

**UK AND REST OF WORLD** 



CHANGING THE FACE OF CANCER



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So, you've decided that scalp cooling is for you. You are about to take your first big steps towards doing everything you can to retain your hair.

#### Scalp cooling can be challenging, but we are here to guide you through every single step along the way, until you complete your chemotherapy and can move on to your next chapter.

This booklet will give you all sorts of information on the different stages of the scalp cooling experience, so not everything will be relevant for you initially, but please do read it all and refer back when you need to, as this should be your first stop when you have questions or are in any doubt.

We know that an informed patient has a better outcome, so we are here to arm you with all the info you need to get the most from your cold capping.

There is also our website *coldcap.com* which is a great supportive resource, so get online and have a look.

#### Let's get started...

You are probably feeling a little apprehensive about your first treatment, so we have put together a guide on the things you need to know as a beginner.

# YOU'VE Got This!

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# A BEGINNER'S GUIDE TO SCALP COOLING

The first chemo is often the hardest as there are so many unknowns. A level of anxiety is completely normal.

This guide will help you to be as prepared as possible to face the unknown and ready for scalp cooling.

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## Watch our cap tutorial videos

Become as familiar as you can with how the cold cap should fit before your first chemo session. Getting a good fit with consistent contact across your scalp is the most important thing you can do to achieve the best possible results. If you can, practice putting your cap on. The first few times can be tricky, but the more frequently you try the process, the more confident you will be that you can achieve a good fit.

### Do your research

Get well acquainted with our website so you understand fully what to expect during your treatment. Or you might want to join our Facebook group. It's a wonderful positive community full of people who have or are scalp cooling and a great place to find advice, learn and get support. Reading the posts will give you an idea of the common problems and concerns that people face and the realities of scalp cooling.

### There are no guarantees

Scalp cooling doesn't work for everyone. It's frustrating, but it's true. It would be wonderful if you didn't have to lose a single hair while scalp cooling, but realistically that is not what is going to happen. Shedding will vary from person to person and from drug to drug. Be realistic, but positive – most drug regimens administered without scalp cooling would leave you without a single hair on your head. We would always recommend giving the cold cap a try – you have a lot to lose and potentially a lot to retain.

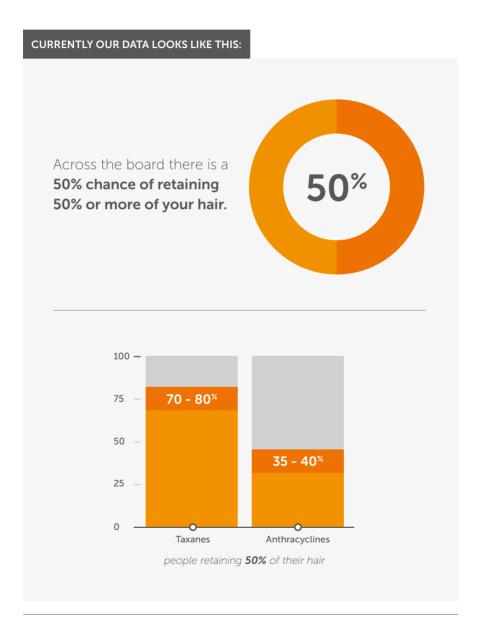
You might want to join our Facebook group.



facebook.com/groups/ PaxmanScalpCooling

## Be realistic in your expectations

The first question a lot of people want to know is how much hair they will keep. The problem is that everyone responds differently to scalp cooling, so there are no hard or fast rules about hair retention.



## Be prepared for treatment day

There are a few items that you can take with you that will make your first chemo a little more comfortable.

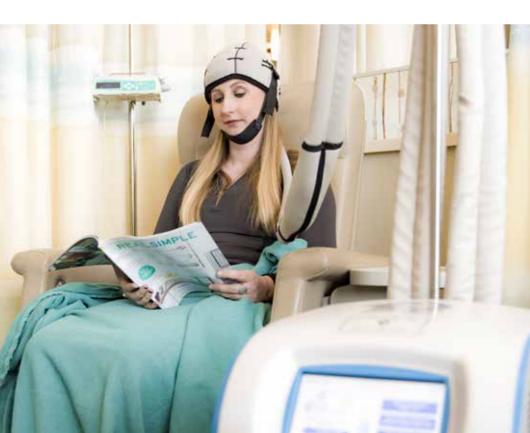
Ensure you take layers so that you can keep warm and something to cover your head for the journey home when your hair is damp (a hat or a hoodie would be perfect).

Some people like to take a neck pillow and a blanket for comfort, and something as a distraction, a book, magazine, music or a film.

Snacks can also be useful, and a supply of your favorite hot drink for before infusion.

It can be a long day, so dress to be as comfortable as possible.







### The first 15 minutes are tough

It's going to be cold! Try distraction. It sounds too simple but it can really work. Have a conversation, listen to music, watch a film, meditate, set a count down and concentrate on your breathing.

You may want to ask your clinical team for a pain killer. Soon your body will begin to acclimatise and you won't feel the cold as much. For the majority of people, it's a numb sensation for the majority of the session. If the cap isn't as cold as you thought, don't worry that the machine isn't working, not everyone finds it uncomfortable. If the system isn't cold enough, it will alert.

## Pre, infusion and post cooling stages are all at the same temperature

Don't worry if for some reason your clinical staff don't change you from one to the next. It just functions as a timer. If you need advice on how long you should be cooling for, there should be a 'Recommended Cooling Times' sheet hanging from the system.

### You can disconnect for a short period

If you need to go to the bathroom, you can disconnect from the system for up to 8 minutes. The system will then begin to alert to tell you to reconnect. Just make sure it's not in your pre-infusion cooling time, or you will have to start the cooling time again.



Try to focus on the hair on your head, not the hair you are losing."



## When you finish your treatment wait 10 mins before removing the cap

This will give it a chance to warm up and be easier to remove. Give it a little rock and if it moves easily then you can take it off. If not, give it another 5 minutes.

### Rinse out the conditioner from treatment day

Try to do this within 24 hours. If you are really tired when you get home you may want to wait until the next morning. There's no need to shampoo unless you want to, just rinse the conditioner out. The longer you leave it in, the less manageable your hair will become.

## Don't panic when your hair starts to shed

Shedding is an inevitable part of the cold capping process for everyone and will start between days 14 and 21 after your first chemo. This is completely normal, and not a sign that scalp cooling won't work for you.

For the majority of people shedding is at its heaviest between cycles 1-3, but you do need to anticipate shedding of some level throughout your chemo.

No matter how much you anticipate it, the shedding can be very scary. Try to focus on the hair on your head, not the hair you are losing; and remember, by scalp cooling you are doing everything you can to retain your hair.



# IDENTIFYING Your hair

For many people their hair is precious to them even under normal circumstances. But given that you have made the decision to give scalp cooling a try, your hair may understandably become something that you are constantly worrying about.

It is really important to tailor your hair preparation methods and hair care to ensure that cold capping is as easy and effective as possible but also to keep the hair you retain in the best possible condition so that you can move forward when your chemo is done.

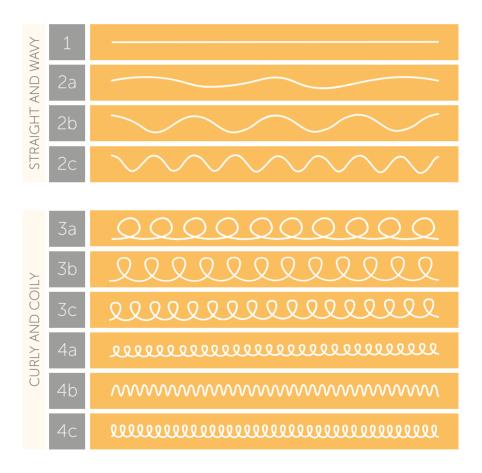
## We have developed hair preparation and hair care guides for all types of hair.

These will give you some simple advice on how to prepare and look after your hair and make the most of what you have during the scalp cooling experience.

While there are lots of similarities for caring for all hair types, there are some specific differences, so get to know the right guide and approaches for you. The image below will help you identify which hair type you have.

Remember this is based on your natural hair texture, so how it would naturally look if it was unstyled and left to its own devices when drying.

Not everyone has the same texture all over their head, so pick the one that matches the majority of your hair.



# BE PREPARED

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# HAIR PREPARATION GUIDE

It is important that you prepare your hair before you fit your cold cap on the day of your treatment.

This will help to ensure that you get the best possible results from the scalp cooling process.

It will be your responsibility as the patient to prep your hair in advance of cap fitting. Get familiar with the process, and if possible practice, so that when it comes to your treatment day you are confident in what you need to do.

#### SCAN FOR TYPE 1-2 TUTORIALS:



# HAIR PREPARATION FOR HAIR TYPES 1 AND 2 STRAIGHT OR WAVY

By prepping the hair, we are aiming to:

- reduce the volume of the hair and get rid of any air pockets which may insulate the scalp
- aid conductivity to ensure heat travels easily away from your scalp
- ensure that the cap is easy to remove once your session is finished

## Hair Types 1-2 (Straight & Wavy)

Use your spray bottle to dampen your hair. There is no specific amount of water required, as each person's hair is different, but your hair will need to be damp enough to slick your hair back, but not so it is drenched.

There is no need to dampen the lengths of your hair if it is long, just the hair that will be under the cap.

Once you have dampened your hair, push it back and away from forehead, particularly if you have a fringe or bangs, so that you can see your hairline.

Use a small amount of conditioner, about the size of a coin, and smooth over the surface of the dampened hair. You don't need a huge amount or to work it in to the hair, the conditioner is only there to aid the removal of the cap once your treatment is complete.







#### SCAN FOR TYPE 3-4 TUTORIALS:



# HAIR PREPARATION FOR HAIR TYPES 3 AND 4 CURLY OR COILY

There are a range of options that you can choose from to prep curly or coily hair. It is up to you which method, or combination of methods you think will work best for you. If you can, try experimenting with prepping your hair ahead of their treatment.

By prepping the hair, we are aiming to:

- reduce the volume of the hair and get rid of any air pockets which may insulate the scalp
- aid conductivity to ensure heat travels easily away from your scalp
- ensure that the cap is easy to remove once your session is finished

## Parting/sectioning the hair

Spreading the hair evenly across the scalp is important to achieve an even cooling process. Sectioning or parting the hair is the easiest way to achieve this with thick hair.

- Section the hair at the crown in to 4 or more sections.
- Sectioning your hair can also aid in distributing water and conditioner through your hair.













### Possible ways to part your hair...







## **Using Water**

Using water in hair prep is important to aid conductivity, allowing heat to more easily leave your scalp. Though, of course, adding water to type 3 and 4 hair is more likely to make it curlier and more voluminous.

- Option 1 for adding water work a thick conditioner through the hair, then add some water with a spray bottle to create an emulsion, this can allow you to slick down your hair.
- Option 2 for adding water get the hair wet, then add conditioner. If your patient has high porosity hair, it may be challenging to keep their hair wet, but the conditioner will help to retain the moisture.

Note: Whichever option you use, ensure that you are using the water at the roots of the hair.



## **Twists or braids**

- Small and loose twists or braids can be another way of getting your hair as flat as possible if smoothing your hair flat is not an option.
- Braids or twists should be done lightly (avoiding any tension at the roots) allowing them to compress under the cap- this will avoid dense sections of hair that might block the scalp.

If an elasticated headband is available position below each ear and on the forehead to create a barrier between the cap and the patient's skin. This will reduce the discomfort.













# PATIENT **Stories**

Hearing from other people who have been through the scalp cooling process can be really helpful.

#### Read the full stories: coldcap.com/stories



I drove the nurses daft for my four-hour session, asking them to check the cold cap was working. I hardly felt anything! The first few minutes were a little cold but after that, nothing.



The thing I was most distraught about was losing my hair. It wasn't necessarily even looking odd during the weeks of chemotherapy, it was the prospect of having to wait years before I looked like myself again.

> I could go out with family and friends and still look the same as normal.

(1)



# YOU'RE **READY TO GO!**

You should now be ready for your first treatment, even if it doesn't feel like it.

Once you've got through the first one, believe it or not, you have probably got through your toughest cycle and jumped the first hurdle.



# BE KIND TO Your hair

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# THE COMMON-SENSE GUIDE **TO COLD CAP** HAIRCARE

It is really important to tailor your haircare to your hair type.

> This guide is for: HAIR TYPE 1-2

If you have straight or wavy hair, please watch our 'Hair Prep for type 1&2 hair' video in advance of your first treatment.



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### Don't wash your hair more than twice a week or less than once every 10 days

For some people this may be very daunting, particularly if you are a daily washer. Keep in mind though that a common side effect of chemo is a drying effect on your hair and scalp skin, and washing very frequently will contribute to and exacerbate this.

Even if you currently wash your hair every day, your scalp adapts quickly and you shouldn't find your hair to be too greasy once your treatment is in full swing.

It is however important to keep washing your hair regularly, even if it's once a week and especially if you are shedding heavily - keeping your hair and scalp clean and manageable is crucial.

Washing has the added benefit of liberating hairs that are in the process of shedding, which can be terrifying, particularly if you are shedding quite a lot and you find the shower drain full of hair. But it's really important to remember that washing will not cause hairs to fall out that weren't already in the process of shedding.

In conclusion, you know your hair best be open minded and follow your instincts, you'll find out what works for you.

# Use color, perfume and sulfate free shampoo and conditioner

It doesn't matter which brand you use if it fits these criteria. They are all ingredients that can act as irritants, even if you were perfectly fine with them before you started treatment.

Chemo will most likely cause your scalp to become very sensitive and sometimes itchy, and your hair to become dry, so these ingredients are best avoided. Also avoid baby shampoo as it is very alkaline, and not gentle enough for a sensitive scalp. It's often suggested as an option, but we know that it has caused people problems in the past.

Try to avoid parabens too, as they are believed to disrupt hormone function by mimicking oestrogen.

# Smooth shampoo and conditioner into your hair, don't rub

Piling hair on top of your head and massaging in shampoo is all very well and good in adverts, but it's a one-way street to tangled, matted hair while cold capping.

Smooth shampoo and conditioner in and run your fingers through your hair, but avoid at all costs the circular rubbing motions you may be used to.

## Brush your hair everyday

This may seem counter intuitive, especially if you are experiencing heavy shedding, but it is SO important to liberate any shedding hairs.

Brushing morning and night will not pull out any hairs that weren't already shed, but will ensure that loose strands, and hairs that are in the process of dropping will be removed, making it significantly less likely to tangle and even mat.

It will also help to brush before you wash your hair too.

# Feel free to use headbands, clips, hats, scarves etc

Accessorize to your heart's content! You can be creative to hide patchy baldness, or thinning with whatever works for you, just avoid tension at the roots, so no tight ponytails etc.

For those with long hair a braid or low bun can be a good solution, for those with shorter hair, pin back front sections of hair, or a soft head band can be great.

## Avoid heated styling

Using straighteners, flat irons or a curling wand, can have a further drying effect on already dry hair, not to mention the tension that it can put on the roots of your hair. It is fine to use your hairdryer on a cool setting, but use your hands and fingers rather than a brush, again to avoid tension at the roots.

# Dry shampoo and coloured root sprays are fine

Always test first to be sure of no scalp sensitivity, but using dry shampoo if you are having a bad hair day, or coloured fibres or root spray to cover patchy hair loss is just fine. Though try to avoid using so much that there is a build-up in your hair.





## Be kind to your hair and yourself.

Most importantly, try not to worry too much. If you follow the above guidelines, and your own instincts you will be just fine.

This is a tough road, but know that you are doing everything you can to retain your hair.



# BE KIND TO Yourself

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# THE COMMON-SENSE GUIDE **TO COLD CAP** HAIRCARE

It is really important to tailor your haircare to your hair type.

This guide is for: HAIR TYPE 3-4

If you have curly or coily hair, please watch our 'Hair Prep for type 3&4 hair' video in advance of your first treatment.



# Wash your hair less frequently than normal

Chemo has a real drying effect on your hair and scalp skin and you will probably quickly begin to notice that your hair doesn't require washing as often. It is important to keep washing your hair regularly though, especially if you are shedding heavily - keeping your hair and scalp clean and manageable is important.

Washing has the added benefit of liberating hairs that are in the process of shedding, which can be terrifying. But it's really important to remember that washing will not cause hairs to fall out that weren't already in the process of shedding. You know your hair best - be open minded and follow your instincts, you'll find out what works for you.

# Smooth shampoo and conditioner into your hair, don't rub

Piling hair on top of your head and massaging in shampoo is all very well and good in adverts, but it's a one-way street to tangled, matted hair while cold capping.

Smooth shampoo and conditioner in and run your fingers through your hair, or alternatively mix some shampoo with a little water and pour over your hair to get right in to the scalp. At all costs avoid the circular rubbing motions you may be used to.

# Use plenty of conditioner and natural oils

Chemo is going to really dry your hair out so use plenty of conditioning products to keep your hair as manageable and healthy as possible.

Use lots of conditioner when you wash, spray in conditioner whenever you fancy, and natural oils such as vitamin E, grape seed or argan oil. Just avoid oils the day before your treatment as it will make it harder to wet your hair in preparation for the cap.



# Use color, perfume and sulfate free shampoo and conditioner

It doesn't matter which brand you use if it fits these criteria. They are all ingredients that can act as irritants, even if you were perfectly fine with them before you started treatment.

Chemo will most likely cause your scalp to become very sensitive and sometimes itchy, and your hair to become dry, so these ingredients are best avoided.

Try to avoid parabens too, as they are believed to disrupt hormone function by mimicking oestrogen.

# Really wet your hair before putting on your cold cap

You may need some help from a friend or assistant if you have really thick hair, but it's important that you really get water through to the scalp and ensure that you get as much volume out of your hair as possible to get a good fit with your cap.

Make sure you get your hair as wet as needed to get it as flat as possible, then smooth conditioner over the surface. It is also important to wet your hair when your cap is sized, to get an accurate fit. If during your treatment you do shed quite a bit you may also want to consider going down a cap size to achieve a better fit as your hair volume may have reduced.

## Avoid all heated styling

Using straighteners, flat irons, blow dryers or a curling wand can have a further drying effect on already dry hair, not to mention the tension that it can put on the roots of your hair. No matter how tempting it is, try to avoid.

### Use a scarf, loose band or hat to keep your hair away from your face

They will keep your hair back without adding tension to your roots. A soft fabric head band or combs can also be great. Avoid clips, pins or tight ponytail bands as your hair is likely to tangle around them.

# Brushing your hair is really important

This may seem counter intuitive, especially if you are experiencing heavy shedding, but it is SO important to liberate any shedding hairs to avoid knotting and matting. Use a wide tooth comb or curly hair detangling brush and brush through thoroughly but gently while it is still wet after you have washed it. Every 2 days, dampen your hair (with water or spray in conditioner/ detangler) and brush thoroughly.

On in-between days make sure that you finger comb your hair. Brushing or finger combing gently but thoroughly will not pull out any hairs that weren't already shed, but will ensure that loose strands, and hairs that are in the process of dropping will be removed, making it significantly less likely to tangle and mat.

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## Be kind to your hair and yourself.

Most importantly, try not to worry too much. If you follow the above guidelines, and your own instincts you will be just fine.

This is a tough road, but know that you are doing everything you can to retain your hair.



### Don't use dry shampoo but coloured root sprays are fine

Dry shampoo will clog your follicles. But coloured root sprays are fine and can be a really simple way to hide roots or cover patchy hair loss. Always test first in case it causes problems with scalp sensitivity, though try to avoid using so much that there is a build-up in your hair.

## No braids or weaves while scalp cooling

The additional tension on the roots of hair can be detrimental to hair retention. Similarly, relaxing should be avoided too, firstly because the chemicals on a sensitive scalp should be completely avoided, but also because it will cause further drying to your hair. It is no problem to wear a wig if it makes you feel more comfortable, but again, avoid additional tension or friction on the roots of your hair.



# WE ARE HERE TO HELP

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## COLD CAPPING PROBLEM SOLVING AND TROUBLE SHOOTING

Problems come up and there can be bumps in the road often for no reason whatsoever.

But where there is a will there is a way, and we are here to help.

In theory, if you are following our guidance on the treatment days and the haircare advice for your hair type, then it should just be a case of getting on with it and counting down your remaining treatments.

If only it was that simple!

Here's some problem solving and troubleshooting information.

If anything these things are common, we see these issues every day, so please remember that you are not alone and you can get through this.

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## **Cap Fitting**

A good cap fit is crucial to achieving the best possible outcome. Please get as familiar as you can with our cap tutorial videos, they walk you through the fitting process and give you guidance on what a good fit should look and feel like.

If you have followed these steps and are still encountering issues, you may find the following helpful.

## Changing cap size

You may find as you progress through your treatment that the fit of your cap changes. If you started with particularly thick hair and have lost quite a bit of hair, you may find that your cap is now too large and you may wish to try a smaller size. Speak to your clinical team about this.

### Tenting of the cap cover

This can happen when the cap cover isn't pulled down sufficiently.

Once you have the inner and outer caps on, make sure that you are pulling the cover firmly down before you tighten the bungee cords. Get your thumbs up inside the cap cover and methodically pull the cover down from the front to the back, and don't be afraid to use quite a bit of force.

Once the cover is pulled down you can also use your palms to smooth the cover from the crown downwards. Remember that the cover doesn't need to be completely smooth (for some people there may be some lumps and bumps in the cover), it is just there to ensure that the bungee cords can do their thing, which is to give a consistent all over pressure to the inner cap.

It is also important that you loosen the bungee cords properly at the end of treatment to prevent the cover from warping during storage.

### Chin strap

We know that the chin strap can be problematic, but this is more often than not a result of it being over tightened.

To get the best possible fit from your chin strap, firstly make sure that it is actually on your chin, not underneath it or on your neck.

Secondly, it is important that the chin strap is pulled very tight, but this is just while you adjust the bungee cords on the outer cap cover. Once this is complete the strap can be loosened, so that it is still secure, but certainly not so that it is tight enough to cause pain, or to prevent you from eating or drinking.

Some patients who had an uncomfortable experience with the chin strap found adding some form of padding to be helpful. Some people have used a sleep eye mask or even a fluffy sock.



## **Realistic expectations**

Everyone responds differently to scalp cooling, but it is important going into your treatment to know what realistic expectations are for you. There are all sorts of factors that can affect hair retention and outcomes including your drug regimen, dosage and how frequently the chemotherapy is given, as well as overall health and hair condition.

We would recommend that you spend some time on our website and look at our hair retention guide and the outcomes of other patients that have had similar regimens to you; this will give you an idea of what success could look like for you.

What can make the difference between disappointment with your outcome and feeling that you have had success can be a positive attitude. Try to remember that without scalp cooling it is quite possible that you would have lost most, if not all of your hair. It is not an easy road to travel down, but by scalp cooling you are giving yourself the best possible chance to retain your hair.

Don't be afraid to reach out to others. There's a community of people who are going through the same things as you are on our Facebook Group, and there may be a support group at your treatment centre or in your local area.

The help, guidance and support of others can make such a difference – you don't have to do this on your own.

There's a community of people who are going through the same things as you are on our Facebook Group.





## Prepping your hair

Prepping your hair effectively before scalp cooling will help to achieve the best possible outcome. When prepping the hair, you are aiming to achieve the following –

- reduce hair volume allowing for the best possible fit
- aid conductivity allowing heat to travel away from your scalp as easily as possible
- ensure easy removal of the cap after your treatment

There are different ways to prep your hair depending on your hair type – one approach for those with straight or wavy hair and another approach for those with curly or coily hair. These methods are explained in our tutorial videos, please take some time to study these videos ahead of your first treatment day to ensure that you are familiar with the process. This is particularly important for those with type 3 and 4 hair as you may need to try the methods in advance to see what works best for you.

If you have thick hair, regardless of hair type, you will need a pre-cooling time of 45 mins rather than 30 mins. This will allow extra time for your scalp to cool to the optimum temperature before infusion of chemotherapy drugs begins.



## Discomfort for the first 15 minutes

The first 15 minutes of scalp cooling can be really tough for some people but generally after this time your body will acclimatise and you will stop feeling discomfort and may just feel numb. There are a few things that you can do to help to increase tolerability in those first 15 minutes and for the whole of your scalp cooling experience.

## Protect your forehead

Your forehead is full of nerve endings, and having the inner cap making direct contact with your forehead will be uncomfortable to say the least. The inner cap only needs to be around 2mm below the hair line, but by using a soft stretchy headband, gauze or cotton pads, you can protect your forehead and make the cap a lot more comfortable.



## Don't be afraid to ask for something that could help with the discomfort

Your clinical team are there to support you, so don't be afraid to ask for something that could help with the discomfort, at the start of your scalp cooling session. Such as a blanket or a pillow and an appropriate painkiller. It can help to make the first 15 minutes a lot more doable.

## Distraction

It sounds way too simple, but distraction can really help for that first difficult period. Do whatever might work for you, but some patients have listened to music, watched a film, chatted to someone or even meditated.

Deep breathing can also really help with the initial stages of scalp cooling. The benefits can include immediate relaxation as well as an improved ability to handle stress and calm down. You'll be so surprised how different cold capping feels after that first 15 minutes, so please stick with it.

It sounds way too simple, but distraction can really help for that first difficult period.









## Infusion times

The scalp cooling process comes in 3 stages which are timed by the system. The system will be operated by a trained member of clinical staff, but all of the stages happen at the same temperature. The change in stage acts like a timer rather than a change in setting for the system.

### 1. Pre-infusion cooling:

This lasts for 30 mins, or 45 mins if you have thick hair. This allows your scalp to reduce in temperature to the optimum temperature for hair retention.

### 2. Infusion cooling:

This stage is for the length of the infusion of alopecia inducing chemotherapy drugs. If you are receiving chemotherapy drugs that don't induce alopecia, or any other drugs, these can be infused during the post-infusion or pre-infusion cooling stages.

### 3. Post-infusion cooling:

This is the only stage of cooling that has any variation depending on drugs. If you are receiving single agent docetaxel (Docetaxel/Taxotere on its own) then you will need 20 minutes post-infusion cooling.

If you are receiving single agent weekly taxol (Taxol/Paclitaxel on its own) then you will need 60 minutes post-infusion cooling.

For all other drugs and any drugs used in combination, you will require 90 minutes post-infusion cooling.

Our Recommended Cooling Times sheet can be found on our systems.

The post infusion cooling times are based on the half-life of the drugs you are receiving. This is the amount of time that the drugs are at their most potent and will have the most effect on your body.

# What if I miss some of my pre or post-infusion cooling times?

It is possible that this will affect your hair retention. It will depend on how much time was missed, and when the time was missed and the drug you are receiving.

If you have to break the pre-infusion cooling time for some reason, it is important to start the 30 minutes again from the beginning. If the drugs are infused before your scalp has reduced to the appropriate temperature, it is quite possible that chemo will target your hair follicles and hair loss may occur as a result.

If you miss some or all of your postinfusion cooling, it is again possible that you could lose some hair. If your scalp warms up while the chemotherapy drugs are still at their strongest in your system, then it could compromise your results. There is no real way of knowing what will happen in terms of hair retention, so prepare yourself for the worst, but hope for the best.





## Patchy hair loss

Shedding and hair loss is a part of scalp cooling. It will vary in quantity from person to person, often depending on drug type and dosage, and will come in two forms - thinning or patchy hair loss. Thinning is loss of hair consistently across the scalp, patchy hair loss is where shedding happens in specific areas.

Patchy hair loss can occur for a number of reasons, and is most common at the crown. It can be because of cap fit issues as a result of the inner cap not making sufficient contact with the scalp - if your cap is too small you may see loss at the crown, if the cap is too large you may see hair loss at the back of the head.

There are over 100,000 different head shapes across the globe, and we have designed our caps to be the best fit possible for the majority of people, but for some people the cap just isn't quite the right shape for them, and this can result in patchy hair loss.

Loss at the crown can also happen regardless of how well the cap fits as the crown is the hottest part of the head, meaning that in some people this area of the scalp just won't cool down to the optimum temperature for scalp cooling.



## **Hiding patches**

There are a few ways that patchy hair loss can be successfully hidden.

Most simply, depending on the location of the patchy loss, you can use your retained hair to cover up noticeable loss. There are lots of way to do this from changing your parting, to clipping, pinning or tying back hair over affected areas. Don't be afraid to experiment. As long as you're not putting tension on the roots of your hair, there may be a simple way that works for you.

Accessories such as wide soft headbands and scarves can also be useful at hiding hair loss at the crown and top of the head.

Another option would be to use colored hair fibres which are widely available online. This approach is particularly effective for hair loss and thinning at the crown, and you'd be amazed what can be hidden with these little fibres.

## Continuing to scalp cool after patchy hair loss has occurred

A lot of people are told that they should discontinue using the cold cap if patchy hair loss occurs. This simply is not the case, if you don't want to stop you don't have to.

We would recommend covering any exposed areas of scalp to prevent direct contact with the inner silicone cap, as this will make the experience significantly more comfortable.

If you can, rearrange your retained hair to cover any exposed scalp. You can also cut gauze to size and cover any exposed areas, and if you have quite extensive hair loss, a disposable theatre or surgical cap could be a good idea. Your clinical team should be able to provide you with gauze or a cap, but if not, they are both readily available online.

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There is no real way of knowing what will happen in terms of hair retention, so prepare yourself for the worst, but hope for the best.

## Knotting, tangling and matting

Chemo has a very drying effect on your scalp and hair, which can mean your hair can become difficult to care for while you are scalp cooling. Dry and damaged hair (particularly if it is colour treated or bleached) is particularly susceptible to tangling, and when your hair is also shedding a small tangle can quickly become a knot or even a mat.

### There are a few simple things that you can do to avoid this situation:

- It is really important that you brush (if it is straight or wavy) or finger comb (if it is curly or coily) your hair every day, preferably in the morning and in the evening. This will remove loose strands of shed hair, which if left in can become tangled and knotted in with your retained hair.
- When washing your hair avoid circular lathering motions, and absolutely do not pile your hair on top of your head and rub, like you see in shampoo commercials. The dryness of your hair in combination with the shampoo and friction can be a one-way street to matting. Smooth shampoo and conditioner through your hair, and try to be as gentle as possible.
- Use lots of conditioner and spray in conditioner or detangler can help too. Try to keep your hair in the best possible condition, as it will make it a little easier to care for during the scalp cooling process, and make sure that your retained hair is as healthy as possible going forward.
- Try a silk pillow case or sleep cap. Silk will cause less friction on your hair than cotton as you sleep, and will help to prevent knots from forming.
- If your hair is long and in bad condition it may be worth considering cutting it to shoulder length or into a bob, as this can make it a lot easier to manage.
- Sometimes, no matter how careful you are, knotting can happen. Often with patience, a lot of conditioner or oil and some help, these knots can be detangled.
- It is often easier for a friend or hairdresser to work on the tangles as they can see what they are working on. Use a pure natural oil such as olive, argan or almond or conditioner and a detangling brush or comb and start at the bottom of the hair.

Slowly and methodically try to detangle the hair. When you start to make some progress, you can move further up the hair. It may be that snipping the worst affected areas may be necessary, and if the hair has matted and fused together there may be no choice but to cut it out. Be patient, it can take a lot of time, and it is always worth trying before resorting to cutting.

## **Extensive hair loss**

For some people, extensive hair loss is something that they have to deal with when scalp cooling. Certain drug regimens can be very harsh on the follicles, which can result in hair loss quickly, or over several treatments.

We would always encourage anyone who has experienced extensive hair loss to continue scalp cooling. We have clinical data to show that by continuing to use the cold cap and protecting your follicles, regrowth is stronger, healthier and faster. Do remember to cover any exposed scalp.

For more info see 'patchy hair loss'.

To shave or not to shave?

For many people with patchy and extensive hair loss, dealing with different lengths of hair can be very challenging. Do what is best for you, but we would encourage you to be as patient as possible and wait until you see regrowth before you cut your hair. It's amazing how quickly regrowth can make a style viable, when a few weeks before it wasn't. You may be able to have a short bob or a pixie, rather than having to regrow everything from scratch.

Topper and wigs are always an option. It may be worth a trip to see an experienced wig seller. Explain your situation and they may be able to give you some amazing solutions to work with the hair you have.

## Cutting hair mid treatment

It is no problem at all to have a haircut or trim whilst you are mid treatment. Make sure you go to an experienced hairdresser, and explain your circumstances.

You may feel more confident having a dry cut, and asking them not to style your hair at all. People often find that having thinning ends cut off leaves their hair looking thicker and healthier, or going from longer lengths to shorter increases manageability. Be open minded, and don't be afraid to adapt your hair in a way that makes things easier for you.



# YOU'VE MADE IT!

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## POST SCALP COOLING HAIRCARE GUIDE

Take a moment to celebrate that you not only finished your chemo, but that you did it all and you scalp cooled.

That's no small feat. You are made of strong stuff! But what can you do with your hair now?

There's lots of questions that inevitably come from getting to this marvellous point. We've answered the most common ones in this guide.

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## You've made it through scalp cooling, so what now?

### Shedding can continue for some time

Don't expect the shedding to stop on the final day of your chemo. It can take a while for the drugs to work their way out of your body, and many people will continue to shed for a number of weeks. If you are getting past the two month mark, it might be worth speaking to your doctor, as additional factors (such as low haemoglobin/anaemia) can cause hair loss.

Regrowth is stronger, faster and healthier with the cold cap

You have done everything you could to ensure the best possible regrowth. Depending on the drug regimen, some people will see regrowth before the end of their chemo, for others it can take a little while. But it does come. There will be fluffy new hairs sprouting before you know it. And it is pretty common to see shedding and regrowth at the same time.

## Losing brows and lashes post chemo

This is really common. They hold on throughout chemo and then when you've finally finished they all drop out. Cruel beyond belief! The good news is that they tend to grow back very quickly, but be aware that losing brows and lashes is a possibility.



## Don't make a snap decision and cut your hair off

Lots of people get through scalp cooling then feel like they can't handle a combination of patchy hair loss, retained hair and regrowth.

But try to be patient for a little while before going for a style change you don't really want. You'd be amazed how quickly hair can grow back in and what all of a sudden works as a style option again. A bob may be possible rather than a pixie crop etc.

## What's normal shedding?!

After focusing on your hair so intensely, it can be easy to forget what 'normal' shedding looks like.

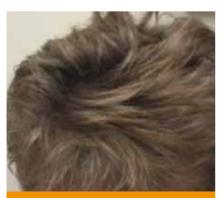
The average healthy person will lose around 100 hairs a day, which is quite a lot really. There may not be a lightning bolt moment where your hair suddenly stops shedding, but you may get to a point where you just don't notice it so much, which means you are probably back to your normal.



Before Chemotherapy Grade 0 Alopecia



After 3-4 weeks and 4 cycles of Chemo Grade 1 Alopecia



Before Chemotherapy Grade 0 Alopecia



After 3 weeks and 2nd cycle of Chemo Grade 2 Alopecia

## Return to your normal hair care routine once shedding stops

Once you reach normal shedding you can go back to standard products and use heat styling tools again. Just be gentle and go carefully, as your scalp may still be sensitive.

You should also be mindful that your hair may now be much drier and more fragile than it was before chemo, which may mean you need different products than those you used before.

If your hair is really dry you should avoid straighteners and curling tongs until your hair is in better condition.

### Any retained hair is often very dry

It's time to start focusing on improving the condition of your hair. Try masks, deep conditioning treatments or oils. Give it some love!

You may also see an improvement if you get a trim to remove any really damaged hair. Hang on in there, it will get better.

### Be careful when it comes to dying your hair

A lot of people are desperate to get rid of roots or greys, but you may want to take your time. You certainly shouldn't be dying your hair before shedding returns to normal and ideally you would be waiting another couple of months after that.

If you do decide to take the plunge, please follow the advice of an experienced hairdresser. They will be able to tell you if your hair is in good enough condition, and it is imperative that they patch test ahead of time.

# THERE IS SUPPORT

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## COLD CAPPING SUPPORT

If you have questions that aren't answered here, or you are just looking for more support and advice, please do not hesitate to reach out.



First of all, our website is a brilliant resource full of information. Please do get to know coldcap.com



If you want to speak to people who are going through the same thing as you, and tap into an international positive community who have wisdom, support and advice in abundance, then our Facebook Group could be for you.

It is private and full of people who know exactly what you are going through because they are facing it themselves.



If you want more information on haircare and would like to read in more detail, our Cold Cap Haircare blog could be exactly what you are looking for.

There is lots of advice in the form of posts and video as well as in-depth information on the science of hair and scalp cooling and guest posts from experts.



And last but not least, we are always here and would be delighted if you got in touch. If you'd like to reach out directly to us, you'll find all our contact details at the back page of this brochure. There may also be someone that you can speak to at your center for support throughout your treatment.

## **CONTACT US**

Please feel free to drop us a line, we would love to hear from you...



We would ask that you visit our websites as your first port of call, but if you can't find the answer to your questions, or would like to speak to a member of our team, please send an email to *info@paxmanscalpcooling.com* or call +44 (0) 1484 349444



If you want to share your scalp cooling journey, head to our website.

# ENJOY!

You've made it to the other side of scalp cooling.

Celebrate you.

## #CHANGING **The Face** Of Cancer







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CHANGING THE FACE OF CANCER