



IN LOVING MEMORY
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www.VitalOptions.org



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CHAPTER #1: Managing the Impact of the News

There are countless thoughts and emotions one experiences when hearing the words, “You have been diagnosed with cancer.” Once taking in the sheer shock, a common reaction is trying to figure out what to do first. Our team members and their family members have experienced this too. We understand.



For many, having an “action plan” can create some sense of order when feeling like their world has been turned upside down. This e-Book is designed to lead you through steps to help you manage your health care and take control of your treatment, so you are the one running your life, and not this disease.

An immensely helpful start is to organize your information and your resources. Organizing will go a long way to reduce your stress and put you in control.

Another important decision is to decide whom you trust to be your patient advocate. It can make a huge difference to have this person go to medical appointments with you, take notes on what the doctor is explaining, and to provide emotional support.



CHAPTER #2: What Do I Do First: Important Organizing Tips



SET UP THE BINDERS & BASKETS



MAKE A LIST OF YOUR CURRENT RESPONSIBILITIES & COMMITMENTS



PREPARE FOR YOUR MEDICAL APPOINTMENTS

STEP 1: SET UP YOUR BINDERS (This applies to digital natives too):

The most important step is to organize your information and your resources. Yes really! Now you may be more digitally inclined. Don't worry, you can move everything to digital in a short order if you wish. To start, however, most individuals find that it is easy to communicate with doctors and family with hard documents in front of them. Doing this now will go a long way to reduce your stress and put you in control. To get started, purchase:

4 three-ring binders (you may wish to have more)

1 three-hole punch

3 packages of divider tabs

1 package of plastic sleeves (for items, such as, medical cards, receipts, prescription copies, CD's with your scanned medical images)



Photo Courtesy of Swingline

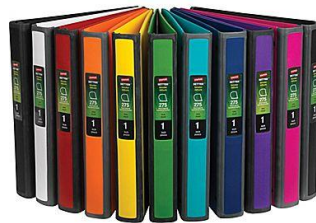


Photo Courtesy of Staples



Photo Courtesy of Office Depot

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Label the binders: MEDICAL
INSURANCE
CAREGIVER
HOUSEHOLD

This step may seem incredibly easy and even a bit outdated; yet the reason most people call a professional organizer is because they find themselves experiencing extreme chaos several months into their cancer treatment. Heed this simple advice of those who have gone before you. The bills, the insurance, the passwords, the treatment, the medication, the tiredness, the kids' schedules – at different points can become too much. We may accidentally leave the most current medical results stuck in a book as a bookmark – nowhere to be found, our spouse can't find the necessary insurance policy to submit for a major reimbursement on a medical bill, and our brains – for just a moment – can't retrieve a familiar password so we can get cable service re-instated after a major rain storm.

STEP 2: SET UP BASKETS :

Create easy access with baskets or bins: You may be spending many hours getting tests, going to medical appointments, or sleeping after chemo. Prepare now to reduce chaos and clutter and gain control. We suggest getting baskets or bins with handles. Label the baskets, such as: "Mail, Bills, Children's School Papers, Free Lance Work," etc. Label the baskets by category and you can go through them at your convenience while sitting anywhere in your home, then put back neatly for easy retrieval. Purchasing or using an inexpensive bookcase from another part of the house will make it easy to store the baskets or bins.

It will also be helpful to purchase a scanner (many medical offices only use fax. If you don't have a fax machine, you can set up an e-fax account).



Photo Courtesy of Fujitsu and Walmart



Photo Courtesy of Pottery Barn

CHAPTER #3: SET UP YOUR SUPPORT TEAM

Sometimes we feel all alone at this point. Sometimes, we feel like saying, “Don’t Mess with Me! I’ll show you!” Perhaps we are somewhere in between. One way to avoid future overwhelm and panic is by taking the time NOW to make a list of your current daily activities, responsibilities and commitments, realizing that many of those tasks may need to be given to others (friends, family, people hired). Examples of that list might include:

- Taking and picking up children from school
- Going to the market
- Bank deposits
- Mowing the lawn
- Taking and picking up children from various activities, such as sports, religious school, music lessons, etc. Whenever possible, it is best to keep the children in their routine.

Once you have selected someone as your trusted patient advocate (or use a professional organizer), ask them to help you organize your “to do” list and add names of friends, family members and volunteers who are willing to support you with your varying tasks.

Organize your LifeCloud™
DigitalLifeCloud.com

Weekly To Do List

Week of: _____

Monday	To Do	Comments
	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	

Tuesday	To Do	Comments
	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	

Wednesday	To Do	Comments
	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	

Thursday	To Do	Comments
	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	

Form LC0048
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When it comes to paperwork (and once you have your helpers in place), be ready to communicate clear instructions to them by labeling the tasks – such as: Shred, File, Scan or Upload to the Cloud - such as Digital LifeCloud®.

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CHAPTER #4: PREPARING FOR APPOINTMENTS – What’s Best for Me?



Having an advocate, family member or trusted friend join you, at a minimum, for your initial doctor’s appointment, and ideally for as many doctors’ appointments as possible thereafter is extraordinarily important. These appointments tend to be a blur due to receiving so much information. Having a “second ear” and someone taking notes will be enormously helpful.

This Step contains essential information for organizing and preparing for your numerous doctors’ appointments. Be sure to always take your medical binder with you – or when you finally have it in place – your digital file.

As mentioned in the introduction of this eBook, setting up varying binders will allow you to keep up with all your important information. It will be accessible and organized to help experience productive medical appointments and easier decision making. When setting up your Medical binder, here are the suggested tabs:



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SUGGESTED TABS FOR “MEDICAL BINDER”

- ONCOLOGIST’S INFO - full name of your oncologist, address, phone number, directions, parking instructions
- ADDITIONAL DOCTORS’ INFO (e.g. radiologist, surgeon, etc.)
- QUESTIONS / CORRESPONDENCE WITH DOCTOR / NURSE
- BLOOD TESTS
- GENETIC TESTING
- MRI REPORTS
- CT SCAN REPORTS
- PET SCAN REPORTS
- ECHO EKG REPORTS
- BONE DENSITY TESTS
- TREATMENT PROTOCOL / MEDICATIONS
- NUTRITION INFO (e.g. certain foods you are not allowed to eat when receiving chemotherapy)
- TRACKING SIDE EFFECTS

Thinking through questions ahead of time before your doctor’s appointment can reduce anxiety, eliminate forgetting to ask an important question and encourages confidence in your own ability to advocate for your best medical care. Here are specific and suggested questions to ask your oncologist before AND during your appointments.

QUESTIONS TO ASK YOUR ONCOLOGIST:

- Does your oncologist take your insurance?
- How will your oncologist get your medical records? Will the referring physician send them or do you need to bring them for your first appointment?
- Ask how long do they estimate for the first appointment?
- Make sure you have a good (physical) calendar so you can write down all appointments or enter them into the cloud.
- Come prepared with questions.
- As you learn about your cancer diagnosis and treatment options, ask your doctor how soon you need to make a treatment decision.

With all your records organized and in your control, seek a second opinion!

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If you have a complicated diagnosis, a third opinion can be considered. Be sure to have your “questions to ask” in your binder when going to your oncology appointment. Have your advocate with you at the appointment.

WHEN FIRST DIAGNOSED – find out:

- What type of cancer you have (request the exact name).
- What stage the cancer is and what does that mean.
- What symptoms you may experience from the cancer.
- What other types of tests you will need. (E.g. biomarker or genetic tests)
- Explore where you can get a second opinion.

YOUR CANCER TREATMENT – find out:

- How much experience the doctor has in treating your specific type of cancer. If he/she is board certified as an oncologist or certified in another specialty.
- If your doctor is associated with a major medical center, medical school or comprehensive cancer center.
- What are the treatment goals (is it to cure the cancer, control the cancer, or relieve symptoms).
- Which treatment(s) is recommended and why.
- How will the treatment be given and how often.
- What the risks / benefits are of each treatment option.
- The side effects that should be expected from the treatment, and how they can be managed and potentially prevented.
- If treatments are covered by your insurance and what options are there to help cover the costs.
- Explore where you can get a second opinion.
- If in advanced stage of cancer or problematic to treat, are there any clinical trials that would be appropriate for you.
- If emotional and practical support services are available to you and your loved ones.

NOTE: Award-winning forms can be obtained at www.digitallifecloud.com which can be printed and put in binders to help keep you organized.

CHAPTER #5: MANAGING INSURANCE AND COSTS



Dealing with the insurance aspect and costs can be hugely challenging. Most of us want to avoid dealing with insurance – yet it can be the key to maintaining financial stability. Keeping a binder with all this information organized will assist in minimizing the utter frustration when communicating with your insurance company and the bills associated with your medical bills. Here are tabs for this particular binder:

SUGGESTED TABS FOR “INSURANCE / COSTS - BILLS INFO BINDER”

- INSURANCE INFO – e.g. co-pay, deductible, % insurance company pays in and out-of-network
- DOCTORS’ / HOSPITALS INSURANCE COVERAGE AND FEES (e.g. oncologist, radiologist, surgeon, anesthesiologist, etc.)
- BLOOD TESTS COSTS / BILLS
- MRI COSTS / BILLS
- CT SCAN COSTS / BILLS
- PET SCAN COSTS / BILLS
- ECHO EKG COSTS / BILLS
- BONE DENSITY COSTS / BILLS
- TREATMENT PROTOCOL / MEDICATIONS COSTS & BILLS

Ask if there is a financial counselor or social worker who can help you find out what will be covered under your plan for your doctors, hospital bills, surgery, cancer treatments, medications and supportive care. Include seeking out information about your co-pays, deductibles, and other costs you may have to pay.

IMPORTANT: Make sure all of the health care professionals and the locations of care you receive are considered in your network or that you understand what it means to be located out-of-network.

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CHAPTER #6: CAREGIVING



When diagnosed with cancer and receiving treatment, the “caregivers” (those who help care for you, your children, your aging parents, and even your pets!) are critically important so you can focus on addressing your own health needs.

This section guides you to set up a binder to help organize information related to caregivers. Be sure to keep it accessible for the caregivers who are helping with your loved ones.

SUGGESTED TABS FOR THE “CAREGIVING BINDER”

- BABY SITTER / CARE-GIVER CONTACT INFO
- ACTIVITY SCHEDULE / INFO FOR THE KIDS
- SCHEDULE / INFO FOR ELDERLY PARENT
- PET CARE-TAKING INFO

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CHAPTER #7: KEEPING YOUR HOUSEHOLD RUNNING SUCCESSFULLY



(free photo from pexal)

Managing the household day-to-day while healthy is challenging enough. When ill, this aspect can be grueling. This binder includes suggestions for organizing and managing household items. Even when life is not chaotic and you're healthy, this information can be literally life-saving!

SUGGESTED TABS FOR "HOUSEHOLD INSTRUCTIONS BINDER"

- EMERGENCY INFO
- LOCATION OF ITEMS IN THE HOUSE
- INSTRUCTIONS FOR HOME ITEMS (e.g. how to open garage if power goes out)
- HOUSEHOLD UTILITIES INFO

Your emergency information should include items, such as, the location of your gas-shut off, main water shut off valve, fire extinguishers, emergency contact list, first aid kit and copy of health insurance card.

It's also helpful to have a list of "Location of Items in the House" such as, the basics of flashlights, batteries, lightbulbs, extra toilet paper and paper towels, extra house key, garage clicker, etc.

Although technology can help make life easier, it can add many complexities. Providing instructions for home items, such as how to use the TV / remote controls, A/C, your house alarm, etc. can be very useful.

Having a list of your utilities info for caregivers is another aspect that can come in handy if there are issues with power outages, Wi-Fi issues, issues of smelling gas, etc.

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CHAPTER #8: ORGANIZING FOR SURGERY

It is totally normal to feel anxious when preparing for surgery. Organizing before surgery and having a system in place during recovery can not only lower your anxiety, it can actually increase your peace of mind and your healing. Being organized also provides your loved ones and caregivers a clear understanding of their role in supporting you.



(free photo from Pixaby)

PRE-SURGERY

- Make sure you are confident with your choice of a surgeon and that your particular surgery is that doctor's specialty. Are you confident with the hospital or outpatient center choice? Gather your insurance information to coordinate your coverage.
- Decide who will be your advocate and who will be communicating to your family, friends, and colleagues.
- Gather a list of ALL medications you are taking (including over-the-counter and other supplements).
- Make a list of ALL your health issues and a list of all previous surgeries and procedures in chronological order. Include any allergies.
- No surgery is scheduled without including a pre-op visit. Usually this would include:
 - Blood tests
 - Chest x-ray
 - EKG
 - Nurse/doctor interview
 - Discuss prevention of surgical site infections with the doctor/nurse during your pre-op visit. Get instructions and necessary supplies in advance to deal with and prevent surgical site infections. This will involve things you need to do prior to surgery and also post-surgery.
 - Review of anesthesia – local (numbs a small area), regional (such as nerve block, spinal, epidural), monitored (IV where awake but in relaxed state), and general (unconscious throughout the procedure). There may be important questions your anesthesiologist will discuss with you.

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- Organize a list of EVERYTHING you will need prior to surgery. Make sure you understand all the instructions.
- Mark your calendar and write a list so you will remember when to STOP taking certain meds and when to START pre-op meds.
- You may be given your surgery date, but often you won't be given your arrival time until the day before.
- In organizing prior to your surgery, ask what you might need for comfort and safety when you return home so you are prepared in ADVANCE. Many times you can get your pain meds and other medications from the hospital pharmacy before you leave the hospital. If that isn't available, make sure that your local pharmacy carries what you need. You don't want to come home from the hospital in discomfort or pain and not have access to what you need.
- If you have food restrictions, arrange for someone to have the appropriate food in your home.
- You will need to sign a "Consent for Surgery/Procedure" form.
- You will need to have a signed "Advance Directive for Health Care". This will require pre-planning to complete and get witness signatures.
- If your hospital has a Patient Portal make sure you can access the information for all your records.

Before Surgery: Follow instructions carefully to prepare regarding, bathing, shaving, cleaning, fasting, discontinuing fluid intake, etc.



(free photo from Pixaby)

During Surgery: If you are receiving a general anesthetic, the anesthesiologist will monitor your blood pressure, heart function, breathing and oxygen content in your blood. You will be given oxygen to breathe through a mask. The anesthesiologist adjusts your medications to keep you asleep and pain free during the procedure. At the end of the procedure the anesthetic agents are stopped and you will receive medications to reverse the effects of the earlier medications.

After Surgery – You will normally go to a recovery room where you will be monitored carefully as you come out of the anesthesia to assess your pain level, nausea, or any other discomfort.

1. If you are going home after the procedure, you will be given discharge instructions, medications and other information before discharge.
2. If your surgery requires you to be admitted to the hospital, you will go to a room after spending time in the recovery room. Loved ones and friends can come to your room and personal clothing and other items can be brought to you in your room.
3. You may see a case manager and/or nurse before discharge who will provide: booklets and information and instructions on emptying and cleaning drains, preventing infection at the incision, your new medication schedule, resuming showering, bathing, and meals. A case manager will prepare you for a successful discharge to your home or other care facility. If you need home health services, physical therapy, or other care, it can be arranged.
4. Anything requiring new or changed routines for exercise during recovery can be discussed with a physical therapist from the hospital. If you need a walker or other equipment, it can be arranged.
5. Much of this can be asked for in ADVANCE so you or a loved one can get the needed supplies, and prepare before going home following the surgery. This will alleviate the problem of leaving the patient alone when returning home.



(free photo from Pixaby)

- Find out if there is a nurse hotline or an ability to call and get advice if something unforeseen arises before you return for the customary post-op checkup with your doctor.
- Make sure you schedule the post-op doctor visit.

Getting Your Surgery Records

Before leaving the hospital you should request a copy of your “Operative Report”. This report is not routinely given to patients but it contains all the details of what was done during the surgery, and anything such as breast implants will be detailed in this report. You should keep this as part of your permanent medical

records, either in your binders or uploaded to your secure cloud storage account (www.digitallifecloud.com). It will be important to provide this information to another doctor or hospital in the future.

Other medical records, such as pathology reports, scans, blood tests, etc. can usually be obtained through the Patient Portal provided by the hospital or doctor's office. These reports should be downloaded and printed to be kept in your binders or uploaded into your cloud account so that you OWN AND CONTROL the information, and can immediately access ALL your health records as needed.

CHAPTER #9 ORGANIZING AND HONORING YOUR LOVED ONE'S LIFE WISHES

Organizing someone's Life Wishes, is that a real thing? Yes. Yes, it is—and there are steps we can take to be organized, as we make the effort to allow our Loved Ones to have lived and perhaps even die without any regrets. We can assist in helping them to realize one last life wish.

DOROTHY'S STORY

For as long as I can remember, my sister Pat always wanted to be a Nun. In fact, in our adult years, we would both look back at our childhood years, where instead of playing dolls or monopoly, my sister wanted to play "Priest and Parishioner." She was the Priest and I was the parishioner. Our Altar was an old blue vinyl record player case, where we had Holy Communion consisting of white vanilla chocolates (to be used as the edible Holy wafers), a stolen crystal wine glass from mother's cabinet (which held our grape juice), and heavenly-smelling peonies snipped from the back hill of our Wisconsin farm house as the Altar decoration. From childhood playtime and throughout the subsequent decades, Pat's commitment to the Catholic Church grew and her conversations with her God became more frequent, especially in the face of her Stage 4 Cancer diagnosis.

Though I floated through my own spiritual confusion, moving from Catholicism to "nothing," to Judaism, and finally landing with a Higher Power of my own understanding, Pat's belief in God and the Catholic Church remained staunch, solid, and sincere.

Whenever one of the Popes from the Vatican visited the United States, I felt like Pat was a reporter for the national news covering up-to-the-minute details of that Pope's every move. I think it was why it was so easy to hear, understand, and easily take action on Pat's life wish to maybe someday see the Pope.

Ten years into Pat's terminal illness, I learned that her cancer had gone to her brain. With the guidance of my husband's experience in caring for his late wife, I learned that it was time to act and act quickly. I got the courage to ask my sister what she would like to do in her life with whatever time she had left. She said, "see Pope Frances." Upon hearing this, I immediately started researching his travel schedule but saw no trips scheduled anywhere in North or South America. I then looked up his daily schedule and learned that every Wednesday, at the Vatican in Rome, he hosted his Papal audience. Fat chance at that, I thought! But somehow when you are looking to honor a life wish for a loved one, it is easier than doing it for yourself. I then put the word out to as many people as possible that I was looking for a way to make this happen for Pat. While you'll learn the step-by-step details of how you (and we) made this wish come true for Pat, let me share with you now, the exact moments around our 3-hour adventure to see the Pope.

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Once my Husband Marty, my sister Pat, and I landed in Rome on a Monday in October, we checked into a comfortable apartment for three, just one block from the Vatican, with a direct view of the Vatican domes and bell tower.



On Tuesday, Marty and I went to pick up the tickets from the Vatican carrying a small letter from the Pope's Secretary. We stood in line for two hours, with fingers crossed, in the hopes of getting these tickets. At the two and half hour mark, only I was granted permission to move forward. I went through a metal detector, had my bags searched, and quietly walked up the stairs past the iconic Swiss Guards, similar to the Foot Guards at Buckingham Palace.



Vatican

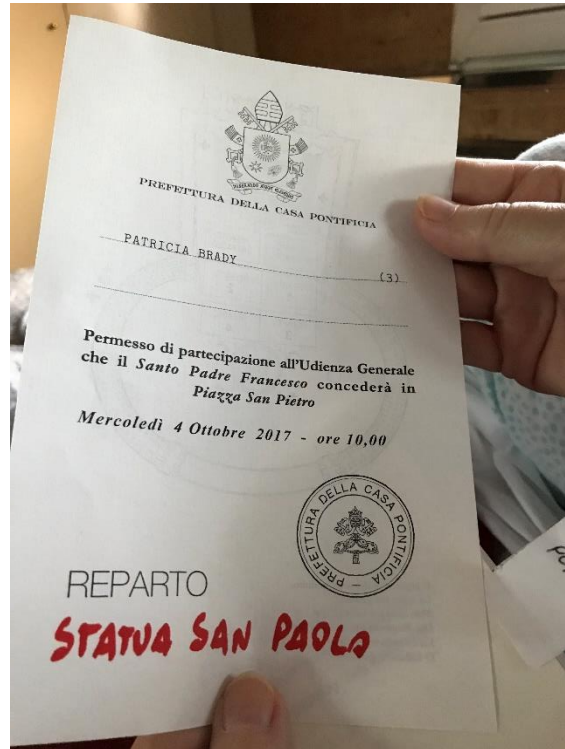


Buckingham Palace

These men stood at command, directing me to a small doorway inside the Vatican, where staff members had boxes filled with tickets in alphabetical order similar to a "will call" at the live theatres in New York City's Times Square. I gave them my sister's last name (with total preparation to be disappointed) but shockingly learned they had 3 tickets for us. Just moments later, I had those three tickets and a document written in Italian (along with a diagram) confirming what we thought to be – but couldn't really tell – was the closest section to see the Pope next morning.

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On Wednesday morning, still with consternation and caution, we were all up at 6:00am. Pat selected her clothing like a first-time bride as she sang along to a Beatles' song that was playing on the radio in Italian. Later she adjusted her European scarf over her bald head selected and sent along by our mom who stayed at home – simply exhausted for the years of caregiving for my sister. We packed Pat's medication and a few snacks and jumped in the taxi to drive the two short blocks to the Vatican. Our cabbie was annoyed. He had no idea why we would flag a cab for such a short trip. He shook his head with frustration as we gave him his Euros. I realized – one can never know what is truly going on with another person. I asked myself to "Remember this for the future, Dorothy."

At our arrival, Marty and I put Pat arm-and-arm between us (none of us over 5' 3" tall) and battled our way through the crowd of 80,000 people. As we approached the entrance to the Vatican Square, we could see in the distance dots of color peppered throughout the crowds. They were flags held by tour guides speaking languages from all over the planet. The clock was ticking closer and closer to 10:00am (the start time) and we weren't even inside the Square. Marty's chest was filled with anxiety, my heart was filled with deep concern that we were so close and that we might not pull this off, and sweet Pat - with all her cancer -remained wide-eyed and hopeful.

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After thousands and thousands of bodies were merged through the main turnstile, we arrived inside an already-capacity-filled plaza. There was absolutely no indication of where we should go. In my broken Italian, we were directed to the Vatican Police toward the upper right section of the Plaza. Continuing to carry Pat between us, her feet sometimes lifted up off the ground like a child between parents at the beach. That alone is a great memory for me. I accepted THAT moment with my sister as my memory and I no longer fretted about making it to the front of the line.

Naturally as soon as I accepted the way things were, everything turned to gold. In fact, it seemed that Pat's lifetime of prayer was being bestowed on her right now. Police Officialle' after Police Officialle' directed us further and further to the front of this oversized crowd until we found ourselves literally in the front row to see the Pope. But that's not all. An elegant man dressed like a fine Sommelier, summoned us even closer. My heart sank as I could see everyone in our section sitting down with no chairs left and Pat would have to stand for three hours. I knew Pat could not possibly do that and make the walk back to the Taxi too. But Pat's prayers and faith continued to guide the day, when the Pope's representative magically produced three chairs from behind an elegant podium.



He motioned to us to move closer. I questioned him in English, "Who Us?" He nodded and smiled. He reviewed our document and placed the chairs down in the front row and told us to sit. He introduced himself to us and explained that he had been working for the Vatican and for the last 3 Popes - his entire lifetime. I sat down in amazement as Pat and Marty turned to each other and asked if this was really happening. The adrenaline was rushing through our veins as we came to terms with where we were and how lucky we felt. Pat prattled on about Pope Frances, Marty took pictures, and I turned around to look behind us. More people than I'd seen in a life time. How could we be here?

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I thought of my mom and wished she were with us. I thought of Marty's mom who created this opportunity for us. I thought of my dad who introduced all of us to the Catholic faith, I thought about miracles. I was moved and inspired to become a better person. But suddenly my day dreaming was interrupted by a roar of excitement by the crowd – the Pope was entering the Square in the "PopeMobile!" We all stood and cheered and waved and yelled with excitement. His car drove through the crowd on roped off paths – surrounded by security and thousands of cameras held high to snap a shot of this momentous occasion. How lucky we were to see him this close.



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Moments later, the car stopped, and the Pope walked up the grand stairs to the Vatican. Cardinals, Bishops, and other dignities followed behind him. We watched in disbelief. We were greeted in many different languages and then the Pope spoke. I held my sister's hand as we listened and smiled. I wondered what she was thinking. We remained quiet and composed. My husband's hand brushed my neck. We were all connected and lost in our own thoughts of gratitude, life, and figuring out how to become better people. The Pope finished speaking and he walked to have some pre-arranged photos taken with groups on the stairs. We got to watch.

The Pope then walked away from the groups and toward the people sitting in the last row of our section.



I came to realize while sitting there, that this section was reserved for the terminally ill. Young people on gurneys, older people in wheel chairs, lots of kids and adults with bald heads and bandages. I understood that we were granted the best day of our lives because everyone in that section was facing the worst circumstance – terminal illness. Gifts come to us in strange ways, huh?



There were seven rows with 20 people per row and it was so touching to see the Pope take a minute to greet some of these very sick people before he left. He held their hands and blessed their heads and accepted hugs from the group around him.

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But something unique happened. The Pope didn't leave. He continued down that row and greeted everyone. We got to see Pope Frances from 6 rows away. No. From 5 rows away. No. From 4 rows away. Wait a second. Could it be that he was greeting EVERYONE in this section? My breathing went into double time and I looked at Pat and Marty, "Do you think?" and before I even finished saying the rest of the sentence – they both answered: "Yes, I think he's coming our way." I jumped when someone tapped me on the shoulder. The Pope was in row 3. Saddened, and based on the "tap of the shoulder," I knew it was our time to leave. Wrong again Dorothy! The Pope's handlers informed us to sit down, face forward and prepare to meet the Pope. They handed us tickets to pick up professional photos of ourselves with the Pope and pressed a Rosary blessed by the Pope into our hands.



We sat there stunned. Each of us adjusting our clothes and practicing what we would say when we, GULP would meet the Pope. My sister was going to MEET the Pope. Yes – me too. But this was her gift. I was just along for the ride. Wake up Dorothy. The Pope is before you! I bowed and thanked him for his world service. Marty shook his hand and the Pope asked Marty to pray for him. My sister stood tall and remained serious as she accepted the blessing from Pope Frances. He took her hands and he knew to give Pat the extra attention. She was dazed by her experience and seconds later sat down and smiled. We all felt a shift and took a moment to collect our thoughts.....and our belongings.

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We were quickly ushered out of the Vatican Square and we walked to our hotel. Pat didn't need a cab or any assistance to walk. She clutched her rosary as we strolled the streets of Rome looking for a celebratory lunch. We toasted. We ate. We laughed. We recounted the experience over and over again. It occurred to me that for 4 hours on that Wednesday in October, Pat didn't have cancer. Her symptoms, pain, and tiredness were all lifted as she enjoyed the realization of her life's wish.



Tomorrow would be Thursday. She would sleep. And on Friday she would return home to another round of chemo. Like Cinderella, the horses and carriage delivered her back home to her own reality – yet forever changed.

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DOROTHY THE ORGANIZER'S STEPS TO HONORING YOUR LOVED ONE'S LIFE WISHES:

STEP ONE: Find tender time for conversation with your Loved One and talk about what they would still like to do with the time they have left. For example, my sister Pat had always wanted to see and hoped to meet the Pope.

My sister Pat had stage four Cancer for 10 years and in March, for her birthday, I asked her the question, "What would make you feel like you have lived life to its capacity?" We agreed to discuss this as she only had finite time and it was unknown how much time was left. Clues began to appear that her life quality was beginning to change. Her gorgeous, impeccable handwriting had become illegible, she began misplacing money, her driving became jerky and less confident and she was losing interest in reading the newspaper, her all-time favorite pastime. All this suggested that we should create a meaningful experience for her. I asked her what she would like to do or where she would like to go. Her response was immediate: "I want to see the Pope."

Great. My sister wasn't interested in a family reunion or a magical cruise to Alaska or even to stay at the Ritz Carlton Penthouse in New York City. No, she wanted to see the Pope. How the heck would I ever be able to make that happen?

STEP 2: Check the reality of the wish your loved one has expressed. Meaning, is your Loved One in a healthful position to travel, be in public with germ risks, or do they have limited mobility? Is the wish doable with regards to finances? If not, what part of the wish could be fulfilled based on the budget that is available.

One of the best parts about honoring someone else's wishes is observing how creative and selfless you can become. In my quest to see how I could assist my sister in making her Life Wish come true, I had enormous self-pride and I was able to come to terms with her death in a meaningful way. I began speaking with every Catholic person I knew. As it turns out, my mother-in-law, Joyce, had seen the Pope herself years ago, and knew a Bishop in Los Angeles who could help us. Seeing how I am a "Type A" personality and an "I can do it kind-of-person, I immediately began to learn how to let others help me for the sake of my sister. I asked my mother-in-law Joyce if she would be willing to contact her Bishop and indeed she started choreographing an entire dialogue with the Vatican on our behalf. Several months later, we learned that we were on a list to possibly receive tickets to attend Pope Francis' audience at St. Mark's Square in Rome. Reality hits.... Are you kidding? Now what?

STEP 3: Share your idea and possible plans with one or two people outside the Family and see what opinions they can share or resources they may know of. Sometimes exciting and wonderful news can jar the family unit. Skepticism and fear can grip family members which can create barriers to making someone's wishes come true.

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While it's true, our Loved One's health and ability to participate in an important event must be factored in, we sometimes become blind to what our Loved One really is capable of, even though they are very sick. That's why it is best to discuss your ideas with trusted, thoughtful and grounded people outside the family.

In my case, I talked to my best friend Jeanette, a therapist, Pat's Doctor, my Business Partner Debby, who had just lost her sister to cancer. My husband, Marty, was very helpful - having been the caregiver for his late wife for ten years. Though all of us were fearful for my sister to take such a trip, my friends and colleagues guided me to move forward if Pat felt she wanted to try. Here's what I did.

STEP 4: Begin researching dates, reservations, travel arrangements and other potential possibilities (or requirements) about the event. Include contacting your Loved One's physician(s) for a clear understanding of their life expectancy and their safety and overall wellness for travel. Ask the physician's opinion of the Life Wish requested by your Loved One and inquire about their true ability to participate in the event. Get the physician's permission to travel, preferably in writing.

Knowing that there was a strong possibility that we could see the Pope, I asked my sister to check with her doctor about the possibility of travel and adjusting her chemo and radiation therapy schedule. Once I learned that she was encouraged by her doctor to take the trip in October, I communicated this to my mother-in-law, Joyce, who then communicated to the Vatican. I learned to take the chance and plan this distant event, even knowing my Loved One might not make it. I learned it can be a good thing. In fact, doing something like honoring your Loved One's wishes may inspire them to live a little longer or fight a little harder. With our October dates in hand, I checked my savings account, airlines for flights, and hotels near the Vatican.

STEP 5: Once you have gathered some basic information regarding the Event, present it to your Loved One. Listen to how they feel about the information and the plans for the event. They may want to help with the arrangements or itinerary, which could be meaningful to them, as long as it doesn't cause stress or upset, where their health may be impacted negatively.

I also asked my sister to verify that she had her passport in place, should we be able to pull this off. She did not, but I'll tell what, without my even having to prompt her, within two weeks Pat applied for one.

STEP 6: Purchase tickets, schedule travel arrangements (including flights and hotels, and car rental). Now that everyone involved is in agreement around the event, look into travel insurance in case you need to cancel some or all of your arrangements. There may not be insurance for all or parts of your arrangements, so you may need to accept this and be at peace with it ahead of time. Keep in mind that your Loved One's health can decrease rapidly without warning.

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Yet, I encourage you to be bold. Make an agreement with yourself that your Loved One may not make it to the event or destination due to illness, extreme fatigue or worse yet, their life ends before the experience occurs. Know that the money you are spending, is not necessarily for them to attend the event or make the trip, but rather gives your Loved One hope and desire to continue living when they are feeling low.

- Schedule Arrangements: (flights, hotels, transportation)
Keep in mind that your Loved One may need extra care.
- Consider shuttle busses, rooms with elevators (not stairs), room service, rental cars that are easy to get in & out of, wheelchairs, or wheelchair assistance and private sleeping quarters.
- Begin to set up an Itinerary for your Loved One and all family members for a back up contingency plan.

Insurance:

- If you are booking a rather expensive trip or excursion, consider insurance protection.
- Always carry your Loved Ones information like doctors' phone numbers, most recent description of current health condition, and medications.
- Hands down, the most secure way to handle this, is to register for a Digital Life Cloud account. Go to www.digitallifecloud.com and easily create folders and store vital information for your Loved One (and yourself) and keep it at your fingertips during the entire trip or experience.

Other important information:

- Get a complete understanding of your Loved Ones symptoms and the treatments or remedies for their symptoms.
- Depending on the severity of their illness, consider researching a local hospital near your destination.
- Prepare a list of healthy foods, snacks and local restaurants.

STEP 7: Ensure that this Life Wish is done through the eyes of your Loved One (not yours). Keep the agenda focused on the experience your Loved One would enjoy most. Consider their well-being and be prepared to sacrifice your personal desires around the event. This is for them.

It was my experience with my sister, that when I took her to meet the Pope in Rome, she and I had very different ideas of what we could and should do. I thought that letting her sleep in and hiring a car and driver to take us around to see the sites would be super easy and would require very little effort for her.

I also thought that a lovely meal at the end of the day would be relaxing and memorable. Boy was I wrong. All the energy my sister had each day went toward resting and sleeping so that she had the energy to see the Pope. She gazed at the Vatican by the morning sun and by moon lit skies each night. I made her meal in our kitchenette and served her tea in bed in the afternoons. So, you see, I started off by making the mistake of planning her trip through my eyes, when in fact we traveled to Rome – not to sightsee, but to see the Pope

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and have quality time with each other. I implore you to ask your Loved One what they feel their energy level is each day of your excursion and make your best assessment about them (and reduce the commitments from there).

Step 8: Create the Itinerary and set reminders for yourself and your Loved One. When will you be traveling? Where will you be staying? What will you wear? How will you pack? How long will you be away? Is there any house care needed while you're away from your own or your Loved One's home? Do prescriptions need filling? Be sure to include rest time for your Loved One before, during and after the Event.

SAMPLE TRAVEL ITINERARY

IMPORTANT PHONE #'S:

Dorothy Breininger xxx-888-xoxo Reachable via cell on land and in port (best to use WhatsAp)
Marty Estel xxx-999-xoxo Reachable via cell on land and in port (best to use WhatsAp)
Pat Brady xxx-777-xoxo Contact Pat through Dorothy
Mom xxx-666-xoxo
Joyce xxx-555-xoxo
Pat's Doctor xxx-444-xoxo

PAT MUST HAVES:

Medications
Passport
\$200 cash – just in case
Eyeglasses
WhatsAP downloaded on your cellphone
Cellphone charger

ALL OF OUR FLIGHT INFO TO ROME:

Oct 1	8:00 a.m.	Dorothy + Marty LAX – CHICAGO	American #362
	5:20 p.m.	Dorothy + Marty CHICAGO – ROME	American #110
Oct 2	9:15 a.m.	Dorothy + Marty ARRIVE ROME	American #110
	10:40 a.m.	Pat arrives Rome	TAP Portugal #834
	11 – 12pm(ish)	MEET PAT AT TAP Portugal at her baggage claim from flight #834	

WHERE TO MEET / WHAT TO DO IN CASE.....

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1. Be aware that we are all clearing customs. Yours could go faster than ours and remember Marty and Dorothy are coming from another terminal to meet you. Please wait at this baggage claim area no matter what.
2. We will be at the airport no matter what time your flight comes in.
3. If our flights are massively delayed for some bizarre reason – keep checking flight arrivals. Do not wait past 2pm. If we have not arrived by 2pm. Buy \$100 worth of Euros and take a cab to the hotel and we will reimburse you. It is a 48 minute drive.

HOTEL: Residence xxxx
Candia, Rome IT 00192
Phone #: 1-888-xxx-xoxo
Confirmation #444-xo-444
All three of us are in one apartment room
Oct 3 Rest at hotel, dinner, Marty to get tickets at Vatican
Oct 4 At Vatican (hopefully see Pope)
Oct 5 Tour Rome
Oct 6 Head to airport to fly home

What to wear/what to pack: Knowing that your Loved One is not well or full of energy, you may wish to help with the very obvious task of carrying their luggage, helping them put on or remove their jacket, or assisting them with their socks and shoes. Toward that end, it is wise for both you and your Loved One to pack minimally. In some cases, your Loved One may be suffering from memory loss and you may wish to pack and hold their passport, cash, doctor's instructions and medications.

The less clothing you pack, the more freedom you have. You will spend less time packing and unpacking and making decisions about outfits, which may not be a priority and more time focusing on your Loved One's health and experience.

Prepare to be away from home: Obviously, if you are going to be away for a short event like a concert, you need not worry. However, if you are taking a trip out of the area or country you will want to do the following:

- Arrange for Pet Care
- Stop mail and newspaper
- Water plants
- Call Home Alarm Company
- Share Itinerary with other family members and friends
- Pay bills in advance
- Spray for ants (if summertime)
- Install inside light timers (lights go on giving the appearance that you are home)
- Fill prescriptions for your Loved One and yourself

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- Make babysitting arrangements for your children or caregivers for aging parents

STEP 9: Do your best to assume the responsibility for decision making. If you are traveling with other family members, along with your Loved One, it is best for one person to become the decision maker to avoid any confrontations, miscommunications, or hurt feelings. Take the responsibility for your Loved One and let others know why you'll be the person in charge. Remember, you are doing this through the eyes of your Loved One; therefore, not all decisions will make sense to everyone.

For example, sleeping assignments: you may wish to give the most comfortable bed or the bed nearest the bathroom to your Loved One. While at Restaurants, you may need to sit closest to the entrance for easy in and out and less walking. While being the person making the decisions, it seems to provide relief to most people who are not well. However, there may be a time that your Loved One may in fact need to make certain decisions.

STEP 10: Document and record the event or experience to the best of your ability for your Loved One. Frame some pictures that were taken or play a video often so your Loved One can continue to enjoy the experience.

Because the event is most likely a joyous event for your Loved One, family and friends, documenting the event is essential. This will allow your Loved One to see themselves with a smile in the face of their own serious illness. It will also allow you a pictorial vision of what you were able to do for your Loved One; thus, extinguishing the often-recurring regret we feel when our Loved One becomes even more sick or passes away.

Some great ways to document the experience include:

- | | |
|----------------------|---------------------|
| • Photos | • Videos |
| • Sketches | • Post Cards |
| • Music | • Souvenir Displays |
| • Event Ticket Stubs | • Concert Programs |
| • T-Shirts | • Museum Stubs |

While I encourage you to avoid perfection at all costs and keep your documents and display projects simple, definitely take the time to frame at least one photo and keep it in the line of vision for your Loved One to see at all times. Also, keep the access to your video(s) nearby to play frequently for your Loved One.

STEP 11: After your Loved One has had time to recover from the outing or experience, make arrangements to celebrate with friends and family. Allow your Loved One to talk and share about their experience as often as possible.

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If your Loved One is well enough, do what you can to set them up to re-live these magical moments as often as possible. You may wish to create postcards of his or her favorite photograph and encourage them to distribute them and talk about them with their doctors, nurses, therapists, friends, workplace colleagues, or cousins who live across the Country. You might also consider posting an Open House Tea Party or BBQ for people to visit and hear about the experience first-hand, from your Loved One if he/she is able.

Finally, if your Loved One is lucky enough to live a bit longer than is expected, have an anniversary party to recall and relive the event with music and memorabilia at hand.

CHAPTER #10 IMPORTANT LINKS THAT CAN MAKE A DIFFERENCE

Babysitters / Caregivers	www.care.com
Baskets for Paper Storage	www.target.com/c/baskets-bins-containers-storage-organization-home/-/N-5xto7
Binders	www.bindertek.com
DebbyBitticks.com (Caregiving, Life Stories, Memories)	www.debbybitticks.com
Calendaring App for Families	www.cozi.com
Cancer Treatment Clothing (Comfy)	www.curediva.com
Communication	www.caringbridge.org
Comprehensive Cancer Resource	www.cancersupportcommunity.org
Decision Making Help	www.decisionbuddyapp.com/
Drug Research	www.drugs.com
Education and Support (for people with chronic & life-threatening illnesses)	patientsrising.org patientsrisingnow.org patientrisingu.org
Errand Runners	www.TaskRabbit.com
Exercise in the Home	www.chairdancing.com
Free Cancer Doctor Interviews	www.vitaloptions.org
Grocery Lists for Shopping	www.groceryiq.com/
Handyman Work	www.localhandymanpros.com
Health and Aging Expert	www.theagingexperience.com
Healthy Food Delivery	www.greatist.com/health/companies-healthy-home-cooking
Laughing – Fun Videos to Watch	www.dailyhaha.com/videos/
Legal Services	www.legalzoom.com

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Medical Organizing Forms (This is your vital information 24/7)	www.DigitalLifeCloud.com
Medical Research	www.webmd.com
Meditation for Healing	www.chopra.com
Organizing Services	www.DorothyTheOrganizer.com www.napo.net
Pet Health & Maintenance	pet-master-pro-ios.soft112.com/
Playdates Scheduler for Kids	www.instantplaydates.com
Professional Organizers	www.napo.net
Ride Sharing Service for Kids	www.hopskipdrive.com/
Second Opinions	www.webmd.com/cancer/features/cancer-when-do-you-need-a-second-opinion-and-why#1
Support Groups (Virtual Support Groups)	www.healtheo360.com
Transportation	
Ground	www.uber.com www.lyft.com
Air	www.angelflight.com
Understanding Lab Results	www.aarp.org/health/doctors-hospitals/info-02-2012/understanding-lab-test-results.html
Yoga	www.doyogawithme.com
Your Vital Information 24/7	www.DigitalLifeCloud.com
Wigs/Styles (Custom wigs & hair pieces)	www.pinybeverlyhills.com/piny-custom-wigs.html
Worrying Too Much	www.webmd.com/balance/features/9-steps-to-end-chronic-worrying#1

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**We would love to add your suggestions to our list! Please email us at:
Info@TheCancerConcierge.org**

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