

Cold Cap Therapy: 101



A supportive care option to prevent hair loss for women—and men—undergoing chemotherapy

Those of us who work in the field of oncology understand that retaining some measure of control is important to our patients. For most patients, shared decision making around treatment, symptom management, survivorship, and/or end-of-life care affords that sense of being “in control.” For others, this measure of control can be achieved through something as specific as the choice to undergo treatment to stop hair loss during chemotherapy. Methods to help patients with cancer maintain hair during treatment have existed for quite some time. This article offers information about one specific method: cold cap therapy, also known as scalp cooling.

Most chemotherapy-induced hair loss occurs from treatment with anti-cancer drugs like Adriamycin, methotrexate, Cytosan, and Taxol, which damage hair follicles as the drugs act to target and kill cancer cells.

Scalp cooling technology reduces the temperature of the scalp a few degrees before, during, and after chemotherapy treatment. This cooling causes blood vessel vasoconstriction in the scalp, which reduces blood flow and, therefore, reduces the number of chemotherapy agents that reach the hair follicles. Since 2019, the National Comprehensive Cancer Network has recommended scalp cooling in its breast and ovarian cancer guidelines.¹ Given the chemotherapy agents that cause hair loss and the patient population most emotionally affected by this side effect, much of the focus on scalp cooling has been on those being treated for breast cancer.

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In the Beginning

The earliest method to cool the scalp and prevent chemotherapy-induced hair loss—still used by some today—is the use of caps like those worn by swimmers. These caps are cooled to very low temperatures by dry ice, placed on the head of the patient during chemotherapy, and replaced repeatedly before, during, and after treatment. Though this method has some success in hair retention, it comes with its challenges. For example, the initial temperatures, the timing of cap replacement, and cap temperature changes are not stable variables across all patients or treatments. This variability makes the practice of cold capping challenging to evaluate



Infusion nurse Amy Anderson (left) adjusts the cold cap on patient Tonya Cooper.



Amy Anderson, RN, starts cooling process for patient Tonya Cooper.

and document in terms of clinical outcomes. Therefore, most cold capping “successes” are demonstrated through anecdotal patient stories. Cold capping, particularly during treatment, can be quite painful for patients due to the extreme coldness on the scalp. Cold capping is also labor intensive because patients need assistance removing and replacing the cap during treatment. Sometimes infusion nurses take on this role even though they should be focused on infusion patients’ treatment.

A Modern Approach

A new generation of cold cap treatment now exists, featuring self-contained units that are clean, easier to use, and standardized for consistent treatment. This technology has led to more stable treatment temperatures and the ability to provide better outcome studies.^{2,3} This new-generation technology is much easier to use and does not require the time and resources of infusion room nurses. However, this new technology comes at a cost to both institutions wanting to offer this service to their patients and to patients themselves because the service is not covered by payers. For patients who cannot afford this treatment, many cancer programs work with internal and external foundations, as well

as other fundraising sources, to assist with or completely cover the cost of this treatment.

Development and Implementation

When Mercy Health Lourdes Hospital in Paducah, Ky., began developing its cold caps program, we started by outlining our primary goals. Specifically, we wanted to partner with a vendor that:

- Utilized the most modern technology available.
- Had strong clinical studies that backed up the use of the technology.
- Had superior marketing materials that we could brand to our hospital and cancer program.
- Would guide our team members and patients every step of the way by providing ongoing support.

Eventually, our research led us to Paxman (paxmanusa.com). From initial contact with Paxman to installation of its equipment in our infusion suite, the process took around six weeks. The vendor’s technical and user support for staff and patients exceeded our expectations.



Cap being adjusted for patient Tonya Cooper during cooling process.

Recognize that cold cap therapy is not for every patient. Decisions about which patients will benefit from cold cap therapy must be based on the treatment regimen and approved by the attending physician.

describe the first 15 minutes as the hardest to cope with but find the remaining time as completely manageable. Treatment time consists of pre-infusion (30-45 minutes), treatment infusion (60-90 minutes), and, lastly, postinfusion (20-90 minutes). Patients always feel relieved after the first treatment and find that future treatments go much easier.

Funding

Our next step was to find a way to make this service free to all clinically qualified patients. It soon became evident that this was not normal practice at other cancer programs. Many cancer programs offered assistance to help defray the costs of cold cap therapy, but we found none that would cover the complete costs of this treatment. Typically, the cost of a full course of cold cap therapy is between \$1,800 and \$2,500. We worked with the hospital's foundation, Mercy Health Foundation Lourdes, to identify and create ongoing funding sources that will pay the vendor directly for cold cap therapy costs normally incurred out of pocket by patients. This fund was put together rather quickly—in about 30 days—because we have such a great and responsive foundation. Though this funding is regularly procured to replenish the account from multiple sources, we have been lucky to have found multiple grants and fundraising efforts, nationally and locally, to help defray these costs. Demand for this service has increased as the program has gotten more visibility, which has also helped gain fundraising for the program. Patient success stories in our outreach materials have been successful and helped our fundraising efforts.

Keys to a Successful Cold Cap Program

For cancer programs looking to offer cold cap therapy, we offer these lessons learned:

- *Partner with a vendor that uses the newest cold cap technology and equipment.* The vendor should also have a strong focus on patient and staff support. Before signing with a vendor, check with other cancer programs that currently partner with the vendor to better understand how they operate. Look for a vendor that has the tools and resources to help you market this new service to your patients and your community.

Today, our cold caps program operations start with a personalized visit with a registered nurse at Mercy Health Outpatient Infusion. While present, the patient will be properly fitted to receive his or her own silicone cooling cap and neoprene cover. Proper fitting will help ensure success of the treatment. The patient will then be given Paxman literature and tips for success, which are quite expansive and useful to patients. Each patient is also encouraged to join Paxman on social media, with support from both the company and past and current patients utilizing the service. The social media groups offer a wide diversity of women and men who are experiencing or have experienced scalp cooling, and this support is helpful for success. Paxman will contact the patient directly and the patient will receive his or her own cooling kit in the mail prior to infusion. This kit includes everything the patient needs for each treatment.

Many patients will feel overwhelmed at their first treatment. Our infusion staff is very aware of this sensitive time in their treatment and are available to continue providing needed reassurance to patients. Time in the cold cap depends on the patient's treatment plan, but on average 2 hours and 30 minutes is spent in cooling. Patients are encouraged to bring a warming blanket from home for added comfort while in treatment. Most patients



Patient Marie Gray (left) with her sister Jaqueline Wilkerson.

- **Recognize that cold cap therapy is not for every patient.** Decisions about which patients will benefit from cold cap therapy must be based on the treatment regimen and approved by the attending physician. It is also important to note that some patients do not want this service and can feel very strongly about it; for example, patients who view their hair loss as battle scars of chemotherapy. Educate patients about this service, but do not do a hard sell. Even though technology has evolved since the days of dry ice, cold cap therapy can still be painful for patients and may cause some to cease treatment, which must be calculated into vendor agreements.
- **Know the operational changes required for implementation of this new service.** Though these state-of-the-art units mostly run themselves during treatment, cold cap therapy will add to treatment times—both prior to and after chemotherapy administration. This time should be considered in infusion budgeting and scheduling. Additionally, infusion center staff must be trained on this new technology and know how to run the equipment.
- **Understand the costs and how you are going to pay for this service prior to implementation.** It is difficult to offer a service

that is out of the financial reach of patients who would like to use it. Fortunately, it has been our experience that raising funds for this type of supportive care is easier compared to other services and/or programs. And because cold cap treatment is not currently reimbursed by the Centers for Medicare & Medicaid Services or private payers, you do not need to worry about violations of inducement rules.

- **Identify champions for this new technology.** Referral champions are needed to educate patients about cold cap therapy so that patients are prepared, fitted for a cap, and trained by the vendor prior to starting their chemotherapy. At our program, champions in breast surgery and medical oncology discuss this option with patients who will benefit from cold cap therapy and help enroll qualified patients into the program as a part of their normal care. Infusion center champions become the “go to” for all cold cap operational questions and act as a guide for those patients receiving the service.
- **Recognize that continuous improvement is needed to maintain and improve a cold cap therapy program.** We found the initial vendor training simple and quick, but true expertise requires commitment from the infusion team. We carefully tracked our patients receiving this service to collect data, evaluate success from both the patient and staff perspectives, and monitor patient comfort levels and pain. We then used these data to improve the service and gain a better understanding of which patients benefited the most from cold cap therapy. In doing so we learned that cold cap therapy has a more subjective level of success than what we are used to seeing in healthcare. For example, from our perspective some patients had little hair loss, yet saw cold cap therapy as a failure based on the time they invested or how they personally felt about their hair loss. Other patients had a great deal of hair loss, except on the sides of their head, and still felt that cold cap therapy was a success because they could wear a hat or scarf and still feel they had not lost their all of their hair. Simply put, cold cap therapy is a personal choice and a personal service, which is reflected in patient feedback. Be ready to monitor your cold cap therapy program, collect data, and make changes to ensure the success of program.

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First Person Perspective

BY CHRISTIE MANGIR

Being diagnosed with breast cancer at age 30 and learning I needed chemotherapy was devastating. I did not feel like I had a choice. If I wanted to live, I had to complete an intense regimen of chemotherapies and targeted therapies. Cancer patients do not have many choices, but one of the only things I felt like I could do was to preserve my hair during chemo. I still lost about 50 percent of my hair while cold capping, but I would do it all over again because it gave a sliver of normalcy and confidence when my body and my life felt it had been ripped apart. When I looked in the mirror after losing 20 pounds and having my breasts amputated, my hair was the only thing that allowed me to recognize myself.

Fifty percent of female patients consider hair loss the most traumatic part of chemo, and 8 percent would decline treatment due to potential hair loss.¹ There are many reasons patients choose to preserve their hair: to have a sense of normalcy for their children, to support their self-esteem and mental health, to have control over when and with whom they share their health struggles, and to avoid the looks of pity and discomfort that cancer patients often receive.

I chose to receive treatment at George Washington Cancer Center in Washington, D.C., because my care team thoughtfully engaged me in shared-decision making and were supportive of my desire to preserve my hair. I was one of the first patients to cold cap at my infusion center in 2016, before the newer generation of U.S. Food and Drug Administration-cleared scalp cooling devices became more widespread. Using manual caps meant that my husband had to take time off from work to carry large coolers of dry ice into the infusion center and change my cold cap every 30 minutes for a total of eight hours. It cost us more than \$2,000 because the technology is not covered by insurance. This time commitment and financial burden is not feasible for many patients.

Hair preservation can ease a variety of patient concerns and improve their quality of life, but awareness, affordability, and access continue to be significant barriers. In 2017, my friend and fellow survivor Liz Lord decided to take action to help remove these barriers for patients with cancer in the Washington, D.C., area. Several other survivors and I joined Liz in forming the Cold Capital Fund, a nonprofit that empowers patients across the District of Columbia, Maryland, and northern Virginia to have the option to preserve their hair.

To improve affordability, the Cold Capital Fund provides financial assistance to people who would not otherwise be able to afford cold capping—as of August 2020 we have supported more than 100 patients. We work with local cancer programs to educate care team members about cold capping and our resources, as well advocate for the installation of U.S. Food and Drug Administration-cleared scalp cooling systems in infusion centers to make cold capping more accessible for their patients.

For too long, hair loss was an unavoidable and distressing side effect of cancer treatment. Now that there is a reasonable therapy to mitigate this side effect, we must work to level the playing field to make it available to all eligible patients. Though hair preservation may not be the right choice for everyone, our mission at Cold Capital Fund is to make it an *option* for all patients who would be candidates for this therapy. Learn more about our efforts at coldcapitalfund.org.

Reference

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