

To Our Patients:

We hope this packet will help you to better understand autoimmune thyroid disease and its various treatments. Thyroid Eye Disease can be very distressing but with patience and commitment, normal function and appearance can be achieved.

We believe that *you* are the person most in tune with your body, and the more you know about your disease, the more accurate an observer you will be, and the more you will be able to assist us in helping you.

Some of the things you read here can be frightening because this literature is written for people across a wide range of disease, and much of this material may not apply to your situation. The most important thing for you to remember is that Thyroid Eye Disease is treatable – all you have to do is be aware of changes in your eyes or vision and discuss them with your physician(s) in a timely fashion. None of the over 7,000 people we've treated have gone blind.

Charles N.S. Soparkar, MD, PhD, FACS

THYROID EYE DISEASE

A General Overview

INTRODUCTION

Thyroid Eye Disease, thyroid ophthalmopathy, thyroid orbitopathy, and endocrine orbitopathy are all names, which describe a disorder resulting from inflammation of muscles and fat within the bone box (orbit) surrounding the eyes. Thyroid Eye Disease may cause the eyes to bulge forward and the lids to become swollen, red, or retracted. This disease occurs roughly 5 times more commonly in females, and although any age group may be affected, it is more frequent among middle-aged individuals. Remember, at least 10% of all women by age 55 years have some thyroid abnormality, and 30% of these people will have clinically significant Thyroid Eye Disease.

ASSOCIATION WITH THYROID ABNORMALITIES

Thyroid Eye Disease is typically associated with disorders of the thyroid gland, which is located in front of the lower throat. This gland produces thyroxine, a hormone that affects appetite, metabolism, heart rate, and body temperature among other things. Symptoms associated with abnormally high levels of thyroxine (hyperthyroidism) include hunger, weight loss, nervousness, anxiety, tremors, perspiration, hair loss, premature hair graying, white spots in the skin, menstrual irregularity, and rapid pulse. Low thyroxine levels (hypothyroidism) may cause cold intolerance, fatigue, weight gain, depression, and facial puffiness. Roughly 30% of people with autoimmune thyroid abnormalities may develop Thyroid Eye Disease. Sixty to seventy per cent of people develop Thyroid Eye Disease during or after an episode of hyperthyroidism (the remainder may have normal or low thyroid levels). ***Although Thyroid Eye Disease is associated with disease of the thyroid gland, the two conditions (Thyroid Eye Disease and thyroid gland disorder) evolve, progress, and respond to treatment independently.***

CAUSE OF THE DISEASE

Thyroid Eye Disease is due to a disorder of the body's immune system, resulting in an attack on normal body tissues, so called auto-immune disorder. Other commonly known auto-immune disease includes rheumatoid arthritis, lupus erythematosus, and certain types of diabetes. In Thyroid Eye Disease, the tissues attacked by the immune cells are the muscles that move the eye, fat that fills the eye socket and acts as the shock absorber for the eye, and numerous specific tear glands surrounding the eyes. As a result, the following symptoms and signs may occur.

SYMPTOMS AND SIGNS

1. EYEBALL PROPTOSIS

Swelling of the tissues around the eye may cause the eyes to bulge forward (proptosis). There are 6 muscles that move your eye. These muscles originate deep behind the eye at the base of the brow and run forward to and attach to the eye just behind the cornea. The muscles cannot be seen on the surface as they are covered by a thin layer of tissue. The immune system attacks fibroblast support cells within the muscles causing the muscles to enlarge. With muscle enlargement the eye is pushed forward leading to the characteristic "stare." Proptosis frequently occurs unevenly, with one eye being more affected than the other; even though both eyes are always involved to some degree. As the muscles get larger, 3 things can happen. The eyeball gets pushed forward, the muscles themselves become scarred and stiff preventing normal eye movement, and the muscles may squeeze on the optic nerve, the major nerve that connects the eye to the brain.

2. EYELID RETRACTION

Inflammation and scarring of the muscles that pull open the eyelids may leave them abnormally open, causing a wide "stare". This may be exaggerated by the proptosis of the eyes. In some cases, the eyelids may be so retracted that they don't completely close, even during sleep.

3. DECREASED TEAR PRODUCTION

The tear glands may become inflamed or scarred, decreasing tear production.

4. DRY EYES OR EXCESSIVE TEARING

Prominence of the eyes, eyelid retraction, and/or decreased tear production may lead to drying out of the eyes with a gritty, sand sensation, aching, burning or paradoxical excessive tearing. Severe cases may be complicated by a breakdown of the surface of the eye (corneal ulcer).

5. SOFT TISSUE SIGNS

Swelling behind the eyes may cause redness and swelling of the eyelids and conjunctiva (the mucous lining of the eye). The swollen conjunctiva may look like a bubble or a blister on the surface of the eye. We strongly advise against the use of eye drops that "take the red out." Such medications can cause very serious problems. If you have questions about what is a good tear drop, visit <http://plasticeyesurgery.com/patient-resources/patient-education/> and read Mastering Tear Supplements.

6. GLAUCOMA

Some patients will develop glaucoma, which is increased pressure inside the eye that is so great, it damages the optic nerve. This condition is generally not painful, but if unrecognized and untreated it can cause slowly progressive vision loss.

7. DOUBLE VISION

Inflammation and scarring of the muscles that move the eyes may lead to impaired eye movement. In mild cases, one might feel a pulling sensation when moving the eyes. With more advanced disease, double vision may occur when looking in certain directions. In some cases, eye movement can be very restricted and the eyes may become obviously misaligned with constant double vision.

8. OPTIC NERVE COMPRESSION

Severe swelling of the tissues near the back of the eye may press on the optic nerve, the cable transmitting vision from the eye to the brain. Early symptoms include perceived fading of colors. That is, reds and blues may not appear as vibrant or intense. Permanent visual loss may occur if this complication is not recognized and promptly treated. Again, severe loss of vision is rare and may be reversible if the pressure on the optic nerve is quickly treated.

COURSE OF THE DISEASE – ACTIVE & INACTIVE PHASES

Thyroid Eye Disease typically has an active, inflammatory phase lasting an average of 1 ½ years (rarely as long as 5 years). After the inflammation has died down, individuals may be left with any of a number of changes, which might require treatment. Recurrences of the active phase are uncommon (about 5% of people). Unfortunately, there is no test to tell when a person has passed from the "active" phase to the "inactive" phase, and we rely on your and our powers of observation. We assume that if your eyes have not changed in appearance or function for 6 months, then you have entered the "inactive phase".

Every person's Thyroid Eye Disease follows a unique course. Some people may have minimal symptoms or signs and others may have a sudden onset of severe problems such as vision loss or major eyelid or eye swelling and redness.

We are still unable to predict accurately which problems a particular individual will develop. People must therefore be followed on a regular basis during the active phase of their disease. Any additional signs and symptoms should be reported immediately, in case specific treatment is needed. ***A concerned telephone call or email to your physician is never "a bother," but a smart and responsible action.***

SMOKING AND STRESS

An association between smoking and increased severity of Thyroid Eye Disease has clearly been demonstrated, especially in women. ***People who smoke and have thyroid disease, should make a particularly strong effort to stop smoking.*** Ask your primary care doctor for help. Stress is also associated with worsening of Thyroid Eye Disease. ***Stress reduction techniques may be very beneficial.***

DIAGNOSIS AND INVESTIGATIONS

Thyroid Eye Disease is diagnosed by the clinical features described above. It may be confirmed by CT scan showing the enlarged muscles around the eyes. Other tests may be ordered to document visual function and eye movements. Photographs, for example, document the appearance of the eyes to judge progression over time.

It is essential to understand that Thyroid Eye Disease is currently a diagnosis made by clinical observations. Certain eyelid signs are characteristic. Blood tests may help to confirm the diagnosis, but even in the most severe cases of Thyroid Eye Disease, all blood tests may be completely normal.

TREATMENT OF ACTIVE PHASE

1. THYROID GLAND MODULATION

The Endocrinologist may prescribe medications to alter your thyroid hormone level. A radioactive iodine drink or thyroid removal surgery may be offered to destroy portions of an overactive thyroid gland. Although these treatments are very important for general well being, they do not appear to directly influence the course of Thyroid Eye Disease in most people.

2. EYE MEDICATIONS

Dry eyes and subsequent reflex excessive tearing can often be relieved with lubricating teardrops and ointments alone. Drops may help glaucoma.

3. SALT RESTRICTION AND HEAD ELEVATION

Swelling symptoms may be decreased by cutting down on salt and alcohol, and elevating the head of your bed by placing bricks under the feet at the head of the bed.

4. ANTI-INFLAMMATORY MEDICATIONS

Moderate to severe inflammation and redness of the eyelids and eyes may be treated with corticosteroids or other immune-modulating drugs. Some people respond to these medications, but others do not. If a person is going to respond to anti-inflammatory medications, they do so rapidly. In cases of optic nerve compression, these medicines may be used in addition to radiation or surgery. Since these medications have potentially serious side effects, they are not used in mild cases.

5. RADIATION THERAPY

X-ray therapy to the area around the eyes has been shown to reduce inflammation and is offered severe cases. (RADIATION THERAPY IS **NOT** PERFORMED ON DIABETICS, AND IT IS USED ONLY WITH EXTREME CAUTION IN PREGNANT WOMEN). Mrs. Bush (prior First lady) had this treatment.

6. ORBITAL DECOMPRESSION

Despite the effectiveness of medications, radiotherapy, or a combination of both, there are some people who continue to have bulging eyes or even optic nerve compression with visual loss. In these people, *orbital decompression* is often offered.

TREATMENT IN THE INACTIVE PHASE

After a person has passed into the inactive phase of Thyroid Eye Disease, a number of procedures may be considered to recapture normal eye function and normal appearance.

1. ORBITAL DECOMPRESSION SURGERY

The orbital space may be enlarged by surgical removal of one or more of the bone walls surrounding the eyes or of the extra fat behind the eyes. This surgery is performed for certain cases of severe, cosmetically troubling proptosis and eye exposure or vision-threatening nerve compression. Orbital decompression may be complicated by double vision. Although we have performed 5,000 orbital decompressions, each person's is tailored to their specific needs. Different procedures carry different risks, which are always discerned on an individual basis.

2. MUSCLE ALIGNMENT SURGERY

Covering one eye should immediately relieve the type of double vision seen in Thyroid Eye Disease. It does not matter which eye is covered. It may be possible to realign the eyes and relieve double with the use of prisms either applied to glasses or ground into lenses. When double vision cannot be corrected with prisms, eye muscle surgery may be necessary. In most cases, physicians choose to wait until the double vision is stable before operating. Operating on a person whose eyes are changing may require repeat surgery. Sometimes it is not possible to completely remove double vision, but the goal is to remove double vision looking straight ahead and in reading position, as these are the most important directions of sight.

3. COSMETIC EYELID SURGERY

The upper eyelid may be lowered or the lower eyelid may be raised in cases of eyelid retraction with "stare". Eyelid surgery can often improve the appearance of a bulging eye and avoid the need for orbital decompression surgery. Blepharoplasty (surgical removal of redundant skin and fat bulges from the eyelids) may also be desired. These operations are performed after the active inflammation has subsided and after any necessary muscle alignment has been completed.

FREQUENTLY ASKED QUESTIONS

Q: The doctors tell me they fixed my thyroid and that it is now normal. Why are my eyes acting up?

A: The thyroid gland and the eyes are independently affected by one or more autoimmune antibodies circulating in the blood. The eyes don't cause the thyroid troubles, and the thyroid doesn't cause eye problems. Correcting thyroid hormone levels has very little, if any, impact on the Thyroid Eye Disease in most people.

Q: I've been told I have both Grave's Disease and Hashimoto's Disease, which do I really have?

A: Many people and physicians use the terms Grave's Disease and Hashimoto's Disease incorrectly. Typically, physicians use the term Grave's Disease to mean a hyperthyroid condition and Hashimoto's to mean a hypothyroid condition. Both are caused by autoimmune antibodies, some of which stimulate the thyroid causing hyperthyroidism and some of which inhibit the thyroid causing hypothyroidism. Still, many people can have multiple autoimmune antibodies, we prefer the term autoimmune thyroid disorder to encompass all of these conditions.

Q: Steroids made my eyes much more comfortable. Can't I just continue taking them?

A: Steroid therapy may be effective in masking the inflammatory phase of Thyroid Eye Disease and partially shrinking the muscle swelling; however, the side effects from steroids are very common with continued treatment and other long term treatments or surgeries should be considered.

Q: Why can't you fix my eyelids now?

A: Eyelid surgery is the last step in reconstruction after a person is in the inactive phase of the disease, because orbital surgery may change eye muscle movement, and eye muscle surgery may alter eyelid position.

AUTOIMMUNE THYROID DISORDERS

Hyperthyroidism refers to a condition where too much thyroid hormone is found in the blood. There are many different causes. If a person takes thyroid hormone pills inappropriately, or in too strong a dose, hyperthyroidism may result. Sometimes, a nodule (usually a small, noncancerous tumor) within the thyroid gland itself starts "doing its own thing" and produces excess amounts of thyroid hormone. Rarely, a tumor of the pituitary gland may make thyroid stimulating hormone (TSH) which acts on the thyroid to cause excess thyroid hormone production. In each case, an attempt is made to determine the cause of hyperthyroidism.

Hypothyroidism refers to conditions in which too little thyroid hormone is made. There are several ways this can happen. For example, if a person who had an overactive thyroid had their thyroid removed, unless they receive thyroid medication, they will have no thyroid hormone and be hypothyroid.

One of the most common causes of hyperthyroidism or hypothyroidism is *autoimmune* disease where the body's immune system mistakenly produces proteins called *antibodies* that interfere with normal thyroid gland operation and can cause either excess or insufficient thyroid hormone production. These abnormal antibodies can also react with proteins and tissues around the eye and cause swelling with bulging of the eyes, double vision, and rarely vision loss.

Sometimes these antibodies react with tissues in other parts of the body, such as the skin over the shinbones causing painful swelling. This uncommon event is called "*pretibial myxedema*."

Bulging eyes and pretibial myxedema do not occur in everyone who develops autoimmune thyroid disorder, but other symptoms and signs resulting from elevated or insufficient levels of thyroid hormone are fairly common. These include nervousness or depression, tremor, weight loss or weight gain, heat or cold intolerance, rapid or slowed heart rate, insomnia, irritability, muscle weakness or cramping, and irregular menstrual periods. Younger people tend to have more of these symptoms than do those who are older.

Medications are available to ease some of the symptoms.

Surgical techniques are available for the treatment of severe cases of exophthalmos.

Research on the immune system and thyroid disease is being done more now than ever before. This includes studies being conducted in our office. Hopefully, new findings will lead to new ways to treat the many manifestations of autoimmune disease caused by a faulty immune system.

MYASTHENIA GRAVIS

Roughly 1% - 10% of people with Thyroid Eye Disease also develop a muscle weakness problem called Myasthenia Gravis. In this condition, the nerve impulses that stimulate the muscles take much longer to "build up a charge" to stimulate the muscles again. The result is that the muscles may seem to get weaker throughout the day or with repeated use. A common manifestation of Myasthenia Gravis is difficulty climbing as many stairs as was once possible, not because of shortness of breath, but because of leg weakness. If you think you might have Myasthenia Gravis, discuss it with your physician.

LIVING WITH AUTOIMMUNE THYROID DISORDER

Many people ask "what can I do about my thyroid disorder?" When one feels helpless and powerless, a sense of hopelessness sets in. Although your thyroid disorder will not go away, there are many things that you can do to have a greater mastery of your life. What you eat, what you do, what you think, and what you know - all these things affect your health and sense of well-being.

Most people who are hyperthyroid eventually undergo thyroid destruction with radiation or surgery, since long-term treatment with medication that decreases thyroid function may have a number of complications. Therefore, the remainder of this section will be geared to people who are hypothyroid.

MEDICAL CARE

Your thyroid medication is essential. This is a replacement for the normal amount of thyroid hormone that your body once manufactured. When your thyroid was overactive, there was too much of the hormone circulating in your gland causing symptoms such as insomnia, anxiety, jitters, heat intolerance, fatigue, heart racing, and weight loss.

If your thyroid was surgically removed or deactivated by radioactive iodine treatments, your body's supply of thyroid hormone (thyroxine) was decreased. Periodic blood tests determine your thyroid level. This level reflects a combination of the hormone produced by your body as well as a similar substance provided by your medication. If your blood level of thyroxine is too high, you will begin to experience similar symptoms as described above with an over-active thyroid.

If the blood level of the hormone is too low, you will experience *hypothyroid* symptoms: slow heart rate, hair and nail changes, dry skin, sensitivity to cold, joint pains, hoarseness, weight gain, loss of appetite, difficulty concentrating, depression, constipation, muscle weakness, muscle cramps, and puffy eyes. *If you begin to feel any of these symptoms, contact your doctor.* Complaining of symptoms is not "bothering" your doctor, it is helping him / her to help you. NEVER ADJUST YOUR MEDICATIONS WITHOUT THE HELP OF YOUR DOCTOR.

NUTRITION

There are a number of nutritional concepts that you need to keep in mind when you plan your meals. Weight control is often a problem for people with thyroid disorder. Your thyroid controls metabolism, and you may have a tendency to gain weight. Eating to reduce caloric intake while maintaining high nutrition requires more effort than you may have been accustomed to if your thyroid hormone level and metabolism were elevated. Focus on fresh fruits and vegetables - these will give you the most vitamins and minerals for your efforts and offer the balance you need in your diet.

Sodium (salt), a preservative in almost all canned and frozen foods; may contribute to swelling. Since swelling is frequently a problem for patients with thyroid disorder, you may now need to be more aware of your salt intake. Alcohol avoidance is also prudent.

For reasons unknown, people with thyroid disorder often develop problems with elevated cholesterol. Therefore, you may have to be more aware of your fat intake. Fish and poultry will be better for you than excessive amounts of pork and beef. Limit rich sauces and cheeses. Have your cholesterol checked.

Learn about nutrition. There are many resources. Both the American Heart Association and the American Diabetes Association have excellent nutritional food plans, as do Weight Watchers, your local hospital dieticians, and registered dietician consultants or nutritionists. FAD DIETS ARE NOT HEALTHY -- AVOID THEM. Adopt a change in your lifestyle, not another diet.

EXERCISE

You will feel better if you develop a regular exercise program. Even regular walking is beneficial. Exercise strengthens your heart and improves circulation and muscle tone, which are needed to keep your cardiovascular system functioning well.

Studies show that exercise reduces appetite and increases your energy level. Concentrate on activities you already know how to do, as well as learning new ones. Have a variety of physical activities to avoid boredom and the limitations of weather.

WALKING continues to be the most overall beneficial activity; and it is available for everyone! If you can't walk, bike or swim, ROCK! Vigorous rocking in a stable rocking chair uses all the muscles in the body! Exercise with a friend. This increases the enjoyment of and dedication to your exercise program.

RELAXATION

Learning to relax refers to reducing the muscular tension in order to increase effective circulation, as well as mental calmness. It is not only an "attitude" but a learnable skill. Relaxation is more than just "getting away". It is a positive and satisfying experience and gives peace of mind. It is well documented that autoimmune thyroid disorders are stress-related illnesses; that is, stress makes them worse. The "stress" is often the result of the fast-paced, action-packed lifestyle that we all lead.

Relaxation may take many forms: learning new things, exercising, gardening, walking in the woods, creative activities, soft lighting, soft music, a bubble bath, a good book. If you are interested in mental exercises to create peace of mind and a relaxed body, there are many to choose from. You may prefer the systematic tensing and letting go of specific muscle groups (progressive muscle relaxation), or you might like imagining beautiful scenes. There is considerable research being done on the efficacy of mental imagery (visualization) and its effect on the immune system. Yoga, Tai Chi, and different forms of meditation are all ways to practice relaxation. Consult your local bookstore or the internet for more information and ideas.

Relaxation exercises should be practiced daily. When you discover your favorite activities, plan to devote at least one half hour each day to them. If you think you don't have the time, remember that the half-hour that you spend relaxing may well increase your overall daily productivity. You have to make a personal commitment to yourself. The National Institute of Mental Health says: "Finding effective techniques for relaxation is not merely a pastime for the idle rich. It is essential for everyone's physical and mental well-being."

SUPPORT SYSTEM

A support system may be defined as those caring, available people in your life who will listen, tell it like it is, and allow you to reciprocate in a caring, sharing dialogue. It is important that people in your support system be available, that is, living near you. Long-distance friends are good to have, but they do not substitute for a support system near at hand. Listening is important. Many times you do not need advice, you just need to say what you are thinking and feeling out loud and have those thoughts and feelings acknowledged. You need to discuss things, not necessarily have problems solved.

Support groups provide the essential ingredient that is needed for everyone that has to live with a disorder: HOPE and a SENSE OF HUMOR!

EYELID SURGERY FOR THYROID EYE DISEASE

The inflammation that occurs in Thyroid Eye Disease can cause scarring of the muscles in the eyelids, resulting in eyelid retraction (the eyelids being pulled away from the eye) with possible development of eye exposure (a vision-threatening problem). Many people will have exposure to a degree that causes their eyes to be chronically "gritty-feeling" and watery. In some people, however, dry spots may form on the surface of the eye causing scarring or infection of the eye. Eyelid surgery can reduce eye exposure so that the eyelids are more able to protect the eye. Before surgery, many people with an exposure situation will have the need to constantly squint or frown in order to keep their eyes from drying.

Additionally, thyroid eye disease may cause extra fat tissue deposits making the eyelids appear swollen, puffy, and unsightly. Surgery can correct these problems as well.

UPPER EYELID SURGERY

To help with upper eyelid retraction, surgical loosening of the upper eyelid retractor muscles and release of scar tissue in the muscles can allow the upper eyelids to lower to a more normal level in order to protect the eyes. At the same time, excessive fatty tissue and skin folds can be trimmed to improve appearance. Formulas are sometimes used during surgery to roughly determine the required amount of loosening of the muscles, but significant differences exist in the amount of scarring among different individuals. There are even other profound differences between eyelids in the same person. Following surgery, there is almost always significant improvement, many times exactly the desired amount, but in some cases (about 10%-15%) additional "touch up" surgery is needed to get the eyelids as close as possible to the desired position.

LOWER EYELID SURGERY

Puffiness and retraction similar to that seen in the upper eyelids can also develop in the lower eyelids, so that the lower eyelids are pulled downwards exposing the white portion of the eye causing an unhealthy vision threatening exposure of the eye. Surgical procedures can improve the protection of the eye and the appearance of the lower eyelid. With lower eyelid surgery, the scarred muscle can be loosened and at the same time extra skin folding and fat can be trimmed, as in the upper eyelid. To be able to reposition the edge of the lower eyelid upward, the outside tendon in the lower eyelid must be tightened and a spacer material may be inserted within the eyelid. Resuspension of cheek muscles may be required. This type of procedure will allow the eyelid to resume a more normal, natural position, protect the eye, and provide marked improvement in overall appearance.

PROBLEMS INVOLVED WITH EYELID SURGERY FOR THYROID PATIENTS

1. **BRUISING AND SWELLING**
There is usually more bruising and swelling after surgery in people with thyroid problems than the standard "baggy eyelid operation" (blepharoplasty), because in autoimmune thyroid disorder the blood vessels around the eye are larger and more leaky. Thus, the tissues tend to swell more. Also, the surgery is more involved. In some situations low dose steroids may be used to reduce the amount of tissue reaction following surgery. Ice packs and head-of-bed elevation help to control bruising and swelling.
2. **POST-OPERATIVE STIFFNESS OF THE EYELIDS**
Even though the eyelids are improved in position so that they can protect the eye and obtain a more normal appearance, stiffness incurred by the scar tissue may persist to some degree, as it is impossible to remove every bit of scar tissue imposed by the thyroid problem,
3. **ANESTHESIA DURING SURGERY**
If a person is having one set of eyelids corrected (usually the upper eyelids) the procedure is frequently performed entirely with local anesthesia in the office. If upper and lower eyelids are operated at the same time, this much longer procedure is usually performed with some degree of sedation.
4. **POST-OPERATIVE CARE**
A person will be ambulatory after eyelid surgery, although application of ice packs and topical medications will be necessary. Sutures will be removed one week after surgery, and a 6 - 8 week checkup will be scheduled.

ORBITAL DECOMPRESSION AND ORBITAL EXPANSION FOR THYROID EYE DISEASE

Once the “active” inflammatory phase of thyroid eye disease has subsided, an individual may be left with structural changes, such as eye protrusion, eyelid retraction, and in some cases, double vision. Luckily, there are corrective procedures that can be performed to address these problems.

In most people the build-up of tissue and swelling behind the eye is not severe enough to damage the optic nerve, but it may cause a striking bulging of the eye which in itself is a distressing situation, not only from the standpoint of exposure of the eye, but also because of the disfigurement that it produces.

Fortunately, orbital expansion and/or decompression procedures can often address eye bulging. With orbital ex, the eye socket is enlarged to accommodate the extra tissue that the thyroid disease has deposited behind the eye. This allows the eye to settle back into a more normal position.

Around the *orbit* (the bone socket in which the eyeball sits) there are a number of sinus cavities that can be used to surgically expand the orbit. The sinus below the eye is called the *maxillary* sinus, and the sinus toward the nose is called the *ethmoidal* sinus. A *maxillary-ethmoidal* expansion is the most frequently used procedures for accommodating the extra tissues behind the eye. However, in some cases, the outside wall of the orbit (lateral wall) can also be removed; and finally, orbital roof, frontal sinus, or sphenoid sinus surgery may be helpful. Most people, however, require only a two wall maxillary-ethmoidal orbital expansion. Using magnification, specific portions of the orbit bones may be carefully removed, allowing communication between the orbit and the nearby sinuses. There is a nerve of sensation that runs through the bone underneath the orbit. This nerve provides sensation to the cheek, the lip, and some of the upper teeth on that side. Great care is taken to nibble the bone away from this nerve so that the nerve is preserved. Despite extreme caution, and the use of microsurgical techniques, some numbness occurs in 50% of cases. If numbness develops , 90% of people have 100% nerve recovery within 9 months.

We have developed and perfected a new technique called “Small Bone Decompression” that is now commonly used in patients with only moderate proptosis and excessive fat accumulation behind the eye. This technique provides outstanding results with much faster recovery and minimal risks. As we’ve discussed, broadly speaking, setting an eye back in the socket can be accomplished in one of two ways. Removing extra fat tissue from behind the eye or making the eye socket bigger. Although both types of procedures are often called orbital decompression, in our practice we often refer to procedures that focus mostly on fat removal with minimal bone modifications as “small bone decompressions” and procedures that are weighted more towards bone removal as “large bone decompressions” or “orbital expansions”. The method used to

perform most orbital decompressions and expansions requires a very small incision in the skin on the outside corner of the eye, and this incision heals very well into the normal laugh lines around the eye.

However, the good news is that in more than 90% of cases, this numbness is only temporary. Additional hidden incisions inside the nose may also be used to more safely approach the very deep portions of the orbit and sinuses. After the bones of the sinuses are removed, the tissues which have built up behind the eye (usually fatty tissue or fat infiltrated eye muscles) are permitted to expand into the newly created spaces. In most cases, if the orbital tissues are soft, an immediate effect will be noted with the settling of the eye into a more normal position. In some cases, however, time is required for final settling to take effect. In fact, most people will observe a progressive effect for up to 12-24 months. Tiny absorbable stitches are placed on the inside of the eyelid and in the small incision of the skin at the outside corner of the eye. After surgery, cold compresses are used continuously along with medications to minimize swelling. Antibiotics are also given.

RESULTS

In over 5,000 orbital decompressions and expansions, we have always achieved an improvement in eye position.

ANESTHESIA

Orbital decompressions and expansions are performed under general anesthesia in the hospital, and the vast majority of people go home on the same day. Once at home, patients may need assistance during initial recovery. We generally see patient within a week after surgery.

ADDITIONAL FACTORS AND RISKS YOU SHOULD KNOW ABOUT

1. DOUBLE VISION

For people undergoing small bone decompression, the cause of double vision after surgery is less than 0.03% or three in a thousand.

For those undergoing large bone decompression, or orbital expansion surgery, the chance of double vision developing or worsening depends on a great deal upon the degree of double vision before surgery and the specific type of decompression performed. In general, if a person has no double vision before surgery, the chance of developing double vision is 5%, significantly better than the national average of 33% reported by other orbital surgeons. If someone has mild to moderate double vision before surgery, the chance of worse double vision after surgery is about 30%. For someone with severe double vision before surgery, the chance of continued severe double vision is close to 100%.

In the vast majority of cases, double vision in primary gaze and reading gaze can be eliminated with prism glasses, eye muscle surgery, or both.

2. MINIMAL SURGICAL EFFECT

Other than bone removal, the main condition that affects the swelling of the eye in orbital decompression is how “stiff” the tissue is which has built up behind the eye. Many people have very soft tissue, and this tissue will settle easily allowing a good retroplacement of the eye. In some people, however, the tissue is very stiff and scarred, and in these individuals, even though the surgery is performed correctly, the tissue simply will not move easily into the new spaces. In such situations, the effect of orbital decompression might be less than hoped for. Usually, it is difficult to determine before surgery what the consistency of the tissue behind the eye will be; however, in general, people who have good eye movements will have softer more pliable tissue behind the eye. In some patients, there may be some asymmetry in the final eye position after surgery. Most pre-operative asymmetry, should it occur, can be compensated for with surgical adjustments of eyelid position. Rarely, further orbital surgery is helpful.

3. NUMBNESS OF THE LIPS AND GUMS

The sensory nerve, contained within the floor of the orbit, supplies feeling to the upper lip and gum, and about half the time a temporary numbness occurs in the lip and gums. This is nothing that is visible, but it can be somewhat of a nuisance, and in most cases, it dissipates within 1 – 9 months. In some people with severe protrusion of the eyes, the nerve may actually have to be removed in order to allow the eyes to settle completely. In these cases, there will be permanent numbness just below the eye, cheek and in the upper lip, gums, and maybe even teeth. However, the nerve is never purposely removed in surgery without prior discussion and approval.

4. SEVERE BRUISING AND SWELLING

The operation takes place in an area where there are a large number of blood vessels, and it is imperative that a person undergoing orbital decompression or expansion take **NO** medication that would prevent blood clotting. Drugs containing aspirin or aspirin-like medication (many arthritis medications) should **NOT** be taken for 10 - 21 days before surgery. Many over-the-counter medications contain aspirin-derivatives. Please check with your physician about all your medications, including over-the-counter cold remedies and decongestants. People with hypertension should have their blood pressure controlled adequately before undergoing surgery. Severe bruising and swelling can impair a successful result and cause additional scar tissue to form. Excessive bleeding and swelling of an extremely severe nature could conceivably cause loss of vision.

5. LOSS OF VISION

We have not had a single patient who has had any permanent loss vision as a result of orbital decompression. However, any time there is surgery around the eye, especially in the orbit behind the eye, there is always a risk of vision loss.

6. SINUS BLOCKAGE

Some forms of orbital expansion procedures essentially borrow part of the sinuses to allow the eye to settle into a more normal position with fat and enlarged muscles filling the sinuses. Sinus decongestants are used during surgery to minimize sinus swelling and optimize sinus drainage. People who already have a tendency to develop sinus blockage may experience sinus obstruction after orbital expansions, perhaps even years later. Therefore, in order to avoid such problems, a surgical sinus drainage procedure may be performed at the time of orbital expansion using an endoscope (microscope) through the nose.

7. NEED FOR ADDITIONAL EYELID SURGERY OR EYE MUSCLE SURGERY

After a person has passed into the “inactive” phase of their Thyroid Eye Disease, there are three groups of surgical reconstructive procedures that can be offered to reverse the destructive effects of this disease.

The first is orbital decompression or expansion (with removal of 1-6 “walls”) when necessary. These procedures must be performed first, as changing the position of the eye may alter the functions of the eye muscles and change the relative positions of the eyelids.

Second, in patients with double vision, adjustments can be made to the eye muscles after orbital rearrangement, but before any eyelid corrections.

Finally, many patients with Thyroid Eye Disease have some degree of eye protrusion and eyelid retraction. After orbital decompression or expansion, the eye does settle backward and slightly downward so that there is often a marked improvement in the lower eyelid position. The upper eyelids, however, in some cases, continue to “hang up” and require surgery to loosen them. In general, eyelid surgery can be done in the office.

Thyroid Eye Disease and its treatments are very complicated, but it is important for you to understand as much as you can about your disease. If you have any further questions about thyroid eye disease, its treatment, or your options, please be sure to ask. We are also happy to supply the names of other experienced physicians if you desire another opinion. *The more informed you are, the more you are able to make important decisions about your care, and the better you will feel about your disease and its treatment.*

PREDNISONE

GENERAL

Prednisone is a drug similar to Cortisone, a hormone naturally produced by the body that decreases inflammation, redness, and swelling and may also relieve pain. At very high doses, this drug and other drugs like it, can shut down the immune system, that is they can increase the risk of serious infections and cause other systemic complications.

HOW TO USE THIS MEDICATION

Take Prednisone with food or a glass of milk in order to prevent stomach upset. Call your family doctor if you develop stomach upset, stomach pain, or heartburn, especially if this pain awakens you during the night. Do not try to treat this yourself.

If we have prescribed only one dose of this medication every day, it is best to take it with breakfast or before 9:00 a.m.

If you forget to take a dose, take it as soon as possible. If that means doubling your next dose, do so, as long as it is on the same day.

SPECIAL INSTRUCTIONS

Women who are pregnant (or planning to become pregnant) or breast-feeding should tell their doctor before taking this medicine.

It is best not to drink alcoholic beverages while taking this medicine, because the combination can cause serious stomach problems.

Do not take any more of this medicine than prescribed, and do NOT stop taking this medicine suddenly without the approval of your doctor. It may be necessary for your doctor to slowly reduce the dose since your body gets used to the medicine.

Do NOT take aspirin, medicines containing aspirin, or medicines similar to aspirin (Motrin, Advil, Naprosin, etc.) without the approval of your doctor. Carefully check the contents of all non-prescription medications, as many of these contain aspirin.

Acetaminophen (Tylenol) is an acceptable painkiller while taking Prednisone.

While you are taking Prednisone, you may gain some weight. This can be due to an increased appetite or increased water and salt in your system. Your doctor may suggest that you lower the number of calories and/or decrease the amount of sodium that you eat.

You may find that you bruise more easily. Try to protect yourself from injuries in order to prevent bruising.

Diabetic patients should regularly check their sugar in their urine or blood and report unusual levels to their primary doctor.

Patients with high blood pressure should have their blood pressure checked regularly by their primary doctor while on this medication.

If you take this medication for longer than five days, you should consider having a **MEDIC-ALERT** bracelet or necklace made. It is very important to tell your dentist, pharmacist, and any other doctors that are treating you that you are on this medication even if you have been off of it for up to one year. Your medic alert bracelet should say "taking steroids" and be worn for 1 year after stopping the medication.

SIDE EFFECTS

Most people experience few or no side effects from this medication when taken in relatively low dosages for a short time. There is extensive clinical experience with this drug and potential side effects are well known. It is important if you experience any symptoms, that you report them properly to your doctor.

The most common side effects include mood changes, insomnia, stomach upset, and weight gain. Less common side effects include elevation in blood pressure, increase in blood sugar, chemical imbalances in the blood, increased susceptibility to infections, weakening of the bones, muscle weakness, stomach ulcers, menstrual irregularities, glaucoma, cataracts, poor wound healing, loss of blood supply to the hip bone, and changes in the skin.

It is important to emphasize that if you stop this medication abruptly, you should be under a doctor's care as you could become very ill.

DIETARY GUIDELINES FOR THYROID PATIENTS

There are naturally-occurring substances that can interfere with the function of the thyroid gland. The foods we eat may alter thyroid function, so having a better understanding of how your diet affects your thyroid will allow you to make the best choices to maximize your health.

There are two general categories of foods that have been associated with disrupted thyroid hormone production in humans: soybean-related foods and cruciferous vegetables. In addition, there are a few other foods not included in these categories – such as peaches, strawberries, and millet (certain small-seed cereals and grasses).

Soybean-related foods

Included in the category of soybean-related foods are soybeans themselves as well as soy extracts, and foods made from soy, including tofu and tempeh (an Asian food prepared by fermenting soybeans). While soy foods share many common ingredients, it is the isoflavones in soy that have been associated with decreased thyroid hormone output. Isoflavones are naturally-occurring substances that belong to the flavonoid family of nutrients. Flavonoids, found in virtually all plants, are pigments that give plants their amazing array of colors. Most studies in the health sciences have focused on the beneficial properties of flavonoids, and these naturally-occurring phytonutrients have been shown repeatedly to be highly health-supportive. However, isoflavones like genistein appear to reduce thyroid hormone output by blocking activity of an enzyme called *thyroid peroxidase*. This enzyme is responsible for adding iodine onto the thyroid hormones. (Thyroid hormones must typically have three or four iodine atoms added on to their structure in order to function properly.)

Cruciferous vegetables

A second category of foods associated with disrupted thyroid hormone production is the cruciferous food family. Foods belonging to this family are called “crucifers,” and include broccoli, cauliflower, brussel sprouts, cabbage, mustard, rutabagas, kohlrabi, and turnips. Isothiocyanates are the category of substances in crucifers that have been associated with decreased thyroid function. Like the isoflavones, isothiocyanates appear to reduce thyroid function by blocking thyroid peroxidase, and also by disrupting messages that are sent across the membranes of thyroid cells.

Should you stop eating soy and cruciferous?

In the absence of thyroid problems, there is no evidence to suggest that such foods will negatively impact your health. In fact, the opposite is true: soy foods and cruciferous vegetables have unique nutritional value, and

intake of these foods has been associated with decreased risk of disease in many research studies.

Because carefully controlled research studies have yet to take place on the relationship between these foods and thyroid hormone deficiency, especially autoimmune thyroid disease, healthcare practitioners differ greatly on their perspectives as to whether a person who has thyroid problems, and notably a thyroid hormone deficiency, should limit their intake. Most practitioners use words like “overconsumption” or “excessive” to describe the kind of intake that would be a problem for individuals with thyroid hormone deficiency. Here the goal is not to eliminate these foods from the meal plan, but to limit intake into a “reasonable range,” whatever that means.

Limiting intake is often much more problematic with soy foods than with cruciferous vegetables, since soy appears in so many combination and packaged food products in hidden form. Ingredients like textured vegetable protein (TVP) and isolated soy concentrate may appear in foods that would rarely be expected to contain soy. A standard one cup serving of cruciferous vegetables 2-3 times per week, and a standard, 4-ounce serving of tofu twice a week is likely to be tolerated by many individuals with thyroid hormone deficiency.

The effect of cooking

Although research studies are way more limited in this area, cooking does appear to help inactivate the goitrogenic compounds (things that adversely affect thyroid function) found in food. Both isoflavones (found in soy foods) and isothiocyanates (found in cruciferous vegetables) appear to be heat-sensitive, and cooking appears to lower the availability of these substances. In the case of isothiocyanates in cruciferous vegetables like broccoli, as much as one third of these substances may be deactivated when broccoli is boiled in water. That is, of course, both good and bad.

Practical tips

Although for many people these foods do not seem to pose a health concern, certain individuals who have thyroid problems may be advised by their healthcare practitioner to limit excessive consumption of foods that contain these compounds. Cooking decreases the impact of soy and crucifers on thyroid hormone production, but it also decreases the overall benefit of these foods as well. Bottom line: everything in moderation, and if you take a thyroid modulating medication, try to be consistent in whatever amount of soy and crucifers you consume.

Autoimmune Disorders

There has been considerable interest recently in “leaky gut syndrome” and autoimmune disorders. Although the data is somewhat conflicting and the evidence is certainly incomplete, many non-traditional practitioners suggest avoiding foods containing the following:

1. Gluten
2. Processed sugar and sugar substitutes
3. Dairy products, including milk, yogurts, ice cream and cheeses
4. Animal meats, specially beef and pork

Examples of food that may affect thyroid function	
Cruciferous vegetables including: Broccoli Brussels sprouts Cabbage Cauliflower Kale Kohlrabi Mustard Rutabaga Turnips	Other Foods: Millet Peaches Peanuts Radishes Soybean and soy products, including tofu Spinach Strawberries

Adapted from The George Mateljan Foundation.

