

Follow Up Care Guide After Treatment Plan, A Patient's Perspective Copyright © 2013,

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PREFACE

Okay, you opened this so therefore congratulations are in order. You got through it! Breathe a nice deep breath, and let it all out, then give yourself a big pat on the back.

This is Part 2, follow up and it is very important to understand why. I am sure you are now torn with both relief and also worry. Cancer treatment from diagnosis to recovery is a whirlwind of emotional and physical ups and downs. It's almost as if you just completed a foreign language course, not by choice. All the new diagnosis words and scans and tests and insurance forms, but you did it, you graduated, so to speak. You are now stepping back out into the world. Every day you are not pre-scheduled and at first it's shocking. You may be thinking to yourself, "Now what?"

Well, here is the *now what*, you still need to be your own best advocate. You now have a level of skills that can help you make sure everything stays in check. This is why follow up is so important.

To most of us, cancer came as a shock, a surprise. Now we want to stay *ahead* of anything that might be a sign of cancer intruding back into our lives and do everything in our power to keep it out of our lives. We want to stay healthy; stop smoking, eat right, sleep well, exercise more, and enjoy life.

Each person is different and each follow up plan is somewhat unique but it is to help you to best live your life to the fullest. Always be smart by staying ahead and know your follow up plan is in your best long-term interest for a great life.

FOLLOW UP CARE GUIDE

Communicate

Just as we learned while going through it, you must communicate if something is bothering you. No one can help you if you do not voice the problem.

Physically

You might have some after treatment ailments. For example, fatigue is a big issue. Everyone wants to get back into full swing, but your body still needs time to heal so be kind to yourself, get back into your life slowly, do not take on too much right out of the gate. Learn your comfort levels and slowly build up. If fatigue is a huge problem and you are wiped out, listen to your body and take baby steps but also speak up. Issues to communicate are; trouble concentrating, trouble sleeping, trouble multi-tasking, even memory loss or pain. Again, baby steps, give yourself a break. If you do too much too soon you will set yourself back.

Expectations

People are all excited that you finished treatment. However, they do not understand that recovery is a slow process and you need to ease back in, versus jumping right back in as they expect. Expectations should be slow and steady — listen to your body!

EMOTIONS

Emotional

You just went through a very emotional and scary ordeal. Let your mind have a little peace. Tools, such as yoga, may be helpful. There is evidence showing that yoga is beneficial to both men and women. Try reading positive books and watching funny movies, try to stay away from cancer blogs on the Internet or a show with someone dealing with cancer. Try to look ahead to the possibilities and realize you can take your life back and change it for the better...or for now just breathe for a bit and relax. *Just be*.

Some explain that after cancer treatment, it seems like a void. Do not worry, you need some time to heal, and you will be watched closely, so now

you can start doing more of what you love or even something that you always wanted to do. Take this time to rebuild your life with things you truly love and less of what now seems unimportant. You have changed but you do not need to do anything drastic. Just try to be you or the new you.

Range of Emotions

You are going to probably have a full range of emotions from the aftershock. Like, wow, what just happened? You might not be "elated" that treatment is over just yet. Sometimes it's more like, hey, where did everybody go? You might be angry at some people who let you down or just mad that this has disrupted your life like a home invader. Some people come out grateful and at ease. Some come out still full of fear. It's all normal, you are human. Figure out whom you need to talk to about letting these feelings out. There are others you have met along the way who are feeling the same feelings. Maybe you just need to be with someone that is just going to listen and not talk.

Support Groups

Finding the right support group can be extremely helpful. Here you do not have to explain why you feel the way you do. They "get it" and have heard it all before. You do not have to hold back "anything". However, be careful because sometimes someone else's story can scare you. You can always schedule a one-on-one appointment with an oncology social worker or speak with a support group leader who can fit you with the right group. Ask your oncology staff, or favorite nurse whom they recommend. Let's face it, you have talked about it to friends and loved ones and sometimes they no longer know what to say, they might just think you should be happy and move on. Make sure you are with a group that fits your needs. Sometimes by going to the support group meetings you find you are now the wiser and can help someone else get their head around the rollercoaster of feelings.

Patience

Patience is truly a virtue. I found my patience level very low for people who were not of the cancer world. Their problems seemed so trivial and insignificant at times. I think it's best to ease back into the real world with some silence, and some grace. If you are not ready and these trivial conversations want to make you scream, then back away for a bit. It takes time. These feelings are all normal.

Regret

You might feel some regret about how you behaved or you might have hurt someone by not accepting their help or keeping them "in the loop." They might actually confront you now that you are "finished" with your treatment. The easiest way is to just say you're sorry, you did not mean to hurt them, but you were going through a very difficult time. That's it, end of story, give yourself A Pass and move on. If you are not ready for a confrontation or any confrontation because you feel battered, then just say you are not ready for this conversation yet, and know you did not have any intention of hurting anyone. Know your tolerance level and respect it.

Fear

You have every right to feel fear. Fear of recurrence that it could happen again is real. However, try not to let it take over your life. It will subside as you start living your life by adding back in the fun things and spending more time with people you truly love to be with.

If fear is keeping you up at night, every night, and seems to be overwhelming, call your hospital oncology social worker or professional. They can help best. You are not the first person who is feeling like this. They have helped many control the fear. Some people find writing it down in a private journal helps let it out in the moment. Everyone is different; some can tune it out with a great book or an uplifting movie. Do not go through this alone, reach out, and let it out... some of it, or all of it, somewhere, somehow to someone.

PANIC!

Okay, at certain times after treatment, I would totally panic and honestly still do. Most of the time it is not a reason to go to the Emergency Room. Nonetheless, you know your medical history and only you know what is best. Therefore, if you know you need to go to the ER, then go. If you can call a primary care doctor or nurse first, and get into your primary care's office, take that step first. However, if what begins as a sudden problem then becomes a manageable problem, I personally try to give it a 1 to 2 week waiting period until I can go through my own steps to figure out what this new pain or problem is stemming from. Eight out of ten times it is from some new medication I started and did not bother to read the side effects on the slip.

If it does not go away, then I try to figure out whom can best get to the bottom of it and fix it. Sometimes, just after my treatment ended, I felt like the "woman who cried wolf." I felt like I was paranoid. This is normal, but your instinct will always be your best guide if you can calm yourself and then react.

Some of you have been lucky enough to have a nurse navigator throughout your treatment; others had to navigate themselves. Most navigators are both as compassionate as they are knowledgeable. In a perfect world we would all have a follow up navigator telling us it's all normal and directing us to who we need to see for what and continually coordinating our care. But now there is a gap that you need to fill in where the navigator once was and **you** need to take back the controls.

YOUR PLAN

Mhy5

Each person has a follow up plan to insure that you are okay physically and emotionally and to continue to live a healthy, happy life. You have probably heard a new acronym, NED (no evidence of disease) or as I like to call it: IN CHECK. Your follow up plan is to make sure first and foremost that it stays "in check." It involves you being a continued advocate for yourself. You are now promoted to co-pilot.

Medication/Drugs

Adjuvant drugs; these drugs follow after treatment to block anything (like estrogen in a breast cancer patient) to decrease the chances of recurrence. Sometimes they bring side effects but typically there is more than one drug that accomplishes the same goal. So speak up if you need to explore another option because you have side effects that are bothering you. DO NOT JUST STOP TAKING THE DRUG. It's like a safety net that is protecting you to live in NED (no evidence of disease). You want to take whatever they give you after treatment regimen because they know it works. They have five and ten-year studies proving that it has helped keep others healthy.

Follow Up Schedules

You will be set up with a follow up appointment schedule (just like you go to the dentist every 6 months to stay ahead of any cavities to prevent a root canal). We have included a form within this package to help you keep your

appointments organized. We all know by now that the earlier you find anything, the easier it is to fix it in every case.

So stay on schedule. You might have oncology visits every 3 months, and then move on to every 6 months. You might have scans, mammograms, x-rays, an MRI or whatever test every 6 months or every year to keep an eye on your health, and to make sure everything is in check.

Once I called to cancel a scan and then again a second time. My nurse said to me "hey, this is not a hair color appointment. You need to stay on schedule for a reason". I now stay on schedule because the time line is important. Make the appointments and keep them, clear your day.

SCANAPHOBIA

Sometimes going back in it can bring back varying levels of fear. I call mine Scanaphobia, fear of scans. I made up the word, but it's real. It can be overwhelming if you are going back the first time or the 20th time. They can give you something for it if need be, but again, *you* need to speak up, and ask. It is very, very, very common to have anxiety, to get nervous going back in to get re-tested.

A whole range of "what ifs" can flood back into your mind. You need to address it because you *need* to go. Stay on schedule, and do not miss the follow up tests.

INSURANCE

By now you are probably either a pro at dealing with the referrals or completely exhausted from it. Keep track of all in-network and out of network referral numbers and your EOBs (Explanation of Benefits). Nothing has changed in the Insurance world. It is recommended to get a case manager from the beginning if possible, if your insurance company offers this.

Piles of Bills

You might find yourself with a boatload of bills and EOBs (Explanation of Benefits) showing what was covered and what was not. It's a chore to go through all these and get on the phone to find out why things were denied. Typically, after a few calls you get the right person, have all the bills in question in front of you and rapid fire them off one by one. It's a huge

weight off your shoulders and feels like you are done with your taxes – relief.

If you cannot even begin to attack this mound of paperwork, ask someone you know who is smart and relentless. Ask them to sort through it and make the calls and clean up the mess. Then buy them something really thoughtful or cook them their favorite dinner. You might have to go through it with them to sort it out at first, but if they are the right person, they will catch on quick and take this off of your plate.

Your Primary Care Physician (PCP)

This is your everyday doctor, the one you go to for a sinus infection or the flu. This doctor now becomes more important once again. He or she needs to know what is going on with all phases of your health. Some hospitals have a system in place that will automatically update your primary care physician on your past and present tests, doctor reports and follow up plan. Other hospitals will not. Either way you need to know what is going on with your own health, so you can communicate effectively.

What is the plan? Your PCP can take care of a lot of your needs that now no longer fall under oncology. It somehow shifts the responsibility back to you and your primary care doctor to follow up on new ailments, for example, sore joints, headaches or sleepless nights. The more you know what's going on with your follow up plan the better he/she can help you. Know your history. Know your schedule, dates, etc. Know your medications and the side effects listed on each medication slip (sometimes that might be causing sore joints or headaches).

Add your annual physical to your oncology schedule, eye appointments, and anything else you need like bone density test, colonoscopy, or pap smear. Try to summarize where you are at physically and emotionally and explain why. For example, if you are feeling a new pain, when did it start? How long have you had it? Did you do something different that might have caused it, like lifting something heavy or slipping on ice?

Your primary care physician can also help you emotionally. You have been through a shock, a huge overwhelming experience, so tell him what you are feeling. They typically are compassionate people and are trying to get a handle on all aspects of your care. You may look like a complicated case so you need to speak simply and summarize it.

Just a reminder, you are building somewhat of a new team here. You need to communicate to all the key players where you are at, where you have come from and what you need *now*.

This will bring the best results to you. If you do not feel like anyone is hearing you, that they are not listening, then you need to find someone who will. You are important and this is complicated. Be smart, and to the point, and most of all, try to be honest. Even if you have never felt comfortable talking about your body or your feelings, you need to try now. Your PCP can refer you to all kinds of specialists if needed such as a physical therapist, neurologist, x-ray technician, pain specialist, or nutritionist; remember it's not always the worst. Sometimes, it's just like before cancer, a quick fix.

TAKE CARE OF YOURSELF

The key again is you. You are the bridge to making sure everybody on the new expanded team is up to date and is listening to you.

f you are doing your part then you are communicating effectively. It show	uld
e short but relevant. For example: I have had headaches for 2 weeks, jus	st 3
ays after I started a new medication	·
rescribing Dr	
Or. Specialty Neurology.	

Example 2: I have not been able to sleep well for 10 days. Nothing has changed, no new meds, but I do have a follow up CT scan scheduled.

Use your follow-up forms to keep your facts straight but not to miss important timelines or changes or anything else that has come up or has been bothering you.

Oncology is oncology. If it is not cancer related, they will now send you along to your primary care physician, who will rule out obvious causes, like a sprain.

Obvious Things to Do

- 1. Get a flu shot (ask doctor first).
- 2. Take care of yourself, try to eat healthy (fruits and vegetables), exercise, 10-20 minute walk in the fresh air, watch your weight.
- 3. Try to stay away from contagious people with the flu or a bad cough or cold. Wash your hands frequently.
- 4. Do fun things again. Surround yourself with people who fill you up.
- 5. Speak up, be heard, be specific but be on top of your past medical history and (short version) current medical issues, meds/new ailments.

If you can summarize the following: diagnosis, surgery, chemo, radiation, what your plan is currently, and what is happening now in 3 minutes or less; then you are doing great. In sales, this is called the elevator pitch, from the time you step in the elevator and the doors close to the time the elevator doors open and you walk off. Do not assume they know your medical history or what you're feeling. This gives you much more time to hear the doctor and let him/her have a clear picture of how he can best help you now and ahead.

Resources:

There are many resources out there but to best serve your needs we recommend you reach out to your oncology team, favorite nurse, case manager, or nurse navigator. They will best direct you on what is available in your area or what they have found most helpful.

One last note - **BE KIND TO YOURSELF**.

About the Author:

Cathy McGrath founded a nonprofit organization humbly named, A Little Easier Recovery®, after having been diagnosed with Stage IIB Breast Cancer. Having lived the experience of navigating through cancer; she has gained and shares tremendous insight. She speaks from the heart. Although nothing is easy about cancer treatment and recovery, she hopes her words empower and enlighten others with her *less is more* approach.

CANCER SUPPORT COMMUNITY RESOURCES

The Cancer Support Community's (CSC) resources and programs are available free of charge. To access any of these resources below, call **888-793-9355** or visit **www.CancerSupportCommunity.org.**

Cancer Support Helpline®—Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon–Fri, 9 am-8 pm ET and Saturday 9 am-5 pm ET.

Open to Options®—Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling **888-793-9355** or by contacting your local CSC or Gilda's Club.

Frankly Speaking About Cancer®—Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

www.CancerSupportCommunity.org/FranklySpeakingAboutCancer.

Services at Local CSCs and Gilda's Clubs—With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. www.CancerSupportCommunity.org/FindLocation.

Cancer Experience Registry®—Help others by sharing your cancer patient or cancer caregiver experience via survey www.CancerExperienceRegistry.org.

MyLifeLine—CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Connect with other caregivers by joining the Caregiver Support online discussion board. Sign up at www.MyLifeLine.org.

Grassroots Network—Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/become-advocate.

This booklet is available to download and print for yourself at **Orders.CancerSupportCommunity.org.**

The Cancer Support Community provides this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

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MY 3 MINUTE SUMMARY EXAMPLE

Communicate effectively.

Keep your facts straight, but do not miss important timelines, changes, or anything else that has come up or has been bothering you.

See example below.

Start off with why you are there.

Today: I am here today because I have a sinus infection that started a week ago. I have face

pressure and it has turned color.

Secondary: I also have a pain in the left side of my back. I have had it for years but it is worse now.

History: Stage IIB breast cancer, 5 plus lymph nodes

Biopsy, lumpectomy, mastectomy, reconstruction, lymph node removal,

all MGH. Dr. Jones phone 617-000-4444

Strong family history of cancer. Grandmother, cousins, aunt – breast and ovarian.

Current treatment: Headaches, neuralgia – Dr. White – New England Neurology

Neuropathy - Dr. Smith - New England Neurology 978-000-4444

Other concerns: Trouble concentrating, not sleeping well, easily annoyed, pain in back worrying me

Turn over to fill in your medical summary.







MY 3 MINUTE SUMMARY

T. J		
Today:	 	
Secondary:	 	
History:	 	
Current treatment:		
Other concerns:	 	

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Name	
Data of Pirth (DOP	om/dd/vaav)

Date of Birth (DOB, mm/dd/yyyy) _





MY SUMMARY OF MEDICATIONS

Example:						
Name of Medication	Amt (mg)	Times per Day	Dr. Name Prescribed med	Dr's Hospital or clinic name	Date Started	Length of Time
Tamoxifen	50mg	1	Dr. Cunningham	HNU Hospital	1/1/2001	1 per day For 2 years
Why: to block estro	gen, reduce	recurrence bre	ast cancer.			
	Side notes	:				
Any side effects you	u are experier	ncing:				
Name of Medication	Amt (mg)	Times per Day	Dr. Name Prescribed med	Dr's Hospital or clinic name	Date Started	Length of Time
Reason why:						
Any side effects?		·				
Notes to self						
Name of Medication	Amt (mg)	Times per Day	Dr. Name Prescribed med	Dr's Hospital or clinic name	Date Started	Length of Time
Reason why:						
	Side notes	: example, tak	e with meals			
Any side effects?						
Notes to self						

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Name
Date of Birth (DOB, mm/dd/yyyy)
Pharmacy name
Pharmacy address
Pharmacy phone

LIST OF CURRENT MEDICATIONS

Name of Medication	Amt (mg)	Times per Day	Reason
le notes: example, take with me y side effects?			
			Reason
tes to self			Reason
tes to self			Reason
tes to self			Reason
Name of Medication le notes: example, take with me	Amt (mg)	Times per Day	
Name of Medication le notes: example, take with me	Amt (mg)	Times per Day	
Name of Medication de notes: example, take with me	Amt (mg)	Times per Day	
otes to self	Amt (mg)	Times per Day	







MEDICAL RELEASE RECORDS

Hospital Name	
Your Name	
Hospital ID#	
Date of Birth (DOB, mm/dd/yyyy)	
Fee if any	
Photo ID needed if picking up!	

Typically you can request any and all medical release records to have for another Doctor, like your Primary Care Physician or for a specialist like a Cardiologist. Or if you are moving and want them with you because you want to keep them on file.

Note: Sometimes it is a ton of paperwork and sometimes I even found it hard to read. But it is smart to have a set if you cannot access it online or you do not use the internet.

Each hospital has a Medical Records Release form. You can call them and ask them to mail you some or you can usually download the request form from their website on your computer or at the library. They typically take 7 days to receive so plan accordingly.



Name				
Date of	Rirth (DOF	3. mm/dd/v	/VV)	



MY MEDICAL SUMMARY

My Medical Hist	tory			
Diagnosis	Type of Cancer		Date Diagnose	d
Additional Diagnosis			Date Diagnose	d
Additional Diagnosis			Date Diagnose	d
Biopsy				
Surgery Type				
Oncologist Name			Hospital Name	
Surgeons Name				
Radiologist Name				
Reconstruction Surge	eon Name			
What stage was your	cancer?	Any positive	lymph nodes?	
Did you have surgery	to remove cancer	? What kind o	f surgery did you have	?
Did you have chemot	therapy?	If so what ki	nd/name of chemothe	rapy ?
# cycles		If stopped re	eason why	
Did you have radiatio	on?			
If so how many times	i	start date	end date	
At what hospital				
My Family Histo	ory			
Is there any family his	story of cancer?			
Mother's side:				
Maternal Mother	Sister	Brother	Cousin	Nieces & nephews
Uncles	Aunts	Grandmother	Grandfather	Grandchildren
Father's side:				
Paternal Father	Sister	Brother	Cousin	Nieces & nephews
Uncles	Aunts	$_$ Grandmother	Grandfather	Grandchildren
Any other important	family history of ill	ness?		
Heart	Lungs	Stroke	Arthritis	Stomach Problems
Any other major dise	ase history?	Explain if you	can	

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Name	
Date of Birth (DOB, mm/dd/vvvv)	



How are you feeling now?
What concerns do you have now?
What is the man of the description of the second se
What is the reason for todays visit?
Best describe your symptoms
When did the symptoms start
Where does it hurt
How long has this been bothering you?
Have you added or stopped any medications?
What can we do to best help you?
Is there anything else we need to know, any secondary ailments or concerns?
Are you sleeping well?
Exercising? Walking? Other
Are you nervous about something?
Have you gained or lost weight?
Are you eating well?
Are you taking care of yourself?
Do you feel comfortable with your follow-up care plan schedule?
How are you feeling overall – how can we help?
What helps? Heat, bath, sleep, rest,
Examples: exercise, ice, no stress, yoga, acupuncture
What helps

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Oncology Hospital Name
our Name
Hospital ID#
Date of Birth (DOB, mm/dd/yyyy)

YOUR ONCOLOGY FOLLOW-UP SCHEDULE

Oncology Visits		ev	ery	m	onths					
Doctor Name										
Doctor Phone #										
Doctor Email										
Doctor's Schedulers	Name_									
Type of Oncologist					(what kind	of cancer	do they t	reat?)	
JAN FEB Month & Day	MAR	APR	MAY	JUNE	JULY	AUG	SEPT	OCT	NOV	DEC
Why: After your tree the right medication months to a year. So the right direction -	ns to kee ometime - so you c	p everyth s they will can worry	ing in che I do sched Iess and I	eck. Some luled follo ive better	times it w wup tests knowing	rill start ou just to do	t every th uble chec g is in che	ree montl k that eve ck, NED.	ns then mo erything is	ove to 6
Radiologist Foll	owup									
Doctor Name										
Doctor Phone #										
Doctor Email										
JAN FEB Month & Day	MAR	APR	MAY	JUNE	JULY	AUG	SEPT	OCT	NOV	DEC
Why: Typically to mappointments.	nake sure	everythii	ng has he	aled well a	ıfter radia	tion. Typic	ally not as	s frequent	as your o	ncologist

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Oncology Hospital Name	_
Your Name	_
Hospital ID#	_
Date of Birth (DOB, mm/dd/yyyy)	

YOUR ONCOLOGY FOLLOW-UP SCHEDULE

Surgica	al Oncol	ogy									
Surgeon	's Name _										
Surgeon	's Phone #	ŧ									
Surgeon	's Email _										
Surgeon	's Schedul	lers Name_									
Type of S	Surgeon S	pecialty _									
JAN Month &	FEB Day	MAR	APR	MAY	JUNE	JULY	AUG	SEPT	OCT	NOV	DEC
healing v Then afte your folle	well. Will s er a period ow up tes	ur surgeor et up follo d of time y ts and app	ow up test ou will se pointment	s to make e his/her	sure ever	ything on	the inside	is looking	g as good	as on the	outside.
		n Follow	•								
		rgeon Nar									
		rgeon Pho									
Reconstr	uction Su	rgeon Em	ail								
JAN Month &	FEB Day	MAR	APR	MAY	JUNE	JULY	AUG	SEPT	OCT	NOV	DEC
•	•	ds on if you sure you ar			n at all bu	t if you die	d same as	above app	olies. The	y are follo	wing

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Your Name		
Date of Rirth (DOR	mm/dd/yyyy)	





YOUR PRIMARY CARE DOCTOR INFO (PCP)

Primary Care Physician (PCP)		
Doctor Name		
Doctor Phone #		
Doctor Email		
Doctor's Schedulers Name		
PCP Referral Name	Phone # if different	
Nurse Practitioner		
Annual Visit Check Up Time		
Additional PCP Follow Up to Remember		
Other Doctors/Specialists		
Doctor Name		
Type of Doctor		
Doctor Phone #		
Other Doctors/Specialists		
Doctor Name		
Type of Doctor		
Doctor Phone #		