Episode 3 Transcript: Why scalp cooling is turning the definition of 'efficacy' on its head

SPEAKERS
Sue Glavin, Dr Conleth Murphy, Richard Paxman

Richard Paxman 00:01
Hi, my name is Richard Paxman. Welcome to the Changing the Face of Cancer Podcast. In this episode, I'll be chatting with Dr. Conleth Murphy and his clinical nurse manager Sue Glavin, who are leading the way in scalp cooling treatment at Bon Secours Hospital in Cork, Ireland. We discuss how patient advocacy played a huge part in integrating scalp cooling into their side effect management practice. And the psychosocial impact that scalp cooling can have on patients. Conleth and Sue, share their own experiences of supporting loved ones going through cancer treatment, and the importance of providing care to limit the impact of cancer on an individual both during and beyond their treatment journey. Hi, Conleth. Hi, Sue. Absolute pleasure to have you here today. I'm really looking forward to getting into a bit of scalp cooling with you and hearing your experience from Ireland.

Conleth Murphy 00:59
Thank you. It's such a pleasure.

Sue Glavin 01:01
Nice to meet you, Richard.

Richard Paxman 01:03
Conleth just remind me when did we meet? Was it ESMO in Madrid?

Conleth Murphy 01:07
I think that was it. Yeah, we had a poster presentation at ESMO in Madrid, there was a medical student who was working with me, who had done a really interesting project on scalp cooling, and we were presenting it at a poster in ESMO in Madrid, and you walked along, and it was quite exciting for me to meet a Paxman, having used the Paxman system for so long. It was like meeting a celebrity really.

Richard Paxman 01:31
I hope it wasn't disappointing,

Conleth Murphy 01:33

Not at all, not at all.

Richard Paxman 01:36
I think my sister might have been even there. It was yeah, a real family affair, which is nice. And it was a pleasure to meet you. I think we were walking down the halls and we hadn't realised that actually, you were presenting that poster. So it was a great opportunity to meet you. And we'll, we'll come back to some of the data that was presented. But let's just start off by asking you both what got you interested in scalp cooling? And how long have you been scalp cooling? And Sue if you want to answer that first and then Conleth, I'd love to hear from you.

Sue Glavin 02:07
We've been doing it since 2014. And I suppose what got us interested is well the patients really. The patients wanted to do scalp cooling, just you know, especially the women, I suppose the breast patients, and they had been using it in Dublin, I think it was and we decided that we try it on a trial basis and see how we got on. But we had a very good response. So we decided we stick with it. We hired I think we leased the machine for a while just to see how we would get on with it. And it was the only one in Cork at the time. So a lot of patients came from other hospitals, I suppose to use it as well. And we had no experience really, but actually I met Claire, your sisters?

Richard Paxman 02:43
Yeah, my sister Yeah

Sue Glavin 02:44
Came over to do the training, it kicked off from there then. So we just tried with a few patients had good success with it and decided that we keep with it. And we did have patients coming to us then from other areas because we had the cooler because they wanted to use it and have their treatments with it.

Richard Paxman 03:01
And you've not stopped ever since

Sue Glavin 03:02
Not stopped since in fact, the demand is higher and higher every time we use it. I suppose we have a double machine. So pre COVID, we were able to use both arms of the machine. For sure. We're still using it. There's a huge demand for it. Yeah, yeah.

Richard Paxman 03:15

Out of interest. What do you think creates the additional demand? Is it patients seeing other patients be successful? Is it word of mouth? Is it how you educate your patients? What do you see as being the sort of driver for more patients wanting it, other than perhaps patient increases in patient numbers?

Sue Glavin 03:31
I would say it's probably patients, telling other patients about it, and definitely word of mouth, or a patient being in the community chatting to her friends or whatever. And they can see her well. You know, they've kept their hair, that kind of thing. And then I suppose a friend of theirs becomes diagnosed with cancer, it's kind of in the community, people would be talking about it. So I think that's what made us keep it really because we were getting good feedback from patients, relatives and other patients who had heard about it from another patient, you know.

Richard Paxman 04:01
Wonderful. So that peer to peer support there. So Conleth, you've been in oncology for a while now, what made you focus and specialise in oncology?

Conleth Murphy 04:10
Oh, I have been working in oncology for 21 years now almost as long as Sue. I would say that it was the first job I did as an SHO. And I had a wonderful boss in that first job who just exemplified everything that is good about medicine. He had very high standards for other people, but he also had very high standards for himself. So he was really, really inspirational. And indeed, some of the doctors on the team that I worked with, who were just a little bit more senior than me, I've ended up working with again, over time now in the hospital that I work in so they were very inspirational to me as well. And I just think oncology is a really fascinating specialty. It's highly, highly evidence based. The pace of change is very rapid so it is never ever boring. And when I look at you know, when in 2000, when I qualified in 2001, I started working in medical oncology, the treatments that we use now are radically different to what we were using at that time. So we're very open to new ideas and new innovations. And we're constantly building on what has gone before.

Richard Paxman 05:19
Yeah, so a great point. And you, of course, we're very niche in our area. But you see, even just the supportive care landscape, changing massively on a regular basis, nevermind the actual treatments for the disease itself, which is fantastic.

Conleth Murphy 05:33
But yeah you know that's really interesting, Richard, because there was a paper out a few years ago that looked at the five biggest advances in medical oncology over the last number of decades, you would think that they would be talking about specific chemotherapy regimens or immunotherapies, and so on. But one of the top five was the development of effective anti-sickness medication for patients. And it just goes to show how important

that whole supportive care area is. You know, we can do all we want with the treatments that we give, and make them you know, build on their successes and make them a little bit more effective. But if our patients are miserable, we're not achieving what we want to achieve.

Richard Paxman 06:08
Yeah, that psychosocial side of things, that emotional wellbeing is critical. And I think critical to outcomes as well, I think, although not always related fully. Has a huge impact on those patients. Sue how did you get into oncology?

Sue Glavin 06:23
Oh, when I was training, actually, I did oncology. I trained in London, and I did oncology twice during my training. And it's just an area that I actually loved, I just loved the difference of it, meeting the patients, they were just a different type of patient really, very special kind of area to work in. And I suppose knowing that you can help them as much as you can, and not always a good result at the end. But you've done what you can really, you know, to help them. And I qualified in 91, and I'm doing oncology since 91. So I've stayed there all the time in various areas, like I've done a little bit of liaison, a little bit of Day Ward, and inpatient wards, for the most part, but the last seven or eight years I've been on the Day Ward. I suppose it's nice to see patients coming in having their treatment in the daycare setting, and actually going home again. You know, I suppose palliative care is a huge issue as well, you know, and I did a little bit of palliative, well, I suppose do a good bit of palliative care when you're in on the inpatient ward, you know, I got to the stage where I just kind of wanted to kind of diversify a little bit, go to the day word, and just nice to see people going home and coming in and out.

Richard Paxman 07:30
So many of you do such an amazing job. I remember being a 16 year old boy and sitting with my mom while she was having a chemo and amazing, amazing the care that you do provide and that support for the whole family, which is seriously just, it's amazing. So yeah, thank you from, from all those families out there really, for what you do. We appreciate it.

Sue Glavin 07:50
Most of us would have been touched by cancer in some way or another in all of our families, like my own mother had cancer as well. So I suppose that kind of makes us realise what extra care might need to be done, or what was missing in your own relatives care, things that you can improve on yourself, you know, so I suppose we've all been touched by it. So it makes you care for them in a better way, or in a different way, you know?

Richard Paxman 08:14
Yeah, a bit like why we're here today in terms of scalp cooling. You know, my mum had scalp cooling all those years ago, and it unfortunately didn't work for her, you know, that's why my dad started to look at well, why didn't it work? And what can we do to help more patients in the future? And, you know, with people like

yourselves, that's what we are doing. And it's pretty tremendous. So, interesting question, which I like to ask, talking about the side effects of chemotherapy treatment. Do you think they sometimes and especially hair loss can be bit more readily accepted? Because the side effects aren't always life threatening? Now, I appreciate some are but hair loss perhaps isn't, do you think it means that they get less attention they're seen as less important by perhaps medical professionals?

Conleth Murphy 08:58
No, I mean, I know from my conversations with patients when I'm talking to them about chemotherapy, when I'm gearing up to say there are two side effects that are guaranteed with breast cancer chemotherapy, I always say fatigue is one. And hair loss is another unless we use a scalp cooler. But you can just see that it's the word that the patient has been waiting to hear. And they almost crumple when you say hair loss, you know, and I think there's a big fallacy out there that trying to maintain one's hair during treatment is somehow a vanity issue. When hair is so much more than about vanity. It's a real public part of you and your perception of yourself and your family's perception of you, and society's perception of you is all bound up in your hair. And there have been many studies that have looked at that you know, the psychosocial impact of alopecia or hair loss. One thing that people often say we use the scalp cooling on men as well. Yes, you know, is that if somebody is out and about in their community, and they've lost their hair, they can see people looking at them and saying, 'Oh God, you know, such and such is very sick' and you know, 'not long for this world.' No, I'd say out of this, you know, and they are so conscious when they're going about around to their community, when they've lost their hair.

Sue Glavin 10:15
I suppose it's an outward sign that something is wrong. Whereas if they didn't lose their hair, nobody might think that they were sick. But if they have that, like altered body image of hair loss, especially women, it's an outward saying that people can see that something is wrong, and it does make them more self conscious. You know, and for women, especially women, I think it's a big issue, like women love their hair, and like to look well, and you know, it's a huge issue for women to lose their hair. I think it's like losing your identity, a part of your identity.

Richard Paxman 10:44
You know, it's such a such a visible sign, isn't it? So we talked a little bit about when we first met in Madrid, what seems like a long time ago, when we could all meet in person and yeah, feel a little bit more normal. And you are presenting a poster, I think it was called 'The uptake, patient satisfaction and efficacy of scalp cooling, among patients receiving chemo in an Irish oncology ward.' So what motivated yourself and your colleagues to collect this information in the first place? What was the driver behind that?

Conleth Murphy 11:15

I suppose a lot of the research that is out there on scalp cooling and hair loss with chemotherapy is from the medical perspective, so the medical and nursing perspective. And when we talk about how effective scalp cooling is, we're talking about the as per the nurses and the doctors. And there's a huge move in oncology research now to talk about patient reported outcomes. And it's really important to measure what the patient feels about their treatment, and the effectiveness of the treatment, and the tolerability of the treatment. So there had been a couple of large studies that were reported in 2017, that had some quality of life measures included, but we wanted to specifically look at those patient reported outcomes. So we said we were going to look back at the patients who had been offered scalp cooling over a four year period, and then contact the patients who had accepted scalp cooling to see what their thoughts were about it and whether they were happy with their choice.

Richard Paxman 12:14
So what were your key takeaways then, what did you just discover with that? And absolutely agree the patient reported outcomes, I think is becoming more and more important. And what I like to see is it's not just the clinicians that are believing this, and of course, the patients support this, but the regulatory bodies as well are actually understanding the importance of this, which is fantastic.

Conleth Murphy 12:34
Absolutely. Well, one of the things that surprised me was that the patients felt scalp cooling was more effective than the medical and nursing staff. So we measured efficacy from the medical or nursing perspective, as the patients who had completed their full course of chemotherapy and continue to use the scalp cooler at the end of treatment. So we said, Okay, so these are patients who have held on to their hair, obviously, because we were looking back retrospectively. From that point of view, we estimated that around 45% of patients it was effective for but when we surveyed the patients who had taken up the offer of scalp cooling, about two thirds of them, about 66%, felt it had been effective. So they had a higher rate. So there were some maybe who had some thinning but felt that they had enough of an effect from it, that they were able to go out in public and not be self conscious, and so on. And interestingly, when we looked at whether patients were glad that they had taken up the offer of scalp cooling, 87% were satisfied with their decision to do scalp cooling, even though maybe their perceived efficacy was slightly lower, they were happy that they had made the choice to do it, and that they had tried it. The other thing that I thought was very interesting was we looked at where they got their information on scalp cooling. So, many of them got it from their liaison nurse, you know the nurse who educates the patients about their planned chemotherapy regimen and gives them all the information about what numbers to call, and so on. So many of them got it from the liaison nurse, some of them reported getting the information from their consultant, but the majority used an alternative source of information as well. So most people did go off and discuss it or look it up from another information source. And I would have thought that people would be going to talk to their GPs actually, that's what I thought that people would use as an alternative source. But very few people spoke to their GPs about it. Most of them spoke about it with family members, and got advice from family members about whether to do it. And then the next kind of highest area was the internet

- people looking up information on the internet. So I do think when we're talking about scalp cooling, we need to make sure that the information is out there in the wider sphere, not just amongst patients because if somebody is going to have a chat with their family, as you know, Richard, there are some misconceptions out there about scalp cooling. We found that the patients who accepted scalp cooling said that they didn't feel discouraged following discussion with family members or by looking on the internet. But of course these were all people who accepted it - we don't know about the people who didn't accept it. So there may have been people who spoke to their family members, and they said, Oh, God, I wouldn't do that, you know. So we need to get the information out there into the broader sphere about this being an effective and a safe treatment for people.

Richard Paxman 15:14
Definitely agree with that. Do you think that the percentage in terms of over 80% were happy with their decision, does relate to the education they've received though, so that real sense of management of expectations, perhaps done by the nurse liasion reall setting the scene and managing those expectations fairly early on?

Conleth Murphy 15:31
Absolutely, you know, it was important for us to kind of have realistic expectations of that is not a guarantee that you're going to keep your hair and we have kind of looked at, you know, with the different regimens, what are our expectations, and then people like Sue, So Sue has been a real driver of scalp cooling in the day ward. So she has such immense experience in oncology in general. But then also now with the scalp cooler, you know, so Sue can really set the standard and inform people and of course, it takes a little bit of time to set somebody off on the scalp cooler so that's a good opportunity to talk.

Richard Paxman 16:02
Do you encourage patients to use our own digital resources such as our coldcap.com website, or our haircare blog, just to support the patient through the treatment?

Sue Glavin 16:12
Yeah, some patients they get a leaflet about the scalp cooling from the liaison nurses when they start their treatment, so they've already googled it by the time they come into us anyway. So some patients come in with your shampoo products, you know, your conditioner, products and stuff. And some people come in with like hair bands, things like that. And they might have obviously looked at the video before they've come in. So then they might say, oh, you know, is it this way or that way, or the chin strap might be a bit tighter, you know, they'll tell you what they kind of want to do. Some people prefer, you know, not to have the chin strap on if they're eating or whatever, which is fair enough, you know, so they kind of have an idea of themselves because they've looked it up themselves. And then obviously, we educate them ourselves about it.

Conleth Murphy 16:53

Yeah, we had a young woman recently, she's just finishing her treatment at the moment. She's 29. She had been working overseas, and she was diagnosed with breast cancer. And obviously, this has completely turned her life upside down. Devastating for her in terms of the way she thinks about her body the way she thinks about the future. And she has a beautiful head of long black hair. And she is getting a chemotherapy regimen where we sometimes worry a little bit about the effectiveness of the scalp cooler. It's called AC T and the anthracycline chemotherapy can be pretty tough on the scalp. So we've had more limited success with that than other treatments, I suppose. But she had been in touch with yourself, Richard, she had really used all the resources. And she said, I know that it may not be effective for me, but I really want to try it. And she was amazing when she came in because she had a resistance band around her head over the cold cap, which was kind of then under her thighs to keep the pressure on the cap and everything. She used all the tips. And she has just finished her chemotherapy, I think, and she has held on to her hair. And that has been such a huge psychological bonus for her. It's been a really tough year for her.

Sue Glavin 17:57
Yeah, she has a beautiful black ponytail all the way through. And she just looks amazing. Yeah, yeah, it's been a pretty Wow. Yeah.

Richard Paxman 18:04
And we'll come back actually on to the the AC regimen discussions. But that is great to hear. It sounds like as well, the ladies most likely joined our Facebook group, which, you know, is a wonderful resource for your patients when they're trying to make that decision. And perhaps their family members may not be fully educated on scalp cooling, and may have heard the different myths about scalp cooling. This is, you know, it's got I think, nearly 4000 members in it now, closed Facebook group, and it's that really strong peer to peer support. So we'd encourage any patient to go on there if they're thinking about scalp cooling, or if they're going through scalp cooling, just to learn from others and to share experience and to gain experiences. It's really invaluable. Just back to the sort of patient perspective versus the clinician perspective. So did you find that the doctor versus nurse perspective was similar? Or was that also not fully aligned?

Conleth Murphy 19:02
Well, we didn't specifically look at that Richard, it would be really interesting to look at that actually, you know. I think that the nurses spend a lot more time with these patients and are very clued into, they'll often have the same nurse on the day or don't say, a lot of the patients, you know, so we actually measured efficacy, because we were looking at it retrospectively, we just measured it in terms of still being on the cool cap at the end of treatment. But it would be really interesting to compare, you know, maybe in a prospective way, maybe the three points of view, the doctors, the nurses and the patient, in somebody who's starting off on scalp cooling and at the end of treatment to see whether there are differences there. And I bet there would be.

Richard Paxman 19:42

Yeah, it's interesting. And remind me what was the efficacy difference between the clinician and the patient?

Conleth Murphy 19:47
It was, as per the clinician, it was approximately 45% efficacy and as per the patients it was 66%.

Richard Paxman 19:56
Wow, so it's quite different is quite a difference. So do you think acknowledging that sort of clinical bias, what do we do about ensuring that we're educating patients correctly in terms of you know, do we have to be careful when we talk about it? If we're strongly as a clinician, perhaps thinking, well, you know, your efficacy is roughly 40%? Do we need to rethink that? Do we need to re message how we're delivering it? Do we need to think about success in a different way perhaps?

Conleth Murphy 20:22
I think so. I think that is one of the reasons why patient reported outcomes are so important in oncology, you know, it's so important to get the patient's perspective on things. I can tell you that this study has been really useful for us in our practice, because we've been able to kind of talk to patients and say, the majority of patients are happy with their decision to try scalp cooling, even if, from our point of view, it isn't entirely effective. And in some patients, you know, it has been really useful. The other thing is that the majority of patients would also recommend scalp cooling to a friend or a loved one. You know, that was one of the other questions we asked in the study. And again, a higher percentage than the people who actually felt that they had received benefit from us, you know, so people are happy with the opportunity to try it. Even those who where it wasn't entirely effective for them.

Richard Paxman 21:10
If we think about then, these different perceptions, and we think about what success means, and success means something different to so many patients, I think we all we all agree there, do you think that as well, it would be helpful for physicians, nurses, or other medical professionals to be armed with what success might look like for a patient, for example, you know, we hear about patients who say, I just want to keep my hair until I've seen my daughter get married. Or I just want enough hair to put on a baseball cap and wear a ponytail and drop my kids off at school. How do you think we can speak together on that messaging I guess?

Conleth Murphy 21:52
You know we get that all the time, don't we Sue?

Sue Glavin 21:54
We do. Patients are always like, they want their vacations coming up or whatever, that they want to kind of keep their hair or little bits of hair.

Conleth Murphy 22:02
But it's not always the case that somebody necessarily wants to have our has the absolute need to have the full head of hair. Yeah, sometimes it's like that, where you'll have somebody coming in, and they'll have that wisp of hair that's coming out from under the cap.

Sue Glavin 22:16
Or they just want a fringe or just some little bit of hair sticking out, you know, they're not really bothered, kind of thin on the top, or they wear a hat in the winter or whatever. But most patients would have some expectation of that, you might get a bit of hair loss with it, or hair thinning or whatever. But they just want to kind of keep little bits like wispy bits that might stick out of the side, or fringy bits or whatever. And then they can kind of put on a cap or put on a headband or whatever, dress it up. They like to kind of have their own hair a little bit, even if they don't have it all, you know.

Conleth Murphy 22:47
Yeah, I think it reminds me of the learning that I have had as a male oncologist treating breast cancer being one of the areas that I treat. As a man, you think when a woman has maybe breast reconstruction after breast cancer, I suppose we're visually oriented, then you think it's all about the appearance of the breast. But the female patients always say to me, it's about actually the shape of the breast under clothes, you know that it's about the contour and about feeling that their body feels normal to them, you know. So that's been a big learning point for me. And I suppose it is always surprised me that relatively few patients end up going on to have the nipple tattooing performed when they've had breast reconstruction. But it's because they're interested in the shape of the breast or the feeling of the breast rather than what it looks like.

Sue Glavin 23:31
But they just want things to be as normal as they should be, or look as normal as they should be.

Richard Paxman 23:36
Yeah, makes absolute sense really does. So one of the things that we are beginning to focus more on as a company based on the work we've been doing with patients, but also the feedback we've been getting over the last couple of years. So that regrowth has become a really key motivator for patients, so less about retention, although of course that is a primary goal. But if patients understand that regrowth is improved, perhaps even if they know they're going to potentially lose their hair, they're motivated to try scalp cooling and continue on scalp cooling. So are you as an organisation seeing faster regrowth with patients that are scalp cooling?

Conleth Murphy 24:20
Yep, definitely. Yeah, yeah, I always say is when they come into my clinic three months later, you know, that's usually the first appointment that somebody has back with me after finishing chemotherapy. And you can see that even somebody who's had some thinning, they will have a much thicker head of hair when they come in to

see me at that point. And I was reading an interesting study from India where they were looking at scalp cooling, and they had very nice digital photographs taken during the treatment and again at four weeks post, and eight week post, and actually very impressive regrowth visible on the photos at that early point post treatment. So I do think that's a message that hasn't always been to the forefront but that is important.

Richard Paxman 25:01
Excellent. And I think we're going to start trying to push that even more. And, again, if it's something that you can deliver in your education sessions, we'd really appreciate it because we know that patients really do see that benefit. There's the Bajpai paper, which was done in Tata Memorial Hospital. In fact, I think she was presenting a poster at similar time to you in Madrid, I definitely met with her. And then there's a couple of other really strong papers out of Japan as well, which you might want to take a look at, so Ohsumi.

Conleth Murphy 25:32
Yeah, I saw one of those as well, actually, because there had been this concern that in Asian patients, maybe the scalp cooling was less effective, but there was a nice Japanese paper showing similar efficacy in the Asian population. Once you get the things right, you know, once you're not using a cooling cap that's designed for a big Irish head.

Richard Paxman 25:55
Brilliant. So we touched on this very briefly earlier, and we talked about the patient actually, who had some wonderful success with AC T. But are you actually using scalp cooling with anthracyclines? Then you must be and do you encourage it? Or are you sort of not as encouraging?

Conleth Murphy 26:12
We're not as encouraging I suppose we have been under pressure with COVID because of the social distancing issues. So we always have more patients interested in scalp cooling than we can get onto the scalp cooling machine actually. And sometimes it comes down to a decision between getting somebody started on treatment within a timely manner, or having access to the scalp cooler. So as Sue said, we have a two arm scalp cooler, but we have been limited to distancing the patients and keeping them further apart. So I suppose we've been trying to encourage the scalp cooler, more in the treatment regimens where we know there's a very higher rate of success with the Taxanes for example, but that particular young woman was extremely motivated and you know, team in the ward were amazing because they pulled out all the stops. They said they realised this was a very important component of treatment for her and it's worked out very well and I guess we may have to rethink things and you know, we may get her to we may have to get her to do a video a 'how to' video. 'Anthracyclines and you.'

Richard Paxman 27:16

It's interesting there as well, we, you know, although a couple of the clinical data reports show yes some poorer efficacy with anthracyclines, and we know overall, it is poorer than the Taxanes. But anecdotally, what we're seeing is more and more success with anthracyclines. And interestingly enough, some of the data in Asia suggests actually, we get better results with anthracyclines over Taxanes, which something we need to definitely learn about more. But I think our messaging now is about well, there is an expectation that anthracyclines will cause more hair loss, but we do encourage you to continue or we do encourage you to try it. Because ultimately, as you're going through the Taxane treatment, your hair's definitely going to start regrowing, and you're going to get back to that sort of full head of hair quicker. So hopefully, moderating patient expectations early on, but talking about regrowth could be something suitable in the future to talk about with your patients, ultimately, when you have more capacity as well. And hopefully, we can help you with that at some point if needed to progress.

Conleth Murphy 28:19
I was going to ask Sue, actually a question if that's okay. I think it was a quite a, you know, it's always a learning curve. When you bring in any new practice, there's a learning curve associated with it. But you know, with the amount of experience you have now with the scalp cooler Sue, do you think we're seeing more efficacy now than we were when we started out?

Sue Glavin 28:38
I do. Yeah, yeah, it's definitely more effective. Yeah. And a lot of people are, I suppose we're training a lot more people have been using it. And it's more effective. And I think even for the anthracyclines, we've definitely seen the definite improvement, things have definitely worked better than they used to before. I definitely think it's working better than when we first started out, I suppose. Yeah, when I was, we can see like successes in it when we wouldn't have been expecting it, you know,

Conleth Murphy 29:08
You've learned all the tips and workarounds.

Sue Glavin 29:12
But I suppose every patient gives you a little tip, like you learn from the patient's really. They, you know, they're on the cooler and they might say, Oh, no look, I put this that way. And I sit this way, or I want to tighten this a certain way or I'm going to tie this band around the top of it or whatever, you know, and like whatever they want to do as well you know, once we're happy that the cap is fitting tightly, and the crown of the head is really tight, you know, because that's where they lose their hair first. So that's an area that we kind of focus on. And once we're happy that everything is kind of to our satisfaction and then if they want to make a few adjustments to make it more comfortable for them, that's fine.

Richard Paxman 29:47

So just moving on to the psychosocial impact of scalp cooling then, and I know we've touched on it throughout but I guess looking at hair loss, slowing down hair loss even not always preventing hair loss in, full moderation of this trauma. What sort of impact do we see on a patient's wellbeing and psychosocial state? Can you sort of describe it in more of a layman's terms? What are patient's able to do better? Do you think? What's the feedback you get from your patients? What do they tell you about it?

Sue Glavin 30:20
Well, I suppose patients, probably mostly women, but we have had men on the scalp cooler as well. And I suppose patients feel like if it's, as they're going on, and it's working, and they kind of are keeping their hair or whatever, I suppose the feedback is that they're out and about a little bit more. Yeah, they're more socially involved in things, going to the you know, the kids school match, or whatever it is, that's important for them, because they look well, they feel well. We had one gentleman years ago, who did the scalp cooling, because he was going for job interviews. That's right, he kept his hair. And it was very important for him to look well, when he was going for job interviews, and the impact psychologically is massive on the patient, because they feel like they're still retaining normality, and self control, and their independence is still, you know, with them. You know, they're not losing control of everything that they want to do really, you know.

Conleth Murphy 31:13
Richard, my mum had cancer when I was just starting out in oncology, and she had always had a bridge with a couple of false teeth on it. And you know, when the doorbell would ring at home, and we were kids, she'd be like, Where's my teeth? They were always in a little bowl by the sink, you know, but when she was going through chemotherapy, the doorbell would ring and she'd be like, where's my hair, and like, run around, looking for the hair. And I remember, you know, when we got married, she had finished a round of chemotherapy, she was there with her wig on, but she was very, very self conscious about it, you know, and she never felt that it looked right, she was always afraid about the wig kind of moving or coming off, you know, there was that paranoia there all the time. I think she would have loved to have had the opportunity to keep her hair for that reason. And to be able to leave the house without, without having to check six times, you know, is the wig on right, and all that kind of stuff.

Sue Glavin 32:08
Actually, I can relate to that too Richard because my mother had breast cancer as well. I was with her when the hairdresser cut her hair. And it was just the most traumatic thing that she's ever been through. And even traumatic for me to have to look at her losing her hair. And I suppose at the time, if we had had a scalp cooler at the time, she definitely would have tried it. She again had issues with the wig, never really used to like it. In fact, my little nephew used to run around the house with it on his head. And she never wore it going out. She used to wear caps and things like that. But always yeah, she felt self conscious. And then about a year later, maybe a year and a half later, I got married. And she was so delighted that she had her hair short and all that it was but as after regrowing for the wedding because she didn't want to wear a wig. It was the one thing she didn't want to

wear at the wedding. So I suppose when you have like kind of myself, when you have personal insight of relatives like our mothers losing their hair, it makes you more aware of how important it is to get it right when you're doing scalp cooling. How big an issue it is for women, especially women, I suppose because we said earlier because it's an outward, it's their outward appearance, they're so conscious about it. And wigs, even the patients who don't do the scalp cooling, they hate the weeks. Yeah, because the wigs don't always sit right, you know. They might look great, now the younger women probably love them because you can get different styles and everything but the older women, they just don't, they're not used them. They don't sit right they come in and they're it's not sitting right on their head and you're kind of like adjusting it a little bit. You know, it's very important, I suppose for women to kind of outwardly feel well, and look well. And I suppose if it had been available for both our mothers, they definitely would have done it. I know my mother would definitely have tried it, you know because was so it was just the most traumatic part of the whole treatment I think actually was when the hairdresser cut her hair and it started to fall out. It definitely was for her the most it hit home then that she had cancer, you know. Whereas up to then I think we'd been talking about it without her really kind of taking too much notice as such, but when her hair came out, she cried and cried and it was definitely the most traumatic experience. Yeah, so I think for women, it's very important you know to offer the cooler, even if it doesn't work, let them try it and let them see how they get on. You know, I just think it's so important you know for them.

Richard Paxman 34:30
And hat's what we really encourage just just to try it out you know it might not work and even if it's not working as well as it should do back to this regrowth, keep on and then like you talked about your mum having shorter hair getting back to sort of that normal feeling sooner than perhaps later. It adds a huge amount of value. I think my mum was the same in terms of the most traumatic part of the treatment initially was her hair loss. Although she when she did lose her hair and she came round to it she coped with it well but she hated her wigs, absolutely hated them. And she had beautiful hair before. She'd end up just throwing a baseball cap on, which luckily, she could pull off but it's just not you is it. It's uncomfortable, and when they're not the best wigs always it's quite easy to tell it's a wig. So it's, it's hard, really hard. So I'm interested to hear what you think about scalp cooling in Ireland. So you guys do an amazing job and you are wonderful with your patients. I think, drawing on your personal experience with your parents has helped, I think understanding the importance of hair loss, which perhaps sometimes other medical professionals don't always see as well. I think we've got 15 centres using scalp cooling in Ireland. If you were Paxman, what would you be doing more in Ireland to make sure other other centres were offering it?

Conleth Murphy 35:51
I think making sure that those myths that are out there are dispelled, you know, because I suppose the one thing that keeps coming up is people are afraid that scalp cooling will somehow give the cancer a sanctuary sites, you know, if the chemotherapy is not getting into the scalp, it could increase the risk of scalp metastasis. Now that has been fairly thoroughly debunked over the last number of years. And I think there was a big stir after those

two big studies in 2017. Really, there was a big move in a lot of the huge US centres to bring in scalp cooling as a standard of care. And I know Memorial Sloan Kettering did which is the centre that I trained in in the States. But sometimes there's so much information out there in oncology, it's so hard to keep up just with the advances in terms of therapy, that we can kind of let the supportive care stuff kind of slide a little bit when we're trying to keep up to date. So it's really important that the oncology community as a whole, both doctors and nurses are aware of the advances in the evidence around scalp cooling. So Hope Rugo did a large meta analysis looking at, I think, 21 studies, and found no increased incidence of scalp metastasis amongst patients using the scalp cooler. So that's huge, but we really need to get that information out there. We need to get it out in the oncology community, and we need to get it out in the patient community, and the patient advocate community as well.

Richard Paxman 37:16
Thank you for that. And it's interesting how that in Ireland still seems to be a sticking point. So you go to other parts of the world, and really safety is low down on the concerns of scalp cooling implementation, it could be barriers in terms of space, or belief in space, lack of space, or chair time, all those sorts of things, but never really safety. But in Ireland, we seem to have this safety concern still. So it's good feedback to say get that meta analysis out there and other data out there. So those are the sites which I agree the Rugo paper, and Hope Rugo is brilliant. She's a great scalp cooling advocate as well around the world, we will try our hardest in doing that, and hopefully doing more.

Conleth Murphy 37:57
I suppose the care about the space is always going to be a concern. Yeah, it's always an issue. We see it in our units, and we're probably under a little bit less pressure than some of the units around the country that are just absolutely chock a block. So that is going to be the other concern. Always.

Sue Glavin 38:13
Yeah you need to have time on the cooler, you can't be rushing it. You have to have this specified time on the cooler pre and post cooling. And sometimes we were it's possible we might have somebody on it in the morning and somebody else in the afternoon. Obviously not the same time because of COVID. But like we're using the scalp cooler twice in the day, as much as we can. But yeah, space is an issue is a problem. And you know, accessibility to it then becomes an issue.

Conleth Murphy 38:38
The biggest thing you need is a champion, you need by in. So Sue is our champion. Yeah.

Richard Paxman 38:45
She's our champion too. But no, that's really good feedback. So last question for you, then. We often use the slogan changing the face of cancer, and it can mean a number of different things for different people. So what does it mean for the both of you?

Conleth Murphy 39:05
Changing the face of cancer, I guess, managing the whole person, managing the whole person probably, you know, cancer is something that happens to a person, but it shouldn't define their person for the rest of their lives. And the more we can do to make that person's journey through cancer treatment, as easy as possible, and not to take out the rest of their lives in the process, the better you know. So that's about better treatments. But it's also about, you know, the people that you encounter when you come to the day ward for your treatment making you feel at home. It's about the supportive care that we use. It's about allowing people who are parents of small children to be able to interact with their children and not feel that they are kind of doing less of a job as a parent. It's about people who are looking after elderly parents be able to interact with them and so on. Limiting the impact of cancer on the individual.

Sue Glavin 39:57
Yeah, I suppose it's about people, not letting it take over their lives, just because they have a cancer diagnosis like they have a life. And it should be just coming into the day ward once a week or twice a week should be a small fraction of it all. I mean, it's about them, you know, maintaining their independence, keeping their identity. Yes, you have cancer, but you still have a life, you still have to live it. Keep up your regular activities as much as you can enjoy your life, you know, to try and let them carry on as if it's only just a little hiccup along the way, not a major incident, you know. I think just trying to let them understand that, you know, yes, it has huge impact when you're diagnosed with it, but like it can't, not to let it to take over completely, you know, psychologically, they have to, you know, be able to kind of do the regular things that they're always doing. And it's about encouraging them to do that and sort of supporting them in that way.

Richard Paxman 40:51
Thank you very much. That was great to have you both on today. Really looking forward hopefully to see you in person in the future. So when time allows and travel allows, I'll get over to Ireland and come and see you in Cork. Thank you so much for today. I really do appreciate it.

Conleth Murphy 41:07
Thank you. It was our pleasure.

Sue Glavin 41:08
Thank you. You're welcome. Delighted to be of help.

Richard Paxman 41:13
Thank you for listening to this episode of changing the face of cancer. Everything we have discussed today can be found in the show notes. In our next episode from the National University Cancer Institute in Singapore, I'll be joined by Dr. Raghav Sundar, Consultant in the department of haematology, oncology. And Aishwarya Bandla,

senior researcher, to discuss their research and one of chemotherapy's hidden side effects - chemotherapy-induced peripheral neuropathy.