

CHAPTER 36

Your Care Book to Keep You Safe

IF YOU HAVE A GROUP that will be taking care of the loved one going through cancer it will be hard to remember what is going on from day to day. One mistake can cause a lot of problems. Doctor's, nurses and care givers can make mistakes they are human. To make care giving easier for the patient, between family and friends helping you need to make a family book. This book can easily be passed between caregivers.

This makes the care giving less scary for anyone helping out.

I have created pages you can download off my website twentyfiveyearsandcountingcancerfree.com to make the book. Please make sure to use it all the time or not at all.

If one person helping does not want to use it, it will be so hard because you will not know if it has been completed and it will make all other people fearful if they should rely on it.

You will be questioned by the doctors and the book takes the pressure off the person at the appointment or in the hospital with the patient.

It could take hours or most of the time days before you see the doctor again. It is a totally different world then when you call your personal medical doctor. Any specialist or surgeon you will not have a chance to call them back most do not accept phone calls.

You will have to ask the nurse who will tell the specialist then the nurse will relay it to you. Your primary doctor relies on reports and some conversation with the surgeon. They will have one point of contact which is you, to put it all together what they are saying is what happened. It is better

to have the same person or people with you taking notes on what they said in the book. So when you talk to your primary doctor you can check if he is informed on what is going on with you.

When you write down things in front of anyone in the medical profession always ask these questions EVERY TIME , I mean EVERY TIME. What is the **date**? And lets see **what time** is it? I need to spell your name right it is and spell it off....

I used to call this in the medical management world a timeline of care. When the doctor comes to see you, he has to timeline his notes as to what he said to you day and time... they should match with what you have in the book, right? It depends when he has time to write his notes or should I say transcribe them to the tape recorder, most doctors now type as they examine you, but believe me they are short with no emotion in them.

Your emotion is just as important as the medical. The coping and the fear can hinder the healing and can cause medical problems in the colon. Not all side effects are easy to see. It truly depends what the patient is feeling as well and that is what they miss all the time. Your colon can be affected by your emotions. They will not ask if you drink water, ate a full meal, had a bowl moment, walked, only what is happening with what they did not how your body reacted to what they did. You have the care book to tell them what is truly going on. If they do not ask tell them to put it in their notes what you tell them.

Medications

Your care book is so important for keeping track of medications. Are you supposed to write every medication down? Yes, you can if you want to. I know, you are thinking, “They are the hospital, why should I have to?”

Because in my case, they tried to add or change my medications all the time. I refused a lot of it when I found out they were only giving it to me *in case* something happens. I kept insisting I didn't want to take certain meds

because of the side effects. “Oh, it’s okay,” they’d tell me. “We always give it to people.”

Yes, you can refuse to take it. Always ask what it is for and what are the side effects before taking any medications. This is not only to help your body, but remember, you will be paying for everything. Nothing is free or “included” in the cost of something else. You only have a set amount of insurance money so do not spend it on things that do not make sense for you.

I have seen hospitals try to give my loved ones meds.

“This is *in case* he gets constipated,” they’d say.

“Wait,” I’d challenge them. “He is not constipated.”

“I know, just *in case*,” came the reasoning.

“No, his body does not need one more drug to overcome,” I’d insist. “Why are you trying to give that to him?”

“It makes it easier *on us* instead of having to deal with it later.”

What?

Every, and I mean every, drug has a side effect to the body. If God did not design it to be included then it’s foreign to the body. The body has to figure out how to get rid of it. As I started to ask questions, I found most of the drugs are not needed. Plus, if taken, I could have more problems to fix later.

Emotions

Your emotional state of mind is so important. How are you truly feeling? Not what you are just saying so as to not be a burden to the family.

“No, no. I’m fine. You can all leave me here alone for hours.”

Is that truly what you want?

The time in the hospital has to be used for both physical and emotional healing. You know there is only a certain amount of time you can be away from the things your family needs from you. Use a video-chat app like

FaceTime to connect with them outside of visiting hours. This way, you can talk about how you are feeling and see what they are up to or need help with. This can be so helpful in making you feel you are still part of the family while you are in the hospital.

You can also assign your loved ones certain times to visit. The important times when you need someone for support are during doctor rounds, tests, meals, when nurses change shifts, at medication times... yes, all of these things are on a schedule in the hospital. Ask when they happen and be ready to make notes in your care book.

Elimination

Something to pay close attention to in your care book is what goes in and what comes out. If you are given fluids, that same amount of fluid should come out. If you are not urinating regularly, that is a problem.

If you are eating, you don't want to become constipated. Many patients become septic because they are not eliminating waste from their body often and regularly. If no one is keeping daily or hourly track, it can't become a problem after it's too late. Why don't they keep track? Because you were admitted for cancer surgery, not digestive problems. A one-time bowel movement is not a bowel movement if the colon has impacted the rest of the food. Think with common sense. If you eat for three days and you have one movement, where is the rest of the food in your colon? Do not let them send you home with a problem. They are primarily watching for complications from your breast surgery. Again, you have to speak up because they won't go on a fishing expedition.

Your body will tell you just about everything you need to know about how it works if you are paying attention. Stress can cause your colon to act differently and bind-up waste. Many heavy pain medications are also diuretics and they rob the body of fluids, causing all kinds of problems.

Just think of how many times you should go to the bathroom in a day. Think of babies and your animals. How often do they go? Adults should eliminate at least twice a day. Your body wants desperately to get rid of what it doesn't want and can't use. You want your cells to be cleaned and they need fluids to do that. This means drinking water throughout the day. If you can't drink it directly, consider asking for fluids to be administered by IV.

If the hospital room does not have a measuring tool in the toilet, they are not measuring your levels of the water coming out. If they just come and empty the hat, they are not watching it. I cannot tell you how many times a nurse would empty the hat without writing down the measurements. I would say, "Wait, don't you have to write that down?"

"Oh, I will later," they say.

"No, you will now because I'm keeping track and I want to know, too."

(Dirty look.)

Meals

One of the most important times to have someone at the hospital with you is during meals. If you are too tired or nauseous to eat, eventually they will take the food away. No one will be told you did not eat. Remember, you need nutrition to heal! The nurses do not have time to make you eat. What are they feeding you in the first place? Is it enough to give your body the strength it needs to heal? It doesn't make any sense to eat what I call "air food" with no nutrition.

You maybe craving an outside food for the taste but at what cost to your body? Is it going to be easy to digest and use for your healing of your body, or make it harder taking healing from your body to deal with it?

You need protein to have the strength to walk and move the body fluids. My husband brought me protein shakes. If asked they will give your loved one what they consider protein and supplements which is Ensure. All you

have to do is read the back to see why you should not take it, it is a drug. There is nothing from God so how can it heal His body? The drink is very high in sodium—which raises your blood pressure—and it's full of sugar: an 8-ounce serving has about 6 teaspoons of added sugar.

Which brings me to picking food on the little menu they give you. There will be limited food that will heal you on the menu because of the what is purchased and how it is prepared. Always go to the easiest to digest for your body with the most nutrition you can find.

For protein, a non-red meat is easier to digest; salad (use olive oil and lemon for a dressing) is good to help you not get constipated; lightly steamed vegetables and rice is okay (brown rice is better); but no bread, no dairy, and no sugar. Select everything you can find that God has a digestive enzyme for to break it down. Try not to pick anything that is a processed food.

Work with your family and plan how you are going to have the best fighting chance to heal while you are in the hospital. Eat as much fresh, organic foods as you can. Ask if you can put a small refrigerator in the room. If they say no, just ask for help in bringing in fresh food every day. If anyone objects, ask to speak to the nutritionist on staff.

And don't forget to put all the diet information into your care book. This way, everyone knows your food plan and what you are eating so they can fill in the holes and give you the best chance to heal.

Walking

In order to get out of the hospital, you need to be sure that when you get home, you are safe. The sooner you get up out of bed and start walking, the sooner you will be home and able to walk to continue your recovery.

Use your care book to mark down your walks. Write down how much walking you need to do on your own as your exit-strategy for getting home.

Have a walking plan for when you do get home and assign someone to help you with your scheduled walks.

Nothing is more stressful than trying to manage your own care. Your loved ones want to help you and be part of your recovery plan. Just as with your food program, get a plan for your daily exercise and stick to it as best you can. Always remember just one step toward healing is all you need to do, then two steps just keep moving ahead everyday

Water

This shocked me, but 90 percent of the time, no one wrote down what I was drinking. How do they know if you are becoming toxic if they do not know how much water you are drinking? How do they expect your body to flush out the anesthesia drugs? How do they expect you to have a bowel movement when they are giving you pain medication if they do not know your water levels going in?

When I was visiting my sister as she was dying, she had been constipated for days. I knew she was in terrible pain from the waste build-up. I found a colonic clinic and took her there for treatment. Mounds of waste came out of her colon. She was out of pain, finally.

During a colonic, a small tube is inserted and warm water will flow in and flush your colon. They hold the water in as they massage your colon. When released, the water and the waste that has been stuck is removed. If you can stand to see it, it will amaze you. Please be sure to only see a licensed specialist in this field. Ask your doctor or hospital to make some recommendations and then do your research. Holistic centers are also a good place to start your search.

If you can't drink water, then find out how to get more water in your system using IV methods. This is so important to keep your bowels functioning. Your insurance and medical staff may tell you that it's not that important. But don't listen to them. If you are not having regular bowel

movements or urinating equal to the water you are taking in, don't listen to them. Be able to point to your records so you can make an informed decision.

There are water IV clinics popping up all over to help with water intake. I would either pay the hospital or go to one of these clinics. Always investigate them thoroughly first to make sure they are clean and know how to properly insert an IV. I was in a hospital once and they inserted the IV wrong and my tissues filled with fluid. I was the one that brought it up to the nurses that I was not peeing. I had to stay in the hospital for three days on diuretics to get rid of the fluid.

Hiring a Caregiver

Here is the order of how staff takes care of you in the hospital: doctors work with registered nurses (RNs), who work with licensed vocational nurses (LVNs) who will take care of you in the hospital. LVNs report to the RNs. They are all human and make mistakes. If you don't see them putting something about your care in your medical record right after they do it, then it is up to them to remember to do it, or they'll tell someone else what you said or did. If you talked about it and they did not put it in the computer, *then was it said?* The LVNs do not have access to the computer and they are the ones getting the information from you because they are around you more than the RNs. Make sure to tell the RNs directly if you want it entered in your record. If you do not see them enter it into the computer, ask them to do it as your doctor checks the computer for updated information.

A Note to Families: When hiring a caregiver or notetaker, remember to go over this with them. So many people think this will automatically be done because they are in a hospital but that is not the case. This is a lot to put on the patient to do by themselves.

Let the patient know someone cares about them and if you can't be there when needed, arrange for someone to be there for you. Even if you have to pay for this, it will cost more later if something goes wrong. It will cost you

the rest of your life if you should have been watching, but did not catch something. I have been an advocate for people sharing my hospital room when they had no one to help them. I think since no one was with them they were treated differently. The more watch dogs you have, the better.

Remember, everyone makes mistakes and there are many aspects to your loved one's care. Computer records are only as accurate as the information they are given by humans. Be active in your loved one's recovery and pay someone to keep the records updated and ask the questions needed. When something doesn't look right, speak up!

Wound Care

After surgery, how you take care of the wounds is a serious assignment and not something you should ever take lightly. Improper wound care can mean life or death. My father died of a leg wound that was not treated correctly by the family members who were watching him. They never told me about his wound until it was too late. I sadly found out they never gave him proper care.

After a mastectomy surgery, you'll be dealing with drain care and wrapping the chest. It is so important both are done correctly. All breast surgeries can lead to complications. The hospital is an infection waiting to happen. Everything you touch can have a germ on it. I used to clean my room when I was bored. It would make you sick to see the filth that came off. The IV pole was the worst, the bed rails were second, and the list goes on and on.

The drains go directly into the wound and can cause all kinds of infections if not emptied often. The drains work by suction and if they get too full, the suction lessens, so less fluid is being sucked from the wound which can build up in the chest.

You'll need your care book to keep exact records of the amounts coming out, including the date, time, amount, and fluid color so you have a log of

the progress. If anything does not look right, take a picture, and send it to the doctor immediately and call the office to make sure they received it. Do not wait. If they do not call you, call them again—it is that serious.

When we have a written account of what's happening, it's the best way of keeping in straight. This way it's not hearsay or we think happened. If an emergency comes up, hand your care book to the EMT or the hospital staff so they can see at-a-glance what has been going on. This could be a lifesaver when minutes count.

Wound healing is the hardest part of any surgery. You need to look at the wound's recovery as a part of your entire recovery. The body has a lot to say to you. Are you listening? A good way to confirm what you are hearing is by keeping your care book updated at all times.

My plan for this book is to keep you safe and allow you to heal without stress and to help your loved ones feel safe when they are taking care of you. This is a way of you working together as a team when dealing with your care. You do the healing and they do the watching to make sure everything is being done correctly while you heal. **You can print a copy of my care book for yourself which is on my website, twentyfiveyearsandcountingcancerfree.com.**

Please make sure you totally understand the above and everyone commits to it all the time. There can be **no gaps** or people won't know if something is accurate or not. Make sure you add the date and time to everything and initial what you wrote so you know who wrote it. If questions come up, you can go to the source and ask.

Be safe, be prepared, take charge, and know it is always your right to ask questions of anyone.

Meal Group	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Drinks							
Milk	OZ.	OZ.	OZ.	OZ.	OZ.	OZ.	OZ.
Coffee	OZ.	OZ.	OZ.	OZ.	OZ.	OZ.	OZ.
Tea	OZ.	OZ.	OZ.	OZ.	OZ.	OZ.	OZ.
Soda	OZ.	OZ.	OZ.	OZ.	OZ.	OZ.	OZ.
Ensure	OZ.	OZ.	OZ.	OZ.	OZ.	OZ.	OZ.
Juice	OZ.	OZ.	OZ.	OZ.	OZ.	OZ.	OZ.
Beer	OZ.	OZ.	OZ.	OZ.	OZ.	OZ.	OZ.
Wine	OZ.	OZ.	OZ.	OZ.	OZ.	OZ.	OZ.
Alcohol	OZ.	OZ.	OZ.	OZ.	OZ.	OZ.	OZ.
Other	OZ.	OZ.	OZ.	OZ.	OZ.	OZ.	OZ.

Recommended drinks: water, decaffeinated herbal tea, carbonated waters (unsweetened)

Weekly Activity Log

Week of _____

	SUN	MON	TUE	WED	THU	FRI	SAT
Water	oz.	oz.	oz.	oz.	oz.	oz.	oz.
Water	oz.	oz.	oz.	oz.	oz.	oz.	oz.
Water	oz.	oz.	oz.	oz.	oz.	oz.	oz.
Water	oz.	oz.	oz.	oz.	oz.	oz.	oz.
Urinate (Pee)	am pm	am pm	am pm	am pm	am pm	am pm	am pm
Urinate (Pee)	am pm	am pm	am pm	am pm	am pm	am pm	am pm
Urinate (Pee)	am pm	am pm	am pm	am pm	am pm	am pm	am pm
Urinate (Pee)	am pm	am pm	am pm	am pm	am pm	am pm	am pm
Bowel Movement	am pm	am pm	am pm	am pm	am pm	am pm	am pm
Bowel Movement	am pm	am pm	am pm	am pm	am pm	am pm	am pm
Bowel Movement	am pm	am pm	am pm	am pm	am pm	am pm	am pm
Bowel Movement	am pm	am pm	am pm	am pm	am pm	am pm	am pm
Walking							
Walking							
Walking							

	SUN	MON	TUE	WED	THU	FRI	SAT
Sleeping Notes:							
Night	hrs.	hrs.	hrs.	hrs.	hrs.	hrs.	hrs.
Naps	hrs.	hrs.	hrs.	hrs.	hrs.	hrs.	hrs.
Wound Care Instructions:							
Wound Care (explain)							
Wound Care (explain)							
Wound Care (explain)							
Wound Care (explain)							
Vitamins (Types):							
Morning	Y / N	Y / N	Y / N	Y / N	Y / N	Y / N	Y / N
Evening	Y / N	Y / N	Y / N	Y / N	Y / N	Y / N	Y / N
Herbs (Types):							
Morning	Y / N	Y / N	Y / N	Y / N	Y / N	Y / N	Y / N
Afternoon	Y / N	Y / N	Y / N	Y / N	Y / N	Y / N	Y / N
Shakes:							
Morning	Y / N	Y / N	Y / N	Y / N	Y / N	Y / N	Y / N
Afternoon	Y / N	Y / N	Y / N	Y / N	Y / N	Y / N	Y / N
Sugar Challenge (See chapter on sugar)							
Number of Packets							

Emotional Support Log

Check in with them (Morning/Afternoon/Evening)

Record emotional state throughout the day

Day _____

Time _____

Notes: _____

Day _____

Time _____

Notes: _____

Day _____

Time _____

Notes: _____

Day _____

Time _____

Notes: _____

Day _____

Time _____

Notes: _____

Day _____

Time _____

Notes: _____

Insurance Communication Log

Take very good notes to back up your claims!

Document every phone call.

Ask for the representative's name and supervisor's name (ask them to spell it if you're unsure).

If sending info, request fax number, address, email address to send paperwork. Always make copies of everything before you send anything by mail.

Representative's Name: _____

Date: _____ Time: _____ Supervisor's Name: _____

Notes: _____

Representative's Name: _____

Date: _____ Time: _____ Supervisor's Name: _____

Notes: _____

Representative's Name: _____

Date: _____ Time: _____ Supervisor's Name: _____

Notes: _____

Representative's Name: _____

Date: _____ Time: _____ Supervisor's Name: _____

Notes: _____

Representative's Name: _____

Date: _____ Time: _____ Supervisor's Name: _____

Notes: _____

Medical Knowledge

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