

# LUPUS NEWS

## TASMANIA

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Committed to understanding and supporting people with Lupus, Sjögren's,  
Scleroderma & Fibromyalgia or any autoimmune disease

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**Osteoporosis in SLE**  
**Scleroderma and Skin**

Office Bearers

Lupus Association of Tasmania Inc.  
Registered Charity ABN 96 163 951 956

**All Correspondence to:**

PO Box 639  
Launceston, 7250  
Tasmania, Australia  
Ph. (03) 64316042  
Email: [lupustas@lupustasmania.org.au](mailto:lupustas@lupustasmania.org.au)  
Website: [www.lupustasmania.org.au](http://www.lupustasmania.org.au)

Patron: Hon. Michael Ferguson MHA  
President: Vic Hartas  
Vice-President: John Dent  
Secretary/Allyson Reedy-Mead

Treasurer: Queenie Ennis  
Committee: Cheryl Dent, Claire Redfern, Queenie Ennis & Moira Keefe  
Librarian: Joan Keefe ph. 63449322  
Northern Co-Ordinator:

Lois Beckwith  
'Phone 03 695353  
Email: [loisbeckwith@bigpond.com](mailto:loisbeckwith@bigpond.com)

North-West Co-Ordinator:  
Denise Hartas  
'Phone 03 6431 6042  
Email: [hdenise@bigpond.net.au](mailto:hdenise@bigpond.net.au)

Southern Co-Ordinator:  
Heather Cowled  
'Phone 03 6272 3096  
Email: [lhcowled@bigpond.net.au](mailto:lhcowled@bigpond.net.au)

Editor: Edna Brock  
Ph. 0419541989  
Email: [sbr87203@bigpond.net.au](mailto:sbr87203@bigpond.net.au)

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The Lupus Association of Tasmania, Inc. does not recommend or endorse any drugs, treatments or procedures reported in this newsletter. The information is intended to keep you informed and we recommend that you discuss any information mentioned with your Doctor.

We would like to acknowledge the Hon Mr. Michael Ferguson MHA for the printing of our Newsletter and his continued support.

**Editor's Blurb**

Another year has flown past. I hope you all had a good Christmas and New Year. We had a good turn out for our Christmas Luncheon as well as a beautiful day. We were well and truly blessed with the weather. We , The Association is at "sixes and sevens" at the moment. Our Association has not enough people on the ground to "man" the positions. We have approximately two hundred members of many varying ages and haven't had anyone put up their hand to take on the offices needed to run our Association. You don't have to be a sufferer of autoimmune disease, you may be a friend or a relative. With out the officers we cannot exist. Please give the situation some thought, Do you want the Association or do you not? It is the Annual General Meeting is on **Sunday March 12th 2017, at the Kings Meadows Health Centre, at 11.00 am.** Please come along and have your say or better still come along and take a position to keep us going. I have enjoyed being your editor and have learned a lot about the autoimmune disease/s as I have researched different articles for the newsletter.

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Our sympathy goes out to the family of Isabel Mitchell, who passed away recently.

Thank you to the family of Janet Wright who donated \$1000 dollars from her funeral.

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Thank you to all those who bought and sold tickets in our raffle, we made \$1002 which will add to our funds.

Winners were:

- \* Child's Quilt Heather Cowled
- \* Set of towels Jane Monk
- \* Zen Tangle book Barry Lumney
- \* Knitted Doll Kathy Pask

Thank you to those who donated prizes for our raffle.

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**Wise Words**

When you do nothing  
You feel overwhelmed and powerless.  
But when you get involved you feel the sense of  
Hope and accomplishment that comes from knowing you are  
Working to make things better

## Southern Report

How can the year be going so fast already? I feel it is too late to say 'Happy New Year' but I will say it any way. Happy New Year and may 2017 be a healthy and happy year for us all.

We had a most enjoyable luncheon in December with most members present.

First prize for the raffle was a most beautiful quilt. With me being the lucky winner, and having a newly married son, I have put this beautiful treasure away in the hope there will be some grandchildren sometime in the distant future- distant probably sounds a funny thing to say, but the bride is just finishing her degree and is looking forward to using it for a while.

Thank you to the person who has done all the beautiful work on it. It is certainly a treasure. Well done!

I have had two separate enquiries about the Lupus group and hope they will come to our February Luncheon to check us out.

February Luncheon, Wednesday 8th at Esus Café, Elizabeth St Hobart. Time 12 Midday. Meals from about \$12.00 , pay for self. Family members, drivers etc. are welcome.

April 12th : Same time and place IF THE ASSOCIATION CONTINUES AFTER THE AGM IN MARCH. We need people willing to come on to the committee to keep the association going. Yes we are all ill, and ill people have been keeping the association going for years, but if you are willing to give some time it will mean we will be able to continue. Spouses have frequently volunteered in positions and are welcome to do so. If you are willing to put your hand up please contact Bruce and Colleen McCormack (clantoss@bigpond.com). They would love to hear from you. And they can provide details of the jobs.

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### How much does a Prayer weigh?

A poorly dressed lady with a look of defeat on her face walked into a grocery store. She approached the grocer and asked if he would let her charge a few groceries. She explained that her husband was ill and unable to work and they had a number of children who need to be fed. The grocer scoffed and demanded she leave his shop. Thinking of her family she said "Please sir! I will bring you the money just as soon as I can."

Standing beside the counter was a customer who overheard the conversation. The customer walked forward and told the grocer that he would stand good for what ever she needed for her family

'Do you have a grocery list?' asked the grocer.

The woman replied "Yes sir"

"OK" he said put your grocery list on the scales and whatever your list weighs, I will give you that amount of groceries".

The woman did this and with her head bowed the scales went down and stayed down. The Grocer stared and said "I can't believe it"

He piled the groceries on and still the scales did not balance . In disgust he took the list and looked at it. He found not a list but a prayer which said, "Which said Lord you know my needs and I am leaving it in your hands."

The grocer gave her the groceries and the good Samaritan customer gave him the fifty dollars and said "It was worth every penny of it "

It was some time later that the grocer discovered the scales were broken; therefore only God knows how much a prayer weighs.

## **Bone Health and Osteoporosis in SLE**

Dr David J Armstrong

Consultant Rheumatologist, Altnagelvin Hospital, Londonderry



For most people with lupus, concerns about bones generally mean arthritis – pain, swelling, stiffness and perhaps deformity of joints. There is however another bone disease strongly associated with lupus, which is possibly more common than arthritis and carries with it significant morbidity. This is osteoporosis, or brittle bone disease.

Although usually associated with older people, and especially older women, osteoporosis is about 5 times more common in SLE, and can affect younger people and patients of both sexes. Some of this increased risk is associated with treatments for lupus, some with changes in lifestyle and other aspects of health associated with having lupus, and some with simply having a systemic inflammatory disease – a ‘triple whammy’ of risk for fragile bones. However, if detected and treated early, it is possible to greatly reduce the chances of fracture, and new approaches to both treating lupus and osteoporosis will hopefully reduce this risk further in future.

### **What is Osteoporosis?**

Put simply, it is increased fragility of bones, which leads to an increased risk of fracture. Broken bones are not just painful but can have a very real impact on life and even survival. Repeated studies show that about 20% of patients with a hip fracture die within 12 months of the break, and that less than 50% are independently mobile again outside the house. Other common fracture sites include the wrist, the shoulder, the ankle and the vertebrae of the spine. Vertebral fractures can often go undetected, which is a major issue, as they predict who is likely to have a more serious fracture in future, and who might therefore benefit from investigation and treatment. In a study by Bultink and colleagues in 2005, 20% of lupus patients of average age 41 had already had at least one vertebral fracture, many previously unknown to the patient or their doctor.

Many factors contribute to the strength of bones, but we tend to group these into either bone density (related to how calcified the bone tissue is) and bone architecture (related to how good the structure of the bone is, related in turn to the rate of turnover of the bone). An easy comparison is with building a wall, where the bone density represents how strong the bricks are, and the architecture how well they are put together. Bone density increases from birth up to about the age of 25-30, after which it should remain constant until your 50s, when a slow decline begins. Women tend to have accelerated bone loss after the menopause. (Figure 1). Architecture is difficult to measure at the clinic (although bone turnover can be measured fairly easily in research) but bone density is routinely assessed using a DEXA scanner, and has been shown to be an excellent guide to who is likely to fracture, and therefore who might benefit from treatment.

If you have had a bone density (DEXA) scan, you may have been told about your ‘T scores’, which are likely to have been a negative number. This can seem confusing, until you realise that all bone density is set against a ‘gold standard’, the average density in a healthy 30 year old male or female. Most people are therefore in ‘negative territory’, but only when the T score falls

below -1.0 does the risk of fracture start to increase. Scores between -1.0 and -2.5 are known as 'osteopenia' – low bone density with a modestly increased risk of a break. When the score falls below -2.5 however, the risk of a fracture increases dramatically, and is referred to as osteoporosis. The DEXA scan usually measures the bone density in two areas, the lumbar spine and the hip, as these have been extensively studied and the data for fracture risk clearly defined (as well as being common sites of fracture) but many programmes now examine the forearm as well. A DEXA is a quick and painless examination (you do not have to go into a tunnel), and should be considered in most lupus patients after the menopause, in lupus patients (male or female) who have received courses of corticosteroids, who have a strong family history of fracture or who have other risk factors for osteoporosis (see below). Almedhed and colleagues in 2007 published research from Sweden showing that 23% of women with lupus (average age 47) suffered from osteoporosis on DEXA scanning, and 56% had osteopenia.

## Changes In Bone Density over time

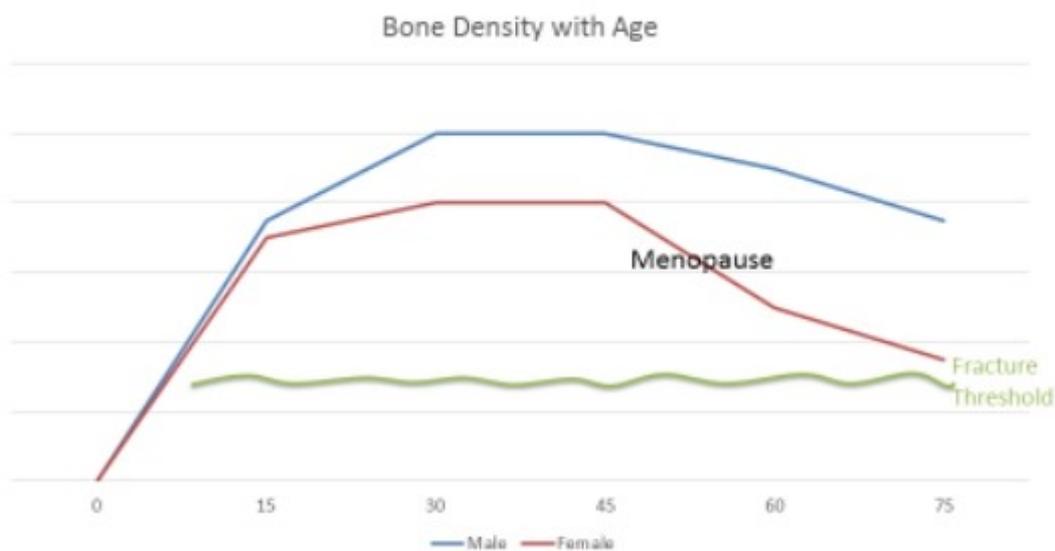


Figure 1

### Why do lupus patients get osteoporosis?

There is some evidence that simply having lupus (or indeed any systemic inflammatory condition) might automatically increase your risk of reduced bone density a little, probably by increasing the rate of bone turnover. The two main reasons however are the necessary treatments for SLE, and the lifestyle changes associated with the disease.

### Treatment

Standing clearly above all other therapies under this heading is steroid. Although life-saving for some lupus patients, and symptom-controlling for many more, regu-

lar corticosteroid use is linked to a range of serious side-effects. Many of these are obvious (weight gain, sleep disturbance) or easily detectable (raised blood sugar, raised blood pressure). One of the most dangerous however, because it causes no symptoms and is often not detected until after the first fracture, is osteoporosis.

Steroid causes low bone density by several mechanisms, including interfering with absorption of calcium from the gut and kidney, and increasing bone turnover. Steroids appear to both extend the life of osteoclasts (which absorb and remove bone) and shorten the life of osteoblasts (which create new bone tissue). There is really little to be said in favour of corticosteroids with respect to good bone health, but they are a major part of successful lupus treatment. Both researchers mentioned above found that more than 80% of their patients had been prescribed the drug at some point, and other workers have shown a doubling of the risk of fracture in the first year of steroid use.

### **Lifestyle**

There is a long list of other factors which contribute to osteoporosis, and many will unfortunately be familiar to patients with SLE. Low vitamin D levels play a role, and yet lupus patients are advised to avoid sunlight, the chief natural source of the vitamin. We did some work a few years ago in Northern Ireland, and found that 60% of our lupus patients had vitamin D deficiency in the Winter, and 54% in the Summer. In general, the further north you go in the UK, the worse the situation becomes with respect to strong enough UVB light to produce vitamin D – even if you were not actively avoiding it!

Other relevant risk factors include low weight, smoking, long term use of PPI drugs (such as omeprazole, lansoprazole, pantoprazole), little weight bearing exercise, early menopause and perhaps avoidance of HRT. In combination with steroid use, inherent risk from the condition itself and a possible family history unrelated to lupus, it is not hard to see how someone with SLE can be at considerable risk of osteoporosis and fractures.

### **What can I do?**

Much of this advice seems obvious, but can still make a big difference to the risk of fracture. Many patients have poor calcium intake in their diet over the years, and I advise patients at risk of osteoporosis to aim for at least 1200mg per day. As a guide, a pint of semi-skimmed milk has about 600mg.

#### **What Can I Do?**

1. Take at least 1200mg of calcium each day
2. Consider Cod Liver Oil or vitamin D supplement
3. Take weight bearing exercise
4. Stop smoking
5. Use as little steroid as possible
6. Keep disease under control

#### **Table 1**

Vitamin D supplementation makes sense for anyone living in the UK – there is even evidence that regular Cod Liver Oil use might reduce activity of lupus itself – but again you should aim for a decent level, at least 800iu per day to maintain levels, and perhaps more if you are deficient to start with. You might your doctor about a vitamin D check.

## **Medications**

A detailed review of all osteoporosis medication is not possible in this article, but many patients will be familiar with some of the commoner drugs.

### **Calcium and vitamin D supplements**

The mainstay of osteoporosis treatment. There is evidence that even without stronger drugs, taking regular calcium and vitamin D in combination can reduce the risk of a fracture.

### **Bisphosphonates**

Drugs like alendronic acid, risedronate and ibandronate, taken once a week or once a month, can dramatically slow down bone loss and have been shown, if taken correctly, to substantially reduce the risk of a break. Any drug is only as good as the amount which gets to the bone however, and these drugs are notorious for poor compliance – people not taking them properly, or at all. Most studies suggest that less than 50% of patients are still taking the drug one year after its first prescription. There are a range of reasons for this, including the relatively common side effects of nausea, heartburn and bloating, and the fact that osteoporosis itself does not cause any symptoms unless you break something – many patients simply forget. They can also be something of a nuisance to take, as the tablet has to be taken first thing in the morning with tap water on an empty stomach. There have also been concerns about very rare side effects, such as osteonecrosis of the jaw.

Having said all that, in general these drugs are very effective if taken properly for a limited amount of time, and can be particularly important as a preventative measure if you need to take long term steroid treatment. One form of the drug (zoledronic acid) can now be given as a once year infusion.

### **Denosumab (Prolia)**

This is a relatively new drug, and is a monoclonal antibody (like rituximab for example) rather than a chemical (like bisphosphonates). It is given by subcutaneous injection once every 6 months. It interferes with communication between osteoblasts and osteoclasts, and puts a firm brake on the function of the latter, leading to increased bone density and reduced risk of fracture. Unlike bisphosphonates, denosumab does not accumulate in the bones or cause problems with the stomach or oesophagus, but like any preparation it is not without potential side effects, and is still reserved for more severe cases of osteoporosis, or for people who cannot take bisphosphonates

### **Teriparatide (Forsteo)**

A synthetic form of parathyroid hormone, this drug is a powerful stimulant of osteoblast function and strongly promotes bone growth. It must be given by daily injection, and is reserved for the most severe cases of osteoporosis. Initial concerns about increasing the risk of a rare form of bone cancer in rats have not been borne out in humans.

## **Summary**

Osteoporosis is very common in SLE, both due to the drugs used to treat the condition, and to some of the ways lupus affects the body and the patient's lifestyle. Awareness is key, as the condition causes no symptoms until a fracture occurs, and DEXA scanning is a quick and easy way to assess risk.

Adequate calcium and vitamin D intake is essential, and a range of drug treatments available. If you are concerned about the risk of osteoporosis, you should discuss it with your rheumatologist, nurse specialist or GP. Further information may also be obtained from the National Osteoporosis Society website [www.nos.org.uk](http://www.nos.org.uk)

*Thank you to Lupus UK News and views for permission to reprint this article from their Spring, 2016, magazine. Volume 108, Pages, 6&7.*

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## Your Health What's Up Doc?

**Q I was diagnosed with systemic scleroderma about 4 years ago. I had been noticing some skin changes and have been having some wound issues on my fingertips because of Raynaud's phenomenon. What is going on? Why is it changing?**

**A** Your skin undergoes changes in the early stages of scleroderma due to the extra collagen in your body ( *Chapman,2006*). Extra collagen irritates the inside of the blood vessels in the skin and causes what is known as inflammation. Extra collagen thickens the blood vessel, and the inflammation causes the vessel to squeeze closed part or all of the way (*Manetti et al., 2010*). When the vessels are closed off, the oxygen the blood carries cannot get past the inflamed (closed) vessels to the cells in the skin. When the cells in the skin cannot get oxygen, they shut down and die over time. That is why the skin on the fingers of someone with Raynaud's phenomenon turns white, then blue, red and finally black and/or breaks open into sores or ulcers. Typically, scleroderma causes skin changes to occur through a predictable process.

### **PHASE 1**

In the early stages, you will notice painless swelling of your hands and fingers, mostly in the morning. Swelling will start at the fingertips and may spread all the way to the wrist and top of the hand. Although painless, this can cause the hands to be very itchy (*Kreig&Takehara, 2009*). You can take over-the-counter antihistamines and/or apply a low-dose corticosteroid cream, such as hydrocortisone, to relieve the itch (*Muratore et al.,2013*).

### **PHASE 2**

Swelling that lasts for long periods of time causes permanent changes to the skin of the fingers, becoming shiny, tight and thick(*Kreig & Takehara, 2009*).

The thickening that starts in the hands usually continues to the face and neck and slowly to the rest of the body (*Muratore & et al., 2013*). Some times patches of skin become lighter (hypopigmentation) or darker (hyperpigmentation) than the rest of the skin– a cosmetic issue– but not feel different from the surrounding skin. As the skin thickens, there will be loss of sweat glands and hair follicles. With these losses (of) too much collagen the skin will become very dry and itchy (*Chapman, 2006*). Blood vessels that swell over time become damaged and can be seen through the skin. These are called telangiectasia, more commonly known as spider veins. The problem is cosmetic and does not change the feeling of the skin (*Muratore et al., 2013*).

### **Raynaud's Phenomenon**

Not all people with scleroderma will experience Raynaud phenomenon (*Alivernini & et al., 2009*). Raynaud is a complex chain of events in the blood vessels of the finger tips that leads to the circulation being closed off for long periods of time because the blood vessels thicken and small spasms around the vessels tighten them even more. This lack of blood flow can result in painful ulcers that can open and become infected (*Marvi & Chung, 2010*).

### **Q What can I do to keep my skin in good condition? What can I do to help my digital ulcers?**

- A**
- 1) Keep your skin moisturized. The best way to do this is with emollients. Emollients are non-cosmetic moisturizers, which come in the form of creams, ointments, lotions and gels. Well moisturized skin will feel more comfortable, less itchy and tight and be less likely to crack (*Kroft & et al., 2009*). Some common emollients are mineral oils, petroleum and Vaseline.
  - 2) Use creams with hydroxyethyl urea and diazolidinyl urea. In addition to emollients, urea-based products will soften skin; provide mild local anesthetic; moisturize extra-dry skin; and promote pH balance to protect the skin's acid mantle (*Kornhauser et al., 2010*). The acid mantle is the body's protective layer of oils and sweat that sits on top of the skin. When healthy, it helps protect your skin from bacteria, toxins, allergens and irritants that can cause further irritation and infection of your skin (*Miller, 2013*).
  - 3) Staying away from certain ingredients in your skin care and personal products, such as shampoo, can also help your skin's health. Avoid ingredients that build collagen, such as retinol, retinoid, retin A, vitamin A, vitamin C and alpha hydroxyl acid (*Fisher & Voorhees, 1996*). Basically, if a product has anti-aging properties, it is not good for your skin. Another ingredient to watch out for is sodium lauryl sulphate (SLS) or sodium laureth sulphate (SLES). This chemical damages the skin's barrier function, altering skin cells and enhancing any allergic response to other toxins and allergens, which will make your skin itchier and inflamed (*El-Sharkawy, 2011*). Anything with fragrance or perfume can also cause skin irritation or allergic reactions.

4) Keep warm! When your skin is exposed to the cold, your body protects important organs by closing down the small blood vessels going to your fingers and toes to keep the warm blood in your body's core. Although you may not be at risk of hypothermia, your body is programmed to react the same way to any cold environment. When small vessels are already thick and narrow because of extra collagen and inflammation, this reaction makes matters worse. Your body will close those vessels even more, which can quickly lead to the skin dying and/or ulcers (*Marvi & Chung, 2010*).

5) Quit smoking! Every time you smoke a cigarette, chemical reactions occur in your body. Squeezing the blood vessels in your fingers is one of those reactions, which cuts off the blood flow to the finger tips of your fingers, which is already compromised by Raynaud's.

6) If you have diabetes, try to keep your blood sugar within the normal range. High sugar levels in the blood further damage the lining of the small blood vessels.

7) Hand exercise, such as opening and closing your hands and stretching out your fingers daily in warm (50 degrees Celsius) paraffin wax should decrease the swelling and increase the movement in your hands. Paraffin wax is better than water, but water will do if wax is not available. Study participants saw an improvement in 30 days (*Sandqvist et al., 2004*).

## **Q What can my healthcare team do to help?**

**A** A doctor or nurse practitioner may prescribe medication to slow the effects of the disease by slowing the immune system's response in the body to prevent additional inflammation or damage. Some of these medications can be taken as a pill or through IV. The most common medications include methotrexate, methyl prednisone, and protein carboxyl methyltransferase (*Manetti et al. 2010; Kreuter, 2005*).

Calcium channel blockers are another type of medication that can improve circulation to the fingers. Originally used to help lower blood pressure by opening blood vessels, calcium channel blockers have also been found to help open vessels affected by Raynaud's. This medication may not be right for everyone, and your doctor or nurse practitioner can let you know if is right for you (*Marvi & et al., 2010; Muratore & et. al, 2013*).

If you are having a severe "flare" of Raynaud's, you might need to go to hospital to have an infusion of the medication called prostaglandins or prostacyclin through an IV (*Marvi & Chung, 2010; Manetti et al., 2010; Muratore et al., 2013*) These medications run over several hours, over several days.

You will be monitored closely while receiving this therapy for possible mild-to-severe side effects, but it is very effective when pills are not enough.

Pain management is very important to preventing and managing ulcers.

Your bodies "fight or flight" response to pain will actually limit the circulation to the area that is hurting. Your body is incredible at protecting itself; when feeling pain or injury, it will attempt to protect the rest of the body by shutting down blood flow to the area in pain so you can continue to "fight" or "flee" in a survival situation. Unfortunately, your body is not quite smart enough to tell when you have a wound that needs blood flow to heal.

The best approach to avoiding this response is to manage pain (*Woo, 2012*). The most common problem when healing any wound is infection. If ulcers become infected, it is appropriate to get a prescription for antibiotics to help fight the infection in combination with dressings.

### **DERMATOLOGIST/WOUND CARE SPECIALIST**

Ultraviolet (UV) therapy or phototherapy is used for treatment of superficial wounds, not for involvement of fat tissue, muscles or tendons (*Andrea, et al., 2010*). UV light increases enzymes that break down collagen in the skin and decrease levels of enzymes that trigger collagen production (*Andrea et al., 2010; Kroft et al., 2008*). It is used in addition to medications, not as a stand-alone treatment. The usual treatment course is 15 minutes, five times per week for eight weeks, but that may vary based on the practitioner's knowledge with past cases. Results include visible improvement, decreased tightness and itchiness and on ultrasound the skin is thinner (*Kreuter et al., 2006*).

Creams such as tacrolimus 0.1% ointment or calcipotriene 0.005% can go right on the ulcers or on thickened skin in the early stages of inflammation. When they are applied to the ulcer under semi-occlusive dressings (gauze or bandage), lesions may resolve in approximately one month. These creams can also help to soften or slow the thickening process (*Teland, 2013; Stefanaki, 2008*). If there are no wounds, you do not need to cover the area with a dressing.

Even a small, clean ulcer should be covered to protect it from further injury and infection. For small, clean ulcers that will only need care for 7-10 days, I recommend applying over-the-counter polytopic ointment daily after cleaning the area with soap and water, then covering the wound with a dressing or bandage. For larger and infected ulcers, I use either manuka honey or a polymer-based dressing that contains silver. Both dressings fight infection from many different bacteria; They are anti-inflammatory, which will help with the pain and circulation to the wound, and they give some moisture to the wound base, which helps new cells move into the wound base to heal.

### **PLASTIC SURGEON**

When medications and dressings are not helping, the ulcers are impacting a person's quality of life due to pain and loss of function or an infection cannot be controlled, surgery is an option. A consult to a plastic surgeon should be made through a doctor or nurse practitioner. In some cases, the surgeon will "debride" or cut away dead and/or infected tissue from the ulcer to give it a chance to heal. In other cases, surgery might be necessary to remove the part of the affected finger that is not healing or has turned black. This is referred to as an amputation.

### **SUMMARY**

Wound care is a team approach with the person with the wound in the centre. The best care requires medical management of the disease (scleroderma), local care of ulcers, pain management, infection control, and management of the other medical conditions, such as diabetes and hypertension. It also includes how each patient takes care of his or her own skin and overall health.

## ABOUT THE AUTHOR

**Alexandria Crowe, R.N. (E.C.), B.Sc.N., N.N.-N.P** graduated from McMaster University in 2007 with a Bachelor's of Science in nursing. After graduation, she began working in Intensive Care. In 2011, Ms. Crowe pursued her Masters of Nursing and Acute Adult Nurse Practitioner certification from the University of Toronto. She now holds the position of Wound Care Specialist at St. Joseph's Healthcare Hamilton. Currently, she manages patients with a range of skin and wound conditions. Ms. Crowe is also a part time Faculty at McMaster University in the School of Nursing and holds an Adjunct Faculty Appointment at the University of Toronto.

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*Thank you to Scleroderma Foundation for permission to reprint this article from "Scleroderma Voice," Winter, 2016, pages 15,16 & 30. The article has defined scleroderma in everyday language which can be understood by people with the disease.*

# For Your Diary

## Please remember

Thursday 23rd February Morning Tea at Kings Meadows Health centre. Please bring along some morning Tea and join in with members. It may be the last get together we have.

## A.G.M.

Sunday 12th March , At Kings Meadows Health centre.  
Joan Marshall Wing at 11.00 am  
This is a very important meeting please come along and have a say in where your Association is going  
Please bring some finger food to share.

### Southern Group

February Luncheon: Esus Café Elizabeth Street, Hobart.  
12 Noon, Pay for self, Wednesday, February 8th 2017.