

Gallagher, Carol

From: Bonnie Senger Karberg <bkarberg@gmail.com> 2017
Sent: Thursday, June 22, 2017 3:24 PM 2016 JUN 23 AM 7: 48
To: Gallagher, Carol
Subject: [External_Sender] my experience with RAI

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Ms. Gallagher,

I was diagnosed in June 2013 with Papillary Thyroid cancer - when looking to extract a bad parathyroid gland. TC. I had 2 surgeries. In a followup with my Endo at the end of August - she told me I needed RAI and I had to go on a low iodine diet for 3 weeks. I was given a poorly copied list of foods I could and could not eat for 3 weeks. That was it for any info.

I did research - as half the foods I could eat to prepare for RAI - I cannot eat for other health reasons. That is when I found THYCA.ORG.

I also researched issues regarding septic systems - as we live in a rural area. I did find out that my only concern was not to have it "cleaned" for 6 months after RAI.

I found out through THYCA about separation and living in a separate part of the house and using plates, cups, and utensils that could be washed separately. So I knew I would stay down in the lower level in the family room and spare bedroom for the duration. EVERYTHING I learned to prepare was through THYCA or other research.

The day of the RAI - I traveled the 70 miles to the hospital with my husband. There I met with the radiologist and he told me about side effects - nothing else. I signed a permission form and a form saying I was informed of side effects - 5 minutes max with the radiologist. Then I was given the 2 pills by the tech. I was given a card with the hospital's phone number to call if I got sick so that their version of the hazmat team would come and clean it up. When I told them I was 70 miles away - they told me I was on my own. I was given a card to carry good for 3 months in case I set off detectors in building or airports. I then walked through the radiology waiting area, the hospital hallways, the main waiting area for the hospital. Was there anyone I should not have been near - I don't know.

We drove home and I sat in the backseat of the pickup truck and had my head out the window. We did speed but figured it we got stopped my husband could tell them I was radioactive and had to get home. Fortunately we made it without incident. The total time in the truck was 80 minutes- 20 minutes past the exposure time my husband should have been near me.

I came home and went downstairs - keeping the dogs upstairs with a gate. I did not come up for 5 days until it was time for the whole body scans - again another 70 mile trip one way.

Again - from THYCA I knew to stay away from pregnant women and young children.

I have heard stories about staying in the hospital - but that was never even explained to me as an option..

Amazingly - the number of newly diagnosed THYCA patients that were not told anything is amazing. A reach out occurs daily. A home plan that I devised worked for me and my husband and animals. But I devised it - with no help from the Endo or the radiology department at the hospital.

My advice is a HELPFUL brochure about the dos and don'ts of RAI. Who provides it? I don't know if my previous Endo would have. My new one would. Does it get sent out by the radiology department at the hospital once arrangements are made? Provide it at least 4 weeks in advance. Include isolation, septic systems, bathing, toilet flushing, clothes, washing, kitchen utensils, and non-washable items like laptops, cell phones, protecting your teeth (I was not warned and I broke 3 teeth in 3 months post RAI), sense of taste and smell post RAI, etc. Given the appropriate info - anyone can deal with this at home unless circumstances would require a patient to remain hospitalized. But even then there are limitations when you return home.

I am educated - an MBA - recently retired - living rural and had a helpful spouse. So - I did OK. I also am very involved in my healthcare and well being - so I did a LOT of research. That came from taking care of a sister with bone cancer and a mother with Alzheimer's.

This is probably more than you wanted to know. But hopefully some of the info is useful.

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