



GRAVES' DISEASE & THYROID FOUNDATION

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A Letter From Your Eye Doctor by Robert Alan Goldberg, MD

It was a privilege to see you today in consultation in my examining suite. For your information and records, and because you are the most important member of your treatment team, I have attached a copy of my findings and impressions.

As you know, we as physicians do not completely understand the factors that cause thyroid eye disease, or Graves' disease as it is commonly known. The best explanation that we can offer right now, based on research done here at UCLA and at other centers, is that your body's own immune system somehow goes awry and attacks your body's own tissues. In Graves' disease, the tissues that are attacked are the tissues of the thyroid gland and the tissues of the eye socket, particularly the extraocular muscles. Understanding this theory makes it easier for you to grasp a concept which many patients find difficult; controlling the thyroid

disease, with medications, radioactive iodine or thyroid surgery, has no direct effect on the bulging of the eyes. This is because the underlying problem, namely the body's immune system directed against the body's own tissue, has not been corrected.

We are working very hard to cure Graves' disease at this fundamental level, and rest assured that if a breakthrough occurs, all of our patients will be among the first to know. However, until that scientific breakthrough occurs, the best we can do is to treat these symptoms, both in the thyroid gland and in the eye socket.

The treatment for the eye portion of thyroid disease depends on the stage that your particular disease is in. Thyroid eye disease typically runs a course in which initially the bulging eyes, redness, and irritation progressively worsen. This initial inflammatory stage typically lasts six months to one year, although every

patient is different. Double vision, due to swelling of the eye muscles, is typical in this state. The enlargement of the eye muscles also pushes the eyeball forward in the eye socket, leading to bulging appearance of the eyes. In severe cases, the enlarging eye muscles can squeeze the optic nerve, leading to decreased vision and requiring urgent surgery to attempt to prevent permanent decreased vision. The muscles of the eyelids are also affected, causing them to open more widely than usual. They may not close completely, particularly during sleep. Also, the inflammation of the eye tissues results in poor functioning of the normal tears. The combination of exposure of the eye to air and poor tears causes the eye to dry out, and particularly because of our climate, this is one of the primary causes of the ocular irritation that you have probably experienced.

You can see, then, that the treatment of this initial stage

of thyroid eye disease is directed primarily at reducing inflammation and keeping the eye moist. I have asked you to use artificial tear drops frequently during the day and eye ointment at night, to keep the eye surface lubricated and to prevent it from drying out. Another measure which some of my patients find helpful is to sleep with the head of the bed elevated slightly; this allows some of the swelling which builds up to drain from the eye socket while you sleep and can reduce the amount of swelling, particularly in the morning. Some patients find that decreasing the salt in their diet can also help control the amount of swelling round the eyes. Sometimes in this initial period the inflammation is so severe that I recommend that you take a steroid medicine by mouth. I will discuss this with you if I feel that it is necessary.

After this initial stage of the thyroid eye disease, in most patients, the disease tends to stabilize for a period of months to years. Often, the inflammation and swelling decrease during this stable period.

It is during this stable period that we most frequently discuss the possibility of surgical intervention to address the various functional

and cosmetic deformities which have been created by the thyroid disease, and rather a staged approach is used. It requires a great deal of commitment and no small amount of courage on the part of you, the patient, to go through the various surgeries. The vast majority of my patients feel that it was well worth it because of the cosmetic and functional rehabilitation which they have achieved. You are an individual, of course, and every case is different, but I will explain to you the various surgeries that I perform for thyroid patients and the expected outcomes.

As you well know, there are many variables involved in any surgery and no results can ever be guaranteed. Not all of these surgeries are needed in every case. The best results are achieved as the surgeries are performed in the order that I will list them now.

The first stage in surgical rehabilitation involves moving the eyeball back into the eye socket to reduce the bulging of the eyeball and to release some of the orbital pressure which compresses the muscles and nerves in the eye socket. This surgery is performed by removing part of the bony walls of the eye socket, allowing the tissue to expand into the sinuses. This

first stage of surgery is usually performed as an inpatient procedure under general anesthesia, and patients usually require from one to three weeks for recovery. The main risk of this surgery is the production of double vision, it is not already present. This occurs in about one third of patients and must be addressed in a second stage of surgery.

The second stage of surgical rehabilitation involves surgery on the extraocular muscles which control the eye movements. The extraocular muscles bear the brunt of the inflammation and scarring that result from Graves' disease, and double vision is a very frequent problem for patients with Graves' disease. In addition, some patients without double vision develop double vision following orbital decompression. (Stage One surgery)

The second stage of surgery, then, involves surgery on the extraocular muscles in an attempt to straighten the eyes and allow them to work together for single vision. This operation is performed under general anesthesia and patients typically go home from surgery the same day, and return to the office the day after surgery for a final adjustment of the surgery. The surgery is successful in restoring single vision in 90%

to 95% of cases and can be repeated in the rare occurrence that it does fail.

The third stage of surgical rehabilitation involves surgery to the eyelids to correct improper positioning of the eyelids. As I discussed above, the most common abnormality of the eyelid is eyelids which are open too widely or which do not close completely. Occasionally, the opposite problem exists in which the eyelids are droopy. There are several different surgical options for addressing these various abnormalities of the eyelids. This type of surgery is performed under local anesthesia as an outpatient procedure.

Finally, in many patients, a fourth stage of surgical intervention is indicated to address the excess fat and redundant tissues around the eyes which often develop as a result of the ongoing inflammation that characterizes thyroid eye disease. This type of surgery is typically needed several years after the onset of thyroid eye disease. When the disease enters a final “burned out” stage in which the inflammation and swelling are mostly resolved, and you are left with only the scarring and other vestiges of the inflammation which

previously passed through your eye socket. Patients often ask me if it’s possible to have the acute inflammatory phase begin again after the disease has quieted down. I have seen this on occasion, but it is very rare and, in the vast majority of cases, once the disease reaches the quiescent, “burned out” stage, no further relapses occur.

It is difficult to face a chronic disease like thyroid eye disease. It is very common – I would say universal – to have feelings of resentment and of “why me?” I will try to help you to maintain a positive attitude and not to get discouraged. There is a light at the end of the tunnel.

There are treatments available for each of the problems that arise in the different stages of thyroid eye disease that I have outlined above, and it is not unusual to hear patients say, after they have been through the various stages of surgery and have reached the final stable stage of the disease, that their appearance and eye function are as good or even better than before the thyroid disease started.

I hope this letter has helped you to understand a little bit more about thyroid eye disease in general and about your case in particular. You will no doubt have further

questions, and I will look forward to discussing them with you on your next visit.

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