

MULTIPLE SCLEROSIS NEWSLETTER

1983

From the office of Roy L. Swank, M. D.

No. 15

Oregon Health Sciences University, Portland, Oregon 97201

Editor - Barbara Dugan

Asst. Editor - Ruth Selby

Production - Ruth Stewart

In former letters, we have discussed factors which influence the health of patients with multiple sclerosis. These included very warm weather and weather changes, nervous tension, physical fatigue, and infections. In this letter, I will focus on urinary infections, their effects on the disease and methods of prevention and treatment.

Burning and discomfort of the urethra and frequency and urgency of urination are early signs of a bladder infection. Fever usually develops and it may do so with very little warning. Fatigue and an increase in neurological symptoms, and even re-appearance of symptoms long forgotten may follow or accompany the fever. In some cases, inability to void (urinate) will necessitate catheterization. Examination of the urine will reveal the tell tale signs of infection, bacteria, white blood cells, and epithelial cells.

Treatment with antibiotics for seven to fourteen days is usually sufficient to control the infections. This should be combined with a liberal intake of water. If infections recur, it is necessary to determine if the bladder is empty after urination. This is done by catheterization after urination. The urine remaining in the bladder after urination is referred to as residual urine, and the constant or even frequent presence of residual urine in the bladder pre-disposes to urinary infections. One sign of failure to empty the bladder is the urge to urinate again some minutes after urination.

Residual urine in the bladder is much more common in women than in men. This is usually the result of childbirth which weakens the support for the bladder and allows the bladder to sag forming a pouch in which the urine collects and in which bacteria can grow. Residual bladder urine can be reduced and sometimes prevented by bending forward and pressing on the abdomen during urination. This simple postural and pressure exercise can often prevent urinary infections, but only if done routinely.

There are those patients who have a tendency to have repeated bladder infections. After the bladder infection has been cleared by daily antibiotic treatment for seven to fourteen days, we have found that a full day's dose of antibiotic one day a week is effective in preventing recurrences of infection. This one day a week treatment should be continued for six to twelve months. This allows the bladder mucosa to become healthy and resistant to infection. The posture pressure exercise during urination should be continued, however.

There are a number of treatments which patients have claimed to be effective in preventing urinary infections. One of these is cranberry juice. I cannot judge its efficacy, but can see no harm in trying it.

Another cause of increase in multiple sclerosis symptoms is a cold or "flu." Multiple sclerosis patients on our low fat diet have few colds. This could be due to the diet plus Cod liver oil or to immunological characteristics of the patients. Even though flu is relatively infrequent in our multiple sclerosis patients, they can occasionally "catch" it. If accompanied by fever, symptoms will always increase and frequently when there is no fever, symptoms will worsen. The most effective treatment is bed rest. Antibiotics should not be resorted to unless evidence of local infection such as sore throat or bronchitis develops. While in bed, liberal intakes of fruit juices and water are indicated.

There has been considerable demand for plasma treatment. I will try to clarify when plasma can be expected to help and when it probably will not be helpful. It is very helpful as a rule in early cases who are in acute exacerbation. Because of the danger of hepatitis from the infusion I will only recommend it when I feel this risk is justified. Mild fluctuations can be expected to recover and do not justify the risk.

Also remember that following the stress of the holidays many patients become very tired and develop slight increases in symptoms or that long forgotten symptoms re-appear. These usually go away with rest and relaxation and do not justify the use of plasma. (See newsletter No. 2, dated December, 1979.)

In addition to the post-holiday problems, seasonal changes are apt to cause symptoms to be aggravated. In the Fall during October-November and in the Spring during April-May the weather is usually unsettled and greater than normal temperature changes occur from day to day. Several days after a series of these weather changes many patients will feel badly and in some patients mild aggravation of symptoms will recur. Rest and relaxation is the best treatment for these periods of aggravation. Also remember that physical exertion in excess of your limitations, will cause aggravation of your illness.

Severely disabled patients who have been disabled for years are usually not helped, or are helped very little by fresh frozen plasma infusions. This leaves a large number of cases between these two groups in which the decision has to be made on an individual basis. We will seriously consider all benefits as well as risks before plasma is recommended in this large group of patients. Please bear with us.

The telephone has been of great help to patients who are ill. It makes possible continuation of treatment without the inconvenience and expense of visiting the office. The great majority of calls have saved time and been helpful in reducing disabilities in patients. On an average day, our phone will be busy much of the time and will occupy a major part of Barbara's, Ruth's and my time. Many of you have expressed some difficulty in contacting us by phone because "the line is always busy." We ask your cooperation in keeping calls as brief and to the point as possible. In this way, we can continue to be available to you when you need us most.

Most calls have concerned insurance and social security or other benefits. These we cannot handle over the phone. If you will write us a brief letter concerning such matters we will handle them expeditiously and also be free to handle telephone calls concerning your illness.

We have installed a new answering service which we hope will help handle your calls. We realize this is impersonal, but we do want to avoid missing your calls. Please help us by cooperating and leave your name and number and we will call you back.

LET'S TALK ABOUT DIET

Several of you have inquired about the new "Healthy Low-Fat Gourmet Fast Food" products on the market. Many of these products are prepared in air tight water proof bags which you simply drop in boiling water for a few minutes and you have a so-called balanced gourmet dinner.

It is our feeling that during the processing of these foods essential vitamins and minerals are lost. The product of course is fortified with those vitamins lost, but how about those vitamins that cannot be replaced? These products contain between two to ten grams of saturated fat. This is equal to one serving of beef. We realize for those patients experiencing periods of fatigue this is very convenient. However, we do not feel you will gain maximum benefit from diet by using these products. THEY ARE NOT ACCEPTABLE ON DIET.

NEW PRODUCTS

Dairy-Lite and Weight Watchers non-fat yogurt can be eaten in unlimited amounts. They are made with skim milk and contain no saturated fat. These can be found in most grocery stores.

COUNT-DOWN CHEESE - It has become very difficult to locate Count Down Cheese. We have found that ordering it from the company direct is cheaper and very convenient. The cost of the cheese West of the Mississippi is \$4.75/2 lb. loaf, and East of the Mississippi is \$4.25/2 lb. loaf. The address is: Diet and Health Products, Inc., P. O. Box 1886, Lima, Ohio 45802.

EVENING PRIMROSE OIL - As you may know, evening primrose oil is one of the sources of essential fatty acids used with the low fat diet in treatment of multiple sclerosis in England. We have not used this oil; instead have been using Cod Liver Oil since 1952. Some of you have elected to use evening primrose oil either alone or in addition to the Cod liver oil. Analysis by the U. S. Department of Agriculture of different samples of evening primrose oil now available on the market have revealed that the imported capsules of the oil from England contain the gamma-linolenic acid which is regarded as the essential fatty acid. One other encapsulated oil sold as evening primrose oil was also analyzed and proved to contain none of this essential fatty acid. This oil was equivalent to soybean oil which one can purchase at the super market.

We would advise those of you who wish to continue with evening primrose oil to be sure the oil is from England.

TASTEFULLY YOURS - The Portland Multiple Sclerosis Society Cookbook is now available with a wide variety of favorite regular recipes and recipes low in saturated fats. The book also includes a garden ideas and helpful hints chapter. In addition, it contains sketches of historic Portland buildings drawn by Carl Adels, a local artist with MS. To receive a cookbook, send a check or money order payable to the Multiple Sclerosis Society of Portland and mail to: The MS Society of Portland; 1226 S.W. 16th, Suite 18; Portland, OR 97205. Please allow 3 to 4 weeks for delivery. Cost is \$7.95 for the book, including postage.

RECIPE CORNER

Regal Chocolate Chips

1/4 c. chocolate syrup

2 tablespoons oil

1 tablespoon liquid lecithin

Mix above ingredients: add and knead in:

1/2 cup powdered instant dry milk

1 1/2 cup powdered sugar

Roll out (in powdered sugar) into long skinny snakes-Cut into chip size pieces-let set to dry.

CHICKEN PASTA SALAD

2/3 cup red wine vinegar

1 1/2 cup olive oil

1 tablespoon Italian herb seasoning

1/2 teaspoon basil

1/2 teaspoon oregano

1 teaspoon chopped garlic

salt and pepper to taste

1/2 - 1 teaspoon Dejon mustard

DRESSING

Cook 1 box pasta (linguini). Toss with dressing while still hot. Do not rinse pasta. Do not need to use all of the dressing. Refrigerate. When cold add:

Chicken breasts (cooked and cut into chunks)

1 1/2 cup cherry tomatoes - quartered

6 scallions - sliced with some greens

1 small can black olives

1 can artichoke hearts - sliced in half

Better the second day.

MULTIPLE SCLEROSIS NEWSLETTER

1983

From the office of Roy L. Swank, M. D.

No. 16

Oregon Health Sciences University, Portland, Oregon 97201

Editor - Barbara Dugan

Asst. Editor - Ruth Selby

Production - Ruth Stewart

I would like in this letter to continue the discussion of some of the problems connected with genital - urinary system in multiple sclerosis. In the last letter, I described those symptoms leading to urinary infections and the means by which infections can be avoided. If infections occurred the basic methods for treatment were also described.

I would now like to discuss symptoms involving the genital or reproductive system in patients with multiple sclerosis.

There is a tendency for both males and females to lose their sexual drive, or stated more clearly, their interest in, or ability to have sexual intercourse. This change can occur early in the disease and to a large extent varies directly with the severity of fatigue. In early cases sexual drive increases during remissions and lessening of fatigue, but often the full intensity of this drive is not restored. In more severely disabled individuals sexual drive may be permanently lost. In males this decrease in sex drive is manifested by impotency, or inability to have or maintain an erection. In females loss of sensations in the vaginal area can be a cause of reduced sex drive.

Impotency is due to lack of filling of the vascular cavities (sinusoids) in the penis with blood. Why this occurs in multiple sclerosis is poorly understood and treatment is often ineffective.

TREATMENT: As most of you know fatigue is an almost continuous symptom of multiple sclerosis. It varies in intensity. During periods of deep fatigue, "sex drive" is apt to be absent. With recovery sex drive improves. This suggests one of the more successful methods of treatment - REST. Testosterone (a testicular hormone) and similar drugs have been used as treatment therapy. The results are usually minimal, but on occasion have been successful.

There are surgical procedures available for males which can be discussed with your urologist.

Counseling for the patient and spouse is very important in some cases. Discussions with your physician and special counseling with experts who deal with sexual dysfunction are often helpful.

In both men and women sedatives ^{and alcohol} often are the cause of reduced sex drive. Thus the use of sedative in the treatment of nervousness in multiple sclerosis patients must be pursued cautiously. Psychological stress leading to anxiety and deep fatigue are equally repressive of the sex drive.

PERSONALITY OF A MULTIPLE SCLEROSIS PATIENT

During the last 35 years of research with multiple sclerosis patients definite personality characteristics in the patients have been observed. Thirty-five hundred patients were seen during this period and over one thousand have been closely followed. Because of this volume we have been able to gain some impressions of the personality of multiple sclerosis patients.

Multiple sclerosis patients are aggressive, energetic and productive. They are generally intelligent and well educated. Their aggressiveness may lead to problems with their health because they have a difficult time slowing down. One of the most interesting characteristics is the discipline these patients seem to have. In the Montreal group before we had any information about the effects of diet and no previous study in any field that we could refer to or copy, patients were extremely disciplined on diet. Our recent review of these patients has revealed a number of them older than 70 years, and the oldest patient on diet is 86 years old. These patients are still ambulant and able to care for themselves, and have been on low fat diet over 30 years. In a later newsletter, we will publish some details of this study, which is at present incomplete.

A detailed and comprehensive study of the personality of the multiple sclerosis patients was recently completed by one of our patients, Dr. Terry Steele. This was done in Southern California where she now resides, but I believe from our experience here in Oregon and Montreal that her conclusions apply to the patients in the Northwest and probably to multiple sclerosis patients anywhere in the USA or Canada. The thesis is some 97 pages long. I will report my interpretation of her conclusions which I believe you will find of considerable interest. The author concluded that the average patient with multiple sclerosis is an individual who is extroverted, competent, somewhat impulsive, persistent, confident of his or her ability to cope with awkward or difficult situations, and willing to take social initiatives. These patients also internalize, rationalize, repress feelings, and use denial as a coping mechanism.

She found these same characteristics in both marital families and non-married patients. The data in the study indicated that the development of multiple sclerosis in a family member did not dramatically change the family functioning in most cases.

Terry Steele has published this information in scientific language in her Doctoral Thesis. We are very grateful to her.

You are all aware of what heat will do to your multiple sclerosis particularly if you already have some disability and have been on diet but a short time or not at all. Cooling oneself off with a plunge in a cool pool, or soaking your feet or hands in cold water, or placing a cold wet towel around your neck will temporarily improve your energy and allow you to get to a cooler environment. More detail on the effects of weather changes can be found in Newsletter #5, October, 1980.

With all good news and useful information a bit of sadness or bad news can be expected. We are unhappy to inform you that Ruth is leaving us. She is moving to Eugene where we feel she will be well received. Surely Eugene will gain.

To take her place Suzy Wood has joined our group. We are confident that you will soon come to depend and trust her as you have in the past relied on Ruth.

Every sunset is followed by a new sunrise.

RECIPE CORNER:

Starter

- 2 c flour 1 pkg dry yeast
- 2 c lukewarm water 1 T sugar

Dilute yeast in 2 c water, add rest of ingredients. Let stand in warm place 3 days, stirring once a day. After each use add 1 c flour, 1 c skim milk and 1/4 c sugar. Store in glass container.

Biscuits

- 1 c flour
 - 2 t baking powder
 - 1/4 t salt
 - 1/4 t soda
 - 1/4 c oil
 - 1 cup starter
- Mix and knead about 10 times on board. Roll out, let stand 10 min. Bake at 425 degrees about 12 minutes. 10-12 biscuits. 1 t oil/biscuit

Pancakes

- 3 eggs beaten
 - 1 c skim milk
 - 2 c starter
 - 1/4 c sugar
 - 1 3/4 c sifted flour
 - 2 t baking powder
 - 1 t soda
 - 2 t salt
- Mix all ingredients and cook on griddle or in frying pan.

MULTIPLE SCLEROSIS NEWSLETTER

October, 1983

From the office of Roy L. Swank, M. D.

No. 17

Editor - Barbara Dugan

Asst. Editor - Suzy Wood

Production - Ruth Stewart

In years past we have reported our research progress in December, and at that time have solicited financial assistance from you. I am told that the holiday season is not the best time to make such a request. Most families are thinking about, and spending for Christmas. We are heeding this advice because our need for financial assistance this year is much greater than at any time in the past. This need will become evident as our report develops.

A. MONTREAL LOW FAT DIET STUDY: Many of you are aware of our Montreal study. This test of the effects of low fat diet in M. S. was started in December, 1948, and we are now nearing it's end. The study started with 153 patients. We have been able to follow and determine the condition of 144 of these same patients. I am at present analyzing the data and can give you a few preliminary conclusions. The study was reported in 1970 after 17 years of observation (Swank, R. L. Multiple Sclerosis: 20 Years On Low Fat Diet, Arch. Neurol. 23:460-474, 1970). We can now add 18 years to this study making a total observation and evaluation period of 35 years. The average age of these patients at the beginning was 32 years. If all had lived the average age now would be about 65 years. Many of these patients are now dead, 17 of diseases other than M. S., such as cancer (6 cases), heart disease (8 cases), stroke (1 case), tuberculosis (1 case), and alcoholism (1 case). Fifty others have died of multiple sclerosis or complications of the disease. Most of the patients who are deceased were severely disabled when first seen and placed on diet; most of the early cases are still alive.

Of importance is the very low death rate of patients who followed the low fat diet as directed, in contrast to those who followed the diet poorly. The former consumed an average of 18 gm. fat daily, the later 38 gm. fat daily. The death rate in the good dieters was 37%, in the poor dieters it was 87%.

Those patients who had had the disease a short time when placed on diet, and also had minimal neurological findings at that time had a death rate of less than 10% (8%). The 92% who survived are ambulant and able to work. Their average age at present is 63 years.

The evidence that the low fat diet is beneficial to M. S. patients is overwhelming in the opinion of your writer. Even those patients who followed the diet poorly were benefitted - they quit having exacerbations of disease and at the end of 17 years were doing very well. However, this group steadily deteriorated during the last 18 years and as a result suffered a much higher death rate (87%) than those who followed the diet faithfully (37%). We will report further on this study as the analysis proceeds, and the material is prepared for publication.

B. A STUDY OF CEREBRAL BLOOD FLOW IN M. S. and in normal subjects was undertaken in 1972. This very difficult study was not completed until 1979-80, and not published until 1982 (Swank, Roth and Woody, "Cerebral Blood Flow in M.S. and Normal Subjects", Neurol. Research, vol. 5, pp. 37-59, 1983). We measured the cerebral blood flow using the Xenon inhalation method, in normal subjects and in patients with M.S. whose disease varied in duration from less than 1 to more than 20 years. The cerebral blood flow decreased at a rate which correlated directly with the duration and severity of M. S. In cases in which the disease was rapidly progressive the cerebral blood flow decreased rapidly. In slowly progressive cases the blood flow decreased slowly. In patients on

low fat diet whose condition remained stable the blood flow tended to stabilize and remain unchanged rather than decrease as it did in patients not on low fat diet.

There is increasing evidence that generalized circulatory changes occur in M. S. patients. For example there are visible changes in the blood vessels of the retina of the eyes in M. S. patients; most patients have cold hands and feet; subcutaneous black and blue marks are frequently noted in patients due to capillary hemorrhage; blood platelets are often adhesive in M.S. patients; and most patients are sensitive to heat and often cold. To this evidence of a generalized vascular factor in M. S. can be added our own study of cerebral circulation noted above. Further evidence of vascular factors in M. S. were presented in a previous progress report (Dec. 1, 1982) in which the red cell mobility test was discussed. By means of this test we were able to demonstrate that a difference exists between blood plasma of normal subjects and of patients with M. S.

We will soon have a paper appearing in the journal "Neurology" which goes one step further. We have also shown with plastic beads less than 1/25,000 of an inch in diameter that the plasma from M. S. patients differs from plasma from normal subjects. (Polystyrene Latex Particles As Indicators of Abnormal Plasma Properties in Multiple Sclerosis, Cherry H. Tamblin, Roy L. Swank, Geoffrey V. F. Seaman, in press.) I have had a vested interest in this work. In 1953 with Quastel and Franklin in Montreal, I found that we could differentiate normal from M. S. plasma by a technique of chromatography, which was new at the time. In a sense we anticipated one of the results of the next study which I will describe in this report. In the 1952 study we observed that following transfusions the paper chromatograms of M. S. patients tended to return to normal. Our recent studies were with a more reliable method, and I believe now that we can be certain that normal and M.S. plasma differ.

- C. EFFECTS OF INFUSION OF FRESH FROZEN PLASMA: This leads me to our most recent study which will be published in the September issue of "Plasma Therapy". This study was undertaken in cooperation with Dr. Peetoom at the Red Cross Blood Bank, Dr. Michael Daley, Cherry Tamblin and Dr. Geoffrey Seaman from this University.

Early work by other investigators suggested that a series of blood transfusions promoted remissions in M. S. patients. I repeated and partially confirmed these observations while in Canada. In Oregon we observed that transfusions of whole blood or of fresh plasma (fresh frozen plasma) prevented exacerbations of M. S. from occurring after operations and after child birth. About 4 years ago we began to observe the effects of normal fresh plasma on patients with M.S. We gave these infusions to patients with early M.S. During exacerbations; patients with active M.S. of longer duration; to patients with chronic progressive disease; and to a final group with very slowly progressive disease, who were at the time suffering from increased activity of M.S. The early active group responded to the plasma vigorously and 90% improved rapidly. The chronic progressive cases responded poorly, except that a few felt better. The other two groups exhibited responses mid-point between the two groups. When the plasma to be infused was first heated there was no or questionable improvement in the patients condition.

We then tested the effect of infusions of fresh frozen plasma on the red cell mobility test. After the first infusion of plasma the mobility test returned normal. After the second infusion the test was normal, and remained normal for 6 to 8 weeks; then slowly became abnormal again. If the patients were infused again the red cell mobility again returned to normal.

On the basis of these experiments we have concluded that the plasma of M.S. patients is abnormal. Furthermore, it is likely that this abnormality consists of a deficiency of some substance or substances which are present in normal plasma.

The nature of this plasma abnormality in M. S. is not known, but the favorable response of patients receiving plasma infusions suggests that the missing elements are important.

PRE PLANS: We have begun studies aimed at isolation of the "active" ingredients in normal plasma. Our initial experiments have pointed to a portion of the plasma which contains this material. The next step will be to confirm that this initial lead is correct, by infusing this portion of plasma into patients having active disease. Fortunately this first step is a very safe one since processing of fresh plasma to obtain the active material will, in all probability, remove the viruses of hepatitis from the "active" fraction.

Simultaneously we will attempt both chemical and immunological identification of the "active" ingredients".

These steps will require infusions of financial aid much greater than at any time before into our research program. We are currently attempting to obtain financial help from other sources but success is both uncertain, and if successful, delayed by 8 to 12 months. Generous patients support will enable us to start almost immediately.

We need to hire at least one senior investigator. We have this person in mind. If your contributions are sufficient we will proceed with the job immediately. I urge those of you able to do so to contribute generously, and make it possible for us to continue vigorously.

Keep in mind that with your help during the past 5 years we have developed methods for objectively evaluating progress of M.S. (Flicker Fusion and balance tests). You have also helped us to confirm and introduce the red cell mobility test. These methods will be used in evaluation of plasma fraction infusions. In other words the groundwork for isolation and evaluation of the active ingredients in plasma has already been completed.

Finally, let me urge you once more to consider our needs and possible benefits to yourself when deciding what to contribute. Donations are tax deductible.

Barbara and Suzy join me in wishing you a pleasant and prosperous future.

Sincerely yours,

Roy L. Swank
Roy L. Swank, M. D.

For your convenience and to facilitate the Foundation's work of responding to your gift we have provided the following form. Those of you who contribute should complete this form and include it with your donation.

Make checks payable to: The Oregon Health Sciences University
Foundation for Dr. Swank's Research

Send checks to: Dr. Roy L. Swank
Department of Neurology
Oregon Health Sciences University
3181 SW Sam Jackson Park Rd.
Portland, OR 97201

CONTRIBUTOR'S NAME: _____

CONTRIBUTOR'S ADDRESS: _____

CITY, STATE & ZIP: _____

AMOUNT OF DONATION: \$ _____

MULTIPLE SCLEROSIS NEWSLETTER

December, 1983

From the office of Roy L. Swank, M. D.

No. 18

Editor-Barbara Dugan

Asst. Editor-Suzy Wood

Production-Ruth Stewart

I often discuss physio therapy (including exercise) requirements with individual patients, and have also included a few remarks in our newsletter concerning jogging, aerobic exercise and dancing, swimming, stretching exercises (yoga), and the importance of avoiding fatigue in any physical activity. In this letter I will discuss this general subject more comprehensively.

To begin with patients in different stages of multiple sclerosis have different physical limitations which determine the types of exercise or physical activities which they can tolerate. If this tolerance is exceeded to the point of exhaustion, the patient is not benefitted, and may be harmed. If the exercises are well tolerated the patient usually benefits. To facilitate further discussion it is convenient to divide the patients into 3 general groups: Those who are normally ambulant; those who ambulate with difficulty; and those who are non-ambulant. This grouping is not rigid; patients may fit partly into 2 groups, and others may be in one group and later find themselves in another.

Normally ambulant patients can engage in a wide variety of physical activities. However, they must observe the general rule - avoid deep or continuing fatigue. The few patients who can jog or run must observe this rule diligently. Fatigue, or symptoms such as numbness, leg weakness, dizziness, foggy or blurred vision, or double vision which develop while running or jogging are warnings indicating that the patient is overdoing. Instead, indulge in less energetic exercise, such as aerobic exercises or dancing. A number of joggers have reported that aerobic exercises can be well tolerated when jogging or running cannot be. Even so it is necessary to monitor your heart rate while exercising, and to stop to rest when the rate exceeds 150/minute, or when the heart rate fails to slow below 120/minute after resting 5 - 10 minutes, or if inordinant fatigue develops. Tolerance for physical exercise may vary from time to time, so that what is easily done at one time, becomes difficult to do at other times.

Not all normally ambulant patients care to jog or aerobically exercise, or because of fatigue can do neither. Walking, swimming, calisthenics, or bicycling are more apt to agree with their limitations or tastes. The same rule governing exercise still applies - avoid lingering fatigue. Through experience the patient should find out what his or her limitations are, and carefully refrain from overdoing. Do not ride a bicycle from your starting point until tired, since you will be exhausted when you return. Ride just half this distance and return refreshed, not fatigued.

Patients who ambulate with mild or severe difficulty will be unable to either jog or aerobically exercise. They are still able to walk, swim, exercise lightly or perform stretching type of exercises (yoga), and ride a stationary bicycle. If working, the physical exertion of the job may be all the exercise that the patient needs or can tolerate. Some will find that they quickly tire and can do very little, but that they recover from the fatigue quickly. Often these patients can repeat the exercises twice or even 3 times a day, each time for short periods. Most of these patients will find swimming several times a week satisfying. The temperature of the pool should be no warmer than 82-84° F. otherwise exhaustion from the heat of the water in the pool may occur.

A few patients in this group will benefit from massage of muscles, and manipulation of the joints, particularly if they are suffering from aching or painful muscles or joints, or if movement of extremities is limited. No less than in the preceeding group, these patients must avoid too strenuous exercise, that which produces inordinate fatigue.

In the third group of patients, those no longer ambulant, active exercises are usually limited to the upper extremities, and upper back and neck. It is then that passive manipulation of all joints becomes very important. All joints should be manipulated through their full range of movement daily to prevent the joints from becoming fixed or frozen. Fixed or frozen joints become very painful, and are accompanied by atrophy of adjacent muscles. The shoulder and hip joints most frequently become frozen. The shoulder joints are most frequently very painful when frozen. Daily manipulation of these joints through their full range of movement will prevent this very painful complication.

Daily massage of the skin with lubricating solutions such as light baby oil, alcohol, or glycerine are advised to prevent breakdown of the skin and subsequent ulceration.

So far we have discussed patients whose disease is fairly stable - in partial or complete remission. Additional rules are needed for patients whose multiple sclerosis is active.

If first seen during exacerbation or in early phases of remission, patients are cautioned to rest as much as possible, avoid fatigue, and enter into very limited physical exertion. They are instructed to rest 1 to 3 hours daily, by lying down, at first, twice daily, morning and afternoon for 1 to 2 hours each time. Later as they improve they need to rest once daily preferably after lunch. Forced rest is continued for 6 months to 2 years, depending upon the severity of the exacerbation, and the rapidity with which they recover. Once "recovered" they are to embark on an exercise program. There are no fixed instructions except that they are not to exceed their limitations. This means that they are to avoid fatigue. As they improve however, their energy increases, they have less fatigue, and they find themselves able to do more. The general rule - avoid fatigue - continues to hold.

Many patients will find it necessary to rest by lying down an hour each day in order to remain reasonably vigorous the rest of the day.

Finally, I would like to discuss mid-day rest in ambulant patients as an important part of our therapeutic regime. Rest by lying down restores needed energy far more effectively than rest by sitting. Mid-day rest is needed by most and desirable by all multiple sclerosis patients because of the persistence of fatigue in all but a few. This fatigue usually lessens in 3 to 5 years in patients on diet, but almost never disappears. We continue to advise mid-day rest for as few as 30 minutes, and as long as 1 to 2 hours, depending upon individual needs in ambulatory as well as non-ambulatory patients. A few very active patients may avoid the mid-day rest, but usually make up for the loss on weekends.

Remember - Those of you who intend to, but have overlooked contributing to our research are urged to do so. Address your check to O.H.S.U. Foundation, and send to Dr. Roy L. Swank, Dept. Neurology, OR. Health Sciences Univ., Portland, OR. 97201.

Painful aching muscles and joints have been the most common complaint this fall. Warm clothing with emphasis on long underwear and long sleeve, turtle neck sweaters have been the best therapy for these complaints. Local heating periodically with a heat pad is often very helpful.

In previous newsletters we have discussed MS and the patient but have not given much support to the spouse and children. In this issue we will discuss some of the problems facing the spouse and children living with the MS patient.

When the diagnosis is made in our office there is an attempt to give as much support to the patient as possible and set up guidelines for him/her to follow to arrest the disease. We advise the family that the patient needs additional rest, and must avoid fatigue and stress.

This puts additional stress on the family. Roles change, i.e., if the patient is female the spouse must assume the responsibility of cooking, cleaning, and added care of the children; if the patient is male many times the spouse is faced with leaving the home and working while still maintaining her household. The children feel more pressure to help out and have been told "don't stress mom or dad".

This adjustment period is as hard for the family as it is for the patient. It is necessary that the family also have guidelines. To follow are a few suggestions:

1. Sit down as a family and discuss the diagnosis and what it means.
2. Make lists of duties and divide them among the family including the patient. It is important that the patient continue to be a working part of the family if it is only doing the dusting. The patient should be honest with the family as to what he or she can handle without becoming fatigued. If the patient becomes overtired the family also suffers. If you (the patient) reaches the point of crying or yelling, do your spouse and children a favor and go to the bedroom for a nap. It's difficult enough, they are trying to help you, do the same for them.
3. It is important that patients support their spouses and children. They are frightened and need for you to let them know that you are OK. Do not dwell on, "oh, I am so tired", and "I can't because I have MS". They know you have MS. Once in a while they may need to be reminded, but no one wants to hear it on a daily basis. Remember your children's feelings, they may be embarrassed by the diagnosis, or feel guilty, or just plain resentful that you can't do as much as you used to.
4. Allow 5 - 10 minutes daily for the patient to air his or her complaints. That should be enough.
5. Your spouse is working full-time and now has the added responsibility of taking care of many household chores. Usually they do not mind the added responsibility if the patient is also doing everything possible to maintain their health. Stay on diet and rest as directed. Can you imagine how frustrating it must be for the family to be working hard knowing that you are not holding up your end of the bargain.

Let's Talk About Diet

In newsletter #2 we discussed oils. Here are a few additional comments.

Frying with Oil

The best oil for frying are those that can be heated to very high temperatures without smoking. Smoking is evidence that the oils are "breaking down" or deteriorating. Soybean oil has the highest smoking point or temperature and olive the lowest. The least refined oils have more intense flavor, but also lower smoking points. Corn oil works well in salad dressings or even in baking, but "breaks down" and begins to smoke when used to deep fry.

Once an oil has been heated to the smoking point, its chemical structure has been changed. The change is irreversible; the oil will not return to its natural state when cooled. Overheated oils can have adverse effects on your health and should be discarded.

Choose an oil for frying that has a high smoking point. You can test the oils by heating to a temperature just above 375 degrees F. If the oil fails to smoke it is satisfactory for frying. It is important to heat the oil slowly. If you heat it quickly or pour it into an extremely hot pan, you may cause it to develop a dank, greasy smell, which is an indication of undesirable chemical changes.

Cold Pressed Oils

The term cold pressed refers to the oils that are expellerpressed from heated seeds, as opposed to oils that have been extracted with solvents. Cold pressed is a misleading term and does not mean the oil is unheated - or unrefined.

Storage

Good oils, especially unrefined ones, must be stored carefully if they are to be kept in top condition. Oils become stale very easily, and turn rancid. Rancid oil not only destroys the flavor of foods, it also destroys ingested vitamins and interferes with

digestion. The following are suggestions for oil storage:

1. Keep all oils in the refrigerator. Remember if they cloud or harden in 3 days do not use.
2. Glass protects the oil better than either tin or plastic containers.
3. It's a good idea to purchase small bottles of oil frequently, instead of keeping a large bottle open over a long period of time.

Cod Liver Oil

If you wish to buy Cod Liver Oil capsules from our office send us a note. The cost of the CLO is \$12.50/1,000 capsules if mailed, and \$10.00/1,000 if purchased in our office. Make checks payable to Medical Research Foundation of Oregon.

The following laxative recipe was sent to us by a patient.

2 2/3 C. bran flakes (like Raisin Bran)
 1 1/2 C. bran meal
 1 1/2 C. bran buds

1 C. sliced raw almonds
 8-12 diced prunes
 16-20 diced dried apricot halves
 1/2 C. raisins

Eat about 1 cup daily.

PHONEY FISH - Imitation crab meat is a recent addition in the seafood department. The bright red, crab-flavored fish product goes by a number of names including "Sea Legs" and "Seafood Sections".

Although the imitation costs less than real crabmeat, upon closer scrutiny it is not such a bargain.

The major ingredient is pollack, a fish which sells for approximately \$1.10 per pound wholesale and approximately \$2.99 per pound retail in the Washington, D.C. area. The fabricated product (which also contains monosodium glutamate and artificial color) costs approximately \$5.00 per pound, which is 100% more than fresh pollack. (Taken from the Finegold Association Newsletter)

Due to an increase in the number of patients Dr. Swank is seeing we are now booking return patients in June. If you cannot keep your appointment, please let us know well in advance so we can take someone off the waiting list.

Merry Xmas & happy new years to you all
Ray D. Swank
Barbara
Suzzy