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BRIEF STVINCENT

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# COOL HEAD

For many cancer patients dreading hair loss while going through chemotherapy, “scalp hypothermia” treatment is a profound game-changer.

**I**T'S A bright, hot day. Outside, the city is baking; through a window I can see a cloudless blue sky. But I am inside, shivering, covered with blankets and hugging a heat pack.

Jammed tightly over my wet hair, secured with a chin strap, is a silicone cap filled with liquid circulating at -4 degrees Celsius. The pain is excruciating – like a frozen clamp screwed tight around my skull. Bits of white gauze have been tucked under the edge of the cap so it doesn't burn my skin, and I've had painkillers, a sedative and chocolate.

Still, it hurts. I desperately want to take the cap off. But I desperately need it to stay on, too. And the truth is that despite the pain, I am overwhelmingly grateful for every agonising second the cap is on my head. Without it, each strand of my long brown hair would drop from its follicle within a few weeks.

JUST WEEKS earlier, I'd been sitting in a doctor's white office, staring dumbly at medical scans and trying to come to terms with an unfathomable new reality.

I am 38, with two small children, a busy job and a lump on my breast that is barely noticeable. But it turns out there are more lumps waiting to be found; another in the breast, and more under my arm. They are not benign.

I am told that my situation is curable. But getting to that point will require months of treatments: chemotherapy, radiation, surgery and the targeted therapy Herceptin. Chemotherapy, I learn, will be first. I will start in a couple of weeks.

Hesitantly, my mind starts ticking over, as I try to process this new information. Chemo, I think. That's meant to be dreadful, I think. And then I remember one of the reasons why.

As awful as my diagnosis is, I can comprehend and accept it. But the thought of my hair falling out feels like a punch to the stomach. It makes no sense to me that treating my illness should cost me my hair. It feels like a punishment, or a curse.

I am a cancer patient, but I do not want to *look* like one. My situation is piteous, but I do not want to be pitied. I want to stay unremarkable and anonymous as I go out into the world. I want to stay myself in front of my children, family and friends.

My littlest child has just started to say and point to “hair”. Her older sister has started drawing our family as stick-figures; I am the one with the big smile and the long brown scribbles on my head.

My sister-in-law – while scrolling through her Instagram feed – remembers a friend of a friend who'd had cancer treatment the year before. The woman kept her hair during chemo with something called “scalp cooling”. I scoff, but look at the photos taken during treatment. In them, she does indeed have hair.

It turns out that my oncologist knows all about this scalp-cooling process and will send me to a hospital that offers it. But there are several catches. First, it will be uncomfortable, perhaps painful. Also, the hair will still thin out – possibly a lot. But the last, and perhaps most significant caveat, is that it might not work for me at all.

IT SOUNDS implausible, but in some parts of the world, it's been known for decades that “scalp hypothermia”, or scalp cooling, can reduce or even prevent the hair loss that comes with chemotherapy.

For the technique to work, the scalp must be kept cold during every chemo infusion – and for a period before and after the drugs are delivered. Various methods of achieving this have been tried over the years. Research papers published in the US in the 1970s reported success using chilled air or cryogel packs. By the 1990s, systems using ice or gel packs strapped to the head were common in the UK and parts of Europe. These systems required the packs to be changed every half hour, and their success was variable, say doctors and nurses who saw them in action.

“[It was] literally cold packs and crepe bandages,” remembers Melbourne oncologist Richard de Boer, who worked in London as a young doctor during the 1990s. De Boer was used to seeing breast cancer patients suffer complete hair loss, but some of his patients kept some hair. “Not great,” he says. “But the scalp cooling clearly worked to an extent.”

In Australia, it was almost unheard of. Former oncology nurse Jane Bartlet says patients who asked about scalp hypothermia during the 1980s and the 1990s were often given the brush-off and told it didn't work.

After returning to Australia, de Boer remembers raising it with other medicos. “They would say, ‘Oh, it's a waste of time, it doesn't work, don't bother, it's not worth it,’” he says. “And I'd say, ‘Well, it sort of *does* work.’”

But by the 2000s, at least two companies were producing systems that could stay reliably, but bearably, cold. Both employ high-tech cooling units to pump chilled liquid through silicone caps. “What has happened,” de Boer says, “is that the technology has caught up.”

There's the DigniCap system, developed in the early 2000s by a Swedish oncology nurse; produced by listed Swedish company Dignitana, the DigniCap is widely used in Europe. Then there is DigniCap's English rival, the Paxman system, which is made by a family-owned company based in West Yorkshire. It was developed by Glenn Paxman and his brother Neil after Glenn's wife Sue – a mother of four aged in her 30s – was diagnosed with metastatic breast cancer in 1992. She lost all of her curly blonde hair to chemo, despite trying the scalp-cooling techniques available at the time.

The Paxman brothers re-purposed techniques from the family refrigeration business, which specialised in beer cooling, to produce their first prototype in 1997.

Sue Paxman died three years later. “She was a great person, a special lady,” says her son, Richard Paxman, who is now the chief executive of the scalp-cooling company. Today, there are about 2500 Paxman units in use around the world, with about 80 per cent of UK hospitals – both public and private – having at least one. In the Netherlands, almost 90 per cent of hospitals offer scalp cooling.

Australia has been slow to catch on. The first of the modern units arrived here in 2012; but even two years ago, there were still only a few hospitals that offered

BY *Ruth Williams*



it. Now, close to 80 machines are in operation across 50 to 60 hospitals, most of them in the private system. Paxman dominates the market, accounting for about 60 of those 80 machines in use.

In Australia, as in the UK, scalp cooling is offered free of charge to patients where it is available. In the US, patients – or, if they're lucky, their health insurers – pay up to \$US3000 (about \$4000) for a course.

The availability of scalp cooling in Australia remains patchy, especially outside Sydney and Melbourne, and in the public hospital system. According to experts who spoke with *Good Weekend*, the treatment is now offered at somewhere between 38 per cent and 50 per cent of decent-sized chemo units.

Still, hundreds of Australians – and by one estimate, more than 2500 – have saved their hair by using the technique. “It is gaining significant momentum,” says Bill Houghton, who sells Paxman units in Australia through Regional Health Care Group.

Both Houghton and Bartlett – who sells the DigniCap system in Australia through Aurora BioScience – say this is in large part due to increasing awareness and demand from patients. “In the old days, people used to come in and they did what they were told,” Bartlett says. “Now, everyone has a choice about all sorts of things, and that’s a good way to be.”

NO ONE quite knows why scalp hypothermia works, though there are theories. One is that it constricts blood vessels in the scalp, reducing the flow of blood and the chemo drugs along with it. Another is that the cold slows down the rate of cell division in hair follicles, making them less of a target to the chemo agents, which home in on fast-growing cells. What is known is that, for the process to work well, the scalp must be cooled to below 22 degrees Celsius – and to achieve this, the cold cap needs to be very cold indeed. For this reason, the fit of the cap is crucial.

When I arrive, jittery and anxious, for my first round of chemo, the nurses give me a spray bottle to wet my hair and some towels. Then the cap-fitting process begins.

My hospital uses the Paxman system. The aim is to have the cap sit as close as possible to as much of the scalp as possible. If the cap is too tight around the side of the head, it will rise up and not sit properly on the top. If it’s too loose, there won’t be enough contact around the sides, and bubbles will form.

When the silicone cap is in place, an outer neoprene cap with a chin strap is pulled over it. Plastic clips secure the outer cap more tightly still. It’s a fiddly, time-consuming process. The cap is then attached via a hose to its cooling unit, about the size of a wine fridge. As the cap fills with cold liquid, a chill begins at the crown and creeps out to the sides. An intense headache spreads with it. But after a while, perhaps 20 minutes, the pain plateaus, then fades – perhaps the meds are working, or perhaps my head is just numb.

The cap goes on about half an hour before the drugs go in, remains in place as the chemo is delivered, and stays on for at least an hour after. When the nurses finally remove the cap, there are tiny icicles in my hair.

I take this as a good sign.

**H**AIR LOSS – or chemotherapy-induced alopecia, to use its medical term – has long been seen as an unfortunate, but unavoidable, part of life-saving cancer treatment. Cancer patients, so the thinking

A Paxman unit at western Sydney’s Campbelltown Hospital, the first NSW public hospital to offer scalp cooling.

goes, have much more important things to worry about than how they look.

“[Hair] has always been seen as something that will grow back,” says Professor Fran Boyle, oncologist at the Patricia Ritchie Centre for Cancer Care and Research at North Sydney’s Mater hospital. “That completely underplays the impact it has on the patient, which is not, fundamentally, about vanity. It’s about identifying you, in a very public way, as a cancer patient. You lose control over who *knows*.”

Hair loss consistently ranks among the most-feared side effects of chemo. One study found that for some breast cancer patients, the loss of their hair was more distressing than losing a breast. A 2001 study reported that up to eight per cent of patients may actually refuse chemotherapy to save their hair.

has largely put these fears to bed. “All of the data that we have got so far says it is not an issue,” Boyle says.

Not every chemo drug results in hair loss, but pretty much every modern chemo cocktail used to treat breast cancer – as well as prostate cancer – contains at least one that does. These include the class of chemo drugs known as the taxanes, derived from the toxic bark of yew trees of the *Taxus* genus. The drug Taxotere belongs to this class. Then there are the bacteria-derived anthracyclines, the most notorious of which is nicknamed “red devil” for its crimson hue and hellish side-effects.

The recently published results of landmark US trials show that scalp cooling prevented significant hair loss – regarded as loss of more than 50 per cent of hair – in at least 50 per cent of patients. The research also found that the discomfort of the process was mostly well tolerated.

But that 50 per cent figure obscures some intriguing details about which patients scalp cooling tends to work for. For people whose chemo includes a taxane, like mine, the success rate is as high as 65 per cent. For those getting an anthracycline – such as Adriamycin, the “red devil” – it will work for only about 22 per cent.

I am trying to be pragmatic about the process. “If it buys me a few more weeks with hair, I’ll be happy,” I tell my friends. But I don’t fool anyone; I’m desperately hoping it will work, and fearfully certain it won’t.

NINE DAYS after my first dose of chemo, I am brushing my hair in the bathroom when I notice strands floating to the floor. More come out in my hand. They’ve come out at their very ends, like uprooted plants.

I tell myself this is the normal shedding I’d been warned to expect. But more comes out over the next few days. My scalp becomes tender, and my hair feels unbearably heavy.

I know what it means: the scalp cooling has not worked. I must cut my elbow-length hair off before it comes out everywhere, blocking drains and covering floors.

My regular salon has no openings, so I walk in the rain to one in the next suburb. I explain things as sensibly as I can to the young hairstylist. We settle on a choppy, long-bob haircut; the shortest it’s been since I was 21. I try not to look at the piles of hair on the floor as I leave.

The next day, I’m exhausted from what would have once been an easy walk. Three days later, I wake in the night with a raging fever – the chemotherapy has wiped out my white blood cells, and an infection has taken hold. In the late-night rush to

hospital, I still think to grab a headscarf, glum that I am to spend my last weekend with hair on a ward. But when I leave the hospital three days later, I still have hair. I turn up for my second round of chemo, then my third, also with hair.

I quickly lose the hair beyond the reach of the cap – in front of my ears, at the nape of my neck. My widow’s peak evaporates; the crown thins. But, to my astonishment, most of my hair clings on. The glossy brunette wigs I’d been lent by a friend stay neatly in their boxes.

FRAN BOYLE is cheered by scalp cooling’s spread across the country, but points to the need for a directory of hospitals that offer it. She hopes that soon it will be available to anyone who wants it. But there are some challenges. There’s the cost of the machines – from \$42,000, though this can be negotiable. Sometimes they are paid for by fundraising and philanthropy groups linked to hospitals, or charities like Dry July.



Boyle is a vocal advocate of scalp cooling. The Mater was an early adopter; in 2010 it introduced Penguin Cold Caps, a modern iteration of the early frozen gel-pack systems. The hospital’s first DigniCap arrived in 2012, and a Paxman in 2014.

She notes that health professionals have often given “bland reassurance” that hair loss is temporary. The problem is that hair does not always grow back. Taxotere, one of the chemo drugs in my regimen, has been linked with permanent alopecia – a rare but real occurrence. US class-action lawyers have filed claims on behalf of hundreds of people, arguing that the drug’s manufacturer failed to properly warn of this risk.

And sometimes, the hair grows back differently – curly when it was straight, or soft “like baby’s hair”. Or white. Some people don’t mind, says Boyle. “But others say, ‘I just want it back the way it was. That was me. I liked it.’”

For a time, there were fears that cooling the scalp during chemo made it a haven for cancer cells. Research



But there is also the crucial issue of “chair time”. Scalp cooling can add hours to a patient’s stint in a busy oncology day ward, stretching the unit’s capacity and potentially taking time that could be used by someone else.

And once a hospital has a machine, high demand can spark difficult questions about who should be first in line. For various reasons, scalp cooling has often been linked to patients with breast cancer – partly because, as cancers go, it attracts substantial research and fundraising efforts. But, apart from capacity, there is no reason why it can’t be given to women with some other form of cancer. Or men – why should they miss out? If it can’t be offered to every patient, surely it is better to offer it to some than none at all? “These are really hard questions, not easy to answer,” says de Boer.

And scalp cooling adds yet more work and responsibility to the nurses, who must fit the caps and monitor the machines. For all these reasons, some oncology units have balked at the idea of introducing the treatment.

Western Sydney’s Campbelltown Hospital last year became the first public hospital in NSW to offer the service – in part at the urging of oncologist Belinda Kiely, who “didn’t think it was fair” that it wasn’t available in the public system.

Currently, at Campbelltown, scalp cooling is offered only to patients with early breast cancer, and only those receiving certain chemo regimens. It was a compromise, Kiely says, given available resources and the big adjustment needed. Plans are underway to expand that.

Initially, there were some “very negative” reactions among nurses says Denise Burns, manager of the hospital’s chemo unit, amid fears about the increased workload and impact on chair times. But two nurses volunteered to be scalp-cooling “champions”, learning how to fit the caps, work the machines and manage its impact.

Scalp cooling is simply “part of our treatment plan now”, Burns says. “You adjust. This is about progress, and this is what we have to be offering people. The general public know about it and they want it.”

FOR ME, it feels like freedom. At the shops, on the street, even in the hospital, no one knows I am unwell unless I choose to tell them. I don’t have to worry if it is too hot for a wig, or too windy. I don’t have to fuss with a headscarf before I leave the house, or avoid eye contact with strangers when I do. I don’t have to put energy into putting on a brave face, when just leaving the house is exhausting enough. My children know of my illness, but because my appearance has not changed dramatically, they have no reason to be terrified by it.

Although the scalp cooling is working, I remain anxious. As I count down my chemo cycles – three to go, then two – my hair keeps thinning. I fear that I’ll eventually run out of hair to lose.

Along the way, on what some people might term my “journey”, I meet and speak with other women in treatment, and with survivors. I have been told that some women cope with relative ease with the loss of their hair. I haven’t met one.

“You lose your identity – you feel stripped,” says my friend Janine Le Febour, 44, whose long dark hair fell out within two weeks of her first chemo treatment four years ago. “And you don’t have a choice.” It was Janine who lent me her wigs. If she’d known there was a way to save her hair, she would have jumped at it – even flying from Perth to Melbourne for treatment.

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Scalp cooling can prevent such anguish; it helped Maria\*, 50, a high-ranking executive in the education sector, hold on to some normality. She found the discomfort of scalp cooling “not too bad”, and by keeping her hair, she was able to keep working when she felt well. Maria’s employer knew, but those around her were oblivious. “I was quite keen not to have that [‘cancer patient’] label attached to me,” she says.

But some people find the cold intolerable – and for others, it just doesn’t work. Like me, Paula\*, 39, went into chemo with long brown hair. But Paula was prescribed the “red devil”. She found scalp cooling unbearable, reeling as she was from the side effects of her fortnightly chemo. With her hair already coming out in patches, she halted the process after two rounds. “I felt like it was going to be almost harder than the treatment, because I disliked it so much,” she says. She doesn’t regret her decision, but still found losing her hair incredibly distressing.

Marisa Stevens is the oncology liaison nurse at my hospital, East Melbourne’s Epworth Freemasons. In the three years since Freemasons introduced scalp cooling, Stevens has seen more than one patient struggle with the inherent uncertainty of the process. “It’s not a guarantee, and it’s physically and emotionally hard, psyching yourself up for every [chemo] cycle,” she says.

Stevens sees its enormous benefits for patients, but she believes there needs to be more recognition of its challenges, too – especially for those receiving anthracyclines, for whom the chances of success are lower. Scalp cooling offers hope – the chance to wrest back some control. But the flip side of this is that if it doesn’t work, the disappointment can make it “10 times harder” to cope with.

“It’s quite easy to go, ‘Scalp cooling is easy and it’s great,’” Stevens says. “It is great, but it’s not easy for the patient or the health professionals. It’s another element for both people.”

Scalp cooling, it turns out, can be a whole other “journey” in itself.

MY SIXTH and final chemo – and scalp-cooling – session is by far the hardest. With less hair between my scalp and the cap, the cold seems to bite. This time, when the cap comes off, I have a small burn on my hairline. That night, I sleep for 14 hours.

I have finished chemo with enough hair to get by. It is not *great* hair – it is very thin, and has not been coloured for months – but I know I am lucky and feel intensely grateful, even elated, to have anything at all.

One day, chemo will be supplanted by something less gruelling, and become a medical relic of the past. In the meantime, scalp cooling may just succeed in diminishing chemo’s fearsome reputation.

Richard Paxman says his company is researching how to improve results in patients receiving anthracyclines; it is aiming for an overall 80 per cent success rate by 2020. Professor Fran Boyle and her team, meanwhile, are researching ways to protect eyebrows and eyelashes during chemo.

I now recognise my panicked decision to chop my hair short – needlessly losing a decade’s worth of length in minutes – as an attempt to regain control, to do *something* in the face of terror and powerlessness.

It turned out that, despite the pain and the stress, scalp cooling gave me a more constructive avenue for that very human compulsion – to be an active protagonist in my own life. Saving my hair feels like a victory.

“It’s not about vanity,” Stevens says. “Women sometimes feel guilty about getting upset about hair loss ... [but] you’re not grieving your hair. It’s about losing who you are, and becoming ‘that cancer patient’, when you’re still the same person. That’s what people don’t want to lose. They want to be themselves.” ■

\*Names have been changed.