



SARCOIDOSIS NETWORKING

Volume XII Issue 5 September/October 2004

SARCOID IMPACT ON NUTRITION

It is well-known that Sarcoidosis can involve any organ of the body. The hallmark of this disease is the non-caseating granuloma, which causes scar tissue, and can disrupt the targeted organ's function. Interruption of digestion can affect total body function.

Nutrition involves ingestion, digestion, absorption and cellular metabolism. These actions process ingested food, so that growth, repair and maintenance of every activity of the body occur. This cycle is continuous. Each person is responsible for providing the body with the essentials needed to combat disease and malaise. A disruption in any stage of digestion is seen as a problematic factor in the process of nutrition. Warning signs can range from a tender mouth, problems with teeth that require a dentist's intervention, esophageal dysfunction, the mimicking of gastro-esophageal reflux (GER), stomach pain, change in bowel habits, to symptoms in the intestinal organs, such as the duodenum, liver, pancreas or gall bladder. Any of the previously mentioned situations must be addressed.

Weight—gain or loss—is a significant nutritional problem. Why so many Sarcoidians lose weight in the early stages of Sarcoidosis is not known. Weight management can become a major health concern for Sarcoidians, especially when taking corticosteroid (prednisone) therapy.

Oral health is the starting point of good nutrition. Care of the mouth and teeth are some of the earliest health preventatives a child learns. The mouth is the first organ of the digestive system. It consists of teeth for chewing (mastication), sensory glands (better known as taste buds) located on the tongue, salivary glands (providing the initial chemicals/enzymes to begin the digestive processes), and muscles to push the food into the throat, down the esophagus and into the stomach. One can see that the links between oral health and nutrition are numerous.

Regular examinations by a dental practitioner can screen for early warning signs of ill health. Caring for the teeth was once the primary concern of dentists. Yet, for some time now, dentists and dental caregivers have been at the forefront of oral hygiene and nutrition education. They stress that certain foods and eating habits can lead to tooth decay and other oral problems. The mechanics of eating are so natural; we often overlook the importance of the natural fluid or saliva, which begins the process of digestion.

Sarcoidosis involving the parotid glands (large salivary glands located on either side of the head just in front of the ears), was an early description of the disease. In 1909, the Danish Ophthalmologist, C. F. Heerfordt, described fever, uveitis, bilateral enlargement of the parotid gland and facial paralysis in three of his patients. [See Heerfordt's biography in the SN newsletter of Jan/Feb 2004, p.6.] Since that time, others have written about similar cases. It was not until the 1930s that enlargement of the parotid glands was recognized as a clinical feature of Sarcoidosis.^[1]

Sjögren's syndrome (decrease in tears or saliva {xerostomia/dry mouth}) in a milder form is mimicked in Sarcoidosis. It is important to maintain adequate moisture in the mouth, not only to help in processing food, but also to keep the delicate tissues (mucosa) of the mouth from drying and thus becoming a breeding ground for harmful bacteria.

Dr. Richard H. Winterbauer, M.D., advocated biopsy of the mucosa inside of the lip as the least invasive site in testing for Sarcoidosis. More than once, in remarks made at patient seminars, Dr. Winterbauer noted the ease of access and the minor discomfort to patients during such a procedure.

IN THIS ISSUE

<i>Sarcoidosis and Nutrition</i>	1
<i>Board Notice</i>	3
<i>Flu Shots</i>	4
<i>Calories from Sugar</i>	4
<i>Prednisone Weight</i>	7
<i>Unwanted Pounds With Medications</i>	8
<i>Grieving Loss</i>	9
<i>Better Health & You</i>	10

REGULAR FEATURES

<i>Around the Country</i>	3
<i>Bytes & Pieces</i>	6
<i>From the Editor</i>	2
<i>Golden Oldie</i> Stages of Lung Disease	4
<i>Healthwise</i> Records for the First Visit	11
<i>Inspiration Corner</i>	9
<i>Library Shelf</i>	11
<i>Living With Sarcoidosis</i>	5
<i>Social Security</i> Benefit Differences	6
<i>Library Shelf</i>	11

NEW BOARD PRESIDENT ASSUMES DUTIES

Marilyn Larsen, member of the Sarcoid Networking Association Board of Directors was elected president at the July 11, 2004 Board meeting. At that time, the Board accepted the resignation of Joe Ornowski. Joe has been a member of the SNA Board since 1994 and president nine of those years.

Ms. Larsen, became a board member in 1993, as representative of the Bellingham WA SNA chapter. She has served as Vice President of the Board since 1995. Elected to take Marilyn's position was Lynn Short. Re-elected as Treasurer and Secretary were Don O'Leary and Kristi Anderson respectively.

New members welcomed to the Board were Jerry Hansen of Tacoma WA and Theresa Lirette of Olympia WA. The remaining members of the Board of Directors are Judy Kay of Lawrenceburg IN and Ted Riley of Wichita KS.

The goal of the SNA Board is to direct the operations of the Sarcoid Networking Association in fulfilling the mission of the Association, which is to provide support to individuals, families and all who share our interest in Sarcoidosis; as well as support health officials and the medical community in on-going research of the disease. Are you interested in becoming a member of the Board of Directors? If so, contact Dolores O'Leary, Executive Director of SNA for more information at 6424 151 Avenue East Sumner WA 98390-2601 or email: sarcoidosis_network@prodigy.net. The Board will meet November 7, 2004 at 1 PM in the Baker Room of Good Samaritan Hospital in Puyallup WA. All meetings are open to the public. If you have concerns you would like the Board to address, contact Ms. O'Leary as directed above.

TIME FOR FLU SHOT

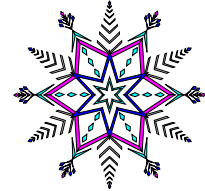
Fall is the time of year we are reminded to take another shot – literally – at preventing illness, in this case guarding against influenza.

You and your physician should evaluate your risk. You may be one of those lucky ones who have escaped the flu in the past. Examine if there have been changes in your health picture that might make you more susceptible this year? Have matters changed in your life, household or environments that give you more exposure to agents that cause flu?

The influenza virus changes constantly. Every year there is a new strain that threatens health, and even lives. Because the flu vaccine is made from inactive flu viruses, the inoculation does not cause an individual to develop the disease. Regardless the strain, the side effects of the vaccine are very similar – headaches, low-grade fever, or soreness at the site of injection. It takes 2 weeks after the injection for the vaccine to become effective.

The flu may not sound like a serious illness. Yet, it can cause life-threatening complications, especially in older people, diabetics, those with chronic cardiovascular or lung disorders, and individuals on immune suppressant therapy. The advice to get a flu shot is sound.

Contact your healthcare provider for flu



SARCOIDOSIS NETWORKING STAFF:

EDITOR-IN-CHIEF

Dolores O'Leary

COPY EDITOR

Rita Plourde

STAFF

Judy Kay

Don O'Leary

Cheryl Szyplik

WEBMASTER

Michael Lafrenière



AROUND THE COUNTRY, AROUND THE WORLD

CONFERENCES on SARCOIDOSIS

The SNA's Twelfth Annual Conference on Sarcoidosis, with the theme "Staying Well-Connected, is barely over and our office staff is busy answering requests for videotapes of the conference. We are also engaged in responding to questions generated by the Presenters, Town Meeting and Round Table discussions.

Planning is already underway for the next SNA conference and for the Patient Forum with the World Association of Sarcoidosis and Other Granulomatous Disorders (WASOG) Conference in Denver, Colorado, June 2005.

The Denver meeting is the first invitation, from WASOG to Sarcoidians and other parties affected by Sarcoidosis, to participate in that Organization's conference. Sunday, June 12, 2005, is the date for that golden opportunity. Make your plans and arrangements now. See you there.

Golden Oldie



STAGES OF LUNG DISEASE

Individuals with pulmonary sarcoidosis will often say they are at a certain "stage of the disease". Nine out of ten Sarcoid patients have some type of lung problem with one-third showing symptoms - usually coughing, either dry or with phlegm and shortness of breath. Some may have chest pain and feeling tightness in their chest. [1]

"Stage" refers to the degree of lung involvement seen on chest x-rays," reported Dr. Ganesh Raghu at the 2003 SNA's NW Sarcoidosis Fall conference. "This is an international classification system that groups any lung disorder in stages." X-rays are only pictures in reverse, like negatives. They cannot tell how poorly the organ pictured is functioning. They only indicate if abnormalities are present. When a disease begins, even these changes may not be seen on an x-ray.

Dr. Robert Baughman, M.D., Pulmonologist at the University of Cincinnati Medical Center outlined the lung involvement seen on chest x-rays using Scadding's classification: Stage 0 = normal; Stage 1 = hilar adenopathy alone; Stage 2 = hilar adenopathy plus parenchymal infiltrates; Stage 3 = parenchymal infiltrates alone; Stage 4 = pulmonary fibrosis.

Gallium scan will be positive in areas of acute disease. Computerized tomography (CT) may enhance appreciation of lymph nodes and high resolution CT scans show peribronchial disease. [2]

When there is pulmonary fibrosis (formation of scar tissue) it does not regress (return to normal) even with steroid therapy. This may be referred to as an obstructive pattern or COPD (Chronic Obstructive Pulmonary Disease). In the last stage, patients have difficulty getting air into the alveoli (smallest parts of the lung), where oxygen is inhaled and carbon dioxide is exhaled - a critical step in breathing. The air exchange is measured by pulmonary function tests (PFTs).

Steroids are the drug of choice in treating sarcoidosis. The purpose is to prevent scar tissue formation, if possible, and subsequent loss of organ function.

[1] National Heart, Lung and Blood Institutes, Publication No. 91-3093, pg. 9

[2] Baughman, Robert, Lower, Elyse; "The 5 Minute Consultation"



TASTY FOOD

Tickle your taste buds without fat or calories by making the most of herbs and spices. Thyme has a light, minty aroma.

Parsley gives kick and color to Italian-accented dishes. Cilantro has a lively, pungent fragrance that lends itself well to salsa, and rosemary pairs well with garlic in a savory sauce.

Spice it up!

Sprinkle chopped tarragon with dill or parsley over grilled chicken, fish, veggies, cottage cheese or soups. Many spice mixes are now salt-free.

Be creative.

Have fun with cooking.

CALORIES FROM SUGAR ADD UP

Why and where should you pay attention to the amount of sugar calories in your daily diet? If a person is hyperglycemic (high blood sugar) or hypoglycemic (low blood sugar), the easiest way to control the body's need for this natural food is to read the food label!

It's not just the amount of carbohydrate in that item, but you must also read the ingredients. Table sugar is not the only kind of carbohydrate to consider. Other "aliases" for the sweetener include: corn syrup, corn sweetener, honey, inert sugar, brown sugar, raw sugar, dextrose, maltose, syrup, fruit juice concentrate and high fructose corn syrup. Beware of ingredients that end in "ose", most often these are a form of sugar. No matter what type, all contain 4 calories per gram. Each teaspoon of sugar equals 4 grams. The average American daily intake of 2,000 calories will contain 12 teaspoons of sugar .

In the June 2004 Tufts University Health and Nutrition letter , "How Much Sugar is Right?" Tufts reports, "You don't necessarily see a 'clear dilution' of vitamins and minerals in the diet until sugar consumption reaches 25% of calories, even a much lower amount of sugar takes its toll."

The World Health Organization and US Dietary Guidelines agree that a healthy diet should contain no more than 10% of total calories from sugar, excluding that which is found in fruits (fructose) and dairy foods (lactose).

The Tuft's report goes on to say that "sugar sweetened beverages like sodas and juice drinks" are "causative" factors in obesity. We should be more aware of these added sugary foods and replace them with more fruits and vegetables as we strive for good

• • • • •
 • The greatest pleasure •
 • I know is to do a •
 • good deed by stealth •
 • and have it found out •
 • by accident. - •
 • Charles Lamb •
 • • • • •

LIVING WITH SARCOIDOSIS

Twenty-five years ago, Lynne Lally was diagnosed with Sarcoidosis. She didn't let that stop her. She continued to work, contributing to the life she and her husband had established for their children. Ten years ago she developed prednisone-related diabetes, but that didn't slow her pace. An accident at work, 4 years ago, did indeed affect her busy life-style. Several weeks of bed rest was ordered, while her shoulder and ankle healed. Her hospital bed was placed on the main floor of their home so she could continue to be part of family life.

A vacation was planned for all to enjoy. Amongst the preparations for the time away from home, Lynne cleaned the family's parakeet cage. Two days later, while on the much anticipated trip, she became ill. Returning to her own doctor, she was hospitalized with a high fever and was soon in a coma. The physicians were extremely puzzled by the suddenness of this strange turn of events. Everyone else in the family remained healthy. Finally, all Lynne's symptoms fell into place when the medical team learned of the parakeet. Lynn was diagnosed with histoplasmosis, caused by the parasitic fungus, *Histoplasma capsulatum*. She had not only inhaled this airborne contaminant in a massive dose, while cleaning the bird cage, but had also been inhaling small quantities from the air vents, while lying in bed near an air duct. Due to the suppression of her immune system by years of prednisone medication, the compromised system could not protect Lynne from the parasitic fungus. The healthy immune systems of the other family members, afforded them the resistance to the disease.

Lynne's brain was the focal sight of the fungal infection. Fluid accumulated in the brain. A shunt, or tube, was placed in the brain so that the excess fluid would drain into the spinal canal, where the body could dispose it through normal body function.

This does not end Lynne's story. A year ago, she suffered a stroke, which the hematologist theorized was not caused by a blood clot in the brain, but rather a "fungus clot". All in all, Lynn has had 6 brain surgeries, 2 of them to replace the clogged shunt.

Today Lynne stays as positive as possible, using humor daily as an outlet for her frustrations. In addition to the Sarcoidosis, she has diabetes and some of the usual health problems that result from long-term steroid use, namely: high blood pressure and elevated cholesterol levels. Medication helps in the control of these situations, but she takes an aggressive approach to management with diet and good nutrition habits. An exercise program has its limitations but Lynne is hopeful that after eye surgery, scheduled for early October, she plans to "really work at it." Currently she rides a stationary bike as her double-vision makes it very difficult to do a lot of repetitive movements.

"I fight like a She-devil," Lynne retorts, "I work hard at being able to accomplish all that I can." Shopping trips with family members are rarely curtailed because of the need of a wheelchair. "I go on my own as much as I can, but sometimes I have to use it," says Lynne. "I prefer to shop for Christmas gifts by catalogue. It may be more expensive at times, but I can take my time and there is no hassle. When they arrive, I wrap them and put them away until the holiday." This is one way she conserves her energy for the more important family activities with her spouse, children and grandchildren. She knows her limitations, is constantly working at reducing the ones she can and accepts those she can't. "I have to avoid soil or places like zoos and parks, where the bird fungus accumulates." This includes no working with flower pots or having a pet bird.

Lynne says, "My sense of humor and supportive family are very important. Life would be pretty miserable without them. I'm determined to find some other ways to make my life meaningful. My family and support network are the keys to achieving my goal."

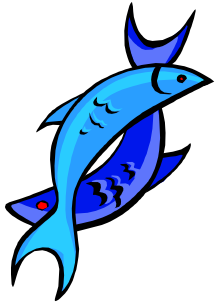


MAKE IT A PERSONAL CALL

A pleasant way to exercise with a purpose—visit in person and hand deliver your message of friendship.

Let them see your face and give your phone or e-mail a rest.

It's old fashion, but such a very nice way to say you are thinking about them.



EATING RAW SEAFOOD?

High-quality, fresh seafood is important.

At a restaurant, it must be sushi grade or high quality, and prepared by highly-trained chefs, who know how to buy and prepare raw seafood for safety and sanitation.

Individuals who should not eat raw or partially-cooked fish, are those with impaired immune systems, liver and/or gastrointestinal disorders, kidney disease, cancer, diabetes, and/or pregnancy.

eDiets, 10/9/04

BYTES & PIECES

By **Judith L. Kay**

All web sites are not created equal and that includes medical web sites. Always try to find reputable medical sites. Some of the good medical sites are sponsored by the federal government, universities, and health care organizations. Look for the following web site extensions: **.gov; .edu; and .org**. That does not mean that there are not reputable .com web site extensions.

Keeping the above in mind, do a Google search (google.com) typing 'sarcoidosis' as the search word. This search produces 161,000 results. If you type 'sarcoidosis support groups' 13,000 web sites are revealed. Now do a Yahoo search (yahoosearch.com) again typing 'sarcoidosis' as your search word. 153,000 web sites are found and when searching for sarcoidosis support groups 23,000 sites are found. Some of the Sarcoidosis Support Group web sites are duplications from the Sarcoidosis web sites.

Be selective when choosing which web sites to view. Be especially alert when in discussions, chat rooms, etc. Some are all "gloom & doom"; some are very informative; some contain mis-information; and some are very supportive. Be cautious!

HAPPY RESEARCHING!

^o^
\/ **Judy**

• • • • • • • • • • • • • • • •

• Everything •

• can be taken from •

• a man or a woman •

• but one thing; •

• the last of •

• human freedoms – •

• to choose one's attitude •

• in any given •

• set of circumstances. •

• To choose one's own way. •

• Viktor Frankl •

• • • • • • • • • • • • • • • •

EARLY RETIREMENT OR DISABILITY BENEFITS

When the early retirement age of 62 approaches, disabled persons, who are still working, should closely examine their options. Some people struggle to keep working in spite of their medical condition(s), but they may be able to receive more income through Social Security Disability (SSD) benefits than from early Social Security Retirement (SSR) benefits. Be aware that if you become disabled before age 65, contact the Social Security Administration (SSA). You may be eligible for SSD benefits.

Full SSD benefits are based on the amount the worker has paid through FICA deductions or self-employment taxes and are not subject to reductions. SSD benefits are paid until full retirement age. The amount of early SSR monthly benefits is reduced by a specified amount if income earned through wages or net self-employment income exceeds the annual earnings limit. Medicare coverage begins 25 months after the onset of SSD payments, regardless the beneficiary's age.

Other factors to consider are whether the person is receiving worker's compensation (WC) for a work-related injury, or private long-term disability insurance benefits (LTD). This class of workers might receive greater benefits by taking an early retirement. WC and LTD payments are deducted from SSD benefits. However, the offsets will stop if early SSR benefits replace SSD benefits.

Calculation of a current retirement benefit is online at: www.ssa.gov/retirechartred.htm. Since there are many variables in each worker's or potential retiree's eligibility profile, concerned persons should contact the SSA directly. Retirement benefits will begin immediately when full eligibility age is reached; however, one must file an application to determine eligibility for disability benefits. Contact the SSA office in your area to evaluate your options. (Editor's Note: The nationwide toll-free contact number is 1.800.772.1213. TTY is: 1.800.325.0778. The SSA's website is at: www.ssa.gov.)

The SSA's explanation of benefits is always free of charge. If you are still perplexed after visiting the local SSA office, or your situation appears very complicated, seek the help of a retirement counselor, or advice from an attorney who specializes in SS law.

Social Security Newsletter©, Jan. 2004
Edited for publication.

MANAGING PREDNISONE WEIGHT GAIN

It is not often that a physician will give detailed information to a patient, who is experiencing a rapid weight gain soon after initiating prednisone therapy for Sarcoidosis. Traditionally doctors receive only the barest of education in nutrition at medical school. Those who are knowledgeable have had to do much self-education and extensive post-graduate study.

In our society and the news media, much attention is being given to the rapid growth of obesity. Many of the diets, that are publicized today, do not begin to help those who have a weight problem due to medications.

In order to understand why one gains weight with prednisone, the specific actions of the drug must be examined. When such is related to food metabolism, each issue must be addressed. A person may be taking more than one medication, which contributes to weight gain. One must be fully aware of all possible contributing factors for effective weight management. In this article, we will only examine prednisone, the primary immune system suppressant.

To combat water retention, reduce the amount of salt in your diet. Any number of "heart healthy" diets will provide numerous ways to control sodium intake. Another advantage to salt restriction is that it contributes to lowering blood pressure, which can be a side effect of long-term prednisone usage.

Additionally, non-insulin dependent Diabetes II can develop in susceptible individuals, who are prescribed long-term prednisone treatment, in order to manage the Sarcoidosis. The term, "prednisone-related diabetes", is sometimes used when care providers discuss such a situation with the concerned person(s). By making changes in their diets, many Sarcoidians have had good control of their blood sugar levels. Reducing the amount of carbohydrate intake and eating fresh, nutritional foods, can avoid the need to use insulin - by either injections or pills.

Long-term prednisone use can also affect cholesterol levels. Lowering the dietary intake of animal fats (saturated fats) is one way to combat the risk of cardiovascular disease. Medications, especially the class known as "statins", are effective drugs when cholesterol and triglyceride levels are unhealthy.

There is any number of ways to combat obesity. Losing weight is *not* easy. Many individuals hope that some food formula or diet craze may be the answer for them. Most likely to succeed are those dieters who include lifestyle changes, and become involved in some increase of activity on a regular basis. Eating smaller portion size, results in less calories eaten. There is no magic potion to make you lose extra pounds. Actually, the only way to lose weight is to make sure you eat fewer calories than you do burn with your daily activities. Simple formula, challenging to solve...but so rewarding to accomplish.

A referral from your physician to a nutritionist or dietitian may be helpful. This person is trained to know the nutritional values of food, and the balanced combination of recommended vitamins and minerals needed for individuals to support their body healthfully. Registered nutritionists and dietitians have the expertise to evaluate lab results and their impact on nutrition. These care providers address abnormal blood values so that a person can focus on changing them with good nutrition. Their mission is to educate. Allergies, food sensitivities and the ethnic foods favored by a dieter, challenge the creativity of everyone concerned. It takes considerable planning, guidance and support from the professional and everyone around the dieter, to successfully develop and maintain beneficial eating habits.

Individuals who must take medications that interfere with the body's metabolism will have to make a great effort to manage their weight. They will need the consideration and support of everyone around them to bring about a healthier lifestyle.



HALT

An easy way to remember a thought or list is with an acronym. HALT is a good way to help one change eating habits.

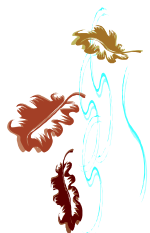
H - hunger. Have a Healthy snack for times when you feel you must eat something outside of meal time.

A - angry. Annoyed? Take a walk, journal, talk with a friend. Find comfort in things other than food.

L - lonely. Less likely if you are around others. Make a point to do something with a friend on a regular basis.

T - tired. Take time for yourself, do something inspiring or take a catnap.

Author Unknown



The air may be cooler and the days shorter,
but there is no better time to turn a new leaf
-- or just enjoy the leaves.

Anonymous



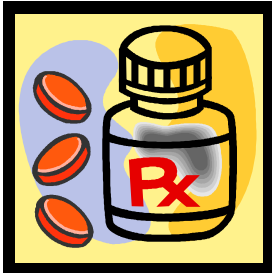
UNWANTED POUNDS WITH MEDICATIONS

Do you suspect that some of those extra pounds with which your body is padded, in usual and unusual places, might have something to do with the medicines you take? Take heart! Lawrence Cheskin, M.D., Director of the Johns Hopkins Weight Management Center concurs. "Medicine-related weight gain has become far more important over the past decades as obesity increases in prevalence and more people are taking medications for chronic illnesses." Weight gain can be from a few pounds to more than 100 pounds and may occur over weeks, months or years. Not everyone is susceptible to weight gain from medications. Be aware that steroids (prednisone) are not the only class of drugs guilty of producing such an effect.

It is no secret, excess weight can cause or worsen health conditions like high blood pressure, other cardiovascular diseases, diabetes, high cholesterol and osteoporosis. Often these conditions are the reason drugs are prescribed in the first place. If you suspect any medication you are taking may be contributing to your weight gain, **DO NOT STOP TAKING IT!** Contact your physician and discuss lowering dosage, or prescribing other medication(s), like steroid-sparing alternatives, that will have a similar effect in controlling your health problem(s), yet not significantly contribute to weight gain.

Why some medications contribute to increased weight is not understood. Some drugs stimulate appetite, while others cause fatigue, thereby reducing energy levels and the resultant lack of motivation to activity. Still other substances trigger water retention.

Below is a list of medications associated with weight gain. Medications listed to treat one disorder may also be used to treat an unrelated health problem. An example is clonidine, which is used to lower blood pressure, is also used in the treatment of Attention Deficit Disorder (ADD). Controlling the illness for which you have been prescribed medication is more important than associated weight gain. To counter-act this, take an active part in lifestyle changes and increase activity levels. Always talk with your doctor about *any possible* side-effects of new and current medications, if you have not already done so. Your pharmacist will always be able to give you detailed information about medications. You have only to ask.



LEARN TO BE PATIENT

You'll live longer.

If you find that you are

being particularly critical of the response time

of the sales help,

check in with your inner critic -- maybe you are as hard on yourself as well.

Perhaps you need to show a little more compassion for others and for yourself.

It's a great time to do a "breath-check".

Use your diaphragm to slow the rate of inhaling.

You might

be surprised at how quickly

the heart rate decreases.

Some of the Drugs Associated with Weight Gain

Antihypertensive

- | | |
|--|--|
| 1. Alpha-adrenergic blockers (<i>clonidine, methyldopa, prazosin, and terazosin</i>). | 1. Switch: doxazosin or guanfacine |
| 2. Beta-blockers (<i>Propranolol</i>) | 2. Switch: selective beta blockers like atenolol |
| 3. Calcium channel blockers (<i>Nisoldipine</i>) | 3. Switch: amlodipine, diltiazem, nifedipine. |
| 4. Direct vasodilators (<i>Hydralzine & minoxidil</i>) | 4. Take in combination with a diuretic |

Ask About these Possible Solutions

Diabetic Drugs

- | | |
|--|--|
| 1. Insulin (<i>Intensive insulin therapy</i>) | 1. Switch: once-daily insulin therapy |
| 2. Sulfonylureas (<i>glipizide, glyburide and Glimepride</i>) | 2. Add metformin, acarbose or miglitol |
| 3. Thiazolidinediones (<i>pioglitazone and rosiglitazone</i>) | 3. Add metformin, acarbose or miglitol |

Antidepressants

- | | |
|--|--|
| 1. Atypical antipsychotics (<i>clozapine, risperidone and olanzapine</i>) | 1. Switch: aripiprazol or ziprasidone |
| 2. Mood stabilizers (<i>lithium, carbamazepine and valproate</i>) | 2. No alternatives available |
| 3. Selective serotonin re-uptake inhibitors (<i>paxil</i>) | 3. Switch: citalopram, escitalopram |
| 4. Tetracyclics (<i>Mirtapine</i>) | 4. Switch to a drug from a different class, i.e. an SSRI |
| 5. Tricyclics (<i>amitriptyline, imipramine, trimipramine, doxepin</i>) | 5. Switch to nortriptyline or desipramine |

Corticosteroids (prednisone, methylprednisone)

Take lower doses to control medical condition

Epilepsy drugs Many drugs used for epilepsy are associated with weight gain especially valproate and carbamazepine.

Seizure medication must be carefully monitored before any change is made.

GRIEVING: IT'S NOT RESTRICTED TO LOSING A LOVED ONE

The stages of grieving are often thought to be related to working through the death of a person. Grieving is actually the reaction to the loss of anything, including our health and/or healthy weight. In her book, *We Are Not Alone*, Sefra Pitzele puts it this way, "We grieve for ourselves. We are sad because of what we have lost, including our health, our normal routines, and the future opportunities that will never be." She also reminds us that we grieve over the loss of control of our own body. We grieve the loss of Self.

The order of the grief stages, as well as the length of time at each stage, will vary with each griever and each situation. According to Dr. Michael McKee of Cleveland Clinic's Psychiatric and Psychology Dept., men seem to have a more difficult time with the emotion of grief than women do. "They don't have as much of a support system to call upon when a tragedy occurs. For one thing, they don't discuss their feelings and are less likely to form close friendships outside marriage."

Loss of health is no different than the loss of a family member, friend, relationship, or employment. One proceeds through the grieving process even though it might be an unconscious behavior mode. The process recurs with each loss, each diagnosis and every relapse. For each occurrence, a person needs to pass through each stage at least once more. It may take only seconds for some; while others struggle at a particular stage before moving on. The process does repeat, regardless the type of loss.

The stages of grieving are:

1. **Denial** - This normal reaction usually presents itself first and lasts until one is ready to accept reality. The less threatening the event, the lower the level of denial: "So what, I can handle it."

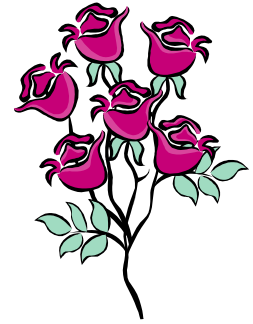
2. **Anger** - This stage can be the most difficult phase to manage. While one learns appropriate ways to deal with this emotion, it requires the infinite patience and understanding of those around us.

3. **Bargaining** - It can occur along with the other stages and ends when one realizes the ineffectiveness of negotiation. With a disease like sarcoidosis, lack of good health is there no matter what we do or don't do.

4. **Depression** - This stage can be the longest and most frequent. It is the predictable phase in the normal process of grieving. It occurs when we seem to have nowhere to turn -- when control of our body is lost. One can feel physically tired, listless and unmotivated. This is the stage where one must take the time to examine and eventually resolve all the issues relating to the loss of health, before moving onto the fifth stage becomes possible.

5. **Acceptance** - At this stage, one acknowledges that illness may have changed the focus of certain goals. One also accepts that priorities and values might need to be adjusted. The determination is made to move forward, by using coping skills and new knowledge to live a productive and rewarding life.

Understanding the 5 stages, permits the opportunity to make change when and where it is needed. Even though illness has removed some challenges, others are given. We choose the matters we can appreciate and not despair over the losses or situations we cannot change.



OBESITY and LIVER DISEASE

The national epidemic of obesity has highlighted the importance of losing weight thereby lowering the risks of coronary heart disease (CHD) and type 2 diabetes. But, anyone who is severely overweight, should also be aware of a third, lesser-known, yet highly important obesity-related disorder. Non-alcoholic fatty liver disease (NAFLD) affects an estimated 25% of American adults. If liver function studies have not been evaluated in the last 6 months, ask your physician to order a liver series.

CORNER

INSPIRATION

WORDS

Words are like feathers riding on the wind.
Words fly about and come to land anywhere.
Words can lead to dysfunction. Words can be life-giving
Words come back to the speaker, others never return.
Words wound and scar, others sooth and comfort.
Words destroy, others build or rebuild.
Words agitate, others calm.
Words encourage, give hope, lift up another.
Words reflect what is in the heart.

Anonymous

PORTION CONTROL

Invest in a kitchen scale, measuring cups and spoons. These tools will help ensure that you're not over-eating. Portion control is critical when it comes to losing or maintaining weight. Learn how to estimate how much you should be eating by accurately measuring your food and before long, you'll be able to "eyeball" the amount you need.



BETTER HEALTH AND YOU

PART I

A balanced diet and regular physical activity are the building blocks of good health. Poor eating habits and too little physical activity can lead to overweight and other related health problems. By eating right and being active, you can stay at, or reach a healthy weight.

Health Risks of Being Overweight

Extra weight can put you at a higher risk for:

- ± type 2 diabetes
- ± high blood pressure
- ± heart disease and stroke
- ± some types of cancer
- ± sleep apnea
- ± osteoarthritis (degeneration/destruction of the joints)
- ± gallbladder disease
- ± irregular periods
- ± problems with pregnancy (high blood pressure or increased risk for cesarean section)

Factors for Weight Gain

People gain weight when the number of they eat is more than the number of calories their bodies use. Many factors play a part in weight gain.

Habit: Eating too many calories can become a habit. So can choosing activities such as watching TV instead of being physically active. Over time, these habits can lead to weight gain.

Genes: Overweight and obesity tend to run in families. Although families often share diet and physical activity habits, which can play a role in obesity, their shared genes increase the chance that family members will be overweight.

Illness: Some diseases can lead to weight gain or obesity. These include hypothyroidism, Cushing's syndrome and depression. Talk to your healthcare provider if you think you have a health problem that could be causing you to gain weight.

Medicine: Some medicines can lead to weight gain. Ask your healthcare provider or pharmacist about side-effects of medications you are taking.

Environment: You can find food and messages about food at home, at work, at shopping centers, on TV and at social events. People may eat too much, just because food is always there. Besides that, our modern world – with remote controls, drive-in services and escalators – makes it easy to be physically inactive.

Emotions: Many people eat when they are bored, sad, angry, or stressed; even when they are not hungry.

Although you may not be able to control all the factors that lead to overweight, you can change your eating and physical activity habits.

TOPS News; August-September 2004

HISTORIC PERSONALITIES

This is the seventh excerpt from an essay by Dr. Geraint James: "The Sarcoidosis Movement and Its Personalities" which honors the pioneers of the medical research and practice communities in memoriam. The series was begun in the SN Sept/Oct 2000 issue.

Sven Lofgren (1910-1978)

Sven Lofgren was a man of Stockholm in the same sense that Louis Siltzbach was every inch a New Yorker. Sven was born on 1 March 1910, received his medical training there and married a Swedish physician, who bore him four children. His medical life revolved around St Goran's Hospital, where he came under the scientific influence of Westergren and Schaumann. Sven grasped the baton handed to him by Schaumann and his own elegant studies brought the mysterious disease out of the shadows and into the limelight as a common disorder with a good prognosis. During the war years, he analyzed 185 cases of erythema nodosum and found 15 patients in whom sarcoidosis was probable despite lack of histological proof. In a second Swedish survey, published in 1953, he obtained histological proof of sarcoid tissue in one-quarter of a series of 113 patients with erythema nodosum and bilateral hilar lymphadenopathy, and quite rightly, this combination has been known as Lofgren's syndrome ever since.

Once he had defined it, the rest of the world recognized it. When he attended the first World Conference on Sarcoidosis in London in 1958, he was strongly of the opinion that sarcoidosis was unlike and unrelated to tuberculosis and he favored a viral etiology. In this London Sarcoidosis Conference, he described renal sarcoidosis with kidney biopsy evidence of granulomas and associated abnormal calcium metabolism. In the Washington Conference (1960), he made an erudite analysis of the course and prognosis of sarcoidosis, and provided a thought-provoking study of cytopathic changes in tissue culture suggesting a viral etiology of sarcoidosis.

In 1971, Sven Lofgren was awarded the title of Professor, an unusual honor in Sweden for a physician practicing outside a university department.

LIBRARY SHELF

Here are some resource books you may want to add to your own health library. The publisher and contact addresses are listed before each section. Be advised that any information, covered in these publications, is not intended to replace the medical advice of your physician, but only to make you a more informed health consumer.

UC Berkeley Wellness Letter, Publisher: Rebus, New York or www.WellnessLetter.com for price and & ordering information.

Wellness Foods A to Z. A guide for health-conscious food lovers by Sheldon Margen, M.D. and the editors of the *UC Berkeley Wellness Letter*. Covers 500 foods in a quick-reference format and easy-to-read print.

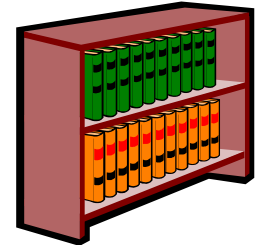
The Complete Home Wellness Handbook. A comprehensive book which tells how to recognize, treat and prevent 160 common ailments with authoritative guidance on home remedies, preventive measures, OTC medications, alternative medicine, diet, exercise and other wellness strategies.

Mayo Clinic Books, Publisher: Mayo Clinic, Rochester MN. Internet search: MayoClinic.com, click on Health Information, then click on Books and Newsletters. Each book is titled: “Mayo Clinic on...” followed by the subjects such as Healthy Weight; Chronic Pain; Vision and Eye Health; Family Health Book, and other topics. These easy-to-understand publications help individuals lead a more active and productive life, with answers from the world-renowned Mayo Clinic.

Another resource is *Johns Hopkins Health After 50*, which publishes books through Rebus, New York. The website is www.hopkinsafter50.com for complete book list and prices.

The Johns Hopkins Complete Guide to Drugs. Find answers quickly and easily to questions and concerns about prescription and OTC medications. Explanations are clear and concise, in understandable patient language.

The Johns Hopkins Comprehensive Guide to Medical Tests. Clear and easy to understand, this book will help you take full advantage of the most commonly used preventive screening and diagnostic tests available today.

**Disclaimer ...**

SNA does not endorse any of the medications, treatments, or products reported in this newsletter. This information is intended only to keep you informed. We strongly advise that you check any drugs or treatments mentioned with your physicians or pharmacists.

PREPARING FOR THAT FIRST VISIT

On the first clinic visit, many physicians will ask new patients to complete a form that may be 3 or 4 pages long. This form will cover a wide range of possible physical complaints, past and present, and may include a request about your family medical history. The answers assist the examining physician by providing clues to your physical, emotional and mental health.

When you make your first appointment, ask if you will be required to fill in a “New Patient Information” form. If so, and there is an interlude several days, request a copy be mailed to you so you can complete the form at your leisure -- and near to your medical records and other resources. Should this not be possible, be sure to give yourself plenty of time at the office, prior to the scheduled appointment, in order to answer the many health-related questions. Go prepared!

Information required of you will cover your entire life. Questions will be asked about operations, when and where they were performed; minor surgical procedures, such as biopsies and their reports; previous diagnoses; also treatments and current medications. If you do not already have a copy of the reports from any biopsy in your home file, contact the physician who ordered or performed the service(s), and request a copy. By law, you may request a copy of your records once a year. A printing fee may be charged. Prior to obtaining copies of office visit notes from a previous provider, ask the staff at the new care provider's office if that professional usually prefers to have such information available at the first visit.

Have you been keeping a health diary? The information recorded periodically by you, will make the task of completing medical history records much easier, more accurately and in a shorter period, especially if you answer the questions at home, without the pressure of being in a different and possibly distracting environment.

Other information asked of you, besides your own health, will be that of family members – your parents, siblings, children—and in some cases aunts, uncles and grandparents. This alerts the doctor about possible risk factors like diabetes, stroke or heart disease.

When you have completed such a form, make a copy or ask the office staff to copy the one you just finished. Keep it in your home file. Having a copy of the intake form in your home file for



**You must be the change
you wish to see in the
world. Gandhi**

**Phone Hours 8 AM-8 PM
Pacific Time
253-826-7737**

**or e-mail:
sarcoidosis_network@
prodigy.net**

SNA Web site

www.sarcoidosisnetwork.org

**No two snowflakes are
identical and no two
individuals with
Sarcoidosis appear to
have identical symptoms.
Therefore, snowflakes
have been chosen to
symbolize Sarcoidosis.**



Our deep appreciation to
Good Samaritan Hospital,
Puyallup, WA for printing
this edition of
Sarcoidosis Networking

**TEMPORARILY
AWAY?**

Newsletters are not held
by the Post Office, but re-
turned to SNA requiring the
organization to pay a first
class postage fee. Newsletter
service will not be resumed
unless the subscriber noti-
fies the office. Please notify
the Editor when and where
to deliver your newsletter
after **each hold.**

Sarcoid Networking Association

6424 151st Ave E
Sumner WA 98390-2601

RETURN SERVICE REQUESTED

NON-PROFIT ORG.
US POSTAGE
PAID
Puyallup WA
98371
Permit #93

**YES! I'D LIKE TO PARTICIPATE IN
SARCOID NETWORKING ASSOCIATION**
(A Not-For-Profit Organization) S/O 04

- An Annual Participation Gift of \$25
- A Special Gift of _____
- Receive Newsletter.
- Sorry, I can't make a donation now.

*No one is refused the newsletter
because of inability to make a gift.*

e-mail or postal address change

OLD INFORMATION HERE:

Name _____
Address _____
City, State, Zip _____
Phone _____
E-Mail _____

NEW INFORMATION BELOW:

Name _____
Address _____
City, State, Zip _____
Phone _____
E-Mail _____

**WHAT IS SARCOIDOSIS
NETWORKING ?**

**SARCOIDOSIS
NETWORKING**

is published by the Sarcoid
Networking Association —
individuals with Sarcoidosis
and those interested in this
disease — six times a year.
Since 1992, its sole purpose
has been to heighten awareness
and form a network with each
other, the medical community
and the general public.

It is not intended to replace
the advice and/or diagnoses by
healthcare professionals.

**You are advised to seek
proper medical attention
whenever a health problem
arises requiring an expert's
attention.**