How I Survived Melanoma Skin Cancer

Seven Survivors Tell Their Stories
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1. Frequently asked questions about melanoma

This book aims to give you the basic information you will need to help you cope after you have been diagnosed with melanoma. Because melanoma is an uncommon type of cancer, you may have some relatively basic questions about what it is, what causes it, and what the outcome may be. As this chapter will explain, being well informed is the first step to feeling in control of your illness and treatment, which is likely to determine how well a person with any type of cancer will do.

1. What causes melanoma, and who is most at risk for developing it?

After being given a cancer diagnosis, almost everyone wants to know what caused the cancer. This is rarely a simple question to answer, because we don’t know all of the factors involved. In the case of melanoma, the simple answer as to the cause might be ‘the sun’, but that answer does not cover all cases or scenarios. Excessive sun exposure, especially if you have had a bad sunburn on more than one occasion, is a major risk factor for melanoma. This is an especially good reason for us to protect our children – there is about a twenty-year ‘lag’ between the sun exposure or burn and the development of melanoma. This means that having been badly sunburned as a child may make you more likely to develop melanoma as an adult.

However, the fact is that many people who go out in the sun do not end up getting melanoma, and many people who never sunbathe do develop the disease. There are other relevant factors, some of which are known, and some of which are still unknown. For instance, we know that having darker skin is a form of natural sun protection. Darker skinned people are less likely to burn, and they are less likely to develop melanoma, too. Fair skin – especially ‘redhead’ type skin – is a risk factor for melanoma. Another risk factor is having a lot of moles. Most moles are harmless, of course, and a perfectly healthy person might have dozens of them. However, if you have the type of skin that produces lots of
melanoma, you are more at risk for melanoma, too. Also, if you have a lot of moles already, it might be harder for you to notice an irregular mole or melanoma. Therefore, people with more than fifty moles on their body should be examined regularly by a dermatologist for atypical moles that might be melanoma.

As with many other cancers, there is a genetic link in the case of melanoma as well. This means that environmental factors – such as sun exposure – are not entirely to blame. It also means that we still can’t put a finger on all of the causes of melanoma.

2. **How can melanoma be prevented?**

Since sun exposure is the most reliable link we have found so far, it makes sense for everybody to limit sun exposure and especially avoid burning. Using a good sunscreen or wearing a long-sleeved shirt and a hat is enough for most people, but people who have a family history of melanoma, many moles, or very fair skin should be especially careful. It would make sense for these people to use sun block year round, avoid the sun in the middle of the day, and go to a dermatologist for yearly check-ups. Remember, even if you are diagnosed with melanoma, the disease is almost always curable in the early stages.

As with any other cancer, maintaining good health and nutrition – especially with regard to eating fruits and vegetables high in antioxidants – is a good prevention strategy as well.

3. **How do I know if I have melanoma? What are the signs and symptoms?**

What the dermatologist will look for – and what you should check for yourself – are moles or freckles with irregular borders or unusual colours. “Good” or harmless moles should have a fairly regular, not jagged-looking, border and they should be symmetrical; that is, if you were to draw a line down the middle of the mole, the two sides would more or less match. If a mole is very asymmetrical – if the two sides don’t match at all – the mole should be monitored carefully.
does not mean the mole is melanoma, or that it will necessarily turn into melanoma; it just means that this mole should be watched for changes.

Once in a while, a mole does turn out to be cancerous. A melanoma mole or lesion is usually blacker than other moles, larger than a pencil eraser, and has an irregular or asymmetrical border.

4. What tests will the doctor carry out to see if I have melanoma?

If the doctor suspects that a mole is melanoma or another form of skin cancer – or even if he just wants to rule out the possibility – he will remove the mole and send it to the lab to be analysed. The vast majority of moles that are sent for analysis are actually benign or harmless – doctors like to err on the side of caution. Later, if you are diagnosed with melanoma, there may or may not be other tests to see whether the cancer has spread. These usually include the removal or biopsy of lymph nodes in the area closest to the original melanoma. Sometimes, radioactive dye is injected into the lymph system in order to allow the doctor to locate the first, or ‘sentinel’, lymph nodes, and these are removed for biopsy. If it is suspected that the cancer has spread to other organs, tests such as a chest x-ray or CT scan may be ordered.

5. What kind of doctor do I see if I suspect I have melanoma?

Unless you already have a dermatologist, you will have to ask your family doctor for a referral to one. The dermatologist, or skin specialist, will usually order the first biopsy of the mole if he suspects that it may be cancerous. If it does turn out to be cancerous, he will refer you to an oncologist (cancer specialist) and surgeon. At some centres, oncologists work in teams to come up with the best treatment plan, but most of the time you will deal primarily with one oncologist. You may also choose to seek out a naturopath, homeopath, nutritionist or acupuncturist, either in addition to or in some cases instead of an oncologist.
6. **How curable is melanoma?**

Melanoma has an overall cure rate of 85%, higher than many other types of cancer. Skin cancer has one ‘advantage’ over other cancers: it is visible on the outside of the body, so it is easier to notice and remove than most other cancers. If it has not spread to other organs of the body, it is almost always curable. Of course, as with other cancers, the more it spreads, the less curable it is, depending on what part of the body it spreads to. However, there are well documented cases of cures even among people with very advanced melanoma.

7. **What are the stages of the disease?**

Stage one melanoma is a small single lesion or mole on the skin. Stage two is a lesion on the skin that is thicker than 1 mm. Melanoma is said to be stage three if it has spread to the closest lymph nodes, and stage four if it has spread to distant lymph nodes or other organs. Obviously, the goal is to catch the disease at stage one, when the cure is simple and effective.

8. **How quickly does the disease progress or spread?**

This is not an easy question to answer, because it varies from individual to individual. As with many cancers, age seems to be a factor. Younger people’s bodies produce new cells more quickly, so melanoma in a young person is likely to progress faster than in an elderly person. In general, the first stage of melanoma is relatively slow – it is common for a lesion to be on the skin for a year or two or even longer before spreading to the lymph nodes. After it has started to spread or metastasize, however, melanoma is considered a fairly quickly-spreading cancer. Again, this does vary among individuals.

9. **How is melanoma normally treated?**

The treatment for most cases of melanoma is simple surgery that can be done on an outpatient basis. In many cases, general anaesthetic is not needed. You may wonder why further surgery is usually required following the diagnosis – after all, the mole itself has already been removed. The reason is simple – the doctors want to make sure that they have removed 100% of the mole, which usually
involves cutting around it a little bit wider than for a simple biopsy. With today's advanced surgery techniques, this generally does not cause a large scar, and the recovery time is very short. For many melanoma patients – the majority, really – this is all the treatment they will ever need.

Removing the melanoma lesion with a wide margin has two purposes. Most important, of course, is the fact that this is the entire treatment in many cases. It removes the cancer and the source of the problem. The second reason, however, is diagnostic – removing the mole allows doctors to assess its size and depth. As with most cancers, how large the lesion is determines the stage and how serious it is.

As mentioned before, melanoma spreads through the lymph system. With a small melanoma, there is little or no chance that it has been in place long enough to spread. If the melanoma is a little larger, the doctor may want to check for further spread. In some case, the lymph nodes closest to the original lesion are removed as a preventative measure and for diagnostic purposes. If the cancer has moved to other organs, western medicine usually recommends radiation treatment or chemotherapy. Various complementary and alternative treatments may also be helpful in supporting the body and immune system and helping to fight the cancer.

10. **What are the common side effects of the treatments?**

Surgery, the most common and effective treatment for early stage melanoma, has no real side effects and a fast recovery time. If there was surgery to remove lymph nodes, for example in the neck, the muscles in the area may take some time to heal. The fact that the patient has lost the lymph nodes in one area of the body is not a cause for concern, as the lymph system is a complex one and there are plenty of other nodes that will take on the job of providing an immune response. Radiation and chemotherapy tend to have a greater range of side effects. Radiation is a localized treatment that does not affect the whole body, but there may be localized burning and pain. For example, if the radiation is in the neck area, a dry, sore throat would be a common side effect. However, the
person is usually able to function fairly normally while receiving a course of radiation treatment, and technology is improving to make radiation therapy more localized and specific to the area being treated.

Chemotherapy has a reputation for being very debilitating, but this is not always true nowadays. In fact, the chemotherapy used to treat metastatic melanoma often does not even cause patients to lose their hair. Moreover, the nausea medication we have nowadays is extremely effective. Many patients go through their chemotherapy treatment comfortably, with minimal side effects. There are also many complimentary treatments which support the body during chemotherapy treatment and minimize side effects. These include herbal and vitamin supplements that support the body metabolically during cancer treatments. They work by removing some of the strain that is being placed on the body, making you feel better and helping recovery. The same can be said for homeopathy, traditional Chinese medicine, and dietary support.

11. What alternative treatments are available?

There is a great deal of anecdotal evidence that suggests certain natural and herbal substances can, in and of themselves, be an effective cancer treatment for some individuals. No matter what you believe, these options are worth informing yourself about. The best thing, though, is to talk to a naturopathic doctor who also has a background in either biochemistry or medicine. An individual such as this is sometimes your most valuable resource, because he or she can provide comprehensive information about a variety of alternative treatments that might be useful, as well as giving an unbiased, down-to-earth opinion of conventional treatments. For example, a good naturopath will not necessarily rule out the usefulness of chemotherapy in all cases, but he will certainly be able to suggest some natural treatments that can lessen the side effects. To start you off, the following are a few alternative treatments that have been around for several years and are worth investigating.

Dr. Michio Kuchi, who has written several books on the subject, argues that a so-called macrobiotic diet enables the body to fight all kinds of cancer, even in very
advanced cases. The diet consists of grains, vegetables, sea vegetables, and small amounts of meat, prepared in a special way. The thinking behind it is that this type of diet is so healthy for the body that it allows the body to spontaneously heal itself. There are many stories of people who have recovered from cancer and other diseases by following this or similar diets.

There are several herbal preparations that are said to be beneficial to cancer patients. One is a tea called ‘Essiac’, developed by a nurse who worked among North American Native tribes and observed how they treated tumours. An informative article about Essiac can be found at [http://essiac-info.org/Sun.html](http://essiac-info.org/Sun.html). Another is a remedy called ‘Iscador’, which is by 60-70% of cancer patients in Europe, but is considered by North American doctors to be an unproven alternative therapy. Like interleukin and interferon, Iscador is thought to work via the immune system. You can easily find a lot of information about it using an Internet search engine such as Google.

Finally, there is a great deal that we still have to learn about the mind-body connection. Some people believe that all physical diseases are caused by emotional issues, while others feel that this kind of thinking ‘blames the victim’ for his or her illness and should be avoided. However, almost everyone agrees that your mental and emotional outlook will have an effect on your recovery.

This short list of alternative therapies is nowhere near complete. New therapies are being developed all the time, and trying to determine what is worth investigating and what isn’t can be very confusing. People also have different points of view about using therapies that science thinks of as ‘unproven’. Sometimes it is useful to remember the words of Hippocrates, the father of western medicine: “First, harm nothing.” Many alternative treatments do have the advantage of being harmless, and there have been many claims and quite a bit of evidence that people are actually helped.
12. **What are the latest treatments being developed, and who is carrying out clinical trials of these new treatments?**

One of the most important new types of cancer treatment is immunotherapy, which is aimed at activating the body’s own immune system to fight the cancer. It has been proven that most people have cancer cells in their bodies most of the time – but in the majority of people, they are instantly destroyed by the immune system and do not actually lead to cancer. We know, therefore, that the immune system can and does fight cancer, and some effort is being made to use this mechanism as the treatment for cancer. Melanoma is particularly suitable for some types of immunotherapy because of the distinct marker cells it carries which make it easier for the immune system to recognise. In fact, there are even cases in which advanced melanoma suddenly disappears on its own, presumably due to an immune response. Two treatments that use, provoke or mimic the immune response are interleukin-2 and interferon-alpha. These treatments have been used on a trial basis for several years to treat melanoma and some other cancers.

Often, your doctor, cancer clinic or hospital will inform you of clinical trials that might be suitable for you. Besides new treatments such as immunotherapy, different combinations of chemotherapy for advanced melanoma are also being tested on a clinical trial basis. In a clinical trial, patients are given a treatment that is still being tested so that the results can be discovered. If you haven’t heard of clinical trials before, you may wonder if these patients are being used as guinea pigs. They really aren’t. All of the treatments used in a clinical trial are safe; many stages of preliminary testing have already taken place. The thing that doctors want to discover now is how effective these treatments are on medical conditions. Often, participating in a clinical trial allows you to take advantage of a more advanced or promising treatment. If your doctor does not seem to be telling you about clinical trials, do some research on the Internet. [www.melanoma.org](http://www.melanoma.org) is often a useful resource, or you could try typing in key words such as ‘melanoma clinical trials’ on a major search engine such as Google. In the United States, the web site [http://clinicaltrials.gov](http://clinicaltrials.gov) allows you to search for clinical trials using
location and disease. If you read about a clinical trial for people with your stage of the disease, don’t hesitate to bring it up with your doctor. See what he or she has to say about it, and get him to find out if clinical trials are being held in your area.

13. **What do I do in the first week after being diagnosed?**

In a way, the week following your initial diagnosis may be the hardest time of all. As well as dealing with shock, grief and fear, you may feel a sense of overwhelming time pressure – as if you have to make a decision and act right now. Occasionally, doctors themselves will reinforce this feeling, as if they wish to fast-track a specific course of action without regard for your opinion or concerns. Regardless of what treatment options you end up using, taking some time to think things through during the first week is extremely valuable. Though melanoma can progress quickly in some individuals, one week will seldom if ever make a real difference to the course of your disease. Therefore, much of the pressure you feel to make a decision is psychological, not based in fact. You can take a week to think things over.

During that first week, if your regular schedule is not too demanding, try to stick to it as much as possible. This will give you a feeling of security and continuity. If you have a very demanding job, you might want to consider taking a few days or half days off to give you time to conduct some research. In either case, do not feel that you need to immediately change your whole self-concept and think of yourself as ‘sick’. Remember, because of the visible nature of skin cancer lesions, most cases are diagnosed before they become systemic. If this is the case, you probably feel and are well – you have a localized problem that can easily be dealt with before it becomes more serious. Remember, also, that even in cases where cancer has spread to other organs, there are many cases of complete remissions and cures. The frequency of cures is increasing all the time.

Besides sticking to a comfortable routine and taking time to relax, there are two real, concrete ‘tasks’ that you should attend to in the week following your diagnosis. You can ask your friends or family to help you with these, but in general, there is a great deal of benefit in your directing the process yourself.
Your first task is to locate a safe, accessible source of emotional support for yourself. Usually, this includes counselling and support groups. Even if you don’t want to go for counselling right away, do the research. Find out about resources in your community; find a place where you will be comfortable going when and if you feel the need. Though friends and family are a valuable support, they should not be your only support. Often it is more difficult for us to express our fear to family members who have a huge emotional stake in our wellbeing. With a counsellor or support group, you will have a source of impartial support. You will not feel as if you have to be looking after the counsellor’s feelings. At one time or another, regardless of the type of life transition we are going through, most of us feel the need for this type of backup. Take care of yourself by having the arrangements in place.

Your second task is to begin your own independent research on your condition. There is a lot to learn, and you will not be able to learn it all in the first week. You can, however, begin assembling resources and do enough reading to get a general outlook on options. **This is important to do even if you plan on following your doctor’s advice to the letter.** You need a clear understanding of what he is talking about and his thinking behind suggesting a certain option. You also need to know what other options exist. Studies have shown that patients who have a sense of control over their disease and treatment are the patients who survive, sometimes against seemingly overwhelming odds. If you view dealing with cancer as a battle, you need to know which weapons you can choose from. If, as is the case for many people, you find that dealing with cancer is like entering an unknown country, you need a map.

So, in the first week following your diagnosis, visit the library and do an internet search, in that order. Start with a general health guide published by a well-known university or medical centre, such as the one put out by Harvard medical school. Use this to get the general, well-established facts on melanoma, even if you feel you already know them. From there, you can branch out in your reading and get a perspective on new and alternative treatments.
Gathering information is an ongoing process, and one that you can involve your friends and family in. It is, however, important to get a start on it early in the process. You cannot afford the luxury of being uninformed about what is going on in your own body.

In the interest of both information and emotional support, communication with others who have been through the same thing is extremely valuable. One of the important ways in which we learn about anything is through the example of others. Dealing with cancer is no exception. Reading this book is a great starting point, in that it provides you with general and ‘alternative’ information as well as the experiences of survivors.

14. How do I get in touch with others who are going through the same thing? What support groups are available for melanoma sufferers or friends and family?

In many cities, hospitals and cancer clinics organize support groups for patients and their families, and these are often specific to a certain type or even stage of cancer. Information about these groups is usually posted in a visible place on a bulletin board. If you don’t see any information, ask your doctor or medical receptionist.

You can also access other support groups that are not affiliated with the hospital or clinic. Organizations such as City of Hope and Hope Cancer Help Centre Inc. have branches in numerous cities. These are non-profit agencies which provide information, counselling and support groups for people living with cancer and their families. Look for listings in your local telephone directory, and if you can’t find any, look up “cancer support” along with the name of your city or town on an Internet search engine.

Of course, this being the Internet age, web-based support groups, chat rooms and bulletin boards are also a valuable resource. Depending on what you are looking for and, in part, on your personality, these may or may not fill your need for support. On the one hand, we should not underestimate our need for physical presence and contact. On the other hand, Internet groups are accessible around
the clock and around the globe. For a start, try www.oncochat.org, www.cancerlinkusa.org, and www.mpip.org/bb/bbindex.html. Most of these sites are monitored to make sure that the atmosphere stays safe and supportive, and users are cautioned that these sites are not an alternative for medical advice.

15. How/where do I get counselling?

In most communities, there are several options for counselling. Usually, you can get a referral to a counsellor who is affiliated with the hospital or clinic through your doctor. There are counsellors in private practice listed in your community telephone directory. As mentioned before, many communities have cancer support agencies such as City of Hope and Hope Cancer Help Agency, and counselling is available through these agencies.

16. How do I get in touch with survivors of melanoma?

Your doctor, hospital or alternative practitioner might be able to put you in touch with melanoma survivors. A cancer support agency will almost certainly have names of individuals who are willing to be contacted. On the Internet, go to http://www.mpip.org/melanoma-warriors.html. This section of the web site has pictures and personal stories of people who have successfully fought or are in the process of fighting melanoma. Some of these include email addresses, showing that they are willing to be contacted.
2. **Dawn’s story**

I was only 25 years old when I was diagnosed with melanoma, but I already had a four-year-old daughter and I was running my own business as a daycare operator. That was almost 10 years ago, and it’s only now, looking back on it, that I can appreciate how much the whole experience scared me. At the time, I guess I shifted into survival mode. I also think it’s possible I reacted to it by purposely ‘numbing out’ to avoid thinking about how much it scared me. You don’t expect to get cancer at 25 – at least I didn’t, though I know now that it’s not that uncommon. It is pretty uncommon to get melanoma so young, though, and it’s not good news. I’ve heard that it’s actually more dangerous, the younger you are. So I was really lucky. They caught it early and I’ve been cancer-free ever since.

Actually, I was really lucky, because it was the doctor that saw it and I rarely went to the doctor. I guess I was sort of cavalier about my health – either that or careless. I had always been really healthy. I was one of those people who rarely go to the doctor. I had an inner sense of my own well-being, and probably the hardest thing about having cancer was that it challenged that notion. The melanoma was on the back of my right calf and it was small, not big or different looking enough to worry me much. I had noticed that it was changing in shape – the bottom seemed to be stretching out. My partner talked to me about it. My g.p. noticed it when I went in for something routine. I’m a person with a lot of freckles and spots – I even have these little red spots, they’re normal, but kind of strange looking - so I don’t really tend to worry about things on my skin that much. A lot of my freckles appeared after a really bad sunburn that I had when I was seventeen.

My g.p. referred me to a dermatologist who took the mole off immediately and sent it for biopsy. I made a point of not asking him what he thought while he was taking it off. I still thought they were being overly cautious. I think this was a regular dermatologist – it wasn’t done through the cancer agency, though later
was sent to a doctor that deals with some early stage melanoma patients. The thing I didn’t like about him was that he criticized me for my sun tan – not directly, but I remember he talked a lot about using sun screen and I felt criticized. I didn’t use much sun screen then – I do now. This doctor is actually known for this – he does a ‘mole patrol’ at our local nude beach, checking people for suspicious looking moles and handing out sunscreen. He’s also in the news quite a bit. I was always nervous around him, but that’s mainly because I didn’t want to hear what he was saying, I think.

Up until this point, I didn’t read or even think much about the possibility of melanoma. As I said before, I think I was blocking it out. I also felt that I had already taken care of it and put it behind me by going for the biopsy. I thought I was finished, ignoring the fact that a biopsy is just a test. So the fact that they called me back to the office and told me I had melanoma came as a huge shock, when really I guess that it shouldn’t have.

That’s when I got scared, though I still didn’t admit it to myself. I can see it clearly now, looking back. I did read some books about melanoma at that point, in addition to the literature that they gave me, and a lot of what I read sounded really serious. I didn’t know that skin cancer could spread throughout the body like that. I think I stopped reading because so much of what I was learning sounded so negative. I was shocked and scared and it all seemed surreal, not like part of my ‘real’ life.

They sent me to another doctor – I guess he must have been a skin cancer specialist, but I don’t remember – I think I’ve blocked it out. I don’t even remember his name, just that he was at the university hospital. He made a wider excision. He cut all around where the mole had been, one inch all around, and deeper underneath where it had been. It was all done pretty quickly, with local anesthetic, and I don’t have much of a scar. Physically, it really wasn’t such a big deal. They tested all that they cut out for cancer. It was all cancer-free, though, which means that I was really lucky. My cancer was stage one, and at that stage
it’s almost always curable. I was relieved, of course, but I think I was still scared, because I didn’t do anything they told me to after that.

This part is kind of embarrassing – I guess because it makes me sound pretty immature. I was considered cured, but they wanted me to go back for periodic checkups – and I never did. They wanted me to have some kind of test where they looked at all my other moles with a special light, and I never did that either. I even changed family doctors so that no one would ask me about my melanoma! I know this makes it sound like I was just in denial and for years I though that was a correct analysis. But now that I think about it, I have a slightly different take on my actions. After all, I did deal with it – I had the surgery – and I’ve been careful about my skin ever since. I always use sunscreen in the summer, and a moisturizer with sunscreen in it year-round. I haven’t had a sunburn since this all happened, because I’m careful.

And I feel like I’m standing up for my right to be careful in my own way, not in the way they tell me to be. I have a gut-level feeling that I know my own body, and that everything will be okay – and it has been for ten years. I think I stopped reading about melanoma and going to appointments because it made me question my gut feeling, which scared me. I also didn’t tell anyone about it at the time, for the same reason – people’s reaction to the word ‘cancer’ would make me question my own sense that it would be okay.

Of course, sometimes I thought it wouldn’t be – I still get scared that I have cancer from time to time, like last fall when I had some stomach problems. Then I use visualization, my own version of it – I picture a little pac-man eating up cancer cells. I think this works, because it works for other things – working with little kids, I get exposed to a lot of colds and stuff, but I choose not to let myself get sick during the week. I’m just too busy. On the weekends I guess I let my guard down, because that’s when the cold or whatever I have tends to catch up with me, but come Monday I’m fine again. I know that sounds like a little thing, but it’s enough to convince me that a mind-body connection exists and that I’m capable of accessing it. If my cancer had progressed, or if I were to get cancer
again, I would definitely look into some alternative or complimentary therapies. In fact, the g.p. I have right now is unusual in that she has as much faith in alternative medicine as she does in western medicine. I would look to her, or someone like her, for guidance, but I would also rely on my own instincts about what I should do.

Looking back, of course the thing that should stand out the most is how lucky I was. This could have been a really bad situation, but it turned out okay. But actually, what I remember most is how much I had to struggle not to get sucked into the fear-propaganda around cancer. I know it might seem very irresponsible that I didn’t go to my follow-up appointments, and I’m not suggesting anyone else do that. But I really felt that it wasn't good for me to be around the fear that surrounds a diagnosis of cancer. I even felt like it was distracting me from what I had to do to stay healthy. At the same time, I was surprised by how matter-of-fact and blunt all of the doctors and other staff were. There wasn’t much visible compassion. All in all, I didn’t find much ‘heart’ in the medical establishment.

So, as I said, I’ve been cancer-free for ten years, and while I don’t obsess about my experience with melanoma, it does affect me. I’m careful about using sunscreen on myself and the little kids I take care of. I have a hard time getting my daughter to wear it, which bothers me a lot. I don’t stay out of the sun, though, and I usually get quite a bit of color in the summer. I think it’s important not to get sunburns, because I do link my melanoma to the burn I got when I was seventeen. I never got into feeling sorry for myself or thinking ‘why me’, because I knew how much worse it could have been. If anything, I’ve come out of this experience feeling healthier and stronger because I have such a clear sense of things I can do to look after myself.
3. Kathy’s story

When I was about seven month pregnant with my daughter (now four years old), it was a hot summer day and I was lined up at the bank machine on Commercial Drive in Vancouver, wearing a sleeveless, backless sundress. As I was waiting for my turn, a stranger who was in the line behind me tapped me on the shoulder. “You really should get that mole taken off”, he said, indicating a mole that I’d had on my back for years, since I was little. “It looks like melanoma”, he said. I remember thinking that it was a very inconsiderate thing to say to a pregnant woman. When you’re pregnant, all your consciousness seems to center around the pregnancy. I wasn’t even that worried. I just thought it was a crazy stranger – there are plenty of those on the Drive.

I decided to totally put it out of my mind, and concentrate on getting ready for the baby. This shows that I had never had a baby before – I somehow thought I’d have more time to think and less to be concerned about after the baby was born, which is crazy, I realize now. But that night, I was lying on the sofa reading a John Updike novel – think it was The Witches of Eastwick – and one line leaped out at me. One of the witches says to some man she’s jinxing, “Unless you do right by me, everything you touch will turn to dust” – or words to that effect, anyway. And then I realized that I wasn’t ‘doing right’ by anyone by not having my mole checked out right away – I wasn’t doing right by our baby, who needed a healthy mom, or by my husband. That line made me feel sick, because I wanted to ignore the whole thing. But then I remembered that my grandfather had had melanoma, and it can run in families. And the principal at my elementary school had died from it. So the next time I went to my doctor for a pre-natal checkup, I asked her for a referral to a dermatologist.

To make a long story short, he looked at my mole, and he did not agree with the crazy guy at the bank machine. He thought it looked fine, even though it was big. He said that that kind of mole had a well-defined border and was unlikely to turn cancerous. I felt silly by then, but I told him I wanted it taken off anyway – it was
big and ugly. He said it could wait till after the baby. A big mole like that would take a couple of stitches. But then he looked again and said that there were some other moles on my back – tiny ones – that he would like to take off, and he did. And, incredibly, one of those little moles, that I’d barely noticed, did turn out to be stage one melanoma, and another one was melanoma in situ.

And that’s my crazy melanoma story. I had to tell my husband, who stayed nice and calm, and I had to go and have a wider excision done that would cover the area where both moles had been – they were quite close together. All of this happened when I was eight months pregnant, and it was not quite the way I wanted to be spending my pregnancy. I had some mood swings; one moment, I would feel so lucky that, with the help of the crazy man, I’d caught this at a stage when it was totally curable. The next moment, I’d be convinced that I was going to give my baby cancer. I hated the idea that something so deadly could have been growing in my body all this time.

Apparently all my ‘margins’ were clear when they did the wide excision, but I still had to go to another dermatologist who specialized in melanoma and he looked at all my moles carefully. I have a lot of moles. He didn’t agree that the big one on my back was necessarily harmless, but he didn’t think it was melanoma. Nevertheless, it was worth taking off once the baby was born and I’d recovered a bit, he said. He found some tiny ones on my arm that he took off, and then he got me worried about one that was itchy between my breasts – but it turned out to be fine, it had been rubbing against my bra. This doctor said I should come back to him at least twice a year to get my moles checked, but I’ve only been back twice altogether. The first time was to get my big mole taken off, and it turned out to be fine; and the second time was for a checkup when my daughter was about one. When he didn’t find anything that time, I didn’t go back again. I was starting to find it too stressful. And my daughter has a couple of little moles already, and she has my genetic link, so I worry about her a bit, too. The dermatologist was adding to my paranoia, saying I should never have her out in the sun in the middle of the day. I think that’s going a bit too far, actually. I don’t want to be thinking about cancer all the time. I don’t think that’s a good way to raise a child. Even
sunscreen – yes, it’s important, but it blocks out vitamin D from the sun, which is also important. In fact, I’ve read that a lot of cancer patients have abnormally low levels of vitamin D. So now I guess I’m in denial – but not really. All of this has made me really motivated to stay healthy, and keep my child healthy. So I switched to all organic food, and when my daughter has an ear infection or something, I treat her homeopathically. My mom doesn’t like that I’m doing this, and she says I’m just running away from western medicine because the mole experience scared me. I think there might be truth in that, but it’s also true that I’m trying to keep us healthy enough so that we don’t need western medicine. My husband is fine with my doing that. He’s pretty relaxed about these things – even when the baby gets sick, he’s the calm one.

Looking back, I would have to say that the strangest thing about this experience was that stranger in the bank machine lineup. How did he know? He wasn’t even looking at the right moles, but he knew I had melanoma. And then, I somehow knew I had to listen to him – the whole thing was really strange. If that hadn’t happened, I might have gone years before noticing anything strange about the other moles, and then I would have been in much worse shape, and at the worse possible time. So, of course, I’m grateful that I went in when I did. At the same time, though, it scared me, and the longer it’s been since I’ve seen the dermatologist, the more I dread going back. I guess I have this feeling that I’m defective in some way, and if I’m not constantly being proactive, it’s bound to crop up again. I know that’s a little dramatic, but it is how that doctor made me feel – like my baby could never go out in the sun because she came from me. That’s just too sad to contemplate, so for now I ignore it. If I ever did get cancer again, I would try to treat it using alternative medicine, which I find a lot less frightening for some reason.
4. Jim’s story

I could have lost my life because I ignored something that was, so to speak, as plain as the nose on my face. About twelve years ago I had a melanoma removed from the left side of my face, right next to my nose. They thought it was stage 2 at first, but it was large enough that they went ahead and did a lymph node biopsy too, and found that it was at the beginning of stage 3. I’ve been okay ever since, touch wood, but it was scary. I mean, this was really quite a large melanoma.

I guess I had some excuse for thinking it was nothing. About two years before the melanoma, I had an irregularly shaped mole removed from that same place. I was on the ball about that one. I think my mother had had skin cancer, but I don’t know what type – she never told me. She doesn’t talk about things like that, at least not to me, but I remember her going for radiation. Anyway, when I started to see this mole change, I did go to the g.p. and he sent me to a dermatologist to have it removed. But the thing is, it was fine. They told me not to worry about it. So, two years later when I got this other mole, I assumed it was fine. It was a little unsightly, but actually I was too busy to worry about it much.

I’m self-employed as an electrician, but I’d done construction when I was younger and probably spent way too much time in the sun. I’ll admit, I always did like to have a tan – ironic how that’s such a healthy look for most people. Anyway, that spring when it started to get big, I put the problem of the mole out of my mind – which is pretty remarkable, looking back, considering that it was right there on my face, staring at me in the mirror every morning. I guess when you get really used to seeing something, you don’t really see it anymore. But that spring, friends started to comment on it. One woman was really blunt; I hadn’t seen her in a while, and she just sort of stared at me and said “what is that thing on your face?” I guess that’s how obvious it was. By this time, it was black, much blacker than a regular mole, and sort of nodular. But it was still smaller than a pencil eraser and it had a pretty regular border, and these were the two warning signs I’d
remembered from reading the literature at the dermatologist’s office two years previously. I knew, by this time, that it was something a little unusual, but I still didn’t think it was cancer. I think if I’d had the internet back then, I would have looked up ‘skin lesions’ or something and looked at pictures that would have scared me enough to send me to the doctor. But this was before the internet, so I went about my days ignoring it for a long time. Well, not so long – probably about six months from the time it really started to get strange looking. But that was long enough.

This is kind of embarrassing to admit, but when I first started to get worried about it, I would come up with theories of what it could be. And at one point I was convinced it was a blood blister – it kind of looked like a fat, black blood blister. So a couple of times I poked it with a pin, to try and deflate it. I know that probably wasn’t the best thing to do. I guess that’s what you call being in denial.

What finally brought me out of denial was just realizing I was in denial, and knowing that that wasn’t a place I wanted to be. I knew it because I’d been pretty good about going for an annual physical. I suffer from asthma, and I wanted to keep it under control. When I realized that I’d gone almost two years without visiting the doctor, I asked myself why, and the answer I came up with was that I was avoiding him because he’d be sure to comment on the mole. When I realized that, I made an appointment the same day. I guess that kind of avoidance just wasn’t something I could tolerate in myself, once I recognized it for what it was.

Well, the doctor fast-tracked me to the dermatologist’s office, a different one from the one I’d seen the last time. The dermatologist told me straight out that he strongly suspected it was melanoma. Up to that point I hadn’t gone so far as to think about different types of skin cancer, so I was still blissfully unaware that melanoma is the type that can kill you. At worse, I was worried about having a scar.

Well, of course, it was melanoma, and it wasn’t particularly small. They wanted me to go in again right away and have a broader excision. This meant that they wanted to cut sort of a triangle of skin around where it had been, then pull the
remaining skin over to cover it. I’d have a triangular shaped scar right on my face. When I asked why this had to be done (since they’d already taken off the mole) I was read the riot act. That was the first time I knew you could die from melanoma. Still, I had to think about it. I took a long walk, going over my options – basically, as I saw it, there were two: to do as they said, or to do nothing and hope for the best. I’d like to say that I have some sort of epiphany that made me decide, but I didn’t. I don’t know what made me come to the right decision. But I walked home and phoned to schedule the surgery.

I thought I was done after that. The facial surgery was done in the doctor’s office under local anesthetic, and it wasn’t as bad as it sounded. I’m a fast healer. I took Tylenol 3s for one day, and after that I felt fine. Now, mind you, I think I have a very high pain threshold. I got that from my mother. The best thing was that it didn’t even look that bad. Yeah, there was a scar, but the lines were very thin, and it was a relief not to have that big mole on my face. In fact, it was almost miraculous to have it gone. I realized I must have been more worried about it than I thought.

So, I had a few days feeling really good about everything. I decided to be proactive and get a hat to protect my face from the sun. I’d never worn a hat before – not to mention sunscreen. But that kind of feeling of relief ended when I got a phone call from my dermatologist who’d done the surgery, wanting to make me an appointment at the BC Cancer Agency. I don’t know why he didn’t tell me that sooner, but I guess it was just me deciding that I was all finished. Even though they didn’t find any cancer in what they had excised from my face, because the melanoma was quite big, they wanted me to do follow-up at the cancer agency. So again, I had a decision to make. In the end, I decided that since I was in, I was in. I was starting to get sort of philosophical about it. I’d had a great life so far – I was forty-four – and I decided that if this was it, then this was it. All of my earlier Buddhist training kicked in, I guess.

Still, it was not pleasant at the cancer agency. First, they keep you waiting for ages, and then, you don’t just see one doctor. A whole group of them parade
through and look at you and your files, and then they have a conference. This was probably one of the most intimidating things that had ever happened to me, and I almost wished I had someone with me. That was impossible, though, because I hadn’t told anyone what was going on.

Anyway, they came up with a bunch of things they wanted me to do. One was a chest x-ray, and the other, probably the biggest thing, was this major surgery I had to do. Because melanoma spreads through the lymph nodes, they wanted to remove all the lymph nodes on my neck on that side. This would do several things – see if there was any more cancer, take it out if there was, and give it nowhere to go if it was starting to spread. So, again, I had to make a decision whether to go ahead with what they were saying or to stop where I was.

One thing I really didn’t like is that the doctors did not make it seem as if it was my decision. They just came up with their conclusions and they expect you to follow along. That’s not quite how I see it, though. I think part of it has to be the patient’s decision.

Anyway, to make a long story short, I decided to go ahead with the lymph node surgery. I also decided that was the last thing I would do. If they wanted to go on from there, I wouldn’t go along with it – at least not automatically. I would look at options and make it my decision. Otherwise, I could see it just going on and on, one procedure after another. I have to mention, too, that I had no physical symptoms at all. I mean, I’d had the thing taken off my face, but I didn’t feel sick in any way. I felt as healthy as ever. I didn’t feel like a person with cancer. Maybe that made me less inclined to want to do any more treatments.

The lymph node surgery was major surgery, with general anesthetic. I was in St. Paul’s hospital here in Vancouver for two days, and I felt pretty rough. They cut into my neck and took out 23 lymph nodes, I think it was. And sure enough, the first one – what they call the sentinel node – had a little trace of cancer. But there was no cancer in any of the others, so it had just started to spread. I don’t know how quickly it spreads, but it seems to me they went in just in the nick of time.
That surgery took a little recovery time because they cut into my trapezius muscle, and there was one movement I couldn’t do – I couldn’t lift something straight out from the side with that hand. I worked on it a bit with some weights, and I got the movement back pretty quickly, I guess. The scars were worse from that one – I had staples in my neck instead of stitches – but all’s well that ends well, as they say.

With melanoma, between stage 3 and stage 4 is the tricky part. Stage 3 was what I had, spread to the lymph nodes. That still won’t kill you, but it’s beginning the migration toward what can kill you. And it seems like they can’t predict how slow or fast that will happen. Stage 3 melanoma is something they take seriously. They had me going for regular chest x-rays for a couple of years, in fact I still have them every three or four years. I guess the lungs would be the next place it would go. I’m glad I’ve never been a smoker. I also see a dermatologist once a year, and he’s taken off several suspicious looking moles, but none of them have tested positive. Right after the lymph node surgery, there was some talk about having me go for radiation treatment in the neck, but I didn’t want to, and finally they decided to just keep going with the chest x-rays.

Most of the time, I just accept that I was lucky. If I had left it any longer, it would have been a much bigger deal. Sometimes I get paranoid, and I think, what if it’s still there, ticking away like a time bomb? The more time passes, the less I think about that, but the thought is still there in the back of my mind. I also think about other things, like the radiation I got from all those x-rays and how that probably didn’t do my lungs any good, ironically enough.

So I have thought a lot about what I would do if the cancer came back, and sometimes I even come up with a kind of plan of action. I think that if it was in a place where it could be cut out pretty easily, I’d let them do it. But I’d also look at alternative medicine. In the meantime, I wear my hat and my sunscreen, and I try to stay positive. I think that’s the main thing. I was lucky that they caught it just in time, and the timing was so lucky it’s almost like it was meant to be – like someone was watching out for me, as they say.
5. **Kevin’s story**

I’m 33 years old now, but I had melanoma when I was just a kid – I was thirteen. I’m okay now, and my cancer wasn’t that serious as cancers go. To tell you the truth, I think it scared my parents more than it scared me. I had that teenage invincibility going for me. I just wanted to get back to my life, not to think about cancer. I’ve probably thought about it more in the past few years than ever before, to tell you the truth. I guess once you get into your thirties, you start thinking about your health for the first time – it dawns on you that you have to take care of yourself. So actually, I’m more worried about getting cancer now than I ever was in the past twenty years. I know that the fact that I’ve been cancer-free for so long is excellent, but I also know that it’s unusual to get that type of cancer so young, so it must mean I’m very susceptible to it. What makes it even more unusual is that I’m Filipino, and we have naturally darker skin. Usually you wouldn’t associate that with skin cancer, especially melanoma. So I think there must be some pretty strong genetics working against me.

My mom dragged me to the doctor to look at a mole that I had on my chin. It just looked like a normal mole to me; I thought my mom was being paranoid, like she often was about my health. She was always putting a hand on my forehead to see if I was feverish and stuff, and making sure I had all my vitamins. I wasn’t too impressed when the doctor wanted the mole taken off. I don’t think I was really scared, I think I just didn’t want all that hassle. But my mom took me to a dermatologist that the GP referred us to, and he took it off right there in his office with local anesthetic. It didn’t hurt much. Then, a few days later when my mom got a phone call from the doctor, telling her I had cancer, I guess, she started to cry. I remember getting mad at her for crying, thinking she was being melodramatic as usual. I was probably mad because I was scared, but it just felt like I was mad. She called my dad at his office and he came home, even though it was the middle of the day. It was summer and I wanted to be doing something. Instead I had to sit there and wait for my parents to finish discussing this thing that didn’t seem like it had anything much to do with me. They didn’t even talk to
me about it, which was kind of crazy. Actually, looking back, that was probably the weirdest thing of all – it was like it had nothing to do with me, but I knew it was caused by me. I mean, it wasn’t like I was three years old – I was thirteen, and I could have understood. Nobody even explained to me about the different types of skin cancer, or that melanoma could spread. I guess if I’d been a different kind of kid I would have looked it up in the library (or on the internet, if it was today) but it never occurred to me to do that.

It seems like a good deal of that summer was taken up with cancer stuff, though. I had to go back to the doctor and they had to cut more around where the mole had been. I really objected to that – it hurt, when the freezing wore off. The doctor was nice though, and joked with me to make me feel comfortable. I sort of watched what he was taking out. It seemed like a lot of bloody flesh. I could feel the tugging as he sewed me up, but otherwise nothing – but a few hours later it hurt a lot. I think that was really the start of my teenage moody period. I didn’t understand – because no one explained to me – why I had to go through all this. It was just because “the doctor says”.

I don’t remember any other treatment after that surgery. I did have a lot of checkups and tests, though. I had to go for x-rays. They felt around for the nodes in my neck and looked at all my moles really carefully. Luckily I didn’t have that many, and the ones I had were okay. And in all this time, no one spelled it out to me why they were so worried. I can piece it together now, having done my reading – my cancer must have been stage one or two, quite early. But they were worried because it’s so unusual to get it so young, and because it tends to spread faster the younger you are. The lymph nodes in my neck and under my arms were where it would have spread next, but I guess they weren’t worried enough about it to think about taking them out.

After that summer was over, we all sort of put it behind us. My mom kept hovering more than usual, and making me eat vegetables. She even wanted me to wear sunscreen when it wasn’t summer. People weren’t as sunscreen-conscious then as they are now, so it was a little weird. About twice a year, I had
to go and get my skin looked at, top to toe, by the dermatologist. When I was about sixteen I started refusing to go, and then I didn’t go again for about five years.

When I was in third year university I had another scare. I felt like I’d forgotten all about the melanoma incident when I was thirteen. I had put it all behind me; I never even thought about it. By this time, I didn’t wear any more sunscreen than the next person. I still lived with my mom, but she’d given up trying to tell me what to eat and stuff. But in third year university, I started noticing this other weird mole on my left arm. I first noticed it when I was driving and had my arm resting on the open window. There was one spot that just kept catching my eye. It was little and black. I got really paranoid about it. I was afraid to go to the doctor, but I kept sneaking into bookstores and pulling out medical books to look up melanoma, which is the last thing you should do if you’re at risk for a disease! That was the first time I found out how serious melanoma could be. I couldn’t believe I’d had it as a kid – the books were saying it was an older person’s disease. Of course, I just got more and more paranoid. I would set deadlines for myself – times by which I had to have made a doctor’s appointment. I broke all my deadlines. I didn’t even know what doctor to go to, as I was sure my GP would just tell my parents. Finally, I just went into a walk-in clinic one day, and I had to pretend I was there for something else. Actually, maybe I waited until there really was something else – I’d wrenched my knee and wanted to find out if it was sprained. Anyway, I finally asked this young doctor I’d never seen before to look at the mole on my arm – I didn’t tell him anything about my history of melanoma, though. He said it was probably nothing, but I could go and get it taken off if I wanted, and I did. And I never heard anything about it, which supposedly means it was okay. They only call you if something’s wrong; no news is good news. Of course, I did have all these paranoid fantasies that they’d somehow lost the mole or mixed up mine with someone else’s, so I really had cancer spreading inside me. I guess I would still be thinking that, except that I would have felt it by now.
I know that experience sounds really trivial, but it changed me. All of a sudden, I felt like quitting university. I didn’t, because my parents would have had a fit – but I sort of got impatient with it. I wanted to travel, I wanted to join the Peace Corps – I wanted a lot of things, but all I really did was mope about them. Then, when I finished university, I actually did go traveling for a year. I know that sounds pretty standard, but it was a bit of a challenge to my parents.

Sometimes I still ask myself why I got melanoma, even though I know there’s no real answer to a question like that. Still, it’s strange. I don’t think anyone else in our family has had it, I don’t have fair skin or a lot of moles, and I don’t think I’ve ever had a bad sunburn in my life. So I think we can try and rationalize why people get it, but there’s this whole random quality to it, too. It does make me paranoid that I will get it again. I’m pretty diligent about wearing sunscreen. And I know this sounds crazy, but sometimes I think I don’t want to have kids, because I’d be risking passing on my crummy genetics.

On the other hand, sometimes I even think they must have been mistaken. I’m sure it happens – samples can get mixed up. Maybe someone else got my mole by mistake and stayed blissfully unaware, without a huge scar on his chin like I have. I do think it was wrong to keep me in the dark about what was going on, but I also know that this was a normal way of coping for my parents. I don’t blame them because they thought I was better off not knowing. I wasn’t, though, because I knew something was going on, and I just assumed it was too bad for them to tell me. In the long run, I think more information is always better than less.
6. Joanne’s story

My battle with melanoma began in 1993, when I had a mole removed from my left leg because it had started to bleed. I insisted on a biopsy, even though the doctor did not seem convinced that it was that serious – in fact, he burned it off rather than cutting it off, as is usually done when cancer is suspected. This made staging impossible after the biopsy came back positive for melanoma – in order to stage it, they would have had to look at how deep it was. In other words, I knew I had the disease, but I had no way of telling how serious it was – I could only hope for the best. A wider excision was done, but that was all – there was no other follow-up.

Two years later, I found out my stage when all hell broke loose. They discovered cancer in my breast, chest, liver and shoulder. It was all melanoma, which meant that my disease was stage 4, which carries a very poor prognosis. In particular, cancer in the liver is usually considered to be incurable. From the beginning, I knew that a positive attitude would be vital if I was to fight this successfully. I didn’t waste time feeling sorry for myself, or saying ‘woe is me’. Though it was difficult at times, I didn’t even fall into panic. For a very brief period, I felt that melanoma had taken over my life, but I soon realized that this was unacceptable to me. I knew that I needed all my energy to fight the cancer. That was my attitude – that I had to put my energy into fighting. I had no time or energy to waste. I quickly started a pretty aggressive treatment protocol – five cycles of chemotherapy, and low-dose interferon three times a week for almost a year. This was a very exhausting treatment, but the results were worth it – miraculously, all of my metastases disappeared, and I was totally cancer-free for the next five years.

I know that this is highly unusual. Even with the aggressive treatments I was receiving, metastatic melanoma does not often regress completely. I have asked myself why I was able to survive it – why I go on surviving it, after almost ten years – and I have not come up with any simple answers. I know part of it is my
attitude – as I said, I’ve absolutely insisted on staying positive throughout this experience. I believe that melanoma hates happy people, so I always smile. I’ve also given considerable thought to the idea that I am that one person in 10,000 with a built-in immunity that has helped me battle this beast. I believe that is the statistic.

I’ve also given thought to the idea that it was my faith in God that saw me through. God is the ultimate healer, after all – maybe he has a reason why he wants me to stick around for the time being. I don’t know what the reason is – maybe it’s just to make me a better person. Maybe it’s to tell others that beating this disease is not impossible.

I did have some subsequent challenges, but I never lost my optimism. In January of 2000, after being clear for five years, my doctor discovered some subcutaneous nodules on my right side during an examination. These were melanoma metastases, but they were just under the skin, not attacking any of my internal organs. So, the bad news was that the cancer was back – the good news was that I was still much better off than I’d been in 1995, and I’d had five healthy years in the meantime. One year later, in January 2001, I felt three more nodules, which the doctor later confirmed. At this point, Dr. Carl Plager at the cancer center in Huston wanted to put me back on the same treatment protocol that I’d been through in 1996. In his opinion, the subcutaneous nodules were absolutely certain to metastasize, and that same treatment had worked on my cancer before. He may have had a point, but I remembered how exhausting the chemotherapy had been. I didn’t want my life to turn into one big continuous round of treatments. I wanted to enjoy my life, and live it to the fullest. I remembered, also, that all my organs were cancer-free. After going over my options, I decided not to have chemo.

This is the other thing that I feel has contributed to my survival – I’ve always been a very proactive patient. I always remember that while the doctors are part of my team, the final decision about my treatment is always mine. I don’t take anyone’s word as law. I have always heard that knowledge is power and it is so very true
with melanoma, since there is no one cure or any one treatment that works for every person. For several years, I have armed myself with knowledge about this disease and I have kept up to date with any and all new treatments and trials. I consider this my job, not anyone else's. I have an excellent general oncologist and I have been under his care ever since 1995, when I was first diagnosed with stage 4 melanoma. However, I don't consider his opinion to be absolute. I trust him, but much as I trust him, there is no way I would put my life into another person's hands! For the same reason, I have looked for several opinions. I think this is essential. I have sought opinions from specialists in Houston, but also at the National Cancer Institute in Maryland. I have spoken to other oncologists in other states and locally. I believe that the more serious the disease, the more important it is to get multiple opinions – to get all of the information that you possibly can.

Another way to look at it is this – my oncologist is a general oncologist, so he has to stay up to date on all cancers. I only have melanoma to research, so that's my job. I stay up to date on treatments and clinical trials. Usually, I'm the one to tell my doctor about clinical trials. Maybe this has value because it makes me feel that I have control over my life. For whatever reason, I know that being pro-active and having a sense of control is very important to survival. I realized this almost from the very beginning, and I feel it is something that people forget all too often. It's easy to feel powerless when you enter the medical system, but that's all the more reason for making sure that you retain your power.

My problem with subcutaneous nodules continued, and eventually I had to seek out treatment. Naturally, the doctors were concerned, and sent me for several tests. I had a bone and CT scan in 2001, and every year since. Each time, the tests turned out to be negative – I didn't have any metastases on any of my organs at all. At first, the subcutaneous nodules didn't grow or multiply either, and the doctor felt that they might be working as a natural immune booster – we decided to leave them in place. In 2002, I still had just the three nodules – we discussed thalidomide and interleukin2 as a treatment, but I had such a severe reaction that I decided to do nothing, just wait and see. In general, I felt great and
was enjoying life. The nodules did eventually grow and cause me some pain, however, so I tried a couple of treatments. I took low-dose Thalidomide for 26 days, but it wiped me out and made me feel like a zombie. Then I learned about a clinical trial for the chemotherapy drug MS-275. I enrolled; however, I soon withdrew because I felt misled about the results. Also – and even more importantly – I felt that no one really believed in this treatment 100%, and there was no feeling of teamwork. Under those circumstances, maintaining a positive attitude is impossible, so I felt it was better for me not to be there.

Now, finally, the subcutaneous nodules are shrinking and I am off pain medication for the most part. Chemotherapy has worked for me once again. My latest tests show significant shrinkage of the nodes, and no cancer at all on any of my internal organs. So even if this can't be considered a total cure, I am still much better off than most people would have predicted. I have been surviving stage 4 melanoma for almost ten years, and I'm in pretty good shape, with my optimism intact.

Personally, I think my success in surviving cancer is due to a combination of many things – my positive attitude, my faith in God, which I have talked about before. My supportive family certainly deserves some credit. My control over my treatment – one thing I have learned is that even though a doctor has earned his degree, that doesn't automatically make him a good doctor! I have met many doctors, good and not so good. None of them are the ultimate authority on what happens to me.

Above all, I like to surround myself only with happy, positive people, and I always keep smiling.
7. Susan’s story

According to western medicine, I never should have seen my thirtieth birthday, but (knock wood) I’m going to be 47 next month.

My story started with a routine visit to my GP. I needed a doctor’s signature before entering a very demanding registered massage therapy program, and I decided to get all my pap tests and stuff done at the same time because I wasn’t very good about doing that. While I was on the table, I asked the doctor to look at a mole on my right hip, right inside the hip bone. I wasn’t too worried about it; it looked like any other mole to me. I always thought that if you had skin cancer, the mole would look clearly ‘wrong’ in some way, but this one didn’t – it was just a regular brown mole. The only problem was that it was starting to sting and bleed. My GP, who tends to be very casual, kind of frowned at it and said it was probably rubbing against the waistline of my pants. He said not to worry about it, but that he could refer me to a dermatologist if I wanted. He didn’t think I really needed to go, though – just keep an eye on it.

There was only one thing wrong with what he was saying – the mole was in the wrong spot to rub against my jeans. It was sort of in the hollow just inside my hipbone (I was pretty thin back then – no hollows now!). For some reason, this bothered me. I felt like phoning his office and asking him whether the only reason he said not to worry about it was that he assumed it was rubbing against my jeans. Was that the only ‘safe’ reason for a mole to sting and bleed? I just didn’t know. But it seemed like a silly question to ask. This whole thing reminded me of why I chose that doctor in the first place – he was easygoing. I met him at a Planned Parenthood clinic when I was twenty-five and needed an abortion. I didn’t have a family doctor because I had just moved to Vancouver. I was really stressed out about the pregnancy, and I knew I didn’t want to go through with it. I had traveling plans. But I had been raised Catholic, and I was paranoid that the people at Planned Parenthood would be judgmental. That’s really silly, I know. But this doctor was the one I saw, and he seemed so laid back that I felt
comfortable with him right away, and wanted him for my GP. He was young and pretty good-looking. He never hassled me about anything. I could get any referral I wanted to out of him, and he never asked me why I didn’t come for my last pap or anything like that. This is important to my story because it shows my mentality – I just wanted not to be hassled or challenged. So normally, I would have accepted what he was saying, given that it was what I wanted to hear. It’s amazing, actually, that I didn’t just leave it at that. But something kept bothering me. I was 28, and I was entering a new phase in my life. I wanted to be a massage therapist, a healer, so that meant I had an obligation to take care of myself first. So, to make a long story short, I made that appointment with the dermatologist.

The dermatologist seemed pretty laid back about it too, but on the other hand, he didn’t waste any time taking it off – he did it during that same visit, and told me it could take up to five days to get the biopsy report. It didn’t, though – I got a phone call only two days later. I knew it wasn’t good when they asked me if there was someone I could bring in to the office with me. I swear, they must come up with that stuff just to make people nervous! I mean, when they say that, you know it isn’t good, but they won’t tell you anything until you come in. So you just have to stew in it. Plus you have to decide who to bring – I didn’t want to bring my boyfriend. The relationship was too new. At the last minute I asked my cousin, Lauryn, who is a nurse. I figured she could be calm around doctors.

My diagnosis was melanoma, and my guess is that they already knew it was a serious one. Even on that first visit, the dermatologist started talking about chemotherapy! I think he thought he was being positive when he said that chemo was an option and most chemo drugs used for melanoma didn’t make you lose your hair. He totally lost me there – you see, I still didn’t know that skin cancer could spread throughout the body! I thought it was a drag that I had it, and that they might want to cut more around it and leave a scar. But I didn’t understand why we were talking chemo. I even thought that if I had to have cancer, skin cancer was probably the best kind, because you could see what it was doing and remove it easily. I didn’t know that you could die from skin cancer.
The doctor didn’t fill me in on this, either – Lauryn did, after we left the office. I immediately sank into a pool of panic which I tried to hide from her. I went from thinking of this as an inconvenience to thinking that I was going to die. I asked Lauryn not to tell anyone in the family yet – her dad and my mom are brother and sister. She said okay. And she told me I would be okay, that doctors always over-dramatize things. She said most melanoma is completely curable. However, I noticed that she held onto a business card that the dermatologist gave her. After making me an appointment with a doctor at the cancer agency, he wrote down the appointment time on a business card and very pointedly gave it to her, not to me. He was telling her to make sure that I went, I realized.

Things happened fast after that. They excised a big chunk of flesh around where the mole had been, and they didn’t stop there – they also went for the lymph nodes in my groin right away. The news from that biopsy was bad – there was cancer in three of the lymph nodes. Actually, the doctor said that they were palpable before the surgery. I hadn’t noticed. While I was still in the hospital recovering from that surgery, they made me go for a slew of tests. I had to have an MRI and a Cat scan. That was probably the most unpleasant test – I was always a bit claustrophobic. Going into that tube felt like going into a tomb. Those tests came out okay, and so did the chest x-rays. That made me feel good. I’d read a bit about melanoma by this time, and I knew the lungs were a common place for it to go first after metastasizing. But when I mentioned this to the doctor in charge of my case – a humorless, middle-aged guy – he said not to get my hopes up. He said melanoma normally travels downwards in the body. Why the brain and chest scans, then, I asked. I was thinking of the toxic radio-waves. The doctor barely answered. Apparently, it doesn’t always go downward, just usually. Or maybe they get paid every time they use that big equipment.

To make a long story short, it had gone down – they found a tumor in my uterus. So, as soon as I recovered from the lymph node excision, I was scheduled for a hysterectomy. I struggled to come to terms with what that meant – no children, ever. Apparently, the pregnancy I’d terminated at twenty-five had been my only chance to have a child. But somehow, out of that knowledge, my strength
emerged – my sense of self. I knew I was ‘supposed to’ be kicking myself for having had the abortion, and mourning my lack of children. But in the middle of that, I realized something – I’m important too, and not just for the children I could have produced. I still thought the abortion was a good decision. And I had enough to be sad about – I wasn’t going to mourn not having children when I wasn’t ever sure I wanted any in the first place. Instead, I was going to be thankful that the tumor was operable. I was going to believe I had things to offer the world, even if I couldn’t have children. Looking back, I think that discovering this belief in myself was the beginning of my recovery.

I had some setbacks. Before the hysterectomy, a checkup revealed two lumps in my groin, where there were supposed to be no lymph nodes anymore. Well, it seems they missed a couple, and they were cancerous. I know everyone has a different number of lymph nodes, so they can’t be sure they got every one just by counting, and they can be hard to find. Still, of the thirty or so that they’d removed the first time, three were cancerous and the rest were clear. So what were the odds that the two they happened to overlook just happened to be cancerous?

Then, after the hysterectomy, they had to let me go into premature menopause. Normally they might use hormone replacement, but apparently there is some link between hormones and cancer. This was a blessing in disguise, though, because it made me look at alternative therapy. I’d always been somewhat interested in alternative medicine, and I knew a few things – for example, I knew eating soy product was good for menopausal symptoms. So I added a ton of it to my diet, and while I was at it, I stopped eating meat. Later, I tried a macrobiotic diet for a while. Later still, a naturopath put me on a semi-vegan diet. All of these things helped, I think, in my recovery.

At about the same time, they discovered a couple of melanoma in situ on my back, where I probably never would have found them. They didn’t seem to think these were related to the original tumor. “In situ” means they are very small and have not begun to spread, so to be honest, I put these out of my mind pretty quickly. Actually, I guess I was lucky to be under so much medical surveillance,
or I might not have found them till much later. It did prove to me, though, that my whole body was prone to this disease. I was convinced I had to fight it on a systemic level.

I had a month’s worth of radiation treatments in my pelvic region, which didn’t hurt but did produce some pretty disgusting side effects – such as diarrhea. During this time I discovered essiac tea, which some people claim can cure cancer. Since it is also supposed to help the body recover from radiation, I decided it was a good thing I could do for myself. I had to cook up a big batch of it every few days and can it. It wasn’t like a regular tea – all the herbs had to simmer for a long time, and then it had to be strained. It has sort of a woody taste that I didn’t mind, though some people really don’t care for it. I still drink essiac sometimes, though not every day.

After the radiation I had one round of chemo, and then I refused to go back. It wasn’t that the chemo was so awful. They already had good drugs to control the nausea, and I hear that now they’re even better. Mostly I just felt tired. But I was reading more and more about natural medicine, and I learned how devastating chemotherapy is for the body. If I’d had any actual tumors at that time, I might have agreed to do it for longer. But I didn’t. All they could tell me was that my risk or recurrence was very high, and there was likely still cancer in my pelvic area because of the lymph nodes that had been left. In fact, someone with my stage of melanoma had only about a thirty percent chance of surviving five years. There were also some ‘spots’ on my liver that they were watching, but they couldn’t tell me that it was definitely cancer. So I decided to ‘quit’ western medicine for a while.

I had other things to deal with. I’d left a lot hanging. For a start, while I’d told my parents that they’d found a cancerous mole, I hadn’t told them anything else. I worked up my courage to phone, only to discover that they already knew: Lauryn had filled them in. I guess they were hurt that I didn’t want them to know, but I was just as hurt that they knew, and still let me go through it alone. That’s not very logical, maybe, but it’s how I felt. Looking for some help with this led me to
the Hope Cancer health center, where they offer counseling as well as meditation and relaxation tapes – I took advantage of all of these things.

Also, I faced the reality that I was not going to go to massage school that fall. Chances are that they wouldn’t even let me. I was an extremely demanding program. Besides, I needed the money I had saved for school to live on while I decided what to do next.

As I mentioned before, I saw a naturopath who specialized in working with people with cancer. He examined a drop of my blood – this is called live blood analysis. It lets you know what is going on in the body on a cellular level. After looking at my blood, he told me that my blood cells were in good shape, considering what my body had been through. This made him believe that I had a good chance of completely beating the cancer. It was the encouragement I needed, and such a welcome change from western medicine. He put me on a whole pile of vitamins and supplements, to strengthen my body and help it recover from the chemo and radiation. I kept on using meditation and visualization.

And basically, that was that. My cancer never returned. I believe that all the treatments and supplements helped, but in the final analysis I think it was my attitude that did it. This whole experience was an exercise in not giving up on myself. I know that I’m still at risk for melanoma, and I do go for skin checks. But I’m confident that if it did come back, I’d be able to deal with it again. I’ve learned how. It was a very valuable lesson.
8. Glenda’s story

People are often skeptical when I tell my story. In fact, when I posted it on a web site for people with melanoma, I got a lot of skeptical and even negative feedback. This is ironic, because I used to be just as skeptical – I would never believe something just because I read it somewhere. It took two major life changing – some would say tragic – events to get me where I am today. I really feel that I was guided. I am also living testimony to the fact that cancer can be fought and conquered totally naturally.

My story doesn’t start with my own diagnosis of cancer, though – it starts with my beautiful daughter, Cathy. She died in May of 1999 after fighting cancer for four years. She had non-Hodgkin’s lymphoma. With her, we went the conventional route at first. She had two years of conventional treatment at some of the best medical centers in our area, but after two years we were told that her case was hopeless. The treatments stopped so that she could make the most of what time she had left, which the doctors felt would be very short. However, she lived for two more years, and for a year of that time, her life was almost normal. She even attended college. This was entirely due to the fact that we had taken her to a naturopathic doctor who had her on supplements and a special diet. She improved almost right away on this regime. However, I now realize that we didn’t go far enough. I think we were all secretly longing to eat beef again! And Cathy, because she was feeling so much better, got lax about her diet and about taking her supplements, and eventually the cancer overtook her.

I don’t think there is anything worse than losing a child. I also feel that in a sense I haven’t really lost her. I’ve even seen her since her death, and I feel that she was watching over me and guiding me during my next big challenge.

Less than two years after Cathy’s death, I went to the doctor to get an ugly mole removed from the back of my right upper arm. As soon as I saw it, I suspected melanoma, and on April 12, 2001 the doctor confirmed my suspicion. This was my first sign – my daughter, too, had been diagnosed on April 12. Around the
same time, during one of the many doctor’s appointments I suddenly had to go to, they discovered and removed another melanoma on my upper back. The news was bad regarding both of them – staged according to size and depth, the melanoma on my arm was stage four, and the one on my back was stage two. This meant that my prognosis was quite bad. I was referred to a surgeon in Pittsburgh for further surgery, but I was told I’d have to wait a month despite the advanced stage of my disease! Coming from the same medical establishment who told me how serious my disease was, this was a little hard to take.

Of course, my perspective has changed now, and I feel that I was blessed to have had that month’s lag time. In fact, that one month changed everything for me. I wanted to find more information about melanoma, and especially about natural or alternative treatments. I remembered how much my daughter had improved with naturopathic treatments, and I guess I was also pretty fed up with the medical system by this time. While doing an internet search on melanoma, I read about a couple of alternative treatments – black salve and a colloidal silver supplement. I had never heard of either of them before, and as I said, I was skeptical. I was curious, but I didn’t think something so simple could really work. However, when I found out my neighbors were using the same thing, the coincidence seemed meaningful. I decided to give it a try.

My surgeon in Pittsburg didn’t mind my using these alternative treatments, but I could tell he didn’t take them very seriously, either. I realized that he and I just weren’t on the same page, and I started to pray for a doctor who was more knowledgeable about and accepting of natural therapies. And sure enough, shortly after, I found one! His name is Dr. James Winer and he is a chiropractor and nutritionist. I first got in touch with him through a radio phone-in show. Less than two days later I was in his office, though it usually takes a much longer time to get an appointment with him.

By this time, I had such a strong feeling of being guided that I had totally changed direction. I turned away from conventional medicine – I even cancelled my surgery – in order to concentrate on the natural healing I was discovering. To be
honest, I feel that my experience with my daughter had a big influence on how I dealt with my own cancer. Everything that I was discovering about alternative medicine told me that we had been on the right track with Cathy. We just didn’t go far enough, or we weren’t consistent enough. At the time – even though I saw the positive results that came with a healthier diet and supplements – I didn’t really understand that you can heal illness through diet. What we call illness actually occurs because we’re not healthy in the first place. Now I felt that my daughter was looking down on me and making sure that mom did it right! She is my angel.

I kept on using the black salve and colloidal silver, on the advice of Dr. Winer, who used muscle testing to determine that it was working for me. More importantly, though, he put me on supplements and a strict vegan diet. This time, I really committed to my diet change, and I believe that this is what allowed my body to heal. Dr. Winer believes that the cancer that western medicine can see and diagnose – the tumor – is just a symptom of an underlying disease. He believes in treating the disease itself, not just the symptom. Eating a natural diet will, in many cases, allow the body to reverse the disease process. This is a thing that I think many people are reluctant to hear. They don’t believe it can be that simple, or they’re not willing to commit to changing their lives.

I’m living proof that it works – almost four years later, I’m still cancer free. I’m in my sixties, but most of the time I feel half that age. I want to tell people that this works, but it’s hard to get past all that skepticism. I know it is – it took me a long time to get it. In my opinion, the drug companies don’t want people to learn about natural treatment. Cancer is a multi-million dollar industry in this country. Most people would look at what I did and just feel that it’s too simple, and couldn’t possibly work.

Well, it can and it does work. And even right after my diagnosis, I was never afraid. I know that sounds strange, but my faith in God made me believe that I would find the right way to fight it – and look what happened. I was led directly to the right doctor and a course of action that worked. It’s also given me a wider
insight – so many people in this country are just not healthy. Our immune systems are not working as God intended, and the food we eat is a big part of it. It’s too artificial, devoid of nutrition. I’m not a medical expert; I have just a high school education, and I’m a wife and mother. However, God has led me to discover something that can really help others. I know that I discovered this for a reason, and I’ll keep on trying to let others know.