

PUBLIC SUBMISSION

As of: 2/1/16 11:02 AM
 Received: January 27, 2016
 Status: Pending Post
 Tracking No. 1k0-8nmp-xi3a
 Comments Due: February 16, 2016
 Submission Type: Web

Docket: NRC-2015-0020

Nuclear Request for Sodium Iodide I-131 Treatment and Patient Release Information

Comment On: NRC-2015-0020-0014

Sodium Iodide I-131 Patient Release Information Collection; Request for Information

Document: NRC-2015-0020-DRAFT-0022

Comment on FR Doc # 2015-29027

11/16/2015
80 FR 70843

11

Submitter Information

Name: D G

RECEIVED

2016 FEB -1 AM 11:02

RULES AND DIRECTIVES
BRANCH
150110

General Comment

See attached file(s)

I am not providing contact information just in case insurers regain the opportunity to exclude preexisting conditions.

I added the Word file with website links because some of them didn't work in the pdf file. The pdf addresses all elements of the inquiry as expressed in the public meeting on Jan. 19, 2016.

Attachments

website information

I-131 release comments from a patient perspective

SUNSI Review Complete

Template = ADM - 013

E-RIDS= ADM-03

Add=

D-B Howe (abh)

1. **Web Site Information**

Link to the NRC brochure on patient release guidelines with help for people to prepare for isolation to protect their families and the general public.

Listing order is NOT a ranking.

Facebook group: "THE LID Life Community"; this group is a forum for patients to share information about the low iodine diet and it includes information on what members did for their isolation. Some medical professionals check it out. Many people have posted their isolation instructions. Reading them shows a variety of stringencies. Also there are members from other countries, so we can see how other nations set expectations for isolation to protect the public.

Links specifically about radiation safety precautions:

http://www.thyroidcancercanada.org/userfiles/files/RAI_precautions_Ian_Adam_2010_revised.pdf

Article updated in 2010 with precautions adapted from the UK>

http://www.thyroidcancercanada.org/userfiles/files/I-131_Patient_Release_ATA.pdf

Article entitled "Radiation Safety Precautions in the Treatment of Patients with Radioiodine (¹³¹I): Best Practice Guidelines of the American Thyroid Association

<http://www.thyca.org/download/document/184/ataradiation.pdf>

http://www.thyroidcancercanada.org/userfiles/files/ATA_Radiation_Safety_Guidelines.pdf

Different links to a 2011 article in THYROID entitled "Radiation Safety in the Treatment of Patients with Thyroid Diseases by Radioiodine ¹³¹I: Practice Recommendations of the American Thyroid Association." This article covers treatment of hyperthyroidism and remnant ablation.

Other links, many less technical:

www.thyca.org

<http://www.thyca.org/pap-fol/rai/>

Thyca article on RAI treatment.

https://en.wikipedia.org/wiki/Isotopes_of_iodine

<https://en.wikipedia.org/wiki/Iodine-131>

Wikipedia: Isotopes of Iodine and Radioactive iodine articles for background on energy emitted and half-lives. Too technical for many people but I found it helpful.

<http://www.mythyroid.com/radioactiveiodinecancer.html>

Background article, good general information.

<http://www.mayoclinic.org/diseases-conditions/thyroid-cancer/basics/definition/con-20043551>

Mayo Clinic article. Good general article.

<http://www.thyroid.org/patient-thyroid-information/ct-for-patients/vol-3-issue-9/vol-3-issue-9-p-7-8/>

At a article about lemon juice

<http://www.thyca.org/download/document/409/DTCguidelines.pdf>

This is the new ATA guidelines. Some patients will want to look at this but it is very long and not an easy read. It is more about treatment recommendations and whether RAI is recommended, not about patient release.

<http://www.thyroid.org/patient-thyroid-information/ct-for-patients/volume-8-issue-8-aug-2015/vol-8-issue-8-p-10-11/>

ATA article on RAI outcomes.

Comments for NRC Sodium Iodide-131 Patient Release Information Collection

Docket NRC-2015-0020

Background: I expressed some of these remarks by phone during the public workshop on January 19, 2016. This written input includes additional information.

I am a 55 year old female trained as a scientist (Ph. D. in synthetic organic chemistry, part of my career was spent doing lab work with ^{14}C labeled chemicals) and I was diagnosed with stage 3 follicular variant papillary thyroid cancer in September 2015. I had ^{123}I tracer dose and WBS in October 2015 and 107 mCi of ^{131}I in December 2015.

1. Web Site Information

Link to the NRC brochure on patient release guidelines with help for people to prepare for isolation to protect their families and the general public.

Listing order is NOT a ranking.

Facebook group: "THE LID Life Community"; this group is a forum for patients to share information about the low iodine diet and it includes information on what members did for their isolation. Some medical professionals check it out. Many people have posted their isolation instructions. Reading them shows a variety of stringencies. Also there are members from other countries, so we can see how other nations set expectations for isolation to protect the public.

Links specifically about radiation safety precautions:

http://www.thyroidcancercanada.org/userfiles/files/RAI_precautions_Ian_Adam_2010_revised.pdf

Article updated in 2010 with precautions adapted from the UK>

http://www.thyroidcancercanada.org/userfiles/files/I-131_Patient_Release_ATA.pdf

Article entitled "Radiation Safety Precautions in the Treatment of Patients with Radioiodine (^{131}I): Best Practice Guidelines of the American Thyroid Association

<http://www.thyca.org/download/document/184/ataradiation.pdf>

http://www.thyroidcancercanada.org/userfiles/files/ATA_Radiation_Safety_Guidelines.pdf

Different links to a 2011 article in THYROID entitled "Radiation Safety in the Treatment of Patients with Thyroid Diseases by Radioiodine ^{131}I : Practice Recommendations of the American Thyroid Association." This article covers treatment of hyperthyroidism and remnant ablation.

Other links, many less technical:

www.thyca.org

<http://www.thyca.org/pap-fol/rai/>

Thyca article on RAI treatment.

https://en.wikipedia.org/wiki/Isotopes_of_iodine

<https://en.wikipedia.org/wiki/Iodine-131>

Wikipedia: Isotopes of Iodine and Radioactive iodine articles for background on energy emitted and half-lives. Too technical for many people but I found it helpful.

<http://www.mythyroid.com/radioactiveiodinecancer.html>

Background article, good general information.

[http://www.mayoclinic.org/diseases-conditions/thyroid-](http://www.mayoclinic.org/diseases-conditions/thyroid-cancer/basics/definition/con-20043551)

[cancer/basics/definition/con-20043551](http://www.mayoclinic.org/diseases-conditions/thyroid-cancer/basics/definition/con-20043551)

Mayo Clinic article. Good general article.

<http://www.thyroid.org/patient-thyroid-information/ct-for-patients/vol-3-issue-9/vol-3-issue-9-p-7-8/>

At a article about lemon juice

<http://www.thyca.org/download/document/409/DTCguidelines.pdf>

This is the new ATA guidelines. Some patients will want to look at this but it is very long and not an easy read. It is more about treatment recommendations and whether RAI is recommended, not about patient release.

<http://www.thyroid.org/patient-thyroid-information/ct-for-patients/volume-8-issue-8-aug-2015/vol-8-issue-8-p-10-11/>

ATA article on RAI outcomes.

2. Patient/Licensee Acknowledgement Form and Best Practices in Making Informed Decisions on Releasing Patients Treated With I-131 Based on Radiation Exposure Considerations

All patients should have their isolation/release guidelines in advance of treatment. They may have to prepare their home, move pets and children out for an interval, or find an alternative place to stay. This can be a daunting task even when you are well, but much harder while you are recovering from surgery, adjusting to the shock of a cancer diagnosis, and possibly very hypothyroid from hormone withdrawal.

The Nuclear Medicine Department tech/physicist where I was treated mailed me their guidelines as soon as I contacted her that I would be having RAI. I had plenty of time to review them and prepare questions before I visited Nuc. Med. During my first visit, which was for a tracer dose of I-123, the radiologist met with me, and interviewed me. She asked questions which would let her assess my living arrangements and ability to isolate at home. Inpatient isolation is not offered at the hospital where I had RAI treatment.

When I returned to the hospital about 5 weeks later for the ablation dose the radiologist had me sign a form (Homeland Security paperwork) that acknowledged that I understood what was going on. She witnessed me swallowing the pill.

3. Guidance for Released Patients

We live in the age of social media and very easy communication among patients who have never physically met and may live many states or even countries apart from each other. So we share information with each other, ask questions, and get quite frustrated and the differences in treatments. While each doctor may be treating each patient for their specific situation, the preprinted guidelines given to us do not take our individual situations into account.

In the end, I used a combination of the guidelines from my doctor plus those of other practices that I saw on Facebook, tips from the Facebook group (The LID Life Community), and some articles ([University of Michigan guidelines and ATA guidelines](#)) to determine how I prepped my home and how long I would stay away from family, co-workers, and the public. Specifically, I was somewhat more cautious than my Nuclear Medicine guidelines indicated I should be.

Having read peoples' instructions from several different practices in different states, I saw varying and sometimes conflicting recommendations. For example: use paper plates and plastic cutlery and dispose vs. do not use disposable utensils and wash your dishes separately; keep your trash separate and hold for weeks or months vs. you do not have to keep your trash. No wonder patients express frustration in the Facebook forum. We want to protect our family members, but how do we know what is best?

In addition, since individuals will have different amounts of uptake and different rates of excretion, it would be nice to have an objective quantitative assessment specific to the patient for "re-entry". That is, using a survey meter on the patient to provide milestones. For example, with X mrem/hr at 1 meter you are now safe to sleep in the bed with your partner, or to ride on public transportation, or to hold your small child close and read to them. While some people do get a "Geiger reading" when they return for the WBS, the impression I get is that they are not told what it means in a practical sense. My hospital did not do a reading on me.

Following are the instructions as I distilled them down for myself. My dose was 107 mCi of ^{131}I . I spent 72 hours in a separate bedroom with access to bath, then 4 more days using my entire house (but the separate bathroom) but keeping >6 feet from my husband, and a total of 13 days away from my workplace (work's preference, as one does not know who might be pregnant). I wore a dust mask and disposable gloves when driving home to avoid contaminating my car.

Room Set Up

Put recliner in guest room
Cover light switches with plastic wrap (painter's tape)
Put baggies (or balloons or gloves) on door knobs
Remove extra stuff so I won't touch it (e.g quilts....) in bedroom and bathroom
Cover headboard/footboard with a beach towel
Put plastic back paper on desk, counter, end table
Trash can with plastic liner
Cover phone and iPad with ziplock or other plastic, make charger set up

During Isolation (excreting interval - 3 days)

Flush twice, clean toilet daily (no bleach or bleaching powder)
Rinse down shower at end of shower
Take a stool softener
Pitcher of water in bedroom
No food prep, rinse dishes well and put in dishwasher
Drink 3-4 liters of water per day to pee every hour during day and 3 hours at night
Brush teeth 6 times per day
Starting at 24 hours (not sooner, so there is less in circulation) suck sours/hard candy/lemon water/granny smith apples/pickles every 3 to 4 hours or rinse lemon juice for a minute and spit it out (**do this for two weeks**)
Avoid coughing on stuff (dust masks?), lots of cough drops
Flush anything flushable, designated trash for other stuff
Wet paper towels or quat wipes for clean up during and after excretion phase
Meals delivered on a tray by loving spouse

Supplies

xSurvey meter
xPlastic backed paper
xDust masks
xGloves
Painter's tape, plastic wrap
Trash can with double plastic liner
Laundry container
xThings to drink
xSours, cough drops
xFlushable wipes

Clean up

Set trash aside for 80 days - not required in PA
At end, discard toothbrush, double wash clothes, sheets, towels, quilt, mattress pad
Wipe hard surfaces with wet wipes into designated trash or flushable wipes

4. **Brochure for Nationwide Use**

Fabulous idea!!!! Thank you in advance.

Where the rules are so different currently, there should be an evaluation and best practices. Why do two people who receive the same dose have different isolation intervals? One may have more uptake, or better excretion, but the person who wrote those guidelines usually wrote them in general with no knowledge of the patient's future uptake or kidney function. The guidelines I received were written before the radiologist met me.

One can find a variety of actual patient instructions from The LID Life Community on Facebook.