

# **Negotiating the Emotional Ups and Downs of Thyroid Cancer: For Patients, Family and Friends<sup>1</sup>**

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## **Introduction**

Like any major illness, having thyroid cancer can be profoundly meaningful for both the patient AND their families, friends and those who form part of their support network. The meaning of the experience – what some call the ‘cancer journey’ -- is highly individual. The following guide will not provide medical information – that you can find elsewhere, for example through Thy’vors’ website and publications. Rather it addresses the emotional aspects of the illness. Even when the prognosis is good, as is usually the case with thyroid cancer, most people fear illness and loss, losing control of mind and body, becoming dependent on loved ones, and of course pain and death. In your journey, you may also experience sadness at the loss of your health; perhaps anger at your powerlessness as a patient within a medical system that seldom provides sufficient information or support; confusion in dealing with changed relationships with family members or friends; and finally; acceptance and renewal in the post-treatment phase.

Being aware of what to expect can go a long way towards calming the fears and easing the pain. We hope that you will find the tips and insights offered in these pages helpful. They are the result of research that one survivor did in order to understand better what had happened to her, as well as some insights of other survivors in various support groups, both on and off line. As your family, colleagues and friends may also be affected by your experience with thyroid cancer, you may find it helpful to have them read it as well.

## **Diagnosis: Waiting, Worrying and “Why Me?”**

There are many steps in the diagnosis of thyroid cancer, often involving long waiting periods to consult with specialists, get test results, or gain access to specialized treatment facilities. Most describe this cycle of waiting, and the worrying that goes with it, as a roller coaster ride. One moment, you may be reassured by a physician or other health practitioner that ‘all will be well’, and the next moment you may hear a passing remark that sends you crashing into despair. Not knowing what the future will bring, it is difficult to make even day-to-day decisions, let alone long-term ones. And, if you chose to wait until a diagnosis is confirmed before telling family, friends and colleagues, you may be facing this anxiety alone, which only compounds the stress. Some deal with this uncertainty by researching their illness on the Internet or through books, however, until a diagnosis is made, this may serve to worry you more than empower you. Others are simply in shock or denial. While it does seem ironic, many people find that even if the news is bad, receiving a diagnosis is sometimes a tremendous relief, as it marks the beginning of active treatment.

**Absorbing the Diagnosis:** How you absorb the news of a cancer diagnosis will depend upon many things: your past experience, your personality, and your relationships with friends and family. No matter how good the prognosis, finding out you have cancer can throw you into a tailspin. This is especially true if you previously felt well and had no other symptoms. On the other hand, if you have had unexplained medical problems or mysterious symptoms for a lengthy

period, and have had difficulty getting a firm diagnosis, the news may be somewhat more welcome.

When and to whom should you share the news? While the patient has the right to set the agenda, you also need to take into consideration those around you. Some of you, in your circle of family and friends, may want to talk about it right away. Others may prefer to avoid the topic for a while. It's up to you. But, remember that quality of life during treatment, even your treatment itself, are improved substantially when you have good emotional and social support. When you are ready, nurture your social network by communicating the news openly with friends, family and colleagues. This will allow them the chance to share their feelings with you and to offer you help. Also, try to send clear signals to family and friends when you are ready to talk about it.

If you have children in your life, resist the urge to try to protect them from the news. No matter how hard you try, they will hear the hushed voices and see the worried looks. If they don't know what is wrong, they will imagine things to be much worse than they really are. As well, children often blame themselves for whatever mysterious upheaval has descended upon their family, and this only adds guilt to their bewildering feelings of fear and of abandonment. Instead of secrecy, try explaining in simple terms that "Mommy (or Daddy) will be sick, maybe tired or even sad for a while, but will get better in time." You'll be surprised at their resilience.

Many people have difficulty communicating their needs to others, especially when they are ill

and vulnerable. But keep in mind that most people will be happy to help and support you, if they know what you need and it is something they can do. Here are some tips:

- Get in the habit of telling people exactly what kind of help and/or support you need, i.e. be specific.
- Be realistic in your requests. Don't ask for the impossible.
- Spread your requests out among a number of people so that no one person is overloaded.
- Make sure your requests are suited to the person you ask.

**Why Me??:** Sooner or later, at some point in your journey, you are likely to ask this question.

Why did *I* get thyroid cancer? What does this major interruption in my life mean? You may explore it at the time of your diagnosis or you may delve into the question later on, after your treatment is finished and you are recovering and/or thinking about prevention. The question comes in two parts. One involves the statistical probability of getting cancer, which in turn relates to the nature of the disease itself and its causes, or risk factors. The other is the meaning that you personally attach to the experience, that is, where and how it changes your life, or, doesn't change your life.

**What Causes Cancer?:** Cancer goes by many names: malignancy, carcinoma, neoplasm, neoplastic disease. Whatever we call it, the word cancer instils fear. Understanding what we're up against may help to dispel some of that fear. Cancer can be understood simply as any mutation in the genes which can lead to an exaggerated growth of abnormal cells. You may find

it helpful to realize that cancer is not one disease, but is actually a group of over 100 different diseases. The common, well differentiated types of thyroid cancer are some of the least threatening of this group of diseases. That is, they have a lengthy latent period before abnormal cells develop into a tumour and grow and/or spread (metastasize) to nearby tissue. Putting it into perspective, it also helps to know that our bodies' immune systems, hormones and other defence mechanisms can often interrupt these growths at different stages.

The causes of thyroid cancer, like all cancers, are multiple, complex, and poorly understood. Scientists can only identify risk factors which make one more likely to develop the disease. These include carcinogens, pollutants, social stress in our work, family or communities, diet and lifestyle, and exposure to radiation. The preponderance of females between puberty and menopause among thyroid cancer patients, suggests there may be a hormonal link. Thyroid cancer is also one of the endocrine cancers, sharing some characteristics with breast and prostate cancer, which occur more frequently in societies where high fat diets are consumed. Another important factor contributing to papillary thyroid cancer is exposure to radiation in the environment. The incidence of thyroid cancer is much higher in geographic areas affected by nuclear fallout such as Chernobyl and Hiroshima, and in the American mid-west where nuclear weapons were tested in the 1950s and 1960s.

Knowing what the risk factors are, however, is often small comfort to an individual who asks "But why did this happen to me?" Many patients want to pinpoint one defining moment in their

lives when they acquired thyroid cancer and/or identify some measure they could have taken to prevent it, or to prevent a recurrence of it. These questions almost never have clear-cut answers but some people find that striving for an answer that works for them can begin a journey of self-discovery. Others want to follow their doctors' orders and get back to normal as quickly as possible. Whatever works for you is the right course to follow. Just remember, the causes of cancer are very complex, and largely out of your hands. Feeling well physically and emotionally is important – and this is something that is within your reach; so is learning about your health care options, managing your stress, eating healthy, exercising regularly and fostering good social support networks.

### **Navigating Your Way Through the Medical System**

As with other cancers, you will likely see a team of specialists rather than one physician for all aspects of your treatment. Your surgeon, who could be a general surgeon, an ENT (ear, nose and throat) surgeon, or a surgeon who specializes in thyroid surgery, will be responsible for the surgical phase of treatment. An endocrinologist will often be responsible for aspects of diagnosis and usually follow up, while a nuclear medicine physician will likely oversee your radioactive iodine treatment, if you need it. In the post treatment period, when thyroid cancer is just a lot of background noise rather than the central focus of your life, other non-thyroid cancer related medical issues may demand the attention of your primary care physician, family doctor or general practitioner, as well. This 'team' brings you the advantages of highly effective and specialized medical science. However, some people feel they pay a price for this specialization in

de-humanized care. You may feel like you've fallen through the cracks of the system when busy specialists don't talk to each other and/or they fail to explain things carefully to you.

While you can't change the system, you can avoid feeling completely lost in it by communicating your needs clearly and keeping in mind that you are a voting member of your health care team. You have a right to be consulted on all treatment and monitoring decisions.

While there are general practice guidelines in thyroid cancer treatment that most physicians follow, medicine is as much an art as a science and there is always room for professional judgement and interpretation in individual cases. Becoming knowledgeable and aware is your best defence. Don't rush your treatment choices. There is always time enough to reflect and research your treatment. It is your body - and it is your choice.

### **Some Communications Tips**

- A primary care physician and/or nurse can be an excellent advocate who can coordinate all the specialists and help you make sense of the medical world.
- Communicate clearly. Many doctors believe that cancer patients cannot, or do not want to, absorb all the information at once. If you feel you want more information than you are getting, say so. Most physicians will respond positively to your cues.
- Much can be missed in rushed appointments between busy specialists and anxious patients. Bring a supportive friend or relative to help you listen and speak.
- Insist on receiving copies of laboratory reports and other critical pieces of

information, so that you can make independent assessments if you are in doubt about the treatment you are receiving.

## **Surgery**

The primary diagnostic test for thyroid cancer is the fine needle aspiration biopsy. However results are not always conclusive. This is one of the more disconcerting aspects of thyroid cancer treatment. Some patients only learn for certain that they have cancer when the pathology report comes back about a week after surgery. That means that the decision to have surgery -- and the extent of the surgery -- is made with less than perfect information. This is very frustrating for patients and can lead to an unavoidable sense of regret. Some patients find out, following a partial thyroidectomy that a tumour that was first thought small and/or benign is actually malignant. This makes a second surgery, often following closely on the first, necessary. On the other hand if you and your physician chose a full thyroidectomy and the growth turns out to be less threatening than first thought, you must live with the knowledge that you had a healthy thyroid removed. While medically unavoidable, it makes for a difficult decision. There are simply no easy answers but it might help to think about your approach to your health care generally when assessing your surgical choices. Are you comfortable with a minimalist, conservative approach? Or, are you determined to have the most aggressive treatment options available in order to eliminate any possibility that the cancer might recur? Keep in mind that thyroid surgery is a major medical intervention and there are some risks, albeit small ones. Damage, although usually temporary, can occur to the vocal chords and/or the parathyroid

glands which help your body regulate blood calcium levels.

Thyroid cancer surgery is often experienced by patients as the easiest part of their treatment. You may have some tingling and numbness but there is seldom any excruciating pain -- the kind that many people associate with surgery. One annoying feature is the tube that is inserted to drain fluid from the incision as it heals, which will feel a little 'creepy' when it is removed. Following surgery, if you have had a partial thyroidectomy and are finished your treatment, you will immediately begin taking a starter dose of thyroxin (T4) to substitute for the hormones that your thyroid formerly produced. Most of you, however, will have had a total thyroidectomy and be scheduled for radioactive iodine (RAI) treatment. In this case, some one on your health care team should prescribe T3, or cytomel, a short acting thyroid replacement that you can take up to 2 weeks prior to RAI. It will make you feel better as you approach the next, and for many, the most difficult phase of treatment, going hypo in preparation for RAI.

**Take good care of yourself.** Surgery is a strain on your body, particularly if you have had two. With further treatment coming, you need to ensure your immune system is as healthy as possible. Get lots of rest, accept offers of help, eat healthy foods – but most importantly, enjoy the company of friends and family.

## **Going 'Hypo' and RAI**

In order for RAI to work effectively, your TSH must be elevated, meaning that you must become

severely hypothyroid. As 'going' hypo may have to be repeated for follow-up diagnostic scans as well as for treatment, its best to know what to expect. The average patient takes six weeks to achieve a sufficiently elevated TSH, that is, at least 30 mU/L. The most common symptoms of hypothyroidism include: fatigue, intolerance to cold, depression, nausea, constipation, slower reflexes, slowed heart rate, muscle weakness, joint pain, mental sluggishness, puffiness around the eyes and/or insomnia. Most physicians will strongly advise you not to drive in the last two weeks due to a slowing of reflexes and mental alertness.

A few people breeze through the hypo state, but most don't. Being hypothyroid is a potentially serious medical condition that can aggravate pre-existing health problems. Depending on your age and health, your TSH level prior to treatment, and whether you have to wait for an isolation room to have your RAI treatment, you may be experiencing greater than normal discomfort. If so, ask your health care providers to test your TSH. Sometimes an RAI treatment can be fast tracked if your TSH is high enough. Other options are to treat related conditions in order to improve your sense of well being. If you are one of the people whose health is compromised by being hypo, the option of using Thyrogen, a new drug which elevates TSH without going hypo, could also be considered. Be aware that it is expensive, and not covered by all drug and medical coverage plans. Ask your physician.

Some survivors have affectionately dubbed hypothyroidism ‘hypo-hell’ as most experience both unpleasant physical and emotional symptoms. It is prudent to be aware, and to let your loved ones know, that you may be especially vulnerable to emotional ups and downs due to the hormonal imbalances and the general slowing of your metabolism. Some people experience rapidly changing, contradictory feelings. Some experience temporary confusion and forgetfulness – a phenomenon sometimes called ‘brain fog.’ A few people become quite withdrawn. They may appear not to care about family, friends...even their own children. Some become emotionally dependent on a caregiver. If any or all of these things happens to you or to a loved one, don’t question your sanity. It is a relatively normal response to the slowing of metabolism and absence of needed hormones. Usually, it is only temporary.

Fatigue, both a significant contributor to mental distress and a symptom of it, should be avoided by accepting help and being aware of your own state of emotional health. If you begin to feel neglected by your spouse, children, friends or family, ask yourself whether they are ignoring you or whether you have simply withdrawn from them. It is natural to cocoon during a lengthy illness. It is the body’s way of preserving strength for physical and emotional recovery.

Hypothyroidism can trigger the onset of depression or mental illness, particularly in a patient who has a predisposition to these conditions. This is not ‘just something you have to suffer through’ -- in fact, suffering can actually inhibit recovery. See your health care provider to assess whether your feelings of sadness and fatigue are temporary side effects

of the illness or if they are symptomatic of a clinical depression, or other condition requiring professional help. A pamphlet called “The Emotional Facts of Life with Cancer” listed in the selected readings offers a self-assessment questionnaire, directed at you, the patient, as well as your caregiver(s). As fatigue and depression can cause great lethargy in the patient, it is often the caregiver who can best assess the situation and take action.

**Radioactive Iodine Therapy (RAI):** In preparation for RAI, your physician may suggest that you follow a low iodine diet. While it is not always recommended and is challenging to follow if you use convenience foods regularly, many thyroid cancer patients find that following the diet is something positive they can do to enhance their chances for successful treatment. It helps them to feel in control of their lives at a time when so much is in the hands of their health care specialists. Further information and recipes may be found on the websites of Thry’vors <[www.thryvors.org](http://www.thryvors.org)>, and Thyca <[www.thyca.org](http://www.thyca.org)>, the American Thyroid Cancer Survivors Association.

Perhaps the worst aspect of the RAI phase of treatment, besides being hypothyroid, is the isolation and the fearful way others may treat you. In some cases, patients are required to stay in hospital, while others may be treated on an outpatient basis. In either case, there are precautions that you must take to prevent contamination of those around you. If hospital personnel refuse to come into your room, and everything is covered in plastic or cellophane to prevent contamination and make it easier to clean up, you may feel like

you've have been kidnapped by the aliens. Particularly at a time when being hypo has you feeling sick and tired, you may find it difficult to understand why everyone is so fearful of this radioactive iodine. After all, you have to swallow it!! While it is important to follow the precautions, it is also important to let others know that you are still a human being, deserving of care. Explain that the radioactive iodine poses relatively few risks after two days, as most of it is quickly eliminated through urine and other body fluids. Once the treatment has been administered, you will begin taking your thyroid medication and will feel better within weeks. But be patient, it takes a few weeks, not days.

### **For Caregivers and Friends**

Caregivers are often the forgotten victims of cancer. Studies indicate that a large number of them feel as much or more emotional distress as the sick person they are caring for. They must take on the role of caregiver, for which they may not be prepared; they face frightening physical and emotional changes in loved ones; and, they assume an extra burden of worry, stress, household work, and possibly financial strain. And the patient, absorbed in the 'work' of getting better, often cannot provide them with the usual companionship and support they are accustomed to receiving. This isn't an easy time for either of you.

**Hugs Work Wonders...** For those in couples, sexual relations can be fragile. Fatigue, illness, loss of self-esteem and changes in both body image and relationships may cause a loss of interest in physical intimacy. Still, illness alone is rarely the cause of infidelity or

marital breakdown. Remind your partner that it is not physical attributes that make one attractive. Rather it is intangible qualities like sense of humour, shared memories, caring and intellect. None of these are lost during illness. Both of you need to keep talking. Don't be afraid to show affection.

It is also helpful to remember that illness is almost always temporary. Your patient will recover in time. You can help that recovery process by being patient, by accepting any offers of help that come your way, and by trying to treat the patient as normally as possible – even if s/he is not behaving normally. Here are some tips from survivors to caregivers and friends which may help the patient recover his/her emotional and physical health faster.

- Invite my family over. Sometimes I need time alone. Even if they're being good, my children can keep me from resting.
- Drive me to appointments until I can drive.
- Handle phone calls, faxes, emails from family, friends and well-wishers.  
Sometimes it's just too much.
- Don't ask if you can walk the dog or do the dishes, just do it. I'm having trouble making decisions right now.
- Listen while I sound off. There's a lot happening to me and I need to verbalize without hurting someone's feelings.
- Act normal, and don't try to cheer me up when I'm depressed. It's normal to be depressed when things are going badly.

- Resist the temptation to lash out in anger. I'm not angry at you, just at fate, or God, or whomever I blame for bringing cancer into our lives.
- Even if I'm withdrawn, talk to me frequently. Sit nearby, read the paper, or just 'be there.'
- Include me in family activities and decisions. I'm only sick, not mentally incompetent.'

### **Post Treatment: "I Just Want to Get Back to Normal"**

The beginning of post treatment life can take some adjustment. There will be a shift in emphasis in your health care team now, away from the specialists responsible for treating you to those who will monitor you for recurrences. You (and your family, friends and colleagues) will want everything to go back to the way it was before your diagnosis. Inevitably this never happens as quickly as you (or they) would like. It's one of the most frustrating aspects of post treatment life. Your body is still absorbing the impact of surgery and radiation, finding the right dose of thyroid medication; and often dealing with emotional issues. Many thyroid cancer survivors take a year, or even longer, after their treatment before feeling normal. Give yourself time. Be patient.

At some point following treatment, you will also have a follow up scan which may or may not involve becoming hypothyroid again. Once that is done, most people can expect to be monitored for recurrence in two, possibly three ways: first, through achieving and maintaining a suppressed TSH; second, by testing your blood for the presence of a cancer

marker called Tg or thyroglobulin; and thirdly by doing periodic scanning and testing of Tg while unsuppressed.

A suppressed TSH just means that you will be slightly hyperthyroid, which is a preventive measure against possible recurrence. As you begin taking synthetic thyroid hormones (T4) and work towards this goal, you may need several dose adjustments. Many people experience confusing swings between hypo- and hyper-thyroid symptoms as they find their equilibrium. Hyperthyroidism may lead to agitation, anxiety, mood swings, insomnia, tremors, weight loss, diarrhoea, heart palpitations and/or intolerance to heat. The regime you follow will depend upon many things, including your risk factors as well as your overall health status. For example, older patients or those who have other health conditions may have more difficulty adjusting to a suppressed TSH. As the thyroid hormone regulates your metabolic rate and affects many different systems in your body, you may find that you have to live with a few side effects. Some hypo- and hyperthyroid symptoms may linger on beyond the treatment phase, including fatigue, memory or cognitive problems, depression, weight gain, anxiety and muscles aches and pains.

Fatigue, often the enduring legacy of cancer treatment, may affect your energy level, concentration, sleep patterns, interest and mood. It results from the physical impact on your body of surgery, radiation and 'going hypo', as well as psychological factors. You may suddenly find that your life is no longer centred on doctors' appointments but you're not sure where to pick up where you left off. Perhaps you see a backlog of tasks left undone during your illness, yet you have less than a full tank of gas with which to tackle

it. Perhaps your priorities have changed. The presence of unresolved emotional scars from your illness can also make you tired. If you find yourself exhausted all the time, have your TSH checked first. Then look at your emotional health, either on your own, or with a professional. Sometimes fatigue is both cause and symptom of a lingering depression and/or anxiety that is common in post treatment thyroid cancer survivors.

Another distressing side effect is memory and cognitive problems, popularly known as 'brain fog'. It can be as mild and annoying as occasionally forgetting things or as frightening as losing your ability to function effectively in your job or family life. Weight gain from temporary hypothyroidism may result in frustrating weight management issues, especially if you are also plagued with joint and muscle pain or weakness, which make it difficult to exercise. Most of these problems prove transient and improve over time. See your physician if they remain or become severe, however. They may indicate an underlying problem that needs to be investigated. Find the practitioner who will best be able to help you sort through what might be transient and what should be fully investigated. Never accept a hasty dismissal that your symptoms are 'all in your head.' Emotional factors may be aggravating your problems, but all physical complaints should be checked out.

In rare cases, physical side effects can substantially threaten quality of life and health, and an individual may need to seek out their own answers. Some studies have reported improvements in mental alertness and energy level in groups of patients given a combination of T4 and T3, instead of T4 alone, suggesting they have difficulty

converting T4 into available T3. Some physicians will prescribe a combination of T3 and T4 -- check with your physician if you think this might be a solution for you. As well, a few patients prefer not to take synthetically manufactured hormone replacement medication. You should be aware that there is an alternative hormone replacement medication, manufactured from the thyroids of slaughtered animals. Some physicians are unwilling to prescribe these alternatives, however, particularly the latter, which is considered inferior due to inconsistent potency and the danger of disease transmission from animals to humans.

**Complementary Approaches:** Growing in popularity with patients are complementary (sometimes called alternative or unconventional) therapies to support thyroid cancer care, especially for post treatment chronic conditions. There are major differences in approach and philosophy between mainstream and complementary practitioners. Mainstream physicians focus on diagnosing and curing a specific ailment. They are committed to western medicine, or what is often called “evidence-based” practice. That means simply that all treatment protocols are subjected to rigorous double-blind studies.

Complementary practitioners often do not focus on a specific ailment, but instead seek to maintain a strong immune system and good overall health in order to support the healing process. They are generally more comfortable with less rigorous (that is, anecdotal or trial and error) evidence of effectiveness. Some point out that in many cases this evidence is backed by thousands of years of practice. They also tend to be more trusting of the symptoms which patients report and rely less on tests. Not surprisingly they also spend more time with their patients.

Complementary remedies should NEVER be used for treatment of thyroid cancer, of course, as standard treatments are highly effective and well proven. However, if you are having difficulty sorting out the transient adjustment problems relating to synthetic hormone use, you may want to try one of these therapies. Finding a reliable practitioner may be challenging as many doctors are not knowledgeable about these fields and often will not refer you to one. You may need to check out some websites and/or local association chapters, or seek the advice of others who have used them. Use common sense to assess safety and effectiveness. Just as you would in choosing a physician, accept services only from those who are members of a recognized professional body, and never accept advice from any practitioner that is outside of their field of expertise.

Some people find that nutritional supplements, herbs or dietary changes have a positive effect on their health. But keep in mind that some of these can interfere with prescription drugs such as thyroxin (T4). To be safe, report any use of these products to your primary care physician or endocrinologist. You should also be aware that non-prescription products are not subjected to the same quality controls and clinical testing that apply to pharmaceuticals, and the potency and consistency of any given batch cannot be guaranteed.

For those who suffer from stress, anxiety or depression, there are various physical therapies which can be employed to enhance relaxation. They may also be used effectively to reduce muscle aches and pains due to hypothyroid and/or hyperthyroid

fluctuations. These include everything from the simple but effective practice of daily exercise, to physiotherapy, acupuncture, massage, therapeutic touch, acupuncture and meditation.

**Returning to Work:** After a lengthy absence from them, you will probably want to return to your former work, education or other role. There are psychological as well as financial benefits to work. It structures your day and gives you the social contact you missed while ill. However, it's best not to rush back too quickly. It takes time to fully recover all your former strength and energy. Most people underestimate the amount of rest they need following a major illness. When you do return, you may have questions about how much to tell co-workers. Again, it is up to you to send the right signals. Most people are genuinely concerned and want to help. They will respect your right to privacy ...or alternately, your need to talk. Generally, most employers and co-workers will accommodate you. However, if you find that ungrounded fears of absenteeism, death or contagion have led to unfair treatment or even dismissal, become familiar with the human rights legislation in your province which is in place to protect you.

Some people have experienced difficulty obtaining insurance after their cancer treatment. If this has happened to you, contact the Canadian Life and Health Insurance Association (CLHIA) who have a Customer Assistance Centre (CAC) for concerns and complaints.<sup>1</sup>

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<sup>1</sup> Call 1-800-268-8099, or for service in French at 1-800-361-8070. Email: [CAC@clhia.ca](mailto:CAC@clhia.ca) . OmbudService: 1-888-295-8112, Email: [information@clhio.ca](mailto:information@clhio.ca) (1 Queen Street East Suite 1605A Toronto ON M5C 2X9).

Many younger survivors of thyroid cancer have concerns about how it may affect their fertility. As the ovaries, like the salivary glands, can take up radioactive iodine during RAI, physicians often ask women to wait six months to a year before attempting to get pregnant. Once you have fully recovered from your treatment and have had a clean scan, however, there is usually nothing that will adversely affect your ability to have a baby.

## **Monitoring and Fears Surrounding Recurrence**

One of the fears associated with cancer is the lingering dread that ‘it will come back.’ Indeed it is not unusual for such fears to temporarily turn a patient into a hypochondriac. You may suddenly find yourself unpopular with your healthier friends, relatives and colleagues or running to the doctor about things that you would have ignored in the past. Try to balance a pragmatic approach with a sense of humour about this. You are not losing your mind. This is a very common reaction in those who have had their confidence shaken by a major illness.

- Become familiar with the way your body responds to hypothyroidism and hyperthyroidism and learn how to distinguish the two. Sometimes it’s a dose adjustment problem.
- Ask yourself – Am I blaming everything on my thyroid cancer?
- You may have a new condition completely unrelated to your cancer, or an aggravation of a pre-existing medical condition. Write down all your symptoms, when they occur, and assess their severity, so that you can tell your doctor everything s/he needs to know.

- Bring only one or two matters to your physician's attention at once. Leave the grocery list at home.

### **How much is enough?**

In your post treatment life, you and your health care team will need to find a workable compromise between maintaining a good quality of life and reducing your risk of recurrence. Besides helping you maintain a suppressed TSH, your physician will monitor your thyroglobulin (Tg) levels through blood testing. As Tg is only produced if there is thyroid tissue present, an elevation in levels indicates benign or cancerous thyroid disease in your body, which may require further investigation.

For those who are at higher risk for recurrence due to their age, distant metastasis, an aggressive variant of thyroid cancer, or persistent thyroid cancer, that is, those who have never had a clean scan, a more vigilant monitoring regime is usually prescribed. This may involved periodic scanning along with a reading of Tg while hypothyroid, or using Thyrogen. You should also be aware that standards in monitoring for recurrence are evolving with the introduction of new diagnostic tools and some physicians are advocating aggressive monitoring even for low risk patients. You may want to think about this in relation to your own philosophy of health care? Are you willing to undergo periodic scanning (going hypo or using thyrogen) as well as your routine blood tests? For some people this provides a comforting reassurance that they remain 100% cancer-free. Others find the process of testing worrying, particularly if it proves inconclusive. It is an unwelcome reminder that they once had cancer, one that reinforces the passive patient

role. If you feel this way, gently remind your health care team that you are more than a cancer statistic, and want to balance the need for prevention with maintaining overall health and emotional well being. On the other hand, if you want to be followed aggressively, make your views known to your physician.

## **The Emotional, Social and Spiritual Legacy of Cancer**

Having cancer has been compared to grieving the death of a loved one. The loss of your health may be initially greeted with denial, then anger, depression, and eventually acceptance. Some well-meaning relatives and doctors may dismiss your suffering by telling you that you are lucky to have had the “good cancer.” This may leave you feeling guilty because someone else’s illness is more severe than yours. This may not be helpful to your emotional recovery. Many people need to acknowledge their feelings, talk to a supportive person, perhaps one who has had the same disease, or even to a professional. Don’t let others push you to ‘move on’ before you are ready. It takes you as long as it takes you.

Expect some changes in people around you learn to deal with your illness. This can affect even your closest relationships, even in our families. Whether we realize it or not, most of us have an image in our minds of the ideal family, one that provides a loving and nurturing environment for all. But the reality is a little different. Families respond to the crisis of illness in ways that reflect their distinctive coping strategies. Some remain open and calm while others react with fear and anger. A serious illness can bring existing

unresolved problems within a family and/or relationship to the forefront. Gender differences in communication and in coping strategies can add further strain. For example, if your partner engages in ‘false cheeriness’ this denies you the opportunity to discuss your fears and concerns and you may feel unsupported. When the patient is a woman and her caregiver a man – often the case with thyroid cancer – the husband may be suddenly thrown into unfamiliar territory. He may be called upon to sooth children’s disputes, keep dinnertime conversations on an even keel, listen and provide comfort. He may become angry and frustrated if he cannot meet these expectations. Sometimes it happens that each partner will suffer alone, the husband feeling overwhelmed with work and responsibility and unappreciated for what he is doing well, while the wife feels emotionally abandoned as he falters in giving her the emotional support she needs. Both may feel powerless to express their resentments because “cancer is no one’s fault.” You and your family, friends and/or colleagues can avoid such problems by communicating openly, and following some of the tips listed earlier.

Young people pose challenges during an illness. As thyroid cancer often affects young women and their families, this is particularly relevant. Children sense the stress in a family setting and may get caught up in parental conflicts or fears. Parents may stop giving them the attention they normally would, or provide the comforting structure that routine and everyday discipline provides. Children may respond either by acting out their fears in frightening or unexpected ways, or become withdrawn. It is important to keep communications open, otherwise children may fear something much worse than what is actually happening and/or they may blame themselves for the illness. Sometimes it helps

to have a friend, aunt or grandparent give a child some extra attention to make him/her feel special at a time when their parents may be pre-occupied with cancer treatment.

You may also experience changed relationships with friends or even the loss of one or more of them. This experience can be a rude awakening. Many people are unsure of how to treat an ill person. They may avoid calling you, or even looking at you. If this happens, ask yourself whether you have withdrawn from this person in a period of anger or depression. Once you are feeling well enough, try contacting them and letting them know what they can do for you. But, if this doesn't work, don't blame yourself. Perhaps your illness reminds your friend of his/her own mortality or forces him/her to relive some particularly painful episode in the past. H/she may have unresolved fears of desertion or rejection. Although it is inescapably sad, many patients have to accept the fact that some people will slip away. It is an inevitable part of the journey.

If you are single, you may feel insecure about relationships and dating either during or following your thyroid cancer treatment. Perhaps you fear that talking about cancer may scare away potential suitors. Just relax and be open and honest with them.

In dealing with all of these relationships, now is a good time to become more assertive of your needs. If this is new for you, you may have to ease into it. Perhaps you have previously played the role of "nurturer" in your family and/or circle of friends or colleagues. You may find it difficult to put yourself first. Ironically, by doing so, you will have more to give to others because you will have become stronger yourself. And, when

spouses and friends learn to nurture better and children to be more compassionate toward a sick parent – and they well – they will become stronger and wiser for their own journeys through life.

**If You Need It, Ask for Help:** While most people can cope admirably well with a temporary emergency, treatment and monitoring for thyroid cancer can extend into months and even years. Don't be afraid to ask for help if you need it. It doesn't mean that your relationship or your family is falling apart. On the contrary, asking for help is the first step in strengthening it. There are many types of help, and what you choose will depend on your unique circumstances. Thy'vors maintains a listserv, where those affected by thyroid cancer can ask questions, give and receive support and vent their frustrations. Many find this beneficial. Others, particularly at certain times in their cancer journey, find it overwhelming because more of the survivors they meet online have had complicated cases. Keep in mind that these are the people who most need to seek support and are not necessarily typical. Whether you need the listserv now or later, we think it's a comfort to know that it is available. Instructions for joining the listserv can be found at <[www.thryvors.org](http://www.thryvors.org)>.

Cancer Connection, a service of the Canadian Cancer Society will put you in touch, by phone, with a volunteer who is a survivor of the same type of cancer as your own. Many cancer clinics offer counselling for individuals and families, whether for emotional difficulties or financial or practical ones. If you feel you need individual counselling, you can also see your primary care physician and ask for a referral. If you're not sure you need

it, refer to the self-evaluation questionnaire offered through “The Emotional Fact of Life with Cancer”.

For some people, the cancer journey can evolve into a spiritual one. Whether you are a practising member of a religious congregation or not, you may find that your illness shakes or reaffirms an existing faith, or leads you to adopt an entirely new one.

Contemplation may take the form of exploring psychological insights, or it may lead you to examine the question of whether there is some form of absolute power and/or a spiritual life after death. These questions can never be answered but you may find that contemplating them helps you to reduce your fear of illness and death, and to live a fuller life.

## **Conclusion**

Every cancer journey is unique. You may need to mourn the loss of things once very precious, and feel that cancer took away more than it gave. Or, you may find that your gain from the experience. Although we should never dismiss the pain, confusion and sense of loss that these struggles can cause in the short run -- and certainly they challenge one's resources of emotional energy for varying periods of time -- in the long run, many people also discover hidden qualities in themselves and others. You may find, as other survivors have, that having faced the dreaded 'c' word, everything else seems insignificant. This can have a calming effect. You may find you worry less over small things, and have the vision to see each day as a precious gift. Maybe this means enjoying enhanced relationships, or starting a new hobby. Maybe it leads to taking on volunteer

work, a good therapy that allows the former survivor to put their newfound knowledge and empathy to use and to repay those who have helped them. Wherever it takes you, your journey is your own, and we wish you luck on it.

## Selected Readings

Canadian Association of Psychosocial Oncology (CAPO), “The Emotional Facts of Life with Cancer.” The pamphlet is available through the Canadian Cancer Society’s Information Service, 1-888-939-3333, or their website <[www.capo.ca](http://www.capo.ca)>.

Alastair J. Cunningham, *The Healing Journey: Overcoming the Crisis of Cancer* (Toronto: Key Porter Books, 2000).

Lance Armstrong, *Its Not About the Bike: My Journey Back to Life* (New York: Putnam Publishing Group, 2000).

Marc Ian Barasch, *The Healing Path: A Soul Approach to Illness* (New York, G.P. Putnam’s Sons, 1993). Marc is a thyroid cancer survivor whose ongoing fatigue motivated him to write the book.

Sidney A. Winawer, MD and Nick Taylor *Healing Lessons* (New York: Little Brown, 1999).

Michael Lerner, *Choices in Healing: Integrating the Best of Conventional and Complementary Approaches to Cancer* (Cambridge: MIT Press, 1994).