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ABOUTFACE VISION:
To foster acceptance of people with facial differences so that they may participate fully in society, with self-worth and dignity.

ABOUTFACE MISSION:
AboutFace is an international charitable organization that provides information services, emotional support, and educational programs for and on-behalf of those with facial differences and their families.

ANY MEDICAL OPINIONS STATED IN THIS BOOKLET ARE THOSE OF THE AUTHORS. WHILE TREATMENT PHILOSOPHIES AND METHODS MAY DIFFER AMONG CRANIOFACIAL TEAMS, THE CARE RECEIVED AND THE RESULTS ACHIEVED MAY BE EQUIVALENT.

ABOUTFACE SUPPORTS PERSONAL CHOICE FOR INDIVIDUALS.
ACQUIRING A FACIAL DIFFERENCE: SKIN CANCER

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INTRODUCTION

When one acquires a facial difference, it is usually sudden and unexpected. A rapid series of events follows, that likely includes many medical consultations and surgeries. Decisions must be made rapidly, and commitments are acted upon with little time for reflection. It may be a life changing time filled with high anxiety and depression. Nevertheless, people are swept along by events, leaving little opportunity to adjust. People can and do adjust, often at different rates, but the resiliency of individuals dealing with an acquired facial difference is remarkable. This adjustment is characterized by many of the following features. The first type of problem facing patients who have acquired a facial difference relates to the cause of the loss. If the loss was caused by some particularly traumatic event, there may also be symptoms of post-traumatic anxiety, such as sleep disturbances and nightmares. If a feared disease like cancer caused the loss, there is lingering concern about recurrence marked by depression. In either case, the individual will be faced with the challenge of accepting the loss and continuing a normal healthy life.

We hope that this booklet will help you to understand the physical and mental health challenges you will be facing, to navigate through the treatment processes that lie ahead, and to ultimately adjust to life with a facial difference.

ACQUIRING A FACIAL DIFFERENCE

STAGES OF LOSS
People whose appearance has changed have to deal with issues of loss. Loss is a state of being without something one has had and valued (Peretz, 1970). Loss can be a very traumatic and painful experience. This triggers a set of emotions similar to the
grieving process of having lost a loved one. It is normal for a person who is grieving their loss to go through stages of denial, anger and bargaining, depression and acceptance. The stages of this process may precede or follow the rehabilitation process. Depending on where one is in the rehabilitation process, these stages of grieving can affect how well one is able to cope with and accept the results of the rehabilitation process.

**Denial**
Denial is often the first stage of the grieving process. A person uses denial as an unconscious defense mechanism so as not to have to deal with the pain of their loss. However, refusal to acknowledge painful realities, thoughts, or feelings can be detrimental to a person’s psychological well-being. There are feelings about changes in identity, and how one will relate to family and friends in the future and in turn how they will relate to the affected person. The “facial difference” has the potential to affect the social functioning of the person. Not surprisingly, this is the basis for anxiety about future relationships.

**Anger**
Anger is the second stage of the grieving process. Anger is a strong emotion of displeasure for what we regard as a wrong toward ourselves. The anger is often shown toward family and caregivers that are trying to help, which seems inappropriate. However, an understanding of the process prevents this from becoming problematic during the care process. It can however have an impact on the acceptance of the finished result of treatment if the affected person is still angry.

Coping mechanisms include developing an “attitude” that defies the problem. This takes considerable energy; so support mechanisms are important for the affected person. In addition, the person’s previous social adjustment may help adjusting to the new situation.
**Bargaining**
At this stage, the individual seems to accept the inevitability of the loss, but still looks for ways to diminish the impact of it. People seek ways to escape the reality if even for a short time, to delay the prospect of having to do the work in facing the reality. For example, a person may choose to defer definitive rehabilitation treatment for what seems like poorly defined reasons. Under these circumstances, this choice is entirely reasonable. It’s just that more time is needed to adjust.

**Depression**
Facing the reality of a loss is hard work and it seems to be “uphill” all the way. It is not surprising then that a person may become depressed. Depression can be characterized by the inability to concentrate, insomnia, and feelings of extreme sadness, dejection, and hopelessness. It can last a short time, or it can persist for months. A person who has acquired a facial difference can feel hopeless about the future, and powerless to change it. These feelings need not go on indefinitely. Time and support can help an individual to come to terms with their loss.

**Acceptance**
Acceptance is the mental attitude that allows an individual to come to terms with their loss. Acceptance of the loss is an important last step for an individual with a facial difference to continue to function normally and happily in every day life situations. The facial difference is a challenge that must be met like any other challenge in life. A more positive approach to family, friends and work becomes evident, and one wants to get on with life, leaving the unhappy events behind. At this point, an affected person is much more receptive to the results of treatment, and adapt more successfully to any changes in routine required by the new circumstances.
ACQUIRING A FACIAL DIFFERENCE FROM SKIN CANCER

WHAT IS CANCER?
A cancer is an abnormal growth of tissue arising from the normal tissues of the skin. This abnormal tissue grows without the usual regulation or control of the normal tissue that surrounds it. Cancerous tissue as it grows often acquires the ability to invade the surrounding normal tissues. In some cancers, this abnormal tissue has the ability to invade into the lymphatic system and spread to lymph nodes in the face or neck. Cancers may also extend into blood vessels providing access to the circulatory system, which could allow the cancer to spread throughout the body.

WHAT CAUSES CANCER?
Cancers affecting the head and neck and in particular the facial skin can be caused by a variety factors. Skin cancers of all types are most frequently caused by excessive sun exposure. Ultraviolet (U V) radiation from the sun appears to be the major culprit. Other Ultraviolet sources such as sun lamps or tanning booths can also cause cancer. In a small subset of patients inherited factors may contribute to the development of skin cancer. Other factors including radiation exposure and chemical carcinogens may contribute. Cancers of the sinuses, lining of the mouth or throat are most commonly caused by smoking or second hand smoke.
TYPES OF FACIAL CANCER

BASAL CELL CARCINOMA
A basal cell is one type of cell that makes up the structure of your skin. Basal cell carcinoma is the most common type of skin cancer accounting for approximately 90% of all skin cancers in North America. It arises from the surface of the skin, usually grows slowly, and rarely spreads to other sites in the body. A basal cell carcinoma will appear as a round bump that is either red, black or flesh tone in colour with a pearly border and may develop into an ulcerating sore.

Basal cell carcinoma
A Squamous cell is another type of cell that makes up the structure of your skin. Squamous cell carcinoma is the second most common type of skin cancer, and it also arises from the surface of the skin. Squamous cell carcinomas have a faster growth than basal cell carcinomas and in a small number of patients have the ability to spread through lymphatics to regional lymph nodes and occasionally to other sites of the body. A squamous cell carcinoma will appear as a raised, red scaly bump which develops into a crusted sore.
Melanoma

Melanoma is one of the more common cancers in North America. Melanoma occurs when melanocytes (pigment cells) become malignant. The majority of pigment cells are in the skin but melanoma may also occur in the eye, and other internal surfacing linings of the body including the digestive and respiratory systems. The chance of developing melanoma increases with age, but the disease affects people of all ages. Melanoma is rare in black people and others with dark skin. When it does develop in dark-skinned people, it tends to occur
under the fingernails or toenails, or on the palms or soles. Melanoma does have the ability to spread via lymphatics to regional lymph nodes and also has the ability to metastasize or spread throughout the body. A melanoma may be an old or new mole that keeps growing and changing and has an irregular border and colour.

TIMING OF TREATMENT

The timing of treatment depends on the type of skin cancer as well as the size of the cancer and whether it has spread to lymph nodes in the region. The relative urgency to obtain treatment of these three types of common skin cancers would be the following: 1) Melanoma; 2) Squamous cell carcinoma; 3) Basal cell carcinoma.

It is generally recommended that all cancer be treated as expeditiously as possible, in most jurisdictions that would mean a maximum time to treatment of two to four weeks.

TREATMENT OPTIONS

TREATMENT FOR BASAL CELL CARCINOMA
Treatment for basal cell carcinoma usually involves some type of surgical procedure and in special cases radiation therapy may be used.

Surgery is when a majority of basal cell carcinomas are cut and removed providing both a biopsy and cure in one procedure.

Cryotherapy or extreme cold is a surgical technique commonly used to treat pre-cancerous skin conditions and small cancers. In this technique, liquid nitrogen is applied to the growth to freeze
and destroy the tumor cells. More than one application may be required to remove the cancer.

**Curettage** and **Electrodessication** is commonly used for small basal cell cancers. In this procedure after the skin is anesthetized the lesion is curetted with a sharp spoon-like instrument and then cauterized with an electrical device to stop the bleeding.

**Moh's Surgery** is also used for basal cell carcinomas particularly those in difficult surgical sites such as around the eye or the nose. The purpose of this technique is to remove all of the cancer and as little normal tissue as possible. Under local anesthesia the cancer is excised, one layer at a time. Each layer is assessed under the microscope for cancerous cells and the procedure is continued until there is no visible tumor in the removed tissue.

**Topical Chemotherapy** is the use of anticancer drugs in a cream or lotion that are applied directly to the skin cancer. The most commonly used topical drug is fluorouracil (also called 5-FU). This therapy is effective for pre-cancerous and superficial growths.

**Radiation Therapy**
Basal cell carcinoma often responds well to radiation therapy. This therapy uses high-energy x-rays to damage and destroy cancer cells. This type of therapy is often used in cancers that are in areas difficult to treat such as around the eye, nose, and ear or for very large tumors. This therapy is also used when surgery does not completely remove the skin cancer. Radiation usually produces an immediate skin reaction much like a severe sunburn and over time may result in changes in both the colour and texture of the skin.
TREATMENT FOR SQUAMOUS CELL CARCINOMA
Treatments for Squamous cell carcinoma are very similar to basal cell carcinoma, with standard surgical removal, cryotherapy, curettage and electrodessication and topical chemotherapy being widely used. Patients with cancers that have spread to the regional lymph glands may be treated with an operation called a neck dissection. In this procedure all the lymph nodes on one side of the neck are removed. There are no long-term consequences from the removal of these lymph glands. Radiation is commonly used as additional therapy in patients with large squamous cell carcinomas or those that have spread to lymph nodes. Chemotherapy or anti-cancer drugs are used for patients with evidence of cancer that has spread to other organs such as the lungs or bones.

TREATMENT FOR MELANOMA
Patients afflicted with melanoma may be treated with surgery, radiation therapy, biologic therapy or chemotherapy. In some patients a combination of treatments may be offered.

Surgery
Surgical removal is the usual treatment for melanoma. The surgeon will remove the tumor and an area of normal tissue around it. The width and depth of the removal is dependent on the size, location and depth of invasion of the melanoma. Some patients may undergo sentinel node mapping. In this technique, a radioactive material is injected into the skin around the melanoma. The surgeon follows the movement of the substance on a computer screen. The first lymph node(s) to take up the substance is called the sentinel lymph node. The surgeon removes the sentinel node(s) to check for cancer cells. If the sentinel node is positive patients may have a neck dissection done as described for squamous cell carcinoma.

Radiotherapy
Radiation therapy is useful in melanoma. It is often used in very large tumors and tumors that have spread to the lymph glands.
It may also be used to treat melanoma that has spread to other organs such as the brain or bones.

**Chemotherapy**

Chemotherapy is the use of anti-cancer drugs to kill cancer cells, and is used to treat selected patients with melanoma. These patients usually have evidence of spread to other organs of the body. The drugs are usually given in cycles: a treatment period followed by a recovery period, then another treatment period. Usually a patient has chemotherapy as an outpatient (at the hospital, at the doctor’s office, or at home). On occasion, depending on which drugs are given and the patient’s general health, a short hospital stay may be required.

**Biological Therapy**

Biological therapy (also called immunotherapy) is a form of treatment that stimulates the body’s immune system to fight the melanoma. For patients with melanoma, interferon-alpha and vaccines against melanoma may be used following surgery or radiotherapy in patients with a high risk of recurrence.

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**CANCER TEAMS**

**CRANIOFACIAL REHABILITATION TEAM**

The planning process for treatment and rehabilitation for cancer will require the opinions of several different providers in order to choose the most appropriate course of action. It is therefore necessary that the providers be part of a structured team that is dedicated to this purpose. All members of the team should see patients in consultation simultaneously. This is to ensure that the opinions of all members are available to help the patient in selecting the most appropriate treatment plan for them. Treatment alternatives can be debated, and the need for preliminary diagnostic materials can be identified efficiently. Similarly, the patient has all members available to answer questions, particularly
where the answer supplied by one member, raises questions for another member. A solid consensus on the treatment plan can then be developed with the full participation of the patient at every step of the way. The role of each of the providers and the timing of the steps in treatment will be clear.

The treatment team or multidisciplinary team is comprised of a number of healthcare professionals with expertise in the assessment of cancer. Typically, they include a surgeon who will be a surgical oncologist, an anaplastologist, and a prosthodontist. A number of other individuals with expertise in supportive care will be part of the team including, psychiatry, social work, speech pathology, and nutrition.

**Surgical Oncologist**
The surgical oncologist may be the first specialist to see the patient. The surgical oncologist will address the surgical management and follow-up of the cancer, and coordinate with the other medical specialists who may be needed for radiotherapy and chemotherapy. The surgical oncologist may also coordinate with other surgeons to discuss surgical rehabilitation. The surgeons will also coordinate with the anaplastologist and prosthodontist to be sure the surgical site is prepared for implants or prostheses planned for the later stages of treatment.

**Plastic Surgeon**
A plastic (facial) surgeon will also contribute to the surgical management of the area, particularly if a surgical reconstruction is contemplated.

**Anaplastologist**
An anaplastologist (a medical artist with training in dental technology) will identify surgical changes needed to make a better prosthesis, and will make the prosthesis.
**Prosthodontist**
A prosthodontist (a dental specialist who replaces missing parts of the mouth) who is experienced with implants will help with the planning and management of implant related issues during the construction of implant retained prostheses.

**Social Services**
If a patient and family need support around the issues of treatment, then a referral to social work or a psycho-educational consultation may be needed. All these professionals will provide their services individually at different times throughout the course of treatment, and the work will be coordinated if the planning process includes simultaneous initial assessment. Similarly, these same specialists should participate in regular simultaneous follow-up sessions as appropriate, so that the management of issues that arise in follow-up can be dealt with in a coordinated way. The importance of a structured team dedicated to this purpose becomes evident.

**SUPPORT**

**SUPPORT SERVICES**
Normally, people are remarkably resilient and adapt amazingly well to treatment for facial differences. But it is recognized that this resilience relates not just to surgical or prosthetic treatment. The social and emotional side of treatment is just as important, and often needs just as intensive care as the surgical side. Since it is well understood that these feelings are a part of the overall problem, psychologists and social workers are often included on the treatment team. They provide support for affected people in their relationships with their family, friends, and members of the health care team. They also help with the practical problems of navigating through the sometimes-complicated health care system. This kind of help has a strong effect on the overall success of the surgical or prosthetic treatments.
SUPPORT GROUPS
Having support during a difficult and trying time can make all of the difference.

Help is needed from family members and friends who can relate to their needs on a personal level. Family members provide for a sense of belonging at a time when the person can feel most isolated. Patient support groups, such as AboutFace, provide a network of individuals with common experiences and concerns who can provide emotional and moral support for one another.

REHABILITATION

SURGICAL REHABILITATION
The surgical wound will be repaired by stitching or suturing the skin in the majority of patients undergoing surgical treatment of skin cancer. In a minority of patients the removal of the cancer will be too large for a simple repair. In this case either a graft or flap will be used. A graft of skin is a superficial piece of skin removed from another part of the body and applied to the tumor removal site. This piece of skin will heal in place relying on the in-growth of local blood vessels for its nutrients. In more extensive defects, complete segments of tissue known as flaps may be transferred into the surgical site. Two types of flaps are widely used; local flaps, from surrounding tissues and, free tissue flaps usually transferred from another site of the body. Local flaps bring their blood supply and nutrition with them, where as free tissue flaps require that the blood vessels to the flap be re-attached near the site of the defect, very much like a transplanted organ.

If a removed structure can be satisfactorily reconstructed using grafts of flaps the reconstructive surgeon will usually do so at the time of the tumor removal. Occasionally for extensive tumors the reconstruction may be delayed to be certain that the tumor
has been completely removed. If the involved structure cannot be satisfactorily reconstructed then the patient will be considered for prosthetic rehabilitation.

Surgical nasal tip reconstruction

PROSTHETIC REHABILITATION
A facial prosthesis is an artificial device used to replace a missing or malformed facial feature. A facial prosthesis can be made to replace an absent ear, nose, or eye with lids. Facial prosthetics offers an alternative to rehabilitation when surgical reconstruction can not be achieved, or is preferred by the patient. Facial prostheses offer various advantages and disadvantages compared to surgical rehabilitation that should be discussed with the craniofacial team.

A facial prosthesis can be easily thought of in the same way as movie make-up that is used to enhance or change the appearance of a movie star. A facial prosthesis is first sculpted and then
molded to custom fit the individual’s tissue site. **Anatomical** landmarks, facial proportion, and **symmetry** are all taken into account to create a convincing, life-like facial feature. Facial prostheses are most commonly cast out of a silicone rubber that can be tinted to match the pigmentation of the individual.

A facial prosthesis can help to protect exposed delicate tissues or provide support for eyeglasses. A prosthesis is aimed towards helping an individual to return to their role in society. A facial prosthesis can help to restore self-confidence and ease the
anxiety one might experience in a public setting. Although a facial prosthesis can often achieve a very realistic look there are limitations to its use. Facial prostheses are made to fool the casual observer in everyday social encounters such as walking down the street, riding the bus, or shopping at the grocery market. A facial prosthesis can often help to ease the anxiety associated with a casual social encounter, but may be detectable under close observation. The practice of making facial prosthetics incorporates as much art as science. Therefore the esthetic results are dependent on the skills of the craniofacial rehabilitation team. A facial prosthesis degrades
over time and loses some of its esthetic value. This is caused by several factors, such as skin oils and ultraviolet light, which slowly makes it more yellow in color. Typically, a facial prosthesis needs to be remade every two years.

A facial prosthesis is most commonly secured in place by one of two methods. The first method requires the individual to apply a medical grade adhesive to the back of the prosthesis to hold it in place. This is the same method used to secure masks and camouflage make-up in the movies. The prosthesis has to be removed at night and cleaned, along with the underlying skin on a daily basis. Certain situations, such as high humidity, oily skin or profuse sweating can cause the prosthesis to come off at an inopportune moment. The possibility that this might happen can undermine the individual’s confidence in the prosthesis. A more secure method for retaining a facial prosthesis is through the use of bone-integrated implants. This process, known as osseointegration, usually requires two minor
surgeries but may be done in one. The first surgery consists of implanting little titanium fixtures into the bone. The implants are left alone for a period of at least three months while the bone grows around them to hold them in place. The second surgery is utilized to extend the implants above the skin surface by using an intermediate titanium extension called an abutment. The abutments can then be used to hold a gold bar so that the prosthesis can be clipped into place. Magnets can also be used. Osseointegration greatly enhances the retention of a prosthesis and enables the anaplastologist to achieve better esthetic results. The prosthesis still needs to be removed overnight and cleaned along with the skin on a daily basis. Unfortunately, not every individual in need of a facial prosthesis is a candidate for osseointegration. The treatment options should be discussed with an experienced craniofacial rehabilitation team.

LIVING LIFE WITH A FACIAL DIFFERENCE

Learning to live with a facial difference can be more difficult for some than for others. You will be faced with the challenge of adapting to a world that often places importance on appearance. You may often worry if there is truly something wrong with you, or you may even feel guilty about desiring to look “normal.” The importance of looking “normal” can even become an obsession and the thought of going out in public with a facial difference can be terrifying. Undoubtedly, you will contemplate having further procedures to improve your facial appearance with the hope that somehow it will make facing the world a little easier. Although facial reconstruction can improve your physical appearance and have an impact on your self-esteem, it is important to recognize that it may not solve all of your problems.

A person who is contemplating facial reconstruction should discuss their motivations for treatment and expectation of treatment with a multidisciplinary craniofacial team. Feelings of
guilt, inadequacy, obsession, depression, or anxiety associated with a facial difference can be indicators of underlying emotional disorders and require attention beyond surgical or prosthetic treatment in order to achieve overall success. Since it is well understood that these feelings are often associated with a facial difference, psychiatrists and psychologists are often included on the treatment team. It is useful to review how to identify pathological anxiety in one’s life and how to take steps towards coping. Whether or not you are contemplating surgical treatment, these emotional issues are serious health concerns and should be addressed.

ANXIETY
Anxiety is an overwhelming emotion of apprehension and fear often marked by bodily distress such as nervousness, tension, and sweaty hands. We all feel anxious in different situations. Some individuals, however, feel anxious in all situations thus causing significant distress for them. For example, many individuals feel some anxiety when meeting new people or on the first day of a new job, however, most individuals do not feel continuously anxious in such situations. When we feel so anxious, fearful and worried that it interferes in our day to day lives, we call the anxiety a disorder.

An Anxiety Disorder is a biological, biochemical disorder that develops in some individuals. Our understanding of the exact chemical cause is limited. Many researchers are studying this disorder of the brain and we know that the neurotransmitter serotonin is involved. Neurotransmitters help the brain process information correctly. People who experience an abnormal amount of anxiety are believed to have abnormalities in their serotonin system. Often, we see a clear history of anxiety disorders in families and there is evidence to suggest that anxiety disorders are genetically based. However, just because a parent has an anxiety disorder does not mean that their child will have an anxiety disorder. For someone who is genetically predisposed
to developing an anxiety disorder, important events or circumstances in one’s life can increase their risk for developing an anxiety disorder. Stressful and traumatic experiences, as well as continual exposure to negative environments, such as abuse or harassment, may exacerbate our anxiety levels. Sometimes individuals develop an anxiety-related syndrome known as Post-traumatic Stress Disorder (PTSD). There are certain criteria that must be met to diagnose an Anxiety Disorder. Psychologists and medical doctors, usually psychiatrists, are the ones who will make the diagnosis.

SOCIAL ANXIETY
Social Anxiety is one of several anxiety disorders that may occur. Social anxiety is a disorder in which an individual feels very anxious and uncomfortable in social situations or when meeting new people. In social situations, the socially anxious person may avoid speaking, eating or drinking in front of others. They may avoid social situations all together and stay at home wishing that they had enough courage to go out. Social anxiety is different from shyness. Shy people may feel a little awkward or uncomfortable when meeting new people, or going to new places or being with a group of people, but they are able to do so. Shy people are able to ‘warm-up’ over the course of the event and feel more comfortable as they get to know people. The socially anxious person usually avoids such social situations all together, always afraid that the worst is going to happen. They often feel very anxious and panicky in social situations and may experience things such as increased heart rate, shortness of breath, and feeling nauseous. Some times, a social anxiety disorder can be so limiting that individuals can not work or interact with other people.

CONTROLLING YOUR ANXIETY
Reducing the amount of stress in your life can help to control your anxiety. Healthy lifestyle changes such as regular exercise, allowing yourself more time to accomplish a task, getting enough
sleep, and limiting your use of alcohol, caffeine, nicotine and other drugs can contribute to lowering your stress levels. If you feel anxious, fearful and worried on a regular basis to the point where you feel your anxiety is interfering in your daily life, it may be helpful to see your family doctor. Your family doctor may be able to determine whether you have an anxiety disorder or s/he may refer you to a psychiatrist or psychologist.

If you have an anxiety disorder, there are many things you can do to help yourself. The first step is to understand the disorder and make a concerted effort to overcome your anxiety. Cognitive Behavioral Therapy (CBT) is a type of therapy that can help individuals to adjust to life with an anxiety disorder. CBT teaches behavioral strategies such as relaxation techniques. CBT also teaches cognitive strategies such as identifying our anxious thoughts and learning to reshape them so that they are more realistic and often more positive. As part of therapy, a person with an anxiety disorder will learn that it is important not to avoid anxiety-provoking situations. Avoiding such situations only reinforces the fears that cause anxiety. As a result, our anxiety builds up, making future social encounters even more difficult. Armed with relaxation techniques and cognitive strategies, CBT encourages individuals to test out their ability to adjust to situations that cause anxiety. It is important to start with situations that only cause a little anxiety and work up to situations that cause a lot of anxiety. This is called building an Anxiety Hierarchy. For example, the socially anxious individual may start with the challenge of spending time with one new person before moving on to bigger social groups.

Sometimes, medications are necessary to decrease an individual’s anxiety to a level so that therapy can help. The serotonin selective re-uptake inhibitors are a type of medication that has been shown to be effective in decreasing anxiety. These medications work on the serotonin system in our brain. These medications are usually taken once a day and do not completely
remove anxiety but help in decreasing excessive anxiety levels. It takes about two to three weeks before a noticeable change in one’s anxiety level can be felt with the use of these medications. Although Anxiety Disorders are lifelong disorders, they are treatable. It is important that individuals with an anxiety disorder learn effective coping strategies that will allow them to live a full, healthy life. Individuals with social anxiety can learn strategies that allow them to function in school, at work, and in social situations.
SKIN CANCER
In 1985, I was diagnosed with a rare form of cancer in the mucus producing glands in the upper eyelid. At that time, I was thirty-seven years old and the mother of three children. The eyelid had gradually become thickened and the eye itself seemed irritated. The surgery that was first proposed would have removed the cancerous eyelid and through reconstructive methods saved my eyesight. Unfortunately, it took four years to obtain the proper diagnosis and by then the cancer had spread to the tear glands and the conjunctiva of the right eye. The surgery that was now necessary involved the removal of all tissue from the orbital cavity including the upper and lower eyelids, the eye and the skin surrounding it. Fortunately, I did not need to undergo either radiation or chemotherapy to obtain a cure.
At the time of surgery, the medical staff attempted to prepare me for what I would look like after surgery but nothing can prepare you for a gaping hole in the middle of your face. Over the years, I have had several orbital prostheses made to give me a more acceptable public face. My first prostheses were held in place using adhesive, but now I have bone integrated titanium implants holding my orbital prosthesis securely in place. The first day that I ventured out in public wearing my first prosthesis, I was convinced that everyone would stare. I thought that they would notice that the eye didn’t blink and that the skin looked different. I wore sunglasses all day. By that evening people were starting to stare because it was getting dark and I was still wearing the sunglasses! The next day, I went out naked (no sunglasses) and while there were those who stared, the majority of people were polite and didn’t intrude on my privacy.

I have learned that I cannot change the behavior of other people, but I can decide on how I will react to it. I try to be accepting of myself as well as of others. Negative reactions from other people can still hurt but I won’t let it stop me from participating in activities that I enjoy. It took me several years to come to a full acceptance of my new self-image but my best supporters are my children and my family. To them, I am still the same person that I was before the surgery even if I look different.

One physical challenge that I have is accommodating for monocular vision. I had to learn to drive again and objects will always appear closer than they are even without looking in the rear view mirror. I find it difficult to tell what lane a car is in and how fast it is traveling. After all these years of practice, I can still miss a glass when pouring liquids but my guesses are getting better.

The cancer did not reoccur and I am now fifty-five years old and living a full life. Having acquired a facial difference as an adult I have found that it is necessary to be patient with myself and with others. Life will always be a series of new challenges, experiences and emotions. Take time to explore your emotions and to accept your new self. Have the courage to set goals and to take the necessary steps to achieve them.

“Courage is the mastery of fear, not the absence of it.”
— Mark Twain
I have been a long time member of AboutFace. My facial difference was acquired as a result of skin cancer.

In 1962, I had my first encounter with cancer – a radical mastectomy. My left breast, three ribs and pectoral muscle were removed. No chemotherapy, radiation or counseling was required, thought of, or given. The next few years, I was cancer free. During the ‘70s a small basal cell carcinoma on my forehead was successfully treated with radiation. Some years later, I was dismissed from that clinic, cancer free.

My decision to have a stubborn case of dandruff treated seemed to be the beginning of my next ten years of fighting basal cell skin cancer. Over this period, fourteen minor and major surgeries were done on my facial area to control the skin cancer.

My philosophy had always enabled me to live with skin cancer. However, the skin cancer skirmishes continued to mount, even after a partial excising of my right cheek (a sort of a reverse face lift). And so, early 1988, specialists at the Toronto Sunnybrook Regional Cancer Centre told me, in essence, that this cancer, uncontrolled as it had become, could KILL. It had never occurred to me that I could die from skin cancer. That single statement drastically altered the rest of my life... from a responsible teacher of music and special education, to accepting the reality of being on long-term disability. This turn of events had certainly not been the way I had hoped to end my teaching career.

For ten years my medical doctor had encouraged me to have my chest wall reconstructed for safety reasons. I had finally been out of the
operating room for a year, when plans were in their final stages to have my chest wall reconstructed. I had decided that this operation would be in celebration of my 25th year of surviving cancer.

Overnight it seemed, my skin cancer went out of control and in February 1988, I had to slam on the brakes and delay the reconstruction. After tests and interviews, I faced two choices: to excise the nose and facial area until clean edges were obtained, or undergo radiation treatments. The decision was made to excise (operate). On April 4, 1988, most of my nose and part of my right cheek was removed in order to halt this insidious skin cancer. The diagnosis; squamous cell carcinoma of the face and nose. The procedure — partial maxillectomy and skin graft of the face.

During the darkest period of my life, three people were introduced to me via radio talk show. I was intrigued with Betty Bednar’s goal for networking and support for AboutFace, an organization founded to support individuals born with or who have acquired facial abnormalities. I was encouraged while listening to Adrienne Alison explain her role in dealing with facial disfigurement — a medical artist and sculptor, who makes prostheses. Jackie Sharpe, a make up consultant who specialized in helping patients camouflage their facial irregularities was an added bonus. How could I lose?

Alone during the evening or before sleep, my mind would flood with “what ifs” and fear of the unknown. During my waking hours, I found things to do and places to go. My aim was to go to bed absolutely exhausted.

My mind was filled with concerns and questions of the past, the present, and the future. Why has the cancer been so stubborn? What had caused this disease? Why me? I was never a summer sun worshipper. Why had I had so many recurrences: how could I deal with the upcoming drastic change in my facial appearance? What about my hobby of singing and my interests in the choir, my interests in sports, and social activities? What about my teaching career? Would they be successful in stopping the disease? How would I manage irrigation dressing or applying and wearing the prosthesis successfully? And what about socialization in the real world, outside my network of friends and associates?

Each day since April 4th 1988, has been filled with challenges.
Challenges to recover, to learn to irrigate and dress the operation site, to be able to continue to sing in rehearsal and concert with the Toronto Mendelssohn Choir, to learn to wait patiently to be seen by the doctors in the medical clinics, to learn all the procedures involved in caring for and placing the prosthetic nose in place, hoping it wouldn’t come off, to learn how to apply makeup to enhance by appearance. The great challenge of all was to face the public and deal with the stares.

By June 1990, the third phase of the osseointegration (hooked on nose) procedures for my prosthetic nose was completed.

How have I coped? One day at a time, sprinkled lightly with laughter, and a positive attitude. Below, I have included my prescription for living. It works.

**My Prescription for Living**

1. Begin each day with a smile

3. Maintain all previous contacts, family, friends and interests. Keep your telephone line and door open for conversation. Limit them if absolutely necessary (time and/or frequency)

4. Maintain a positive attitude and approach. If you begin to feel sorry for yourself, look around, you can always find someone in a worse situation.

5. A sense of humour is absolutely essential. If you don’t have one, do all you can to develop one.

6. Put your best side forward — foot, face, finger — each day. Look your best — it will provide you with a warm, cozy feeling about yourself.

7. Keep busy. If you like to bake, then bake! To skate, skate; to sing, sing; take a computer course do it now. Do something you have always wanted to do.

8. End each day with a smile, a hug, a laugh — all are relaxing aides for sleeping.

9. Give positive feedback whenever possible.
Positive Thesaurus Guide
Choose a different word each day to improve your spirit.

Monday:
Attitude, Acceptance, Ability, Affectionate, Amicable, Articulate

Tuesday:
Behaviour, Belief, Balance, Bravado, Buoyant, Bond

Wednesday:
Courage, Confidence, Candor, Comfort, Consult, Calculate, Celebrate

Thursday:
Desire, Discipline, Dedication, Decision, Devotion, Deliberate, Dynamic

Friday:
Educate, Embody, Engender, Eminent, Enjoy, Endear, Entrust

Saturday:
Family, Friendly, Fellowship, Fortify, Flexible, Firm

Sunday:
Gallant, Gutsy, Gumption, Guts, Generous, Genial, Genuine

Others to consider:
Love – Laughter – Life – Live
Result – Relief – Recover – Rejuvenate
Try – Test – True – Trust – Triumph
ABOUTFACE PROFILE

Every year in Canada over 10,000 babies are born with rare and unusual craniofacial differences making it the second most common birth defect. Moreover, over 50,000 Canadians acquire a difference every year, through accident or disease such as cancer or stroke.

The goal of AboutFace is to provide a helpful, supportive place for individuals to rebuild their sense of self and move back into the community. AboutFace provides information services, emotional support, public awareness, and educational programs for and on behalf of those with facial differences and their families.

At AboutFace, we provide:

• Community ambassadors who provide local access to programs and services;

• A national database that helps connect peer-to-peer so that individuals can learn from others experiences;

• An information clearinghouse and lending library with information on syndromes, conditions, and other issues related to living with a facial difference, including psychosocial, teasing, self-esteem, talking about differences;

• Educational programs to help kids integrate into the school community with openness and respect (preschool and elementary);

• A quarterly newsletter to share personal stories and resources among the client base; and
• Educational and awareness programs to help individuals integrate into their community and help to dispel myths about facial differences.

For more information on AboutFace programs and services, or if you want to network with other cancer survivors, please call AboutFace at 1-800-665-3223 or visit our web site at www.aboutface.ca
GLOSSARY OF TERMS

Anaplastologist: A health care provider who has special training in art and dental technology.

Anesthetized: Made numb or insensible.

Basal Cell: A type of cell found in the deepest layer of the skin.

Benign: Of no danger to health.

Biopsy: The removal and examination of a sample of tissue from a living body for diagnostic purposes.

Carcinoma: An invasive malignant tumor derived from skin tissue.

Cauterized: To sear closed.

Curetted: Scrapped away with a sharp spoon-like instrument.

Lymphatic system: The interconnected system of nodes and vessels between body tissue and organs by which lymph fluid circulates throughout the body.

Lymph node: Any of the small bodies located along the lymphatic vessels, particularly at the neck, armpit and groin, that filter bacteria and foreign particles from lymph fluid.

Lymph gland: Lymph node.

Malignant: Life threatening, cancerous.

Melanocyte: Pigment cell of the skin.

Metastasize: To spread, especially destructively.
**Prosthodontist:** A dental specialist who has special training in the replacement of parts of the mouth and face with artificial devices (prostheses) such as special kinds of dentures.

**Surgical Oncologist:** A surgeon who has special training in the surgical treatment of cancer.

**Tumor:** An abnormal growth of tissue.