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- Scleroderma Society for Residents Outside of Toronto**1-800-321-1433
- Arthritis Self-Management Program**(416)979-7228
- The Scleroderma Society of Ontario Web Page**www.sclerodermaontario.ca
- The Arthritis Society Web Page**www.arthritis.ca
- SSC Web Page with link to SSO**.....www.scleroderma.ca

Psychological Impact of Scleroderma

by Shirl Yarko-Halpen, Scleroderma Voice 2003, #2 and 2006, #3 - (condensed)

I am a 48-year-old psychotherapist who was diagnosed with diffuse scleroderma two years ago (2003). It has taken me that amount of time to sort through my reactions and feelings, to begin to adjust to the change in my sense of self and my life and regain some sense of equilibrium.

We all make narratives of our lives that make our lives seem predictable and provide a sense of security for us. One of the most powerful effects of being diagnosed with scleroderma was to completely undermine my narrative, my dreams of how the coming years of my life would play out. I was heartbroken that my future with my family and career would not happen and I was terrified at how unpredictable and uncontrollable the

future suddenly seemed.

Both the diagnosis and rapid progression of the disease were traumatic experiences for me. My physical appearance changed rapidly. Within months, I experienced a loss of independent functioning and found myself needing assistance with even the most basic tasks. I was not sure if I could continue to work and was upset about the pain I was causing my children. I also felt very isolated.

The overwhelming worry about my health, the need to figure out what I could and could not do and the need to adjust to new limits and physical dependence, all led me to re-direct my emotional energy inward. I became more self-preoccupied. I lost interest in the "outside" world and even to some extent in my friends.

In retrospect, these were signs of depression. Yet the inward focus was also necessary, as I struggled to adapt to and regain my equilibrium. At the age of 47, I had to adjust to be more dependent and seemingly diminished "Shirl," and to figure out who this Shirl was and could be.

As I continued to adjust on many fronts, I also began to think about my life in new ways. Talking with my husband about my fears and feelings was a critical foundation in this process. He helped me feel I was not quite so alone with the disease. I realized I could still have expectations, relationships, work; I had not lost my competence as a professional, mother and wife. I began to build a new narrative. This one was far more flexible to accommodate constant and unpredictable health problems and other uncertainties. I decided I could not put my life on hold each time a new health issue arose. I had to get and give pleasure, no matter what was going on.

I paid closer attention to my diet and made sure I walked every day. These provided health benefits and helped me regain a modest feeling of control over my life and my body.

I realized that, while in some ways the scleroderma caused a complete break from my previous life, in other ways, it was part of life.

I had faced difficulties before and they had shaped me as well. I know that I will likely experience many difficulties in the coming years. I am still scared yet I think I have a bit of foundation to stand on again. I hope we will also begin to pay fuller attention to its psychological impact.



SCLERODERMA REPORTER

SCLERODERMA SOCIETY OF ONTARIO SSO NEWSLETTER
A specific disease association of The Arthritis Society (Ontario Division)

November 2006

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DISCLAIMER
The Scleroderma Society of Ontario does not endorse any treatment, drug or diet reported in this newsletter. We wish only to keep you informed. Check any treatment with your doctor.

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HELLO TO ALL:

I want to express my most sincere gratitude to each and all of the members of the Board of Directors for their significant contribution to the Society. All members of the Board, except one, are married. Most have children at home and work full or part time and yet somehow they manage to find the time and energy to drive forward the three tenets of our "Mission Statement". Thank you on behalf of the membership and personally. Unfortunately, after two years of contribution, our Treasurer and the Director of Membership are not able to remain on the Board. We will miss your help. Thank You again.



This year, the Reporter has been prepared by Cynthia Busch, from Hamilton, and mailed to the membership 4 times along with Strides whenever it is available. In the event that you wish to receive it by e-mail, please let us know. This will reduce costs to your Society. The Windsor Support Group, as well, prepares and distributes some 2000 of their own Newsletter quarterly. It is distributed with their local Penny Pincher publication.

Our website, thanks to Carl Stager, has garnered attention provincially, nationally and internationally. It has proven to be a most successful tool for disseminating information to members and non-members as well as for public awareness. Current information is posted regularly.

The present membership stands at 235 including another 10 new members. Both the individual membership of \$25.00 and the family membership of \$35.00 are fully tax deductible and receipts are issued. To prevent confusion amongst all as to when your membership becomes due, your Board has adopted a plan to allow memberships to coincide with our fiscal year. All memberships will become due on April 1st in each year commencing 2007. Those who have paid their membership within 6 months of April 1st 2007 will receive an extended membership to April 1st 2008. The revenue from membership is significant. As important though, is the fact that by joining your Society you give the Board confidence to continue in its work. Your lack of membership isn't as encouraging.

Let me share with you the good news about our fund raising. Windsor, Hamilton, Mississauga, Pembroke and Pickering individually and collectively raised more monies for Awareness and Research than in any previous year---and ----they have each started their plans for an even more successful event in '07. Of significance as well, is the fact that many unsolicited funds are being received from the likes of CIBC Wood Gundy, a BIA in Hamilton from the sale of cook books, a professional speaker turning the proceeds of one of his presentations to "my favorite charity" and this list of newer donors is constantly growing at this time. These events grow awareness at a rate that few can afford through media releases and certainly your Society most definitely can not. Thank you to the organizers of these events and to each donor. Please keep up the good work.

Our new Task Force selected from Board members encouraged the Board to purchase the many articles such as Thank You Notes, car magnets, scleroderma cloths for opening jars etc., book marks and the new publication of The Scleroderma Book, pamphlets etc., etc. In addition it planted the seed for a Support Group Chair Conference which I will talk about later. In addition, this Task Force is in on-going discussion with TAS to improve our relationship to the mutual advantage of all.

Awareness is the "buzz word" to-day that everyone constantly hears. There is huge competition from those who are better prepared financially to buy attention. Having said that, great strides have been undertaken by your Society members. A PSA announcement was prepared and circulated to every radio station in Ontario for release-at no cost to your Society. Statements were made from the floor both in the House of Commons and at Queen's Park declaring June as "Scleroderma Month." Numerous media releases surrounded each fund raising event and we were fortunate to again arrange a declaration with the recital of our website in the June statements of the Union Gas Company.

Research remains one of our main goals. In addition to funding projects by Dr. Sindhu Johnson and Andrew Leask, we have, after a stringent peer review, issued a cheque for \$50,000 to Dr. Murray Baron, a member of the Canadian Scleroderma Research Group, to assist in the education of interns in scleroderma research. I would be remiss if I didn't share with you the hopeful message of Dame Carol Black, a world renowned clinician from the UK. Dame Carol Black said at the AGM for the SSC that where there was no patient knowledge, patient support systems, lack of knowledge amongst the medical fraternity and hopelessness everywhere just 20 years ago when she started her career. To-day, there is hope, many support systems, huge research projects as well as world wide networking amongst researchers and much patient knowledge, in part, as a result of the internet. Most encouraging.

Nataly Koester, our new Support Group Director, organized and hosted a very successful Support Group Chairperson Conference in Kitchener. All support group chairs, or an alternative, were invited to a Friday evening informal "meet and greet" reception. On Saturday, after a buffet breakfast, a welcoming by Nataly and a few remarks by yours truly, Dr. Khalidi, a rheumatologist from Hamilton and a member of the CSRG, gave a slide presentation to all. His topic, "Scleroderma Update" was most informative and was well received by everyone. A question and answer period followed. Heidi Koester did give a short presentation on her experiences with the London Day Program she took part in over the summer. After lunch Aline Laporte from Ottawa and Babe Sliva from Windsor spoke of their experiences as Support Group Chairs and fundraising. All went home with binders full of scleroderma literature and a bag of gifts from the Society as a small indication of thanks for their outstanding contributions. Questionnaires were collected at the meeting's end. We hope the results will be helpful in the planning of future conferences. Thank You Nataly.

Peter Woolcott

MEMBERSHIP APPLICATION

Please make cheque payable to the **Scleroderma Society of Ontario**
Send to: Kathy Donn, Treasurer
Scleroderma Society of Ontario
98 Rand St.
Stoney Creek, ON L8J 1A8

Annual Membership Fee is \$25.00
Household Family Membership \$35.00

1. Join: One Year Two Years
2. Renew: One Year Two Years
3. Give a membership to:
(Donor's Name _____)
Amount Enclosed \$ _____ Date _____

I am a Scleroderma patient.
 Yes No

I am interested in helping with a
Support Group _____

Name _____

Street _____

City _____ Prov. _____

Postal Code _____ Phone _____

E-mail Address _____

* tax receipts are issued for full amount of membership

Keeping Hands Flexible

by Elaine Sobin, (originally published in "Scleroderma Voice," 2002 #3) (condensed)

You simply must fight scleroderma's impact on your hands. I saw a lovely lady who had both hands frozen into clenched fists. I then decided to dedicate time to my hands.

Making a Commitment to My Hands - - I exercise my hands one to two times daily. If I skip a day, the skin starts to harden. Below I describe my hand routines.

Heat and Massage - - I like my heating pad set on high wrapped around my hand for 15-20 minutes. My hands love Bag Balm bought at a local feed store. It is the most penetrating cream I have tried. I divide the container into smaller plastic bottles to keep uncontaminated and fresh. Massage it into both hands until you can almost feel it going under your skin. Use more if needed.

Stretching and Bending Hand Exercises - - Perform every motion firmly but gently. If a motion feels useful, repeat 10-20 or even 30 times. Time is money and your return on this investment will be more valuable than money.

Note: Try to alternate stretching and bending exercises.

1. Holding your four fingers with the other hand, press the fingers away from your thumb. At the same time, stretch your thumb as far away from the fingers as possible.
2. Try to bend the knuckles on all four fingers at once, as far as possible, using the other hand to apply pressure.
3. Now try to bend the knuckles on each finger individually, as far as possible, applying pressure with the thumb on the other hand.
4. Press both hands together, trying to straighten your fingers at the knuckles. Try to press each hand backward at the wrist, as far as possible.
5. Keep massaging the flap of skin between thumb and forefinger.
6. Press a couple of fingers of one hand between each finger of the other hand.
7. Stretching your hand from thumb to pinky (as hard as possible), twirl and stretch each finger with as much effort as possible in one direction and then the other.

Exercising with Toys

Note: You can also do your mouth exercises while you do these.

Balls: I happen to have a pretty stiff foam/rubber baseball and a beanie bag type of squeeze ball. I squeeze each ball 60-100 times with each hand.

Weights: I have the old fashioned 2-pound iron dumbbells. Bend your arm, holding a weight in each hand, and curl your wrists only up and down slowly 30 times. Turn your hands facing the other way and repeat. Then holding the dumbbell with two fingers only, curl the dumbbell up and down 30 times; repeat until all fingers have been used.

Clothespins: Holding a clothespin between thumb and forefinger, press 30 times. Repeat with thumb and all fingers.

More Ideas for You

Add, subtract and tailor the exercises above to your own needs.

- The driver's wheel in my car is a great place to press curved knuckles straight; when you are a passenger you can do the same thing on the elbow rest.
- In a Jacuzzi with your palms spread next to your body, raise yourself by your hands, concentrating on straightening your fingers. (If this is too hard, Aquasize or work with a "noodle.") Also, flatten your palms and try to raise one finger at a time.

The Scleroderma Foundation recommends that you consult with your physician before embarking on this or any other treatment or exercise regimen.

Scleroderma Society of Ontario Mission Statement

The Scleroderma Society of Ontario is committed to promoting public awareness, advancing patient wellness and supporting research in Scleroderma.

The Scleroderma Society of Ontario is committed to protecting your privacy and maintaining confidentiality of your personal information. We do not sell our membership list to anyone. Save and except for the Arthritis Society of Ontario, we do not trade this information with others that may use it to contact you about their own products or services.

The SCOT Study: Taking scleroderma research one step further, by M.E. Csuka, MD, Scleroderma Voice 2006 #2

The subject of stem cell transplantation appears regularly in the news. Just this February (2006) the Journal of the American Medical Association (JAMA) published preliminary results from a stem cell transplant study done in patients with lupus, which like scleroderma, is an autoimmune disease. In the lupus study, 50 patients with the most severe form of the disease received a stem cell transplant and at five years, 50 percent of those were disease free.

So can this type of treatment be used in patients with scleroderma? For the 10 to 15 percent of patients with the severe forms of scleroderma, stem cell transplant may indeed be a lifesaving option. An encouraging pilot study from the Fred Hutchinson Cancer Centre in Seattle followed 33 scleroderma patients treated with stem cell transplants between 2001 and 2004. Based on the outcomes measured, these patients showed significant improvements in lung function, skin scores and quality of life measures. Most patients saw their scleroderma go into remission.

Stem cell transplant is not without risks. Five of the patients in the pilot study died due to complications stemming from the transplant. Because of these deaths, additional safety measures were promptly implemented and patients' safety did improve. No matter what steps are taken to reduce risk, patients must understand that stem cell transplantation is associated with serious side effects, including death.

Although investigators are cautiously optimistic, more research is needed to fully understand the usefulness and safety of stem cell transplantation in patients with scleroderma. A European study called ASTIS (Autologous Stem Cell Transplantation International Scleroderma) is currently underway and in the United States, a large nationwide project called SCOT is enrolling patients.

IN MEMORIAM

Dorothy Armsworthy
Cora Bauer
Shirley M. Binette
June Brown
Patricia Chiaramonte
Mary Cordell
Glen Ward

Evelyn Dyer
Ian Fleming
Linda Hayes
Margaret Hayward
Baby Hetherington
Steve Johns
Helen Jones

D. Anne Kendall
Steve Kost
Rita LaFrancois
Laura McLean
Walter Milotzki
Darlene Quinn
Kazymyra Skrypec

Paula Takacs
Morris Taylor
Mona Toniolo
Lucia Ventura
Adilyn Dicks
Margaret Scott
Gaetanina Mannella

Earl Brown
Gayle Friendly
Mark Wilson
Lorraine Polley
Marjorie Linton
Edward Breen
Roy Whitehead
Terry Goldwin

QUESTION and ANSWER from Scleroderma Voice 2006 #2, by Jaye van Dussen

Q. Is there a lotion or cream that will help my skin tightness?

A. Scleroderma affects the sweat glands and thus makes the skin extremely dry. Moisturizers and creams can help the skin feel less dry and tight and using them may help the underlying problem that is causing the skin tightness.

Skin tightness (fibrosis), occurs because the immune system is causing an overproduction of collagen which makes the skin hard. Over time the skin may soften on its own, so that the most important treatment during the early phase is aggressive physical therapy to maintain as much mobility as possible. Immunosuppressant medications may also help.

Various treatments (none proven in clinical trials) that have been used for systemic scleroderma skin fibrosis include: D-penicillamine, methotrexate, cyclophosphamide, cyclosporine, mycophenolate mofetil. For localized scleroderma, antimalarials like hydroxychloroquine sulphate may be used. Other options may include, methotrexate, prednisone, phenytoin, potassium P-aminobenzoate, D-penicillamine, PUVA (phototherapy).

Self care to help with tightness includes keeping skin moisturized, wearing gloves to protect hands, using humidifiers and most importantly doing aggressive physical therapy to maintain mobility. Ask your doctor to prescribe a physical and/or occupational therapy programme for you. Some people also find massage helpful.

LITERATURE ORDER FORM

1. Understanding & Managing Scleroderma.....FREE
New! By Maureen Mayes, M.D.,M.P.H., & Khanh T. Ho, M.D. This booklet is intended to help persons with scleroderma, their families and others interested in scleroderma to better understand what scleroderma is, what effects it may have, and what those with scleroderma can do to help themselves and their physicians manage the disease.

2. Helpful Hints: Living with Scleroderma.....\$2.00
A compilation of helpful information submitted by Scleroderma Foundation (USA) members.

3. Sjögren's Syndrome.. UPDATED 2003.....\$0.25
A general overview of Sjögren's

4. What Causes Scleroderma?.....\$0.25
Also available in Spanish. Discusses the scleroderma "puzzle".

5. Perspectives on Living with Scleroderma.....\$16.00
By Mark Flapin, Ph.D. Features Dr. Flapin's insightful articles on coping, including his personal story. 233 pages

6. Successful Living with Scleroderma: Guidebook.....\$15.00
New! By Robert Phillips, Ph.D. Dr Phillips is Director for the Center for Coping.

7. The Scleroderma Book (2005) 2nd edition.....\$20.00
By Maureen Mayes, M.D. A definitive guide for patients and their families.

8. Pulmonary Hypertension...UPDATED 2003.....FREE
A general overview of PH in Scleroderma

Book #	Price	Quantity	Total

Please enclose cheque or money order payable to:
Scleroderma Society of Ontario
393 University Ave Suite #1700
Toronto, ON M5G 1E6
(Prices subject to change without notice)

Subtotal \$ _____
Shipping & Handling \$ **\$3.50**
Total \$ _____