Head and neck cancer forum

Saturday, July 21, 2018

Panel discussion with A/Prof Martin Batstone, Dr Megan Carroll, Ursula and Rene Kloeti, Lucy Bailey and Anna Gordon

ANNA GORDON: I just wanted to mention, we have also Ursula Kloeti who joined us, whose Rene's wife. So carer's perspective, any questions from carers, perhaps, things like that. Okay. Has anyone written questions or is anyone ready sort of to kick it off? Sure.

PARTICIPANT: I have two questions for Dr Carroll. One of them is Proton therapy, there is a treatment for cancers in the United States. The second one that you didn't cover, problems that relate from chemotherapy treatment - chemobrain.

ANNA GORDON: Sorry, I will just repeat the question for the sake of captioning and the video. So the question was about Proton therapy and chemo brain?

MEGAN CARROLL: I will start with the proton therapy question. Proton therapy is a different kind of radiation particle. It is similar in a way to photons, but the benefit is that they have an ability to stop at certain depths and because they don't travel all the way through the body like a photon does, we can hopefully limit long-term side effects to those organs at-risk, that might be sitting just underneath the cancer. You may have heard in the news recently that Adelaide was successful in obtaining a Proton machine and we in Queensland are very keen as well to invest in that technology. It is very expensive and that's why it's more common in America and in Europe as well, for that matter. But it is something that we as a nation are trying to obtain. Not only would it have a benefit for head and neck cancer patients, but it has a very positive benefit for our paediatric patients as well, because they are prone to long-term side effects when they grow up. So we know that there's been some work done; and hopefully one day we will be able to sit here and talk about the benefits of proton therapy and hopefully that will be something down the track that we will be using.

With regards to chemobrain, my specialty that I am training in is radiation. We do learn a little bit about chemotherapy, but it is not my expertise. I don't think there's a lot of data out there looking at the long-term side effects of forgetfulness. I think that's what you were sort of meaning?

PARTICIPANT: Yes.

MEGAN CARROLL: I think it is a combination of probably the physicality of chemotherapy but, also, the emotional side of treatment and that diagnosis which probably is expressing itself in that physical manifestation of chemobrain. There probably is a lot more to it than what we realise and hopefully through further research, we might be able to have a better understanding of that grogginess almost that people experience and hopefully come up with ways that we can treat it in the future.

ANNA GORDON: Anyone else, questions?

PARTICIPANT: Yes, I have one. Do you get sick of cancer; do you get sick of dealing with it? I get sick of being here.

ANNA GORDON: Can you repeat the question?

MEGAN CARROLL: The question is "do you get sick of cancer?" .

RENE KLOETI: Who are you asking?

PARTICIPANT: I am asking whoever wants to answer. Doctors will be good ;-).

PARTICIPANT: I think you mean by being here, not being in this room.

PARTICIPANT: However you want to interpret it; that's an open question.

MEGAN CARROLL: No, it is a good question. I think in any career, when you put your whole passion into it, people can have burn-out. But it is my passion. I loved my job as a radiation therapist, but I wanted to delve deeper into the treatments and how I could be part of long-term care, not just treatment phase. It can be long days; it's hard work; but at the end of the day, it's always worth it. We are human; we are all human and some days you do get tired, absolutely; but, yeah, when you come in and you see a patient that you have known for years, there is nothing better than-----

PARTICIPANT: Okay.

MEGAN CARROLL: -----seeing them able to live a good life.

PARTICIPANT: Yeah, go on, have a crack ;-).

MARTIN BATSONE: All the trainees tell me these days I am getting too philosophical, usually.

PARTICIPANT: Rip into it, brother ;-).

MARTIN BATSONE: Uhm, it's a good question. I don't do much other than cancer surgery and when you get into cancer surgery, you are interested in the technical aspects of it; using your hands, trying to get a good outcome, seeing things that work and don't work. But as I have got further and further into my career, I would echo exactly the same thing that Megan said. I like talking to people. Of course, there are very bad days. You have young people who don't have a good outcome; that's emotionally draining and destroying for a clinician because you have failed, haven't you, or your team has failed, the whole system has failed. But on other days, you give someone a hug and you say "goodbye, it's all fixed, go and enjoy your life". We have the same conversation that Rene had, that people want to come back and say "hello". You know, that's incredibly rewarding on the other side of things. No-one is in cancer therapy for money, that I know anyway. We are all in it because we want people to get better. And it's complex; it's interesting and you have an emotional connection with your patient. So it's rewarding.

PARTICIPANT: Thank you.

RENE KLOETI: Well, of course, there are consumers and we see ourselves as helping you doctors stay in the job, getting good income and make us feel good at the same time.

PARTICIPANT: Thanks, Rene   :-). I have got a question-----

RENE KLOETI: No, sometimes, you have to think: when it happens, it is pretty shitty, actually; devastating and we were shocked to the core. But we have a very good coping mechanism. I am very lucky to have a wonderful wife and family, wonderful friends-and we have had some adversity in our lives, with family, family tragedies; lost dad at a young age, my mum died of cancer. We had a business; that wasn't always tops. So we travelled; it wasn't always rosy, backpacking, living on the cheap, but you cope. You cope with life. When this cancer hit us, after having a good cry, and then getting Michael to join us in Panama, we sat down the three of us and said, "Now, okay, well, this has happened. Now, what do we do?" And we very quickly accepted the reality and said, "Okay, practical things. We have got to return home; and start the fight." Because we were retired, we had the time. I appointed myself "project manager of my life"; with the assistance of my wife; and we went from there. And a bit of luck as well along the way. And they say "luck happens when preparation meets opportunity", and that's how I think in terms of this immunotherapy. I had known about immunotherapy for many years over in Europe and I kept my ears open; and when I heard about it here in Australia, I was prepared, and the opportunity came; and I grabbed it and the rest is history; and I'm still here.

PARTICIPANT: To Dr Carroll: could you please give advice to an oral patient with oral necrosis and osteoporosis, who has been on oral Bisphosphonates. A bone from the maxillary helped. Do you think this patient should go back on an oral Bisphosphonate and I do have one more question but I would like that one answered first.

MEGAN CARROLL: Sure. The patient had osteoradionecrosis of the jaw and-----

PARTICIPANT: Oral necrosis.

MEGAN CARROLL: Oral necrosis and they were using a Bisphosphonates as part of the treatment for that. And did they have surgery as well? They did, okay. So that's probably a good question maybe for both of us. We can try our best to answer that. It is difficult to answer-----

PARTICIPANT: We have Dr Batstone's answer. Could we please have your answer?

MEGAN CARROLL: Well, I would love to give you an answer, I really would. I'm a radiation trainee.

PARTICIPANT: I know who you are.

MEGAN CARROLL: So I am probably not qualified to give you an answer as much as I would love to. It's a complex question because the disease of the side effect is both complex and… the irony with Bisphosphonates, is that sometimes they can be used to treat osteonecrosis, but the drugs themselves, that is a side effect as well. They can be used for people who - for example, ladies who have breast cancer, if it travels to their bones. Sometimes they have bisphosphonates to help with bone stability, but that can cause risk of necrosis in the jaw. So I really couldn't give a conclusive answer for this case, if they should/shouldn't go back on it. It probably it would be something really that their treating team, who knows all their personal details, would have to sit down and chat to that patient; do a physical examination as well, to come up with the right answer.

PARTICIPANT: Could you give an opinion of any patients that you would know of then?

MEGAN CARROLL: Ooh, uhm, every patient is different. We were talking about not just from a psychosocial point of view but from a physicality point of view as well. Cancer in its many different forms, also presents in many different stages; and that has to be taken on from a personal perspective. Medicine is moving more into individualisation of treatments. What we are hoping to be able to develop is looking at an individual's case; sometimes even genetically profiling their genes, and making a decision specifically for that individual. So I think it's a little bit harder, probably a bit out of my field, to give a broad definition. But Bisphosphonates ironically can sometimes help with osteoradionecrosis, but they can sometimes cause it as well. So it is a dilemma, unfortunately. But hopefully with a broad treating team, they can come up with the right answer for this individual.

PARTICIPANT: My other question is: could you give an opinion and some description of Frey Syndrome?

MEGAN CARROLL: I'm not aware of what that syndrome is.

MARTIN BATSONE: I can answer that. Frey Syndrome is after someone has had a salivary gland taken out and the nerve that makes you salivate, that goes to that gland, regrows and gets an abnormal connection. It is like joining up a motorway to a road that it wasn't supposed to go to. The nerve that makes you salivate joins up to the nerve that makes you sweat. So when you eat, you should salivate, that is a normal response in your body and that nerve instead is going to the skin because there's been usually surgery in that area; makes the skin sweat instead. So that's what Frey Syndrome is. And there are several different treatments.

PARTICIPANT: Very good explanation.

MARTIN BATSONE: -----there are several different treatments for it, from mild to wild. The simplest treatment is to put anti-perspirant on the skin; that can work. You can use botox, which is the drug that people use to have their wrinkles ironed out; that will stop the nerve transmitting the signal, blocks the pathway; or you can even have more surgery but that's an extreme solution.

PARTICIPANT: I have been waiting for that answer for years. I don't sweat anymore but I used to profusely when I ate. So that's it? Good.

ANNA GORDON: There was a question there. Yes?

PARTICIPANT: There's been a lot of research done over the last couple of years around head and neck cancer. I know that the QUT has done a lot of research into HPV positive and finding, using swabs to give an early detection of HPV. They are also working with blood at the moment, to detect SCCs in the blood before it becomes a big issue.

Over the 14 years, we have seen a lot of changes in head and neck cancer treatment. What do you guys, as well as you Rene, what do you think as the biggest change that's happened.

ANNA GORDON: Could you repeat the question?

MEGAN CARROLL: There's been lots of change in head and neck cancer and the question specifically was: what do we think the biggest changes have been?

From a radiation point of view, the ability for us to conform our radiation therapy very tightly to cancer is probably one of the largest changes that we have seen. And that is even only within a short period of time. When I was a graduate radiation therapist, the way we used to treat is very different from the way we are treating it this day and age. And it's a combination of not only improving the actual treatment machines that deliver the radiation, but our new planning programs that allow us to predict where the radiation will go and what dose; and, also, our ability to see how a patient has set up on that treatment couch.

Previously, we could only take X-rays on the treatment couch. Now, we are taking cone beam CTs, which means we can see the soft tissue. So occasionally, we can see the tumour; and when we are inserting little gold seeds even to some cancers, like prostate cancer, "Yes, we are coning down nicely, therefore we can escalate the dose; but, also, we are minimising dose to those healthy tissues." Immunotherapy has been mentioned a lot today. It is very, very promising. There are lots of trials coming out. It is essentially a new form of treatment that enables the T cells, part of the immune system, to recognise cancer; which would otherwise invade or hide from our own bodies.

And what we are looking at is: "what's the best way to use that? Should we use it before or someone has surgery? Can we use it together with radiation therapy?" There's lots of different ways that we can use it. So to not only developing immunotherapy, but "what's the best approach to use it?" And "who benefits the most?", is the other research area. We need to find out which people/cancer is going to be more susceptible to immunotherapy.

MARTIN BATSONE: Do you want me to answer as well, Marty?

PARTICIPANT: Yeah, sure. I am interested because I have seen a huge change, moving forward. And to me, the biggest change has been with the support group: when we first started, the doctors would come and say, "This is what happens when you get head and neck cancer." And we would say, "No, it didn't happen to me." So we have engaged in this conversation between the patients and the doctors; and now we are starting to see - sorry, Rene, I hate the word, too - "consumer input" into what's going on-----

RENE KLOETI: It's alright ;-).

PARTICIPANT: -----and that's been the biggest change. But everyone is talking about, "What happens when you get head and neck cancer?", because you are talking about eight clinicians and one person; and everybody's different. Anybody want to comment on that?

PARTICIPANT: Yes, well, with the cancer treatment, everything that I found as a service from the hospital, which is fantastic - I greatly appreciated it, but the group meeting that I have had here has, you know, met other people with the same experiences and the information transfers not as a medical reason but it is coming from someone who has been through it, to you; and it's probably the most helpful thing I have come across. It's been great, this whole group, out of everything. The hospitals have been great, too, very good, but the group was probably the best that I have come across.

RENE KLOETI: And you still need to come to the pool, join the swimming.

PARTICIPANT: Yes, I did that when I was younger. Chlorine is too much. Get the saltwater.

RENE KLOETI: No, the water-soluble cancer cells

PARTICIPANT: Could we hear Dr Batstone's version of changes over his career and treatment?

MARTIN BATSONE: Why, things have gotten better?

PARTICIPANT: Changed, yes.

MARTIN BATSONE: Uhm, I can. I think it's going to be really boring. It's going to include Megan's answer and say: I think things have improved because everything we do, we have got better at. Radiotherapy has got better; surgeries got better; chemo has got better. Not just the drugs have got better because there are new drugs but everything is incremental. Probably the last thing you want to do, when - you said you get sick talking about cancer, I felt it was obliged reading for me, to read “Cancer The Emperor of All Maladies" which is a book that somebody might have heard of. It is really thick, so don't engage unless you are committed. If you go back 50 years ago, people thought they would give them a drug, one big bullet and everyone would be cured from cancer; and that's not happening. Cancer is almost becoming a chronic disease. Rene, sorry to pick you out, you are living proof; we got a bit better at everything. The cure rate has gone up. It's got a lot better. I am giving a talk next week on the cure rate for oral cancer. In the 20s, it was 30/40 per cent. And now it's 80 per cent and we are still doing surgery and radiotherapy and chemotherapy, same three treatments; but we are applying them better to individuals; trying to decide who gets what in what circumstance. It is not about "everyone gets everything all the time". It is "who gets what, in what circumstance, that gives them the best chance?" And there will be more incremental progress, that will be my suspicion. Immunotherapy is not going to cure every one of cancer all of a sudden but it's going to cure a proportion of people and make a proportion of people live longer and do better; and it's boring/exciting at the same time.

PARTICIPANT: Martin, there's an added aspect to that and that is: with surgery, re-construction, thanks to people like Martin, has become a lot better. It used to be sort of "cut half your mouth/head whatever off and you live with that." Since Martin's come back from overseas, re-construction bits that have been cut out have gone forward in leaps and bounds because of people like him.

ANNA GORDON: Just thinking of time. We have probably time for a couple of questions but I was wondering, we have also Rene, Ursula and Lucy here. Are there any questions for either of them?

PARTICIPANT: I would like to ask Ursula, just for transparency sake, I do know Ursula and Rene, in the head and neck cancer support group, but Ursula: I am three years post-treatment and one of the big things I find hard to grapple here is just that fear is cancer returning; and all the logical things, but the illogic side is the hard bit. I had a conversation with Rene who said, "Yeah, I don't have that problem anymore." -----

RENE KLOETI: Don't fear it anymore.

PARTICIPANT: -----so how did that impact you? Because I thought it was interesting how you had your loved ones around you and Judy was saying about the impact on them; so that's what I would like to hear, your perspective?

URSULA: The second time was just as much of a shock. Sorry, should I have repeated the question?

ANNA GORDON: Yes, please.

URSULA: How the recurrence of Rene's cancer affects me. And the second diagnosis was just as shocking as the first one. It was, well, we had to start coping all over again; and luckily, I did have some coping mechanisms that work for me, like yoga and walking and talking about things and writing things down-----

RENE KLOETI: Painting.

URSULA: Painting, yes. I do have some coping mechanisms. And I find them also very helpful. But the diagnosis second time round was very bad, too.

PARTICIPANT: Great.

ANNA GORDON: So maybe one more question. I know Gerry, you have a question-----

PARTICIPANT: This is a question for Lucy: my days for treatment at the PA, I am now at RBH for everything, when you weren't coping, the button they pushed was a consultation with the psychiatrist which I didn't find helpful. I found more helpful - they want to pump you with drugs - I found it more helpful talking to the social worker and psychologist but they didn't have that available then; because you go to the psychiatrist and within five minutes they are writing a prescription and that is not cognitive enough for most people who are going through coping problems with cancer. What's your experience?

LUCY BAILEY: The question was that: some time ago, when you were treated, things were very different; and when people expressed distress, perhaps, the practice was to call a psychiatrist in at the hospital to see the person. What this gentleman here found hopeful was actually the social worker, talking to other people in the Health team. Looking at a perspective about how things might be a little bit differently now - is that right? Does that sort of encompass-----

PARTICIPANT: Yes.

LUCY BAILEY: Yes, lovely. I guess there are many options. What we do now: we identify that stress is part of cancer and the cancer experience. There is education and within the hospital system, some of the training has been conducted by Cancer Council in the past. So training nurses, doctors and allied health professionals in cancer teams, about how to pick up stress, what cues to look for, and how to identify if someone might need some psychosocial and emotional support. I think that's come a long way. We talk about it so much more, with the Health teams and we have quite close connections with many of the treatment teams. And we try to educate as many of the Health Professionals in the community as well about referring people to 13 11 20. We drop those cards everywhere. Every time we go over to the treatment centres, we take them to hospitals, we encourage the Health Professionals to give that card. If they are in a consultation and the person is distressed or if they need to speak to someone, to feel confident to refer them to us. But, also, within different treatment centres, there's support that can be available, that might be in the form of social workers; sometimes there's hospital psychologists. There are a range of different options. So it might depend on where the person is situated, which hospital, where they are regionally; but certainly we really encourage people to be in touch with us and then we can chat about what they might be looking for.

We talk to people more broadly about "who are the people in their circle of support?" For some people it might be their GP, "I feel confident and comfortable chatting with my GP with where I am at." So we encourage people to put themselves - sometimes draw a diagram, put themselves in the middle, a circle, and map out, "Who are the people in their circle of support to talk to about their feelings?" For some people, it might be local Health Professionals; it might be their treatment team; it might be calling 13 11 20; there could be a whole range of people in there; and to really consider who they can reach out to when they are needing to talk about how they are feeling.

ANNA GORDON: Thank you. Unfortunately, that's all the time we have for today. Thank you so much to all our speakers.