

Just the Basics:

Suggestions, Remedies & Helpful Hints for Morgellons Disease

- *The CEHMDF officially recommends you consult with your health care professional before using any medication or treatment, as only you and your medical care provider know your own unique and individual medical issues.*
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...The Charles E. Holman Morgellons Disease Foundation

Sunny's personal Note...

In the beginning of my own Morgellons (MD) journey, I focused primarily on cleaning the environment (home, etc.) and secondarily on myself. It was only when I switched to putting *myself* first that I began to see improvement. I finally realized that I could not sterilize my home, etc. I had to concentrate on my physical and emotional health. I have been on numerous Rx medicines and most of these "other" remedies in some way since 2002. At this point, no one knows the magic cure or the answers we need. The biggest break for us all came in 2010 -2011 when *Borrelia* was confirmed via laboratory analysis to be in MD patients. *Borrelia* is a bad "germ" that is very difficult to ID and even more difficult to treat. Whatever else is involved with Morgellons Disease is yet to be uncovered. However, we do know that we have at least one 'real bad' bacterium to deal with.

I have tried to keep my mind on staying positive even at my lowest points. Today, I am better than in the beginning (2001 -2002) and am thankful. I have good days as well as bad. I do not have the horrible symptoms every day. Yes, they still come back but not as severe and for shorter periods. I am a long way from being well. The remissions I experience I view as blessings, like a glimpse of the future without Morgellons. I keep focused on the medical research, which is the way the solution will come. I am reminded of some wise words from Ms. Joyce Meyer, "*Worry is like a rocking chair—it's always in motion but it never gets you anywhere.*" Keeping a positive mindset builds strength and faith. I have had my faith strengthened during these years. We *will* get to that future day without Morgellons.

Gwen "Sunny" Simmons, RN, PHN-B



Diagnosing Morgellons Disease

Morgellons Disease (MD) is currently a clinical diagnosis made by knowledgeable medical care providers. The key diagnostic criteria for Morgellons disease is the presence of unusual filaments beneath unbroken skin or projecting from skin. Dr. Ginger Savely published the best article to date on recognizing and diagnosing Morgellons, "*Morgellons Disease: Analysis of a Population with Clinically Confirmed Microscopic Subcutaneous Fibers of Unknown Etiology*"

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3047951/pdf/ccid-3-067.pdf>

Visualize the fibers or filaments in the skin with a 60x lighted hand-held microscope.

These can be purchased inexpensively via the Internet and at:

A) -- Radio Shack *Illuminated Microscope -Model: MM-100| Catalog #: 63-1313*
<http://www.radioshack.com/product/index.jsp?productId=2179604> (about \$11.00)

B) -- The CEHMDF Merchandise *Mini-Microscope* www.thecehf.org/cehf-merchandise.html (for \$8.00)



These helpful hints are not complicated nor require buying expensive products.

Many have tried those expensive items only to find such things did not work any better and in some instances, not as well.

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I. General

1. Drink plenty of water—at least 8 glasses each day.
2. GI problems can become a major issue for some people. The important thing is to keep the bowels moving well to keep eliminate the waste.
3. **Diet:** There are many theories and opinions about diet and nutrition for MD patients. Unless there is a specific need such as Diabetes, consuming a normal healthy diet is the best plan. Limit the intake of sugar, carbohydrates and processed foods.
4. **Rest:** The sleep cycle is often disrupted with any disease process. Morgellons patients seem to have a major issue either with too much or too little sleep. Many experience both issues like a cyclic rollercoaster during the illness. Being deprived of adequate sleep worsens pain, increases fatigue, causes depression &/or exacerbation of emotions and suppresses the immune system.

A. Over- The- Counter Sleeping Aids (*Nytol, Sominex, Sleepinal, Compoz*)

The main ingredient in over-the-counter sleeping pills is an antihistamine. Antihistamines, in brand name medications such as Benadryl, are usually taken for allergies, hay fever and common cold symptoms and can have side effects, such as next-day drowsiness.

B. Herbals Sleep Aids:

Melatonin—a herbal supplement used to help with sleep difficulties. Take note that Melatonin is also a naturally produce hormone with the body which helps with the circadian rhythms, the normal wake-sleep cycle.

Valerian Root— Valerian is a flowering plant, the root of which is dried and used as an herbal remedy with sleep problems, anxiety, and mood swings. Take note that it has a very ‘stinky’ smell in the bottle.

L-Theanine—a natural amino acid found in green tea that has a calming effect on nerves; found helpful with anxiety and sleep.

6. Headaches

Many have terrible headaches. The usual over the counter products such as Tylenol, Advil types, BC Powders & plain aspirin provide some relief. Icepacks placed on top of head, at the back of neck and behind ears while lying down in a darkened room works well.

Note: Have your blood pressure checked during a headache episode to be certain it is not elevated.

7. Laundry

The abnormal tissue changes that occur in MD often make it more difficult to get our clothes to feel clean. Any residue from the body can be irritating to already compromised skin. Products with enzyme-based action seem to help remove this residue. Here are a few of the more simple solutions that work well:

Wash-- any detergent + add ½ to 1 cup of ammonia to the wash cycle;

Can also add Borax to wash cycle, if desired.

Rinse cycle- add ½-cup to 1-cup white vinegar;

Dryer-- dryer sheets.

NOTE: If you need to whiten or tackle stains with bleach, DO NOT use bleach with ammonia. Do a second wash cycle for this!

8. Cleaning and Environmental Issues: Many with Morgellons have become fearful of homes, cars, clothes, etc. In addition, the constant worry of spreading this to others or even re-infect ourselves, seems to linger as an afterthought. *This is NOT spread from the shed materials from our bodies.* Save your energy and learn from the experiences of others. *Your environment cannot be sterilized!* The one confirmed pathogen in Morgellons, *Borrelia*, is spread through a ‘vector’ such as ticks & possibly from sexual contact (new research released in Jan 2014). Excessive cleaning is not necessary. The best we can do is to maintain as typical a home environment as possible. Most MD patients are very “energy challenged” & can only do so much! The shed Morgellons material does not infect others nor does it re-infect you. This debris may be irritating to both patient and others around, similar to pollen or dust. This may be a reason for others seeming to react or itch/scratch when around MD patients. Vacuuming, dusting with the Swiffer or Endust type products & a typical cleaning with ammonia, vinegar, Murphy’s Oil Soap and Dr. Bonner’s Peppermint soap, etc., seems to work well. Febreze has an enzyme that breaks down protein material, is safe for most fabrics in homes and cars that cannot be washed.

A final though worth mentioning...

I have come to realize and accepted that while most everything I see may look like “Morgellons”, it likely is not. Keeping things realistic & reasonable, maintaining a positive outlook and knowing that research is going as fast as possible should help in the day-to-day life we each must live. Just hold on to your faith because the answers we need will come. *Never give up or give in!*



II. Skin

1. Topical (for use directly on lesions/skin)

Neosporin oint; ; Bactroban; Betadine; Vaseline; Vicks Vapor Rub; Band-Aid Advanced Healing Blister - by Johnson and Johnson; Salicylic Acid Lotion - "Demarest"; Zinc Oxide; Tea Tree Oil; Noxzema; Gold Bond Powder; Cornstarch powder; Benadryl; Calamine lotion: Caladryl; Tanning Beds, Tea tree Oil; Sea Buckthorn creams and salves; Sulfur soap and Sulfur cream.

2. Soaks (*at least once a day--can do as many as you need*)

A. Soaking in a bathtub with choice of:

---1 to 2 cups of salt-- regular Morton table salt or Epsom Salt or Dead Sea Salt;

---8 to 16 ounces of Hydrogen Peroxide

--Vinegar – white distilled (some use apple cider vinegar) 1 cup or more as desired;

-- Baking soda - as much as a full 'box' in bathwater;

-- Borax – ½ cup up to to two cups in bathwater;

-- Keep the water as warm as possible & submerge in water, including head. Stay in tub for 20-30 mins.

-- Can Finish with a cleaning shower after soak, if desired but not necessary.

3. Shower/Bath

A. Make a scrubbing body wash out of liquid soap. Dawn works very well. Pour into a container & add salt until thick; Use this as a body scrub &/or shampoo;

4. Soak Variations:

C) -- rubbing alcohol ½ to 1 cup;

D) -- Betadine liquid 1 to 4 ounces;

E) -- Oatmeal ... can use uncooked Quaker Oates or Aveeno that can be pricey;

F) --Vicks Vapo-Liquid (for steamers) --add ¼, ½ or 1 bottle depending on size of bathtub; soak head to toe;

After soaking with Vicks, *DO NOT RINSE OFF.*

This Vicks remedy works very well to help with temporary skin sensation relief, to help get a more restful sleep and sinus relief.

G) Natural Spa at Home

Sit in a hot bath that contains a handful of Epsom or Sea Salt, 10 drops of Lavender Essential Oil and 1/2 cup of baking soda.

Soak for 20 minutes; come out feeling relaxed & refreshed.

5. Itchies:

A) -- Zyrtec (Cetirizine --over the counter allergy pills --generic is ok);

B) -- Claritin (Loratadine --over the counter allergy pills --generic is ok);

C) -- Benadryl (diphenhydramine-- over the counter allergy pills --generic ok);



III. Scalp, Hair

1. Selsun Blue ©, Nizoral © or T-Gel ©, Head & Shoulders©, Johnson & Johnson No More Tears Baby Shampoo©, Sulfur 8 Shampoo (store brands and generic versions are ok);

Pour shampoo into cup and add table salt until thick. Wet hair. Put shampoo/salt mix on head.

Be sure to massage into all hair and scalp well. Rinse then repeat.

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Do a 2nd application and *Leave in hair* securing with towel or shower cap. Leave in as long as desired (...the longer the better... even overnight); Keep in at least 1 hour.

When ready, finish washing hair & scrubbing scalp well. Finish wash with plain shampoo to clear all salt.

Rinse well. Add any conditioner and massage into hair and scalp.

While conditioner in hair & using a small toothed-comb, comb hair from scalp outward.

There will usually be many tangles & loose hairs coming out. Continue combing until none.

This may take a while esp. the first few times.

After finished combing, rinse out conditioner.

2. If you have a major scalp problem, keep head wrapped with scarf or bandana. This will lessen the irritation of areas on face, neck-back-shoulders and arms; In addition, you will have less problems with ears, eyes, and nose.



IV. Feet

1. In foot-bath or large pan –fill with warmest water add **any 1** of the following:

--½ to 1-cup table salt plus ½ cup of hydrogen peroxide.

--½ to 1 cup Epsom salt plus ½ cup of hydrogen peroxide

--1 packet of Johnson’s Foot Soak. Most Wal-Mart type stores carry this for about 1.50 / box (small box has several packets).

-- 1 cup plain uncooked oatmeal

2. Put feet in water. Wiggle toes and move feet to mix and circulate water mixture. Keep in water for 30 mins,

3. Using a body scrubber **or** wash-cloth wash feet with the liquid scrubber body wash (made as in “Skin” portion of this).

Vigorously wash feet, between toes, heels, and ankles. Rinse well in clean water. Towels dry with vigorously rubbing to get any remaining skin/surface debris.

4. Keep toenails trimmed.

5. Put on clean white cotton socks.



V. Register with Oklahoma State University

OSU-CHS Center for the Investigation of Morgellons Disease
Tulsa, OK.

<https://centernet.okstate.edu/morgellons/registration.cfm>

Let your voice be heard. Registration only takes a moment to do. It is so very important and confidential under the HIPAA law. The increasing numbers of patients reporting Morgellons will substantiate the reality of MD to the CDC, hopefully, making them do their lawful duty.



VI. Medical

Medical treatment of Morgellons Disease can only be determined by the individual patient and their medical care provider. There is currently no recognized medical protocol for MD. Many people with MD have been found to have Lyme disease (Borrelia) and associated co-infections. Treating for these conditions seems to help with Morgellons symptoms.

A word of caution: It is important to realize there is no cure or specific treatment for Morgellons Disease known at this time. Please be cautious of "snake oil type" treatments and charlatans who are trying to make a quick dollar off the suffering, misery, and desperation of other people.

Morgellons is a very real, physiological condition and the importance of seeking medical care cannot be stressed enough. MD is a multi-systemic disease, much more than just a skin condition. Patients have also reported experiencing various

neurological issues, visual disturbances, and GI problems, as well as other health infirmities. It is important that you try to find a compassionate medical care provider who can monitor your physical condition to evaluate and treat any symptoms that may develop. Finding a doctor can be a challenge because many medical providers at this time are not aware of Morgellons or have been falsely educated to believe it is not a real physical affliction. It is important to establish a relationship with a provider so they can determine a baseline assessment of what is normal for you. They can use this baseline assessment as a comparison, if other health problems should arise.

To date, Morgellons is usually not recognized or accepted within the mainstream medical community. Some consider it psychological in origin, despite sound physical evidence to the contrary. Education of and a better understanding by medical providers everywhere will continue to happen as on-going research reveals more and more. Due to the close similarities with Lyme Disease & the identification of *Borrelia* in MD specimens, Lyme Specialists have offered medical management to MD patients. This group of specialists understands the bacteria, *Borrelia*, and has experience necessary to manage this serious spirochetal bacterium as well as any possible co-infections. You can check out referral resources for an LLMD at www.lymediseaseassociation.org and http://ilads.org/ilads_media/physician-referral/

If you have any 'helpful remedies' that you would like to share,
email your ideas to us via the website.

As we do periodic updates, suggestions we have received
will be added for others to benefit.

Thank you!

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www.MorgellonsDisease.org