

## Checklist for the Newly Diagnosed

The following guidelines are based on "**My Carcinoid 11 Point Start-Up List**," originally developed by **Mary Ann Hicks**. This list is updated/modified and expanded upon as more helpful tips by other "noids" become available.

1) Contact the Carcinoid Cancer Foundation - call 888-722-3132 (Tuesday-Thursday between 9:30 am - 4:30 pm, Eastern time) to get a list of carcinoid specialists. You will need a specialist to lead your local oncologist in your treatment because, unless you are an exception, the local doctors will not even know how to spell carcinoid. The main quality you need from your local oncologist is a willingness to follow your lead. A list of experienced physicians can be found by clicking [here](#)

2) Know that you can FIRE your local doctor if he/she is not willing to provide you with the correct treatment.

3) After you visit with the specialist, encourage your local oncologist to call him/her and discuss your condition and treatment.

4) Read all you can about carcinoid and other related neuroendocrine tumors. The first websites you may want to visit are:

- <http://www.carcinoid.org> the site for the Carcinoid Cancer Foundation. Read and reread the transcripts from symposiums by the specialists.
- Visit Susan Anderson's home page which has a wealth of information and links to many other good sites <http://www.carcinoidinfo.info>.

5) It is important to note that a lot of the information you read on the Internet will be out-of-date, so don't be frightened by the statistics you see. If you are newly diagnosed, the first thing you may look for are the statistics. That's only natural when you have been diagnosed with a terminal illness. Most of the statistics you see are based on old data. Look at the dates of the reference material. New drugs and procedures have been developed over the years, which have very positive bearing on your longevity.

6) Immediately start a notebook/medical record summary to bring with you when visiting your doctors. Let your doctor know that you are going to be very proactive in your treatment. and that your treatment will be a team effort right from the start. My treatment was going to be a team effort right from the start. A sample version of a medical record template can be found below.

7) You will be having lots of tests and procedures, and you should keep an updated profile to give to your doctors, and also to keep on your person and/or in your car in case of emergencies. Also make sure to obtain copies of all tests and reports and keep them in your notebook.

8) If you have carcinoid or carcinoid syndrome, it is advisable to wear a medical alert bracelet or necklace tag indicating that you should not receive epinephrine, which could precipitate a carcinoid crisis. Octreotide (Sandostatin) will control this crisis. One exception is the administration of epinephrine in the case of an allergic anaphylactic reaction (i.e. a bee sting), so it cannot be avoided in this case, just make sure that octreotide (Sandostatin) is also available.

9) There are several online support groups which might be of interest. [CLICK HERE](#) for a list of online groups.

10) As soon as possible, attend a local support group function or a national carcinoid seminar. For a list of national support groups [CLICK HERE](#) or can be obtained by calling 888-722-3132.

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(Tuesday-Thursday between 9:30 am - 4:30 pm Eastern time).

11) Don't sit around and isolate yourself. It is very easy to get depressed. Get out and work with others as much as possible.

## MEDICAL RECORD TEMPLATE

Sample medical history supplied with kind permission by Susan Anderson.

Susan Anderson's medical record template

Susan Anderson's Homepage: <http://www.carcinoidinfo.info>

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### Diagnosis ICD Codes and Date Diagnosed

1. Carcinoid Cancer of Ileum with mets in Liver...ICD: 152.2 -- 10 May 1995
2. Infiltrating Ductal Carcinoma - right breast...ICD: 174.9 -- 18 June 1999
3. Hypothyroidism (under active thyroid).....ICD: .244.9 -- 29 June 2000
4. Rosacea.....ICD: .695.3 -- 7 Dec. 2000
5. Hyperlipidemia.....ICD: 272.4 -- March 2001
6. Neuropathy..(started in mid - 1980's).....ICD: .337.0 --
7. Rectocele..... -- 3 July 2002
8. Plantar Fasciitis..... -- 23 June 2004
9. Type II Diabetes Mellitus.....ICD: 250.02 - December 6, 2004
10. Seborrhea Blepharitis.....ICD: 373.02
11. Rosacea Conjunctivitis.....ICD: 695.3
12. Tear deficiency.....ICD: 375.15

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### CURRENT MEDICATION (as of December 17, 2004):

- Sandostatin LAR 30 mg, injection every 28 days (began 11 March 1999) Before LAR, I injected 300 mcg, 3x day, began Feb. 1998
- Vitamin B12, 1000 units 1M, injected monthly (began 28 June 2001)
- INTERFERON ALFA 2b: Inject 3.0 million units 3x week (began 21 May 1999) stopped & changed to -->
- Peg Intron-A 0.3mL changed to 1X @ week on Jan. 22, 2003
- Synthroid, 1x day 0.05 mg 7/31/00; some adjustments now .112 mg
- Neurontin, 100 mg, 1 cap 3 x a day (began 20 August 2004)
- Vit B6 400 mcg 1x day
- Vit B3 (Niacinamide) 500mg 1x day
- Multi Vitamin, 1x day
- Omega-3 Fish Oil 1000 mg 1x day (hit and miss)
- Multi mineral, 1 x day (hit and miss)
- Estrace, (cream) little "dab" as needed (began 2 June 2000)
- Tetracycline, 1x day (250 MG),(started 7 December 2000) (or as needed for Rosacea)
- Metro Cream 0.75%, 2x day, thin film on face (started 7 December 2000)
- Stopped: Tamoxifen 20 mg, 1x day (6 July 1999 through 2 August 2004)
- Stopped: Bellaspas Tablets(Bellergal-S),1x day 2 Jan.2000 thru July 2004)
- Stopped: Lipitor, 20 mg,1x day(Began 3-27-01-Stopped 11-9-03) Muscle damage, ankles, feet, legs, pain, weakness
- Stopped: Glucosamine Sulfate 500 mg 3x daily (began 24 March 2002) (did not continue)
- Stopped: Crestor 10 mg, Began Apr 24, 2004,last June 22, 2004 (trial)
  
- Mefloquine 250 mg 1 x week for 6 weeks, March 5 -- April 9, 2004
- tPA (tissue plasminogen activator) infused 40 CCs:  
June 24, 2002, March 31, 2004
- Cortisone injection (for plantar fasciitis) 23 June 2004, 17 Sept. 2004
- Neupogen, 400 mcg, Aug. 12-15; Oct. 22-24, Nov. 1, 4; Dec. 2-5, 2004

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July 24, 25, 28, 2003 ONLY

- Diflucan 150 mg, Jan. 22 & 23, April 7, 2002 ONLY

- As needed: - Acyclovir 400 mg,- Codeine Sulf 30mg or - Percocet 5mg/325mg

-Metformin, 500 mg, began December 6, 2004, 1 capsule 2xday; changed on December 15, 2004 to 2 caps 2xday

-Neurontin, 100 mg, 1 4x day (8/20/04); Changed on December 13, 2004 to 300 mg 1 cap 3x day.

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Allergic to Sulfa - Avoid Morphine - DO NOT USE EPINEPHRINE

-----> -> Use Hueber needle to access Groshon  
"port"

(Groshon "Port" in left breast)

CARCINOID SYNDROME MAKES A CARCINOID CRISIS POSSIBLE:

-- Treat LOW blood pressure with: sandostatin (octreotide) and hydrocortison

-- Treat HIGH blood pressure with: nitroglycerine and verapamil

- DO NOT USE EPINEPHRINE

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Chemo we have used for Carcinoid:

- Late Feb. 1998 through end of May 1998 (Once a week for 12 weeks)

-- Leucovorin 35 mg/m<sup>2</sup>; -- 5-FU 400mg/2m; -- Streptozotocin 350mg/m<sup>2</sup>

- Sept. 1998 through March 1999 (Every four weeks for 7 months)

-- 20 mg Decadrom & 5 mg Zofran followed by -- 650 mg/m<sup>2</sup> Dacarbazine (DTIC) diluted

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HRT: Fall 1987 -> June 1999: Premarin 0.9 mg, 1x day (for years)

RADIATION: July 19 - Sept. 14, 1999: 33 radiation treatments for breast cancer (IDC)

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1944 May - tonsillectomy

1954 - no surgery, BUT mononucleosis AND Hepatitis

1973 Sep - hysterectomy (left both ovaries)

1994 Jun - gall bladder removed

1995 May - small bowel resection (85 cm) and six lymph nodes - Carcinoid diagnosis

1998 Oct - left subclavian Groshon central line implanted with subcutaneous port

1999 Apr electro cauterization inside left side of nose

1999 Jun - surgical biopsy right breast

1999 Jul 19 - Sept. 14 - RADIATION - 33 radiation treatments for breast cancer (IDC)

1999 Oct - Partial liver resection of segments 5 & 6; full exploratory laparotomy; lysis of adhesions involving the omentum, small bowel, large bowel & bilateral adnexa; right ureterolysis; bilateral salpingo-oophorectomy; removed nodules from descending colon, bladder serosa & cul-de-sac peritoneum.

2002 Nov. 5 - Four posts implanted in lower jaw, preparing for full dental implants

2002 Dec. 6 - Remove old Groshon central line & implant new Groshon central line

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Dr. Richard R. P. Warner, M.D., Mt. Sinai Medical Center, New York City Phone: 212-241-4299-- FAX: 212-426-5099

Dr. Jack R. Cavalcant, M.D., ph: 480-969-3637, FAX: 480-969-6568

Dr. Matthew Borst, M.D., ph: 602-253-5300, FAX: 602-253-4400

Dr. Sandra Levitt, M.D., ph: 480-820-1133, FAX: 480-820-2175

Dr. David A. Suber, M.D., ph: 480-838-1000, FAX: 480-491-6894

Dr. J. Greg Rula, M.D., ph: 480-969-4138, FAX: 480-969-0630

Dr. David B. Leff, D.O., ph: 480-834-0771

Dr. Bruce W. Krell, DPM, ph: 480-807-8532, FAX: 480-807-0420

(Please note the above phone numbers are not necessarily current)

**NOTE:** It is with great sorrow that we report the passing of Mary Ann Hicks on November 9, 2004. Mary Ann will be remembered for the invaluable contribution of her "11 Point Start-Up List".

**Source URL:** <http://www.carcinoid.org/content/checklist-newly-diagnosed>

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