

## The Day after Diagnosis

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It may have started with a persistent cough or a pain in your lower back that just would not go away. Or maybe it was a lump or a mass you felt during a shower. Maybe it was after that other driver who hit you many months ago. However it started, it may be hard to move on from that day the doctor told you that “this” (whatever your “this” turns out to be) is not going to go away. Whether your diagnosis threatens to shorten your life or forever change the quality of your life, there are steps you can take to manage what is happening. Any crisis is best managed by having a plan. A health crisis is no different. I am about to suggest such a plan to you – a plan that will help you “SCORE” in the coming weeks, months or even years.

**S – Support is critical for you and your caregiver.** From this moment on, the cape comes off. You must realize that you cannot be a super hero. Do not try and do this alone. There is nothing to be gained by being stoic and doing this all by yourself. Get help and lots of it –as much as you can find.

There are a lot of suggestions in this article. You need not feel overwhelmed by them. Delegate parts to friends, family, a trusted financial advisor, and a competent attorney. For example, you will be getting plenty of mail and handed numerous documents that may end up piling up on the dining room table or on a home office desk. With all the paperwork that will be involved in your journey, you will need to prioritize.

Ask a friend to help you sort through all the paperwork and divide it into two piles labeled as “information” and “action.” For example, divide paperwork which requires action, such as a bill, from paperwork that merely provides information such as magazines, circulars, brochures, etc. With the paperwork that requires action, see if someone can help you take the needed action. Ask family and friends help return phone calls, research information or just stay on hold for you while you get something else done.

Remember that family and friends are not the only ones who can provide emotional support. If you are feeling overwhelmed or frightened, consider seeking professional help. Having a life altering medical condition can be very frightening but it can be made less frightening by talking to someone who has experience in dealing with people in similar situations. Consider joining a support group to talk to other people

going through what you are going through. Whether it is a therapist, a trusted friend, a pastor or a support group, have a safe place to talk things out. Use what I call “informal” support. You will find out that you are not “losing your mind” but going through the normal stages of sadness and grief.

But you will also need to pay attention to “formal” support networks comprised of professionals such as a financial advisor, an attorney, the business office manager at your healthcare providers, or a claims manager at your health insurance carrier (someone you can call by name when bills get messed or you need help paying for treatment). You should also think about visiting the social worker at your hospital who can help you discover all the medical and non-medical services offered by your hospital as well as help you find other resources.

Most people understand that they need someone to take care of them during this difficult time. But most people don’t understand that their caregiver also needs support. It is important to make sure that the one who is taking care of you is also being taken care of. I recently spoke to a client who told me that his wife was going to a caregiver’s support group and it really made a difference. It was his suggestion that his wife go to caregiver meetings because he realized that his wife needed to be supported in her care for him. He said he realized that he was not the only one whose life was being altered. By making sure she was taken care of, he was taking care of them both. This gave him some sense of control which, in turn, made him feel stronger.

### C – Contact associations that are dedicated to your medical conditions.

Your experience with cancer or heart disease, or whatever your condition may be, is new to you. But it is not to others. There are people who deal with your issues day in and out and have been doing it for years – decades even. These kinds of people are found in organizations whose existence is dedicated to help people get through it. Organizations such as American Cancer Society or the American Heart Association can give you not only moral support but in many cases help you locate financial support or low cost or free services and goods. There is an organization dedicated to almost every medical condition. Find the one or ones that make you comfortable. Such an organization can help you plan for a future with your illness by helping you anticipate needs and equipping you to meet them.

### O – Organization is powerful protection when information comes in on tide waves.

I once had a client who described the amount of information coming to her as a “tsunami.” Most people think a tsunami is just one big wave, but it isn’t. It is a series of waves. One powerfully big and fast wave after another. This is the best analogy to describe the amount of information you will receive during a health crisis.

Large volumes of information will be asked of you and will be given to you in the upcoming weeks, months or even years. A “tsunami” of forms, applications, letters, brochures, booklets, pamphlets will hit you by email, snail mail and in person. You must find a way to keep track of appointments with doctors, tests, professionals such as

lawyers and financial advisors, and even lunches with family and friends. Organization will be key to saving your time as well as your life.

You need to be organized to save time. I have talked to clients who could tell me the date of every blood draw. However, I have also talked to other clients who could not tell me the address of their oncologist or the date of their last scan. Most of the clients who knew the date of their last blood draw have a big kitchen calendar on which they keep all appointments. Many clients keep binders of doctors' names, addresses, tests taken, policy numbers, etc. Some keep track of everything with Excel spreadsheets. The clients who are the most meticulous are the ones who find they can complete forms and answer questions in less time and with less aggravation. They have wised up to the fact that they will be asked the same questions over and over again. These are the ones who realize they not only can save time by being organized, they can save their lives.

It is comforting to think that your doctors will always keep track of everything that has been done to you. But it is not realistic. The healthcare industry deals with billions of pieces of information. Information stored electronically does not always show up when and where it was intended. For example, keeping a list of all medications is important to avoid duplication and possibly deadly drug interactions. Knowing what tests were taken when can give you a leg up on what tests have not been taken yet. Find out what method of organization works best for you and your caregivers. Once you find such a method, stick to it. It will help you keep down the stress at a period in your life where you can afford it the least.

### **R – Research your disease, your treatment options and how to pay for it all.**

Many times you will be asked to sign a paper that indicates your consent to a procedure or some administrative action. These will be critical decisions you cannot take back. It is important to use all the resources of your informal and formal support networks to find out information effectively and efficiently. This means checking out sources that have a track record of providing good information and good advice. Consider this analogy. When you know where you are going on a trip and have been there many times before, you can afford to take the back roads to your destination. But when your journey is to a new destination and you are short on time, it is best to stick to main highways and well-traveled roads. The same is true when researching information when you are sick. This is a new journey and time can be of the essence. Be careful of shortcuts and back roads. Be "effective" in your research by sticking with only reliable resources.

**Research your disease.** I have spoken with too many clients that don't know their diseases. They don't know what type of cancer they have or how far the cancer has spread. Some people don't know exactly what is wrong with their heart. Some people just don't want to know. Everyone does what they are capable of doing. If keeping yourself in the dark is what is getting you through this, then go back to "S" for support and find someone strong enough to research for the cold hard facts. But if that is not you, then start out by asking your treating doctors for information on your condition and suggestions for more research. A good doctor will appreciate a well informed patient. If

your healthcare provider resents questions or seems annoyed that you want information - get out fast. You need to be part of a team in the fight of your life, not left in the dark.

The greatest weapon in your fight can be the Internet. But it can be a sword you can grab by the wrong end. Research on the Internet about life and death issues must be done with extreme caution. When approaching any website regarding your disease and treatment, always look first at the source. Know who is speaking and with what credentials they speak. Then find out their motivation for giving you this information. Ask yourself whether the website is intended to sell you the product or service that they are telling you about. Be very careful of websites that end in ".com" and be particularly wary of blogs by people without a medical degree. Concentrate on websites maintained by teaching universities whose websites end in ".edu" or nonprofit groups that are disease specific such as the American Cancer Society, the American Heart Association or other organizations whose web address end in ".org." Also lean heavily toward websites that end in ".gov" such as [www.healthfinder.gov](http://www.healthfinder.gov), [www.Medlineplus.gov](http://www.Medlineplus.gov) or National Institutes of Medicine at [www.health.nih.gov](http://www.health.nih.gov). While websites that end in ".org" or ".gov" should be at the top of your list, you can also make wise choices if you are selective about which ".com" websites you visit. Many world renowned medical centers have ".com" websites such as MD Anderson Cancer Centers or Mayo Clinic.

On a more personal note, know when to stop reading. Getting tired, weepy or frightened may be signs that it is time to stop and turn your attention to other things. If you are getting depressed to the point of being not able to keep appointments, seek therapy and delegate the research to someone else.

### ***Research your treatment options.***

"I did not know that it would do this to me." "I did not know that I could have been given drug therapy instead of surgery." I hear those statements all of the time. I am not advocating that you become suspicious or confrontational with your treating doctor but you should insist on being a *partner* with him or her by knowing what is being done to you and why.

Know what the treatments options are. Know the success rate and have some understanding of why certain treatments are better than others. For example, some breast cancers can have long survival rates even when just the lump instead of the whole breast is removed. Also have a clear understanding of whether the treatment is intended to *stop* your disease or simply *slow down* its progression. I have had too many conversations with clients who were heartbroken because they did not know the difference. Just as sad are conversations with clients who did not understand the cost in terms of the side effects of their chosen treatment. Peripheral neuropathy (numbness or pain) is a common side effect of chemotherapy. In most patients, it goes away in about a year or two. But in some, it never goes away. This is important to know because such neuropathy can be as nominal as a slightly diminished sense of touch to something or as substantial as a chronic burning sensation that impairs use of hands or feet. No one can chose for you the acceptable benefits and risks in a given treatment. But you start out ahead when you have a clear understanding of what those benefits and risks are.

### **Research how to pay for it all.**

I am not just talking about paying the hospital bill. Some conditions change a life for a few months and some change it for few years and others do it for a life time. So how do you take into account all those changes and be ready to meet them?

- **Know how your employer can help you**– find out about sick leave, donated leave from co-workers and what disability insurance policies you have at work. Find out how much you can work if you are able to work. Find out if you can work part-time or irregular hours or even work from home. In working with clients, I have found that companies take a wide variety of approaches to acutely ill employees. Helping ill employees can take various forms such as providing special paid leaves because of years of service, allowing telecommuting, setting up “Skype” meetings to meet job responsibilities, turning the client’s position into a consultant position for the time in treatment, or extending health insurance benefits that delay COBRA payments. Examine your employee handbook or visit your human resources office to find out how your company can support you as you try to continue to support yourself and your family.
- **Know your health insurance policy.** Don’t be embarrassed if you have never read your policy before. This is your chance to visit the company’s website and find out the particulars of your policies. Learn the right questions to ask so you get the right answers. Try your best to match up your benefits with the right provider.
- **Private benefits.** Disability insurance benefits are a good example of “private benefits.” These are important to understand especially since most people don’t familiarize themselves with the terms of these benefits when they sign onto a new job. Most policies require you to file for Social Security disability so that the insurance company can offset what they have been paying you every month with what Social Security will pay you. These policies also generally allow your disability carrier to take any Social Security retroactive benefit payment that is given to you. Knowing this will help you budget wisely and avoid stressful surprises. Know what your policy says about working during your illness. You may feel that the bills are coming in too fast and you need to work to keep up. To work and get private disability benefits legally, you need to know whether your policy allows you to work 10 hours a week, 20 hours a week, or any amount of time less than a certain percentage of your salary, or maybe not at all. You need to know the rules so you don’t break them and end up with what was a very avoidable crisis.

Also think about where you have worked and in which organizations you are a member. Pensions are another source of private benefits. Find out if you are entitled to any pension payments under the rules of former employers. Another place to check for resources is any fraternal or business organization to which you belong. Even if they don’t have services or resources that they provide directly, they may offer help in looking.

- **Public benefits.** Medicaid, Medicare, Social Security disability (SSDI), Supplemental Security Income (SSI), or veterans benefits are good examples of public benefits. But remember these benefits are not always a panacea so they should not be the only resources you consider. Medicaid and Medicare have eligibility requirements that are getting harder to meet and these programs are anticipating cuts and drastic changes. Also SSDI is only a monthly cash benefit. The accompanying Medicare benefit is only available after 24 months of receipt of the monthly SSDI payments and it is not free; there is a premium to pay. Be particularly careful about making plans to rely solely on Medicaid.

Consider the possibility that the best models of care for your disease may be offered by providers who do not accept Medicaid. Know what type of benefit your chosen providers will take before you go through the time (and stress) of applying for Medicaid or the expense of having someone help you qualify for Medicaid.

- **Research resources and services to take care of you.** Missouri has an information referral system that operates like 411, except it is called "211." It is an United Way program created to provide free and confidential access to community information and referral services. Counselors and caseworkers can help you find food, housing, health care, and other services available in your community. There are also federal agencies which help people, with or without health insurance, find ways to afford the cost of their treatments or medications. For example, the Social Security Administration provides a website at [www.healthfinder.gov](http://www.healthfinder.gov). This website includes links to various programs and services which provide free to low cost medical treatment and prescription drugs. Another example is a website provided by the U.S. Department of Health and Human Services at [www.rxassist.org](http://www.rxassist.org). This website helps people navigate their way through various medication assistance programs.

**E – Execute the right legal documents.** You can also manage your health crisis by taking action with the right legal documents. The "right legal documents" means having a will, trust or estate plan and appointing a power of attorney (POA) to make health care decisions and deciding on advance directives so people will know what you do and don't want to have done to you in the event you are unable to communicate. Don't worry that executing these documents will somehow "jinx" your chances of recovery. You will need these documents so that things will go smoothly for your loved ones in case you become incapacitated and never get well. These documents may only be needed on a temporary basis if you have a rough patch. You need these documents for yourself and your loved ones in case you become incapacitated and then live. You don't want to live to regret all the difficulties that can be caused without these documents.

If you pass away without a will, the state of Missouri will give away all of your possessions as it seems fit. The Missouri legislature enacted a statute that establishes the state's intestate order of succession, in other words, the who gets what if you don't have a will.<sup>i</sup> Under Missouri law, all of your possessions will be given away by "priority." This means

that your property will be given first to your spouse and that person will only be given all of your property if you don't have any surviving children. But if your spouse and children do survive you, then Missouri law dictates how your estate will be divided between them. If you do not have a spouse or children who survive you, then Missouri law will decide to which relative to the "ninth degree" gets your property. The state's order of distributing your property may be exactly what you want. But if not, then you need to have a will, or better, a trust or estate plan.

You will also need a power of attorney (POA) to designate a healthcare agent to make healthcare decisions for you if you become incapacitated. Remember that a POA is a document but a healthcare agent is a person – documents don't take care of people, people do. You will need a person to make healthcare decisions for you in you cannot speak or cannot understand what is happening. Such a condition could last for days, weeks, months, or even years. Planning for a time when you cannot speak for yourself does not mean that you will not pull through. It means you love your family or friends enough to make sure that they will get through your period of incapacity. During this time, you should also consider other types of powers of attorney besides one that designates a person to make healthcare decisions such a POA to designate someone to make financial decisions for you. Maybe this is not a good time for you to try to sell property, manage your own business or handle your finances. A competent attorney can help you draft POA documents or other documents which address your particular needs and concerns.

You can help your healthcare agent by executing advance directives. Such directives spell out what you do or don't want done to you if you cannot speak for yourself. Unfortunately, there is considerable misunderstanding and apprehension about advance directives. Most people think of advance directives as having someone to "pull the plug." While that scenario certainly occurs, advance directives are used in less dire situations. Advance directives can direct one type of treatment over another. Perhaps there are certain surgical procedures you do not want to have done or certain types of experimental approaches you don't want to ever be used. By having advance directives in place, you can maintain some control over what happens to you even in a situation where you cannot communicate your wishes.

It is important to remember that just as advance directives can be used to shorten a life, they can be used to lengthen one. Advance directives can be used to stop anyone from withdrawing life support such as a ventilator or a feeding tube. They can be used to instruct healthcare providers to use every resource at their disposal to keep you alive. They can be used to instruct that specific treatments be used to keep you alive and yet prevent others from being or only be used for a certain amount of time. For example, an advance directive could be used by your healthcare agent to make sure that you are placed on life support but, if it is your wish, make sure that you are not left on life support for more than a designated amount of days, months or years. But be careful in getting too specific in writing down in what you do and don't want done. Missouri law requires that your healthcare agent does what is in your "best interest."<sup>ii</sup> Although well stated, advance directives will guide your healthcare agent to act according to your definition of what is in your "best interest," you want to be sure to give that person the flexibility to act according to your wishes but also in light of what is



best for you given the circumstances. Remember you are planning for circumstances that may have many variables that you never thought of. You want your healthcare agent to be able to respond to them even though you did not leave specific instructions for such variables.

It is important not to let the idea of being incapacitated make you feel fatalistic about your condition. First, think of drafting these documents as planning for an event that could occur to anyone at any age. Anyone could end up not being able to speak for themselves and that reason has nothing to do with a life threatening illness. I am reminded of this every time I hear about a drunk driver destroying the life of a teenage driver. Second, a life threatening illness is all the more reason to have these documents in place. Do these things for yourself. Do them for the people you love and who love you. A health crisis is often unavoidable but it can be managed. Start managing your health crisis by making a plan to "SCORE" today.

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<sup>1</sup> Missouri's law on intestate succession is found in RSMo. 474.010.

<sup>2</sup> See RSMo. 404.710 (5).

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