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Gallagher, Carol

Subject: FW: information on I-131 Patient Release topic

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From: Gary Bloom [mailto:gbloom@thyca.org]

Sent: Thursday, March 03, 2016 1:37 AM

To: Howe, Donna-Beth <Donna-Beth.Howe@nrc.gov>

Subject: [External_Sender] information on I-131 Patient Release topic

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Dear Donna-Beth,

My name is Gary Bloom and I'm the Executive Director of ThyCa: Thyroid Cancer Survivors' Association, Inc. and I am also a 20+ year papillary thyroid cancer survivor.

ThyCa has a very comprehensive, medically-reviewed website, www.thyca.org. It follows the entire patient journey from diagnosis through treatments to include lifetime monitoring. We include radioactive iodine, testing and ablation, if and when necessary; also, discussing precautions that should be utilized.

We also provide support services that are identified on our website, both face-to-face and electronic discussion groups, which allow people to speak to others about their own experiences. This is not medical advice. It is meant to share experiences, to try and help people either create clarification in their journey or to help them clarify ideas for questions to ask their medical practitioners when the opportunity presents itself.

In considering the possibility of using radioactive iodine (I-131), I believe it's important to keep in mind a number of factors, including:

1. Is the patient hypothyroid? Many people are still being treated in a hypothyroid condition versus using Thyrogen as a part of the treatment process. Patients who are hypothyroid oftentimes have a diminished level of comprehension. Medical professional must account for this otherwise the patients may not understand or retain the instructions.
2. Going through I-131 is an experience unlike any other, whether it is using a small testing/tracer dose or a much larger ablative dose. The medical professional has to deliver instructions, but the patient has to be able to understand them. This means the dosing facility people need to know the health condition of the patient they are working with (withdrawal vs. Thyrogen preparation).

I would encourage in any circumstance, but especially if a patient is hypothyroid, that is would be great to have a loved one or friend in the appointment so there is the opportunity for better receipt of instructions.

I have been treated at two different facilities, and I can only speak with confidence of my own experience. I do believe most, if not all, medical professionals are sharing good information, but that doesn't mean it is being heard well or received well or understood well. We have to consider what we do to improve the receipt of information as much as what do we do about the delivery of the information? Having more than one person hearing the information would be a good step.

Timing matters. In my life as an advocate, I'm amazed how many people I have met who said their sequence of events was, "I'm here to take this dose of radioactive iodine. At this time, the medical professional says we're going to talk to you about what precautions to take." This is a bad sequence. Instruction has to take place with enough time for the patient to make adjustments to his/her personal situation. I don't think that happens very often, but if it happened once or twice, it is too many times.

It is very important that the sequence be reasonable. Precautions can be revisited after the dosing and should be, but there has to be a conversation at least 2-3 weeks in advance of being treated, so that there is a quality dialog. This allows for discussion about the entire process in front of the patient, including discussing the Low Iodine Diet, whether or not

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Thyrogen will be involved, understanding precautions, does the patient have somewhere safe to stay (if not in the hospital), the possibility of not treating with radioactive iodine. At least some questions to consider in advance:

- What is the home situation?
- Is there somewhere for the person to go once he/she has received the radioactive iodine if the home situation is a problem (shared bathroom, little children, pets, 1 bedroom, etc.).
- Who can do food preparation and clean-up?
- Who can care for young children, or elderly family members, etc.?
- What type of transportation will the patient use? Private or public?
- Will the patient need to ride an elevator?

People are being treated with radioactive iodine. What are we going to do with them? There is a period of the timeline we as patients are hot; we are radioactive. And so, we patients need to have a plan. Again, it is necessary to make the plan before being treated not after.

To me, the messages are:

- Are there enough people in the meeting between the medical professional and the patient for the patient to walk out with good information and understanding?
- Does the patient have mental acuity? Is the patient hypothyroid or being treated using Thyrogen?
- Does the patient actually have mental acuity, regardless of hypothyroid or Thyrogen? To be blunt, every patient has a different level of intelligence. Additionally, some very bright people are distracted because they have recently been told they have cancer. It's also possible the patient is mentally overloaded due to other factors in his/her life. This can also be enough to cause the patient to not understand the instructions offered.
- The optimal process would be to provide the patient with written instructions to read in the waiting room while waiting to meet with the medical professional. Then, when the meeting takes place, the medical professional should encourage the patient to take notes during this preliminary meeting. The medical professional should also ask some questions to ensure that the patient understands. He/she shouldn't accept the dismissive "I understand." Confirmation is needed!

I can only speak about a cancer scenario. So, I am not discounting the hyperthyroid patient being treated. But when a person is told they have cancer, some people become anxious and their ability to hear instructions, which is specialty instruction because it is about their health, is diminished. ThyCa always encourages patients to have at least one additional person with them in medical meetings. Additionally, what is the patient's ability to digest this special information? This medical experience is not as simple as trying to find a loaf of bread. This is special information that most of us are only going to hear once or twice in our lifetime, and it is out of the norm.

Consequently, the person giving this instruction has to be aware that the person receiving it maybe a little off-balance mentally due to the above factors, and that the information being addressed is unique. We talk about level of understanding in terms of just a general educational level (4th grade level or maybe 6th). We encourage lowering the message down to a lower level of education, using more routine words, less big technical terms, and accounting for a language factor. In the U.S., we live in a melting pot. I am reminded, when I lived in California years ago, at the time you could take your driver's test in 38 languages, which I thought was pretty remarkable. Now most facilities can't handle that, and I am not asking them to, but they need to make sure that the patient can understand the medical message.

Also, this process needs to account for what happens when the patient is not a native English speaker and the medical professional is a native English speaker or vice versa. We need to have a process to make sure that the message is delivered and understood. It isn't enough to say message delivered. How is the message heard?

Medical professionals need to be sensitive to the anxiety of the person who ingests the radiation because it is not routine for us as patients.

I believe medical professionals should work off of a standard checklist of instructions so that all patients would get as close to the same instructions regardless of whether the facility doses one patient or 100 patients a year. Ideally, the patient and medical professional should each have a copy of the same instructions so the medical professional can say "okay, item 3 (as an example), and they both know what is being discussed."

Every facility that treats people with radioactive iodine should have to ask some very basic questions such as how are you going to get home after being dosed? What is the method of transportation? That kind of thoroughness is imperative, and this is an example. It may be too basic to make the point. But this type of question should be asked at all dosing facilities. Every patient who may be dosed should be asked: how are you going to get home after you are given this radioactive material? It's important to remember the person sitting in the next seat (of the bus or train) could be a newly-pregnant woman who doesn't show it. Another question: Are we exposing people unnecessarily? Will I get on an elevator next to someone pregnant? We need to ask this type of question over and over about so many scenarios.

Now these could be patients that are released immediately after receiving their radioactive iodine or they could be patients that are released after they have been isolated in a hospital for a day or two, or possibly only delayed for a few hours before they are being released.

Instructions should be reviewed three weeks in advance of the treatment, and again the day of treatment (or release if different). Again, the importance of this timing is it allows for planning. It is a perfect opportunity to say, "Here's what is in front of you to the patient. And now, let's really delve into these instructions about what you need to do before we get to the dosing and, then, what we are going to need to do during it," and then after treatment. Reviewing instructions in the sequence of before, during, and after, breaks it up allowing for better understanding of each step of the process.

Any instruction has to be carefully presented from an understanding level or simplicity level, but, then, there the instructions also have to be comprehensive or thorough. These instructions can't be so simplistic that they miss points that are very important.

Where you going to stay? What kind of home life do you have? Those are questions that need to be discussed in advance of dosing because the patient may have to postpone dosing, and this should be determined before the facility has purchased the isotope and before the person has gotten mentally anguished over what is in front of him/her.

It is this idea of the worst scenario where there would be no conversation until after treatment. That is the definitely the one that has to be addressed most proactively. But I think that all of these situations should be addressed to be as preemptive as possible. Let's give as much opportunity to build a plan, a roadmap, before we even go into any danger points.

Of course, equally, there is always a chance that, once we go down that path of planning for radioactive iodine treatment, that the physician and the patient will ultimately decide that it is not necessary. So, that also is part of that upfront discussion.

For the patients, to make them understand it is possible a treatment won't be necessary, and up until the last minute, we could go down that decision path as well. I think it is important to make the patient understand all of the circumstances and possibilities.

Medical professionals have to work across their areas of expertise. As we discuss ways to improve this process. One of the complications is when the patient is working across medical centers or out in the community, as opposed to within a center where all of the specialists work together routinely. The process is easier in a center than with doctors who are not part of the same institutions. The question exists how do you get people on the same page when they are not working together as a routine.

The best medical outcomes will likely result when patients are actively involved and a partner in their care.

Patients need to be informed that lemon drops or sour candies, and hydration are very important after treatment. Hydration increases the output, and avoids retention of radioactive iodine in the salivary glands which is shown to be lower in the more hydrated state. It also increases the likelihood of faster excretion of the iodine that does not end up in the target areas. Another advantage of hydration is it will cause the need to void repeatedly. That reduces the potential radiation dose to the bladder.

As part of a feedback process, the medical professional should ask after the fact if the patient followed the instructions. Not with a general question, but based on notes, should ask questions such as "you'd mentioned you live in a one

bedroom apartment with a spouse and an infant, what was your living situation after you were treated?" This should result in improved instructions over time.

This will allow for answering the question: Did I get my message across to the patient? And did I, as the patient, follow those instructions?

ThyCa, as a patient organization, needs to really step up our side of this process and try to make sure that we have very visible and even more comprehensive materials, so that we can be there as an information portal to patients. We don't provide medical advice, but we can create medical empowerment to people who we reach which will allow them to initiate processes when they aren't aware of them routinely.

The medical community has to initiate or those of us who have walked the path before have to help try to lay it out. Ideally both will occur.

I think one consideration would be for patient organizations, in addition to providing the information about what kind of side effects to expect or what kind of precautions or personal experiences you share with the patients who are going through it now, I think it may be important if you also mention that patients insist on having a discussion with your nuclear medicine physician well in advance of receiving your radioactive iodine. More and more patients will read that in advance, will start thinking about it and act on it

Thank you.

Respectfully,

Gary

Gary Bloom

Executive Director

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- Visit our website: www.thyca.org
 - Free education, support services, and awareness materials
 - Research fundraising and thyroid cancer research grants
 - September is Thyroid Cancer Awareness Month, sponsored by ThyCa
 - Come to the 19th International Thyroid Cancer Survivors' Conference in Los Angeles, California, October 21-23, 2016
- Visit our YouTube Channel: <https://www.youtube.com/c/ThyCaThyroidCancerSurvivorsAssociationInc>
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