To operate or not to operate on tonsils? That question has been hotly debated in medical circles for decades, and although the number of tonsillectomies is dropping, it is still a very popular form of surgery. This month, my Newsletter examines the question of tonsillectomy, and it also deals with the damage that was done 30 years ago when doctors found an alternative to tonsil surgery -- irradiation. It took years for the chickens to come home to roost after what we doctors once considered a "perfectly safe" procedure. During that time, thyroid nodules developed in the throats of those once subjected to this "best" medical treatment. As you read the letters from patients who now have to decide on a course of treatment to reverse the medical mistakes made on them, think about the "popular, sexy" medical treatments of this decade and try to project what their legacy will be 30 years from now.

I just read that millions of unnecessary operations are performed every year and that these needless surgeries cause thousands of deaths. How can I protect myself and my family against unnecessary surgery? -- D.M.

The following five rules should help you avoid unnecessary surgery:

1) Unless you have known your doctor long enough so that he has gained your absolute confidence and respect, get a second opinion. Don't get your second opinion from a doctor in the same group practice; in fact, don't even get it from a doctor on the same hospital staff. You may even have to go to another city to secure a truly independent opinion.

2) Spend some time reading up on your kind of case. Books, medical journals and magazines available at the public library should provide you with a wealth of information.

3) Be especially wary if you're advised to have one of the most common operations, such as tonsillectomy or hysterectomy. Even a trusted family physician may sometimes prescribe such surgery too routinely.

4) Even when surgery appears indicated, as in the case of breast cancer, ask several doctors what type of surgery should be done--radical, modified radical, simple mastectomy or lumpectomy. Such consultations can usually be arranged within a matter of a few days.

5) Report conflicting opinions to your first doctor and give him a chance to respond to them.
Q

I fear a recent reply of yours to a person who requested assurance against unnecessary surgery lacked edification and only added confusion to already muddy ideas. My specialty is otolaryngology, and I am chief of that department at a local hospital.

Suppose I recommended a tonsillectomy and adenoidectomy to a patient, and then he sought another opinion, which conflicted with mine. What then?

Your response was: "Report conflicting opinions to your first doctor and give him a chance to respond." The insidious implication is that the second opinion is always right, and the first is erroneous. As you know, most people will bend toward the recommendation of no surgery. My indications for T's and A's are strict and precise.

I cannot help but feel that you have sentenced many children with chronic ear problems to life with a hearing aid--or worse--by emphasizing only one facet of tonsillectomies.--J.M., M.D., West Seneca, NY

A

Tonsillectomy

Even though some of my best friends are otolaryngologists, I still think that far too many unnecessary tonsillectomies are performed; tonsillectomy is one of the most frequently performed operations in the country today. But the rate is dropping--doctors across the country are removing 24 per cent fewer tonsils today than they were six years ago. So, mine is obviously not the only hand that's trying to stay the surgical knife.

The indications for tonsillectomy have been controversial since the operation was first described over 2,000 years ago. In his publication On the Psychology of Childhood Tonsillectomy, Dr. Samuel D. Lipton of Chicago concludes that indications for tonsillectomy today are just as "muddy" as they have ever been. Furthermore, the risks of the operation, such as hemorrhage and gagging from the anesthesia, have generally been underpublicized. And removing tonsils and adenoids from the throat may merely cause infective agents to move to the next line of body defense--the lymph glands in the neck.

While I doubt this issue will be completely resolved in our lifetime, I'll certainly continue to warn people about the dangers of unnecessary surgery.

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Once the most commonly performed operations in the United States, tonsillectomies have declined by 50 per cent during the 11 years from 1965 to 1976 and are still on the decline. Writing in a recent issue of the Archives of Otolaryngology, Harvard Medical School researcher Rita Nickerson reports that most tonsillectomies have no effect on preventing recurrent throat infections in children, and she points out that tonsils may well play a role in the body's natural defense system.

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Q

My 3-year-old grandson has a cold most of the time. He has had an ear infection on two occasions, and he has pressure from fluid on his ear drums right now.

Our pediatrician has been treating him with oral antibiotics, but he now feels the child has had enough of these. He thinks the trouble may be an allergy, so milk and citrus fruits have now been eliminated, but it makes no difference--my grandson still catches cold. The pediatrician now talks of surgery during which tubes will be inserted. Do you know anything of this procedure, and what do you recommend?--R.B.

A

Ear infections are an everyday concern for pediatricians, and yet the amount of good scientific information regarding treatment is incredibly meager. Doctors as well as patients are frightened that untreated infections will lead to deafness, yet a cause and effect pattern has not been scientifically established.
If a high percentage of untreated ear infections were to result in hearing loss, the incidence of deafness in children would be staggering, since many ear infections are undetected by the mother, undetected by a physician, inadequately treated (since not all patients take the prescribed amount of medication), and often not checked afterward to see if they have disappeared. Some school screening tests have shown children with a loss of hearing acuity who, when tested some months later with no intervening treatment, showed normal levels of hearing.

The tubes you mention (which I have recommended myself) serve as an alternative to the much more risky removal of tonsils and adenoids.

Food allergies are suspect in this condition, and one recent study conducted among Eskimos showed that bottlefed babies have a higher incidence of middle ear infections than do breastfed babies.

It is not known whether this phenomenon is due to the constituent nature of the milk or to the position of the infant during feeding. If a baby takes milk lying down, it makes sense that milk may be pumped or pushed directly into the middle ear, setting up inflammation or infection. The pediatrician is on the right track in being suspicious of cow's milk, but if other allergies are suspected, it might take a Sherlock Holmes to find the offender.

In the future, we doctors may have to consider whether the entire panoply of therapy for simple ear infections (antibiotics, antihistamines, insertion of tubes, tonsillectomy) does not represent overkill for a condition that is almost always self-limited, except in the case of malnourished children. I would like to see a great deal more intelligent research done in this area.

My seven-year-old grandson has had scarlet fever with strep throat three times during the past year and once before that. He was treated with different forms of penicillin which did not seem to help, then he was given Erythromycin for quite a bit of time--September to December. However, he now has scarlet fever again with strep throat and a rash.

I am very worried. My daughter asked me to write you since she is going to school studying to be a nurse and is very busy. She doesn't want to have her son's tonsils removed. He seems like a sturdy little guy, never runs a temperature, so they don't realize how sick he really is. There are two other children in the family, but they are not affected by this disease. The doctor who treats my grandson is amazed. Can you help?--Mrs. E. McG.

I'm just as amazed as your grandson's doctor, but probably for other reasons. First, how can your grandson's condition be called "scarlet fever," when, according to your report, he never runs a fever? How has your grandson's physician distinguished the rash from the many other rashes (allergic, German measles, viral rashes, drug-related rashes) which closely mimic the scarlet fever rash? Is your grandson's physician aware that a high percentage of healthy, asymptomatic children (often as many as 20 per cent) carry strep in their throats during the wintertime? In other words, the finding of strep in the throat plus a rash does not necessarily equal scarlet fever.

Tonsillectomy is not, repeat NOT, the treatment for scarlet fever or for strep throat or for rashes. So unless you have further information which is not contained in your letter, this doctor has failed to prove the diagnosis of recurrent scarlet fever. Until he does, treatment with medications as powerful as penicillin and Erythromycin (which often fail to get rid of the strep and, even more often, produce rashes of
Their own) cannot be justified.

Since your daughter plans to become a nurse, careful investigation of her son's case may well be the most important part of her curriculum.

Our 18-year-old daughter inherited my tendency towards respiratory illnesses although she has not had too many bouts of these illnesses during the past three or four years. However, this past spring she had several cases of tonsillitis, and six weeks ago the doctor who has been treating her for ear infections recommended a tonsillectomy. We were concerned, and we questioned whether this would be the proper answer to her problem. We asked two other doctors: One said hers is a borderline case and, while he could not criticize the decision to operate, he would suggest waiting to see if she had another attack before agreeing to surgery. The other doctor, a pediatrician who has treated our daughter all her life, said she would not recommend the operation unless her hearing is affected. Doctor #1 claims hearing loss develops only in young children and wouldn't be a valid basis of judgment in this case.

We recognize that there is a certain risk inherent in any surgical procedure. And we also worry because there is a history of asthma in my wife's family and our daughter is subject to allergic reactions. We understand that a person's susceptibility to allergic reactions very often increases after the tonsils are removed. The pediatrician said wheezing and coughing attacks may develop if she proceeds with this surgery. Incidentally, our daughter is a member of her college swim team.

Please comment on tonsillectomy.--B.M., Jr.

You are to be congratulated on the careful investigation you have conducted. Dr. Richard Rapkin, professor of pediatrics, New Jersey Medical School, points out that tonsillectomy and adenoidectomy result in an estimated 100-300 deaths per year with a complication rate of 16/1000 cases. Rapkin states, "Removal of the tonsils makes streptococcal pharyngitis more difficult to diagnose, reduces the body's immunologic competence, and may increase the risk of developing Hodgkin's disease." I shun tonsillectomy except in the extremely rare cases in which the tonsils are so huge that they obstruct breathing. Obviously, this is not the case with your daughter.

In case you want to pursue your investigation further, one of my alltime favorite references on this subject, On the Psychology of Childhood Tonsillectomy (The Psychoanalytic Study of the Child, 1962), was written by a Chicago psychiatrist, Samuel D. Lipton, M.D.

Dr. Lipton first analyzes the psychologic repercussions of the operation and later presents a magnificent review of the medical literature of its 2,500 year history, demonstrating that this operation was and still is scientifically invalid. This classic study, which should be required reading for every patient contemplating tonsillectomy, states, "It is the operation itself which has survived rather than the indications."

My husband recently discovered that, because his tonsils were removed by irradiation (x-ray therapy) 25 years ago, he runs a high risk of developing a growth in his thyroid gland. He's afraid he may have to have thyroid surgery. Will it be necessary to remove this thyroid?--V.R.

There are almost as many conflicting opinions on this as there are physicians. The recommendations run the gamut from periodic physical examination of the thyroid, through radioactive iodine studies, all the way to the extreme measure of preventive removal of the thyroid gland.
The conservative approach recommends periodic examinations and excision of any nodules that may develop. If your doctor prescribes a procedure that your husband does not understand thoroughly, ask him to explain it and to advise if there are any potential hazards connected with it. Your husband has already been burned once, and he should do everything within his power to avoid a future conflagration.

During the past two years, I have been reading about the possibility of cancer in people who had x-ray treatment of tonsils when they were children. But none of those articles listed centers to which such people could go to have a thorough examination.

My son had these x-ray treatments. He now lives in the Washington, D.C., area, and he went to a doctor there who felt his glands and did nothing more. I called our family doctor, and his nurse said the usual exam was an x-ray of the lung area. The local cancer society could give me no information, and the National Cancer Society never answered the letter I sent, which asked for the name of a clinic where my son should go.

Please tell me where to go for this type of checkup.--Mrs. T.C.

Go right back to the doctor and/or hospital who gave those original x-ray treatments.

During my yearly physical, I told my doctor I had had x-ray treatment for tonsils when I was a teenager. I was concerned about the possibility of thyroid cancer because of what I had read. The doctor said I did have a small lump on my thyroid, and I either would have to undergo a yearly thyroid scan or I would have to take pills for the rest of my life to inactivate the thyroid.

I decided to have the thyroid scan, but now I'm concerned about whether this yearly x-ray won't just add to the problem. What information can you give me?--M.M.

Letters like yours continue to come in from people who have been damaged by x-ray treatment either for diseases which never existed (enlarged thymus gland) or diseases which could have been managed much more safely and effectively through other treatments (acne, enlarged neck glands, ringworm of the scalp, large tonsils).

Many people are unaware that the thyroid scan involves irradiation. According to the booklet Information for Physicians on Irradiation-Related Thyroid Cancer (U.S. Department of HEW Publications Number NIH 77-1120), the new agents deliver much lower radiation doses than those previously used, but that's hardly a reassuring statement to those already damaged by supposed safe doses of radiation. This booklet adds that, "the risk-benefit ratio of repeated scans is not known at this time."

If hormonal therapy is elected, the patient must be re-examined annually to check the adequacy of the therapy and to make sure that the dosage is not producing chronic hyperthyroidism.

When surgery is prescribed, one should remember that the incidence of nerve paralysis to the vocal cords is about 10 per cent, and there is also a significant incidence of tetany and permanent hypothyroidism.

All the above new treatments for x-ray damaged thyroids are long on theory and short on clinical experience. Therefore, before submitting to scans or swallowing the pills, you should ask your doctor what the documented experience is of those patients who have agreed to these treatments vs. those who have rejected them.
And I wonder how many patients who receive diagnostic radioactive procedures are properly instructed to eat separately from the rest of the family, refrain from feeding or bathing small children, and abstain from sexual intercourse for at least two weeks to avoid spreading the radiation.

My 32-year-old son was contacted by the Cancer Society and was asked to participate in a study being conducted at the Roswell Park Institute in our home town, Buffalo, N.Y. This study would determine whether he had malignant tumors as a result of x-ray treatments which he underwent as a teenager.

My son joined the study, going to the hospital once a month over a six-month period. He took the medication prescribed for him. At the end of that time, three doctors (one of them a surgeon) reported their findings and suggested treatment. An operation was advised to remove the nodes (or nodules), and all or part of this thyroid gland was to be removed. He was told he must take medication (desiccated thyroid gland) for the rest of his life even though there is no malignancy.

My son, his father, and I are very much against these procedures! Dr. Mendelsohn, can you suggest an alternate treatment or some other place he can go for further consultation?--A.C.

Several of my own patients whom I referred for x-ray therapy 20 years ago have surprisingly returned to me seeking advice on what they should do now. I am flattered by their faith in me, but I am skeptical about their judgment in seeking the opinion of the same person who damaged them originally.

The doctors at the center you mention as well as all the other cancer hospitals around the country are the direct descendents of all of us doctors who pointed the x-ray beam in the direction of the skin, tonsils, chest and lymph glands decades ago. And just as their ancestor-doctors experimented with radiation, these cancer doctors are now experimenting with surgery and hormones.

Lest anyone draw the improper conclusion that Buffalo is in a category by itself, let me assure you that the advice your son received could have emanated from any other high-quality, prestigious medical center in the country. My own hospital, Michael Reese Medical Center in Chicago, several years ago began offering a highly-publicized recall program providing free examinations for everyone to whom they had given this kind of irradiation in the past. Laudable as this program is, I hasten to point out that the management (surgery, thyroid scans, thyroid hormone, continued surveillance) resulting from these examinations is not free.

Now, back to your questions. Since your son, his father, and you all are opposed to the recommended procedures, the burden of proof lies with the doctors who believe in those procedures. I would advise you to ask them the following questions:

1) Since the treatment of accidentally irradiated thyroid glands has been going on for quite a few years, what are their own statistical results?
2) How many of these thyroid tumors have metastasized (spread) with a fatal outcome? How many have not?
3) What do the doctors think of the evidence that the overwhelming majority of such tumors, while appearing malignant under the microscope, do not spread in the patient?
4) What is the mortality rate from the surgery?
5) What are the complications of these methods?
6) What is the experience with the considerable number of these patients around the country who have rejected both surgery and thyroid hormones?

7) Since you ask for alternative treatment, are your son's doctors familiar enough with various nutritional approaches to provide a carefully considered judgment?

In addition to the verbal responses of the researchers, they should also be able to provide you with published scientific reports of their own and of other medical centers which can back up their recommendations. Only by thoroughly examining the evidence can you intelligently decide whether the advice you are getting represents a true advance in medicine or whether it represents a compounding of one bad experiment with another.

According to the December 24, 1979, issue of Medical World News, the principal diagnostic tool for determining whether a person is likely to have a heart attack is unreliable to an extent which was never realized before. The report quotes two studies which show that angiography, a way of x-ray ing the vessels of the heart, often either underestimates or overestimates artery blockage. Thus, some patients have had unnecessary bypass surgery, while others didn't have surgery which they may have needed.

In one of the studies, Dr. Harvey G. Kemp, Jr., chief of cardiology at St. Luke's Medical Center in New York City, had doctors at three medical centers look at the same x-ray. Dr. Kemp found the centers disagreed on the interpretation of the films 39 per cent of the time. And even when the same films were again processed through the same centers, the experts differed with 32 per cent of their own original readings.

In the other study, performed by the National Heart, Lung and Blood Institute in Bethesda, Maryland, and at George Washington University Medical Center in Washington, D.C., three independent experts examined coronary films of 28 patients who had died within 40 days after receiving the x-ray. These experts underestimated the degree of narrowing of the major coronary artery for 13 of the 28 patients, and they overestimated it for 10 of the 28 patients. Of 12 arteries narrowed to a dangerous degree, all were under- or overestimated by at least two of the three experts.

Dr. Arthur Selzer, chief of the cardiopulmonary laboratory at Presbyterian Hospital, San Francisco, says patients "without question" have gone to surgery on the basis of misinterpreted x-rays. But when asked whether these latest findings will slow the rate of bypass surgery, Dr. Selzer responded, "Not likely. There's too much money and pressure involved. It's become a self-perpetuating industry."

Dr. Mendelsohn's new book, "Confessions of a Medical Heretic" (Contemporary Books, $9.95) is now available at bookstores throughout the country.
Laurel was the only one of our seven children who had her tonsils removed. When she was four years old, the surgery was done on the advice of an ear, nose and throat specialist who felt it might improve her hearing. Concerned about the traumatic effect hospitalization can have on a child, we carefully prepared her for what lay ahead, and we made arrangements to take her into the hospital early on the morning of surgery. I would stay with her all that day and would bring her home the same night. Since she did not have to stay in the hospital over-night and was never left alone, it was a bit of a shock to me when she described her remembrance of that event 20 years later. She said she was scared when we arrived at the hospital and was perturbed that her eyes might be bandaged like those of the little girl in the next bed. But her strongest impression was that of being wheeled off to surgery while her mother walked away. "You just disappeared," she said. I was aghast, because I remember walking right alongside the cart as far as the elevator. It had been painful to see her go and I had tried to smile as the elevator doors closed. But, when her mother did not enter the elevator with her, what was a four-year-old supposed to believe other than that her mother had simply walked away?

Such an event may seem inconsequential in terms of the many other things that happen to us during a lifetime, yet, on reflection, I see it as just one more instance in which rules and regulations weaken the links that keep families together in spirit as well as in fact. How frightening it was to Laurel to surrender her consciousness while apparently deserted by her mother and surrounded by strangers! Once something like that happens, there is no way to undo it or make it up.

It seems to me that hospitals pose one of our greatest threats to family stability. We enter them when we are most vulnerable and when we most need to have someone whom we trust and love around. But hospital rules often make this all but impossible. At a time of crisis, when relationships could be strengthened, they are disrupted. Why aren't parents allowed to stay with their children while they are being anesthetized, and why can't parents be there to greet them when they awaken in the recovery room? What good reason keeps children from visiting hospitalized family members and friends? Who can justify keeping a parent outside in the hall when her child is brought into the emergency room in fear and pain? What short-term benefits can justify the long-term damage?

Ordinarily I hate to visit pediatric wards in hospitals. Yet, it was a genuine pleasure several years ago to visit the children's unit at Tarancke Base Hospital in New Zealand at the invitation of Leo Buchanan, M.D., head of pediatrics. At Dr. Buchanan's insistence, visiting hours had been abolished and parents were encouraged to room in with the sick child. Indeed, Dr. Buchanan isn't beyond phoning a parent in the middle of the night, telling her to get down to the hospital because her child misses her. Realizing that mothers often have another young child to care for, provisions are made at the hospital for the other child to accompany the mother while she stays at the hospital. And friends, as well as family are always welcome.

Medical care, if it is to be really "caring" must examine its procedures in terms of the effects it has on the families involved. We as parents must stand on our rights to protect the best interests of our families.