warm, have some things to keep busy, and to take a Panadol, or two, about 30 minutes prior to the treatment – I did this every treatment.*

*For my first treatment, I fronted up with everything I could think of to keep me warm; a blanket, woolly slippers, my puffer jacket, my big tea cup and tea bags. I liked having the blanket around me for comfort. I found after the initial 20 minutes or so, the cold didn't really bother me, but it was cold! Once the cap was on and the treatment started, lying back for the first 20 minutes made it easier.*

*On my first treatment I met a lady who was unfortunately going through scalp cooling and chemo for a second time. She advised me to be very gentle with my hair. To use a wide tooth comb and to only wash my hair when I had to (ideally only once a week).*

*For my last chemo, a decision was made by the nurses for me to discontinue scalp cooling as I had lost a substantial amount of hair from the top of my head. However, I wanted to go ahead with the scalp cooling, so I did.*

*In the end, I lost a lot of hair and ended up cutting it short as it was easier to manage. I wasn't as gentle as I should have been with my hair, especially earlier on. I asked my hairdresser to wash my hair and it turned into a bird's nest of a knot which pulled out a lot of hair.*

*I wore beanies while undergoing treatment, but still had something of a fringe and some hair showing. I had my last chemo in November and just before Christmas took off the beanie. After a trip to the hairdresser, I was sporting a short, curly "salt and pepper" coloured hair style. I haven't coloured or cut my hair since, and it has been very easy to manage.*

*All the best for your journeys.*

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*Take care of your hair and be gentle with it, start a hair care routine right from the beginning*

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## Further information

Video Tutorials: Video guides about fitting a scalp cooling cap, preparing your hair for treatment and caring for your hair.

<https://www.paxmanusa.com/patients/instructional-videos/>

Information for your hairdresser.

[https://www.paxmanusa.com/wp-content/uploads/2017/12/US\\_Paxman\\_Hair\\_Stylist\\_Info.pdf](https://www.paxmanusa.com/wp-content/uploads/2017/12/US_Paxman_Hair_Stylist_Info.pdf)

Hair care information: A lot of the information within this site is not relevant to the Paxman scalp cooling offered at Peter Mac. However, the **Hair Care Section** offers some great information applicable to you.

<https://dignicap.com/patient-support-center/>

## Acknowledgments

This project was a collaboration between the Cancer Nursing Research Group at the University of Melbourne and the Peter MacCallum Cancer Centre. Our thanks goes out to the many people, women with breast cancer, their family members and health professionals who generously gave their time and wisdom to this project.

## References

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