GIVE IT YOUR ALL
Help for when you, or someone you care about, is diagnosed with cancer

Joseph Liguori
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Contents

Why I wrote Give It Your All » 2-3

Section 1: Diagnosis » 4-7
An overview of the diagnosis process

Section 2: Treatment Options » 8-10
From surgery to immunotherapy and promising new discoveries

Section 3: Living with Cancer » 11-16
Insurance, support groups, nutrition and more

Addendum » 17-20
Helpful links to online cancer information

Special Note: Blue underlines in the document are links to web sites
Get ready to Give It Your All

I wrote this guide to help cancer patients -- and their family, friends and caregivers -- through their very difficult time after diagnosis. This information will help whether you just got hit with the devastating news or you are an already diagnosed patient who wants to learn more about what you can do to help yourself.

My primary goal is to help you to get the best outcome possible for your situation. I want to provide you with insights into what I have learned in the last 12 years as a person with stage 4 lung cancer, and pass it on to help others who could potentially benefit from this information.

All of the information in Give It Your All will increase the probability of your getting more years with a better quality of life. The more time you can have with your family, friends, and even strangers, the more you will appreciate every day of your life!

One thing I have learned is that there is no one magic bullet that can solve everything. There are, however, many things you can do to help beat or contain this disease for many years.

Cancer is a very complicated disease. I cannot possibly hope to cover every type of cancer, or every treatment plan, or every special circumstance, but I will detail my experience.

Try not to get overwhelmed by what you read. Just take it piece by piece for your own areas of questions and/or concerns. I believe this information will help guide you to the Give it Your All approach I speak about -- using education to help you do everything you can for a better outcome.

My Story

I have been battling stage 4 lung cancer (non-smoker) for the last 12+ years. I have learned many things and want to help others by passing this information along.

When I was originally diagnosed in May of 2005, I had no idea where to begin. My prognosis, as given to me by the physician, gave me only 3-6 months to live. Obviously, I was devastated and frightened. It would have been great if someone, or an institution, could have helped me by sharing the detailed information you are about to read.

Give It Your All is my way of filling that gap.

During my last 12 years I have helped many people. But due to the timing of when I got involved, this info has either helped them tremendously, or if I got involved too late, did not help them at all. This bothers me immensely.

After my recent experience when I got involved too late, I decided to put my perspective and knowledge down in writing and send it to many people I know ahead of time, before it would be too late to help.

Please be aware that I am not a doctor. I am an engineering and IT guy, fighting stage 4 lung cancer like it is a manageable disease. My information here is not 100% complete or 100%
accurate. But it is my honest advice. It is not intended to replace your doctor’s opinion, or to be used to make a diagnosis or to recommend a specific treatment plan.

For more details about my personal story, I have included an article from *Coping* magazine in the Addendum.

As you read through the following pages, I may have been somewhat harsh on doctors not keeping up with new data, methods and technologies. But in their defense, the insurance industry has made it extremely difficult to spend as much time with their patients as they would like, as well as keeping up with the scientific discoveries and new technologies happening now. There are some great doctors doing the best they can in this environment. But be aware there are also average doctors and weak doctors. Make sure you search for the great doctors.

Lastly, you can do whatever you would like with this document. Use it today with someone who needs help, or save it for the day you may need it, or discard it if you don’t want to be bothered by this stuff. But, at least I have done everything that I could possibly do to try to help you, or someone you care about. I don’t want to realize I could have helped someone more, if only I had reached out to them sooner. So here it is!

Please feel free to contact me with any questions, comments, or improvements to this document.

Thank you,

Joseph (Joe) Liguori  
joseph.liguori@gmail.com
Section 1: Diagnosis

The Big Picture
It is very important to understand that every single patient is unique! Be careful of what I call “standard treatment” or “standard of care” and put more emphasis on “personalized treatment.” Two people with the same disease, undergoing the same treatment, can have widely different outcomes. One possible reason is that the DNA makeup is different in every person. Finding the right treatment for your specific DNA is extremely important. (More on this topic later in Section 2.)

I strongly feel that each person should take their health situation into their own hands. You should listen to all advice given, but then you (and your loved ones) should make the decision on what your next move should be. You should not make your health decisions based exclusively on one doctor’s opinion, or one family member, or one friend, or me. Take all the input from everyone, but again, you make the calls going forward. This is what I refer to as “taking control of your health situation.”

Be ready. Before you visit the doctor, write down your questions ahead of time. Bring this list with you to your appointment. It is always good to bring someone along with you to listen to what the doctor is saying! This could be a family member, relative, or a friend. Many times the patient will have difficulty focusing because they are still suffering from the shock of their lives with the cancer diagnosis. This is more than they can handle by themselves.

It’s always good to bring a pen and paper, or laptop, or even a recording device (with your doctor’s permission) so that the person you bring with you can document what is said, including proposed treatment. Trust me, after you leave the doctor’s office you will question and talk about what was said in the office. Notes really help out, especially for the terms you may not have heard before, or treatment options available to you, or other advice from the doctor.

Always have the doctor explain anything you are not familiar with. It is OK to go slow and make sure you understand everything. Remember you are the consumer and the doctor is the provider. If you can, try to keep a journal of what is happening during every visit. Also, for every test you have -- blood work, scans, etc., make sure you keep a copy of the results for yourself. This is very valuable to indicate trends, as well as information for other doctors.

When you are diagnosed with cancer it is very traumatic. You will ask yourself, “What do I do now? Where should I go? What should I do next?” It is very depressing and frightening at first for you and everyone you care about. You are going to experience the sad/horrible days, and that is normal. But after those first few depressing days, pick yourself up and say, “OK, how do I move forward to beat this disease?” In the following Sections are elements that I believe will help you tremendously in your journey/battle.
Your Diagnosis: What you should know
Finding the origin of your cancer can sometimes be difficult for doctors ... but absolutely needs to be done ASAP. I have witnessed many wrong diagnoses with patients I have helped over the years. There are numerous types of cancer including breast, lung, colon, liver, bladder, pancreatic, etc. and cancer can travel to many other organs after it spreads (this is called metastasis). This usually happens in stage 3 or 4 of a cancer. It is critical to know what the “primary tumor” is!

Knowing the origin of your cancer will lead to better treatment options. For example, I had multiple tumors in my body when I was diagnosed, i.e. chest, spine, and lung. But where was the origin? In my case it was the lung. But I was misdiagnosed in the beginning. Originally I was diagnosed with melanoma (skin cancer) since I’d had surgery a few years earlier to remove melanoma cells. Getting a second opinion, and getting another set of eyes on the tissue biopsy slides, identified my cancer as lung cancer.

Starting off in the wrong direction is what you want to avoid. Typically the origin is identified by a tissue biopsy of the tumor cells. If you want to be sure you got the correct diagnosis, you can transfer that existing tissue sample to another institution for a second opinion. This was what I did.

Know the stage of your cancer
Typically, there are 4 stages of cancer: stage 1 being localized and up to stage 4 where it has metastasized to other places in your body. Your doctor should tell you your cancer stage up front, and it is critical to find out ASAP. Here is a link to a website that describes all stages in more detail. Stages of Cancer. (All links in this document are expanded with the URL in the Addendum.) There are some slight variations in staging terminology at different institutions.

Get more than one opinion
Another set of eyes on your personalized individual situation will never be a bad idea. Doctors, no matter how good, are looking at your situation from their perspective and their experience. A good doctor will always welcome a second and/or third opinion. If they do not, you are seeing the wrong doctor. In my experience, this is a critical point. I do understand this is a very vulnerable time for you and your loved ones. But remember, you are not offending your first doctor. You are only doing what is in your best interest in battling this disease. For you and your family’s sake, be strong and do the right thing for your situation. Again, a good doctor will always welcome a second opinion.

Go to top-rated cancer institutions for second opinions
The two top-ranked cancer centers in the U.S. are MD Anderson in Houston, Texas and Memorial Sloan Kettering in New York City. (They’ve held the top rankings for 20 years!) Another great institution in the top 10 is Dana-Farber Cancer Institute in Boston, MA. You cannot go wrong with any of these institutions if you can get there. Special note: some institutions are doing telephone conferences -- also called remote second opinions -- if you can get your data/information to them ahead of time for a doctor evaluation.
You don’t have to travel to get good care
Many people I talk to do not have the financial resources to go to any of those three locations. My advice then is to put your specific city into a Google search for the top 10 cancer hospitals in your area. For example, if you live in San Francisco, CA what are the top ten cancer institutions closest to you? If you live in Miami, FL what are the top ten closest to you? Find out which doctors specialize in your type of cancer. Then make an appointment with one of the best cancer hospitals in your area. Bring all the scans and reports you have accumulated so far.

Some cancer institutions are tops on a specific cancer field.
There are many other great intuitions that are the best in the country for specific types of cancers ... again, if you have the means to get there. For example, if you had a glioblastoma (brain tumor), Dana-Farber Cancer Institute in Boston, MA, in my opinion, is tops in that specific field. The same is true for some other specific cancers where a tremendous amount of time and research goes into a specific cancer. It is extremely beneficial to do the research to help your specific case.

Tissue versus Liquid Biopsies
The “standard treatment” is to do only a tissue biopsy. Again, this is vital to determine the origin of the cancer. This is appropriate for all stages of cancer and is all you should need at stages 1 and 2. But for stages 3 and 4 you need to add the liquid biopsy test!

A liquid biopsy (genomic testing) is a simple two-vial blood test. One of the companies that developed this test is Guardant Health. When you link to their website, Guardant Health, double click on the pictures on that web page for more detailed information on how this test works and the results it will provide for you.

This DNA information is critical to move forward with your treatment. I think you will be very impressed. Guardant Health is capable of identifying roughly 73 different DNA mutations/cancer genes and also determines if you have any specific mutation (like EGFR, BRCA1, BRCA2, etc.). Then it will recommend every approved treatment option for your specific case ... this is called “personalized treatment.”

Foundation One is another company known for this type of genomic testing

Many times people get confused on “genetic” and “genomic” testing. Here is the difference (from Foundation One site) - Genetic testing detects hereditary (inherited from parents) alterations in DNA, while genomic testing detects acquired (over the course of a lifetime) alterations in DNA. Acquired alterations are responsible for the majority of cancers and may impact tumor growth, spread, and response to therapy.

Remember, many institutions today only do a tissue biopsy, and do not do genomic testing. Please make sure genomic testing is done! If they do not, or refuse to do a genomic test, then look for another oncologist who will. Some institutions may do a genomic type test of the tissue sample, but in 2017 it won’t be as accurate as doing both tissue and liquid biopsies. This test is the newest advancement in medical technology and not all institutions will suggest this test for
There are times when you can have cancer with no mutations. This is actually more common than those with mutations. However, you should still do the liquid biopsy test to know whether you have a specific mutation, or none at all. This will drive the best treatment plans for your specific case.

In my specific case, I had the EGFR mutation and was given an oral medication specifically designed to stop the cancer growth. It worked, and I am gratefully here 12+ years later. **Had I not known about my specific DNA mutation, the standard chemo and radiation treatments would not have saved my life ... and I would not be here today.** This is not a cure, but something that can extend your life until someday we can possibly find even better treatment options for your cancer. There are many treatment advances on the horizon and/or in clinical trials that will definitely extend lives ... and hopefully either contain the cancer, or eliminate the cancer completely. You want to hang around as long as possible for these options to present themselves to you ...and enjoy life along the way!

**Get as much info as you can**

There are many bad sites on the internet related to cancer and cancer treatments. Most are looking for your money by offering promises of false cures, use fake statistics, and more, and try to take advantage of your emotions with these false claims. These sites and the medications they sell usually do not have FDA approval and could even be dangerous to your health, as well as extremely expensive. Please try to avoid them and get info from the legitimate sites listed below.

**Ignore statistics on survival rates**

Most all survival statistics are very outdated, and with the technology of today they are not accurate. You are unique, and technology and treatment options available to you are far better today ... and these will continue to advance. This is about your personal battle to exceed all the old statistics and continue to live a high quality of life. The physician who gave me my original diagnosis told me, “There have not been any advances in lung cancer treatment in the last 20 years!” He also was offended by my choice to get a third opinion. I’m sure you can see how absolutely wrong he was!

**General cancer information:** [Cancer Treatment Centers of America](http://www.cancercenters.com) (nice video explanation here), [National Institute of Health](http://www.cancer.gov), [American Cancer Society](http://www.cancer.org)

**Information specific to your cancer:** I recommend going only to legitimate cancer sites i.e.; [National Institute of Health](http://www.cancer.gov), [National Cancer Institute](http://www.cancer.gov), [American Cancer Society](http://www.cancer.org), [MD Anderson](http://mdanderson.org), [Memorial Sloan Kettering](http://mskcc.org), [Dana-Farber](http://www.dana-farber.org), to name a few.
SECTION 2: Treatment Options

Is surgery right for you?
Surgery is typically an option for patients with stage 1 or stage 2 cancers, and sometimes stage 3. Surgeries have a higher level of risk to your body than non-invasive methods to eliminate tumors. But again, each case is different and you want what is best for you. That brings us back to getting more than one opinion, and you with your loved ones make the call.

Sometimes surgical removal in the earlier stages may be the best option. I would be very cautious on any surgery for stages 3 and 4. Once the cancer has advanced to stages 3 or 4 it means that your cancer has spread throughout your body within your bloodstream and can start to grow anywhere. Trying to do surgery for more than one location really drives up the risk. There are other techniques at these stages that are less risky.

Here’s one example: I helped a patient whose husband was going to have surgery on his brain to remove a tumor that metastasized there. I told her about a technique which could zap that tumor without surgery called Cyberknife (more on this topic later under radiation). I suggested they ask their doctor about that procedure. She did, and he had never even heard of it before because it was relatively new. I did help her find a location close to them that offered this procedure. They did go and it ultimately prevented her husband from having a very risky and dangerous brain surgery.

In my case, I currently have 1 tumor in my left lung, 3 tumors in my chest, 5 tumors on my spine, and 8 tumors in my brain. I have never had to undergo one invasive surgery for any of them. These tumors are all still present, but either dead or dormant. I was treated with targeted oral medications, targeted chemo and targeted radiation ... with no surgeries.

Chemotherapy options
Chemotherapy should by no means be the “standard” or “go to” procedure for everyone who has cancer. Chemo does kill cancer cells, but it also kills a lot of good healthy cells in your body. When the cancer origin or DNA mutations are unknown, doctors will prescribe this type of chemo.

Remember, chemo chemicals that are put into your body are harmful to your body and can lower or compromise your immune system, making you much more susceptible to other infections or diseases. However, if there are no other options, this may be the only treatment available to you.

Targeted chemo is a much better option. These are specific chemotherapy drugs that are targeted to hit cancer cells more than normal cells. Some are also specifically aimed at attacking cells specific to your type of cancer or DNA mutations.

Maintenance chemo is a long-term chemotherapy regimen after your initial chemo combo is complete. It is typically not as strong as your initial chemo treatments, and also more likely to be targeted chemotherapy, which is better. I will share later in the “Lessons Learned” section where I went wrong with maintenance chemo.
**Closing note on chemo:** Most all chemotherapy will make you ill to some level. Typically, the first couple rounds are the worst. You could have serious side effects, or very minimal ones. Each person is different. There are numerous types of newer nausea medications available to you, if needed. Again, each person is unique and medications can affect each person differently. You know your body best, so you and your oncologist can make this decision better than anyone else.

**Targeted therapies**
Without a doubt, targeted oral medications are some of the best treatments for cancer patients! Typically, they’re the easiest to receive and one of the most successful treatment options to fight your specific cancer. Of course, you need the details referenced above regarding your cancer i.e., origin, stage, and the tissue/liquid biopsy results to insure you have the targeted information you need. In my case, I originally took Tarceva (designed for the EGFR mutation), and, after progression, switched to Tagrisso which is designed for EGFR and T790 mutations). I believe this helped me fight my advanced lung cancer better than the chemo. Use every option available for your specific illness.

**Radiation in cancer care**
Radiation oncology is another very important topic. Technology has changed drastically and in the right direction regarding your treatment options here. The latest radiation techniques have been greatly improved. It’s disappointing to hear, but today some doctors get in a rut on radiation oncology and choose the option of the older “standard techniques” or whatever they have locally in their institution.

Today there are many, many options available. You need to decide what option is best for you. Learn about the top 2 or 3 and then make your decision ... again, with everyone’s input. I cannot express strongly enough the differences and importance of the various treatment options you have available.

**Do not always accept “standard” radiation treatment.** As I mentioned earlier, when I ask patients to question their doctor about these new techniques, some are unaware of the new technology ... or know very little about it.

Below are a few video links that I have previously recorded for local ABC and CBS channels discussing the advanced and effectiveness of the Cyberknife option.

Videos on link: [ABC 1](#) (Dr. Kresl video), [ABC 2](#) (Joe video), [CBS](#) (Dr. Kresl & Joe video)

Other radiation techniques to investigate with your doctor are TrueBeam STx , SBRT, and Proton Therapy to name a few. The point here is there are many options. Ask your doctor(s) which is best for you, not what they have on hand at their institution. It is 100% ok to go to the best radiation technique geared for your specific case.

**Immunotherapy: The next wave**
Immunotherapy -- or I/O -- is one of the most improved and promising research areas in the fight against cancer. This method uses your body’s own immune system to kill the cancer cells. There are approved immunotherapy drugs for many cancers, including melanoma and lung cancer.
There are other techniques like CAR T-cell technologies that were recently approved by the FDA. I believe this is the most promising area to watch for us all. For a moment, imagine not having to deal with major chemo. Then imagine the same for radiation therapy. We can get there!

This is another reason to Give It Your All and be there when these promising technologies will be ready. Just recently I watched a show called First in Human on the Discovery channel. This program documents the real life stories that are currently taking place in building #10 of the National Institutes of Health, where the first in-human studies are being conducted with these amazing immunotherapy techniques. More to come here!

There’s more information at these websites:

Memorial Sloan Kettering - CAR-T Therapy
Dana Farber – Cell Therapy
Columbia University Medical Center – CAR-T therapy

There are many more options not listed here ... but they are out there and possibly available to you. A couple more examples below.

**Hormonal drugs:** Taken from National Institutes of Health website: “Hormones can encourage the growth of some cancers, such as breast and prostate. But, in some cases, they can kill, slow or stop cancer cells from growing. Hormone therapy usually involves taking medications that prevent cancer cells from getting the hormones they need to grow.”

**Tumor Vaccines:** Taken from the Dana-Farber Cancer Institute website: “Cancer vaccines represent another approach to marshaling the immune system’s disease-fighting forces against cancer.”

Another available option is a clinical trial. When and if needed, you should discuss this option with your oncologist. Typically this happens when existing treatment methods are not working, or your case is very unique, or you are looking for additional options with the latest technology. This is best described in the following two links:

**Clinical Trials**

**Description of Clinical Trials:** A good overview from American Cancer Fund.

**NIH database of Clinical Trials:** A service from the National Institutes of Health.

**Closing comment on all treatment options:** Again, get all the information you can, but I strongly suggest getting another viewpoint/opinion from another institution. If they match, great. But in some cases they do not. This can be a life and death decision if you choose the wrong treatment plan. There is nothing wrong with validating the first doctor’s opinion on treatment options. Be strong, and be informed! It could save your life.
SECTION 3: Living with cancer

I am sad to say, but the issue of health insurance covering the cost of your treatments is almost as hard as fighting your cancer in some cases. I could write a book on this topic alone, but I will try to keep it short and to the point.

It is well known that the expenses with any serious illness are extremely high. My average costs for treatments at one point averaged about $250,000 per year. I was covered well until my company filed for bankruptcy and canceled my health insurance.

Fortunately, my wife was working and I was able to get on her plan. At that point, I said to myself, what would have happened if she didn’t have health insurance? Like some other people I know. The choices are bleak here. The number one reason for bankruptcy in this country is medical costs. Some people are faced with a very difficult decision ... should they go forward with their treatments, or refuse the treatments due to cost? This can be a life and death decision. These are horrible choices for anyone to have to deal with.

Remember, there are times when you can negotiate costs and pay a portion, or get financial assistance based on need/income, as well as in the case of high cost prescription drugs, write to or call the company and ask about their individual assistance programs.

I have experienced, and know people who had either had minimal coverage, or good coverage, who could not get the health care they needed. In my case, I have been denied PET scans and MRIs because I didn’t fit within the insurance policies. At one point, my doctor at Memorial Sloan Kettering (top cancer hospital) said I need a PET scan every 3 months due to my stage 4 illness. Then some random insurance claims person denies my request because it does not agree with their policy. My doctor and I fought for this and won.

In another case my wife and I helped a young female patient with two small children get a very expensive drug called Tarceva (at that time about $150/pill/day) by filling out an application for assistance. The sad part of this story was she was in treatment for lung cancer at a nationally known institution getting the “standard treatment.” When I asked her to ask her doctor about Tarceva (targeted oral med) and Alimta (targeted chemo) the doctors actually said her insurance would not pay for those. Horrible answer! She got in touch with me and my wife and we got her the Tarceva pill for free from the manufacturer. The very sad news is that it was too late. She should have had this option six months earlier and she may have survived for many more years. Another reason I am compelled to get this information out to others who just don’t know what options are available to them.

Another example was an insurance company that would not pay for “targeted” chemo but would only pay for “standard” chemo since it was less expensive. This happened to a guy I was having chemo with and he said “I guess I will just die now.” The oncology nurses and I got involved and were able to fight for him — he got the target chemo! I could go on and on with different examples, but I will try to sum it up below.
Dealing with insurance companies

Be your best advocate -- that includes health insurance. Every case is different, and it's almost impossible to know in advance what will and will not be covered by your insurance company. What I can say is **fight for what you and your doctor believe you need to do for your specific health situation ... and check out all options for financial assistance.** If you have great insurance and everything is covered, you are doing great.

Insurance companies love to tell you what is covered and what is not ... and stick to it. That is easy. What they are missing is that every patient is different and may require things outside the norm. This would be putting doctors and patients first, and profits second. That normally doesn’t happen without a fight. I have spent hours and hours on the phone basically fighting for my cases. The insurance companies now will only talk to the doctors in disputes. The catch here is insurance companies know the doctors are way too busy to fight for each patient. Here is where you need to make the call with your doctor, to fight or not, on each specific denial case.

Support groups

One of the biggest challenges for most people is improving their mental state or recovering from the shock when they have been delivered this news. As I said earlier, this news is devastating for everyone. Some people can bring themselves up on their own and have a positive attitude and then begin to fight for themselves. Others cannot do that so easily.

**As a patient, it is 100% OK to get help.** It could be from a family member, friend or a professional. Do not isolate yourself. Talk with someone. You must think as positively as you can ... and then get your fighting spirit on and proceed forward to beat this disease. Not only for you, but for your family, your friends, and strangers you may be able help in the future. It is easy for someone to tell you to have a positive attitude. But believe me, I have been there and I know firsthand that it is not so easy ... but it can be done, and with help if needed.

**There are a great number of support groups today dealing with your illness.** It can be a local support group in person in your area, or online support groups in the U.S. and around the world. Both are very good. You can find support groups for cancer in general ... and support groups for your specific cancer, i.e., breast, lung, kidney... It’s great to get support and talk with people who may be going through the same issues you are. I’ve participated in both local and online groups. They’re great places to give and receive support. For ideas, look at these websites:

Cancer in General Support – [Cancer.net](http://Cancer.net)
Specific Cancers Support - [Cancer.net](http://Cancer.net)

Nourish your body, not your cancer

You are what you eat and you need to do the best you can to help your body gain the strength to fight during this time. What you put into your body is critically important. It’s the body’s best defense against cancer. Now is the time to change any bad habits that some of us have had over the years. I have come to the realization we can all do better, not just cancer patients, but everyone ... based on scientific data and not marketing campaigns.

In my years of research, my best suggestion in this area is a plant based diet, i.e., fruits, veggies,
grains and legumes. This is not easy for most people to do, but I say try to get there. Very few of us are perfect on a diet. The more you can do to eat more nutritiously, the better. It is hard to get to 100%, but try to get as close as possible.

I am not there yet myself after 12 years, but I have improved my eating habits by roughly 90% better than before my cancer diagnosis. However, most everything in your grocery store is processed food, which is not very good for us. There are times when you cannot get away from it, especially around holidays, family gatherings, and other special occasions. So dessert or something that is not that nutritional every now and then is OK in my mind. Just try to keep it to a minimum.

Blending and/or juicing is a great way to feed your body the nutrients it needs. There are many informative books and videos on this subject. I was introduced to this by another cancer patient who came over to my house with a juicing machine. He said this helped him get the nutrients he needed.

After 12 years I still blend 3-4 times a week using usually 3 veggies and 3 fruits in each one of my juices. Juicing/blending tastes great and is healthy at the same time. You can mix and match an unlimited amount of fruits and veggies. Even the healthy fruits or vegetables that you don’t like to eat -- simply put them in the blender and you won’t even taste them in the juice. My wife did this for years and never told me.

There are a variety of documentaries that helped convince me of this approach. I’ve shared them below and invite you to check them out. It is always your decision on what diet approach is best for you. These documentaries are available through a variety of methods, i.e. Netflix, Amazon Streaming, to name a few, as well as other sites. These sites are sometimes free or usually at a relatively low cost. I also believe you can purchase DVDs on Amazon.com for a low cost.

Please take the time to watch at least some of these. They are very educational and I believe they will definitely help you in your fight against cancer.

- Forks over Knives
- Fat, Sick & Nearly Dead
- Food Choices
- What the Health
- Food, Inc.
- Fat, Sick & Nearly Dead #2

Do what you can to maintain a healthier diet and lifestyle to the best of your ability. It’s part of how to Give It Your All!

Exercise, one step at a time

Exercise as much as you can. There is scientific evidence that supports exercising to help prevent cancer as well as fighting cancer if you have it already. This does not mean you need to go to the gym or become an exercise fanatic. This means starting out with very simple exercises you can do at home for free. It merely could be going for a short walk if you can, stretching, using no weights, or very light weights if you have them. Try to work out different parts of your body chest, legs, back, cardio etc. with very light exercises you can do by yourself, and avoid the risk of injury. Once you do that, you can possibly move up to more aggressive exercises matched to your ability. Start
off slow and build slowly based on your ability.

When I was going through my first round of bad chemo I could only go on short walks with very little exercising. I also tried some deep breathing exercises. As I got stronger, and was able to tolerate more, I raised the level of my exercising to include light/medium weights as well as increased cardio. I know this has helped me in my success.

Do what you can on exercise to the best of your ability. It’s part of how to Give It Your All!

Faith and Cancer
If you are a person who feels strongly about your faith, it can help you emotionally. But what I say to all cancer patients … please give yourself the best chance for success by using modern medicine, as well as the other information about nutrition, exercise, etc. in this document. Just putting it in God’s hands (which I have heard before) is not what your God would want you to do. God gave you the ability to fight the best you can for you and your family. That is what you need to do. This is not an easy journey, but definitely worth the effort! If your faith makes you stronger … then use it to help yourself!

New Technologies to Watch as of October 2017

**Tumor Paint**: This is another potential breakthrough for surgical removal of tumors. This technique is amazing … and my best guess is that this will become mainstream in the near future. Typically when a tumor is removed by a surgeon they like to think, *I got it all*. In some cases they do get it all, but in many cases they do not. Cancer can be so small and unnoticeable in nearby locations of the tumor that is being removed.

This so-called “paint” will light up the tumor cells that are normally not visible to the human eye. This will definitely help with the removal of cancer in surgeries. It’s like when you put a black light on a scorpion in the middle of the night, it will light up thanks to luminescence. Using this technique will allow the doctor to remove tumor sections that he or she previously could not see … the paint lights up the abnormal cancer cells!

See examples here: [Example 1](#) from Seattle Children’s Foundation, and [Example 2](#) from CNN.com.

**Early Detection Blood Tests**: Today scientists are taking the existing liquid biopsy test and developing an early detection blood test. Today’s liquid biopsy test is only used after the cancer cells have spread in stages 3 and 4. With this new technology, scientists want to identify cancer cells much earlier, in stages 1 and 2. This test is in the early phases of development, but is proving to be very promising.

**Some lessons I learned the hard way over the last 12 years**

1. Neulasta – One of my favorite stories. This one example depicts an approach I try to use in all of my medical issues.

Neulasta is a shot I would get the day following every chemo treatment, which was every three weeks in my case. It helps boost the white blood count that the chemo kills during your treat-
ment. We do know that the lower your white count, the more you are prone to infections and illness. I was told that this shot is the “standard treatment.”

Every time I got this shot it made me extremely sore in my neck and shoulders for about 3 days after the chemo treatment. So after a year or so following this standard treatment, I asked the doctor if I could reduce this shot from 6 mg to 5mg in an attempt to reduce the pain I was experiencing. He agreed to try reducing the dose and the pain was slightly less and my white count remained the same, no loss. As you can guess, I went down to 3mg and eventually down to 0. There was absolutely no change in my white count, and a lot less pain and discomfort for me. I no longer needed, or got any more Neulasta shots after that ... and that was 10 years ago.

As I reduced the amount of the shot, I still got charged the roughly $6,000 per shot whether I got the 6mg, 5mg, 4mg or even 3 mg. That extra 3 mg would go directly into the garbage can. Imagine the profit on this drug for all these cancer patients doing what I am doing and maybe not needing it, but getting it because it is simply the “standard treatment.”

Neulasta now has a patch you can wear on your arm instead of the shot. Just ask questions if your doctor suggests this drug and remember my story. Neulasta may work for you because each person is unique. But try to insure everything you put into your body is helping you, with data to back it up.

I am not advocating you do anything drastic with your care, but question everything and maybe try things with the consent of the doctor to make your journey the least painful and most successful it can be for you.

2. Maintenance chemo – Here is an area where I made a mistake that cannot be fixed.

Most people are not on chemo for long periods of time. However, if your treatment is going well and you are asked to stay on maintenance chemo, be aware of my example here.

I was on chemo/maintenance chemo for 9 years straight. For the first 5 years I was doing really well with the targeted oral medication and the maintenance chemo. I did most everything that I could do before my illness. At this 5 year point I started questioning all 3 of my oncologists about how long I should be staying on chemo. I was concerned about long term negative side effects.

All three basically said you are doing so well with this combo, why change a good thing? I understood and was hesitant to alter something that was working so well for me. No one was willing to change anything that might cause the cancer to return. One oncologist said he has never seen stage 4 lung cancer patients live that long, so he was very honest in saying that he “truly doesn’t know.”

3. Staying on a treatment too long. Years 7 and 8, I started to notice I was losing my balance and year 9 my balance was and is still very bad. The first two neurologists I consulted misdiagnosed what my problem was. They said it was the misalignment of the crystals in my inner ear causing vertigo and sent me to physical therapy. The third neurologist did some careful research and found a “not so well known” cause of my problem. It was the extended use of a chemo drug that
caused me to lose 100% of my vestibular system (which controls balance). He told me most oncologists do not know about this. He used my case to publish a medical paper to warn oncology doctors about this scenario.

In this case, I waited too long to get off the chemo. I know I followed the advice, of several doctors, but I should have realized they really didn’t know about this adverse side effect. I should have made the call myself at year 5. I have adjusted my lifestyle with the balance issue ... and I am still glad to be here trying to helping others who are in the same boat I was at one point!

5. Be knowledgeable and cautious about a chemo drug called Zometa. Zometa is in the family of bisphosphonate medications. Any bisphosphonate medication can cause oral/dentistry problems. If you have taken any bisphosphonate medications be sure to tell your dental provider before any work is done. There is the potential for serious side effects with certain dental procedures.

I was on Zometa for a couple of years due to metastasis in my spine. When I went to an oral surgeon and gave him my medical background, he refused to pull one of my wisdom teeth due to the risk involved. I thanked him for that since no one had even told me about the risk with bisphosphonates and dental procedures. Here is a link with more info from the American Dental Association.

See the Addendum on pages 17-20 for URL addresses to the links included in this document.
ADDENDUM

My personal story from Coping magazine article (August 2014)

STILL STANDING
with Late-Stage Lung Cancer
8 Years and Counting

by Joseph Ligori

If I’ve learned anything from my battle with cancer, it’s that cancer can find anyone; it doesn’t discriminate. But more importantly, I’ve learned that a frightening and bleak cancer diagnosis is not necessarily a death sentence.

My entire life was turned upside down when I was diagnosed with lung cancer eight years ago. I had enjoyed an active, healthy lifestyle. I didn’t smoke. I watched what I ate. It wasn’t until a physician friend of mine expressed concern about my cough during a game of basketball that I had any reason to see a doctor. Everyone in my office had a cough, so I didn’t think much of it. Still, I took my friend’s advice and visited a nearby hospital to have it checked out.

I was shocked to learn that my cough wasn’t merely a symptom of a cold going around my workplace. I had stage IV lung cancer that had metastasized to my chest and spine. What’s more, I was told that the cancer had spread so far that neither surgery nor chemotherapy would help and that I should get my finances in order and go on a vacation with my family.

Instead, I decided then and there that I would do everything I could to beat this cancer. I was sure there were more options, and I was determined to find them. My local hospital had a great reputation nationwide, but it specialized in cardiovascular care, so I decided to seek out the top cancer treatment centers this country had to offer.

I believe it is because of my perseverance in pursuing the best possible cancer care that I am still here today. I did some research, chose a cancer center, and began an aggressive treatment regimen to fight my lung cancer. In addition to the tumors in my lung, chest, and spine, the cancer had metastasized to my brain, resulting in recurrent brain tumors for which I’ve received various forms of targeted chemotherapy and brain radiation, including stereotactic radiosurgery, a treatment that delivers a high dose of targeted radiation over a short time.

While my journey with cancer will never truly be over, I am thankful that advanced options for cancer treatment are available for people like me with late-stage cancer. I still make a conscious effort to live a healthy lifestyle, which includes eating nutritious and exercising. I also stay up to date on the latest developments in the field of oncology and continue to work with an all-star team of doctors to manage my ongoing care. Taking these steps helps me feel more in control of my own destiny and proud knowing that I’m playing an active role in yielding my best possible chance of survival. My advice to fellow cancer survivors is this: Advocate for yourself, seek out the most advanced cancer treatments available, and most importantly, never give up hope.

Joseph Ligori is a stage IV lung cancer survivor living in AZ.
Section 1
Understanding cancer
Explanation of stages of cancer

Tissue Biopsy and Liquid Biopsy

Guardant Health
http://www.guardanthealth.com/guardant360/ (click on pictures to see the videos)

Foundation One
https://www.foundationmedicine.com/genomic-testing

The Genetics of Cancer:
https://www.cancer.gov/about-cancer/causes-prevention/genetics#results

Great cancer information websites:
Cancer, Treatment Centers of America (nice video explanation)
http://www.cancercenter.com/what-is-cancer/

National Institutes of Health
https://www.cancer.gov/about-cancer/understanding/what-is-cancer

American Cancer Society

National Cancer Institute
https://www.cancer.gov/

American Cancer Society
https://www.cancer.org/cancer.html

MD Anderson
https://www.mdanderson.org/

Memorial Sloan Kettering
https://www.mskcc.org/

Dana-Farber
http://www.dana-farber.org/
Section 2
Radiation Oncology
ABC 1 (Doctor video)
https://www.youtube.com/watch?v=UYR3awlJ958&feature=player_embedded

ABC 2 (Doc & Joe video)
https://www.youtube.com/watch?v=ItYBomzYCWY&feature=player_embedded

CBS (Dr. Kresl & Joe video)
https://www.youtube.com/watch?v=lqv9TfnTSjc

Immunotherapy
MSK (Memorial Sloan Kettering)
https://www.mskcc.org/immunotherapy

Dana-Farber
Cell Therapy Link 1
http://www.dana-farber.org/Adult-Care/Treatment-and-Support/Treatment-Centers-and-Clinical-Services/Cellular-Therapies-Program.aspx?_ga=2.207460241.303238674.1502817609-774165500.1500557288#About

Cell Therapy Link 2

Columbia University Medical Center – CAR-T therapy
http://newsroom.cumc.columbia.edu/blog/2017/08/30/5-questions-on-car-t-therapy-with-oncologist-prakash-satwani/

New treatments
Hormonal Drug Therapy - National Cancer Institute
https://www.cancer.gov/types/breast/breast-hormone-therapy-fact-sheet

Tumor Vaccines - Dana-Farber
http://www.dana-farber.org/Adult-Care/Treatment-and-Support/Treatment-Centers-and-Clinical-Services/Cellular-Therapies-Program.aspx?_ga=2.207460241.303238674.1502817609-774165500.1500557288#Tumor_Vaccines

Clinical Trials
Clinical trials explained
https://www.americancancerfund.org/cancer-101/clinical-trials/?gclid=CjwKCAjw3f3NBRBPEiwAiixGledXfNrdT49-TeCXmIPiMynny6cWJaG3JQfzI1TVkpdGY2AdMQcxcC56QQAaD_BwE
NIH database of Clinical Trials:
https://www.clinicaltrials.gov/

Section 3
Support Groups
Cancer in General Support – Cancer.net
http://www.cancer.net/coping-with-cancer/finding-support-and-information/support-groups

Specific Cancers Support - Cancer.net
http://www.cancer.net/coping-with-cancer/finding-support-and-information/cancer-specific-resources

New Technologies to watch
Tumor Paint: Blaze BioScience
http://www.blazebioscience.com/

Example 1 http://pulse.seattlechildrens.org/tumor-paint-brings-light-to-toddlers-brain-tumor/


Early Detection Blood Tests
http://www.nbcnews.com/health/health-news/blood-test-finds-cancer-symptoms-start-n793181

American Dental Association
http://jada.ada.org/article/S0002-8177(14)64933-3/pdf

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