

NOTES ON MORGELLONS SYNDROME

Patient Information and Notes from the Institute for Molecular Medicine and the Morgellons Research Foundation

Morgellons syndrome or ‘fiber’ disease has been characterized by unusual skin wounds, fibers and specks that appear to be extruded from the skin along with peripheral neuropathies that are described as itching or crawling feeling under the skin. According to the Morgellons Research Foundation (<http://www.morgellons.org/casedef.html>), Morgellons can be characterized by six major signs and symptoms:

1. Skin lesions, both spontaneously appearing and self-generated, with intense itching. The former may initially appear as “urticarial-like” (commonly called “hives”), or as “pimple-like” with or without a white center. The latter appear as linear or “picking” excoriations. Even when not self-generated, lesions often progress to open wounds that heal abnormally and usually incompletely. (e.g., heal very slowly with discolored epidermis or seal over with a thick gelatinous outer layer.)

2. Crawling sensations, both within and on the skin surface. Often conceptualized by the patient as “bugs moving, stinging or biting” intermittently. Besides the general dermis, may also involve the scalp, nares (nostrils), ear canal, and body hair or hair follicles. The sensations are at times related to the presence of easily seen insects, arthropods, and other human and non-human-associated parasites that require serious attention from the treating clinician.

3. Fatigue and weakness significant enough to interfere with the activities necessary for daily living.

4. Cognitive difficulties, including measurable short term memory and attention deficit, as well as difficulty processing thoughts correctly. Described by patients as "brain fog".

5. Behavioral effects are common in many patients. Many have been or will be diagnosed as Attention Deficit Disorder, Attention Deficit Hyperactivity Disorder, Bipolar Disorder, or Obsessive-Compulsive Disorder. Almost all, if previously seen by well-read physicians without prolonged observation, will have been labeled as “Delusional Parasitosis”. A temporal relationship to skin lesion onset is not known.

6. Presence of “Fibers” in and on skin lesions. They are generally described by patients as white or black, but clinicians and patients also report seeing blue, green, red, and other fibers, that fluoresce when viewed under ultraviolet light (Wood's lamp). Objects described as “granules”, similar in size and shape to sand grains, can occasionally be removed from either broken or intact skin by physicians, but are also commonly reported by patients. Patients report seeing black “specks” or “dots” on or in their skin, as well as unusual 1-3 mm “fuzzballs” both in their lesions and on (or falling from) intact skin.

Other signs and symptoms include: changes in visual acuity, balance problems, bloating and swelling of legs, neurological symptoms, including changes in mood and personality, painful extremities, tinnitus, gastrointestinal symptoms, skin sores that do not heal, changes in skin pigmentation and texture and other changes, arthralgias or arthritis-like symptoms, sinus problems, breathing problems and chronic infections (*Borrelia burgdorfi* or Lyme Borrelia, *Mycoplasma* species, among others) or skin parasites. Also, in some patients small, sometimes colored, dart-like structures have been removed from under the skin. In addition, many patients have co-morbid conditions, such as Chronic Fatigue Syndrome, Fibromyalgia Syndrome or Sarcoidosis. Often patients with the Morgellons Syndrome are thought to be delusional, or they are accused of self-inflicted skin lesions. Thus obtaining appropriate medical assistance is often a challenge, because most practicing physicians have little knowledge of new or emerging illnesses that may be outside of mainstream medicine.

Although the cause of Morgellons is unknown, it is thought to contain several elements of known microorganisms. Similar to Lyme disease, Morgellons likely includes several types of unusual infections, including bacterial (*Mycoplasma*, *Borrelia*, etc.), parasitic (a previously unknown parasite has been found), fungal and even insect (for example, the extruded material from some patients appears to be similar to chitin, a very tough mainly polysaccharide material).

Patients who do not have medical assistance or are trying to augment the treatment they are receiving may want to consider the following information below developed from anecdotal studies and patient feedback. The regimen described is only suggested for patients, and it is intended for long-term use and requires daily maintenance. The suggestions below may or may not help suppress your Morgellons, and the information is not intended to replace a physician's care or instructions. There is no known cure for Morgellons, and new information in the future may change the suggestions below.

This suggested regime must be adjusted to individual patients, the stage of the illness and co-morbid conditions. Consult with your physician in order to determine the most favorable approach. Recovery from Morgellons is very gradual and varies from patient to patient. Often patients' signs and symptoms become worse before they slowly get better. The first treatment consideration is general diet and dietary supplements.

1. Diet is important. Most patients do not consider diet important, but it is quite important in all chronic illnesses. The Institute for Molecular Medicine has posted some dietary advice on its website under Treatment Considerations (<http://www.immed.org/>). In Morgellons Disease an alkaline diet is important.

2. Vitamins and Minerals are imperative. Most chronic illness patients are deficient in Vitamin B Complex, Vitamin C, Coenzyme Q-10, among others. Information is listed in the first document in the publications section of Treatment Considerations (<http://www.immed.org/>). Since some vitamins can interfere with uptake and action of certain drugs, they should not be taken at the same time of day as other medications, such as antibiotics or other drugs.

3. Immune Enhancement should be considered. There are various supplements available that can boost your immune system. The Institute for Molecular Medicine has posted some information on immune enhancement supplements that you can purchase over the counter (OTC). They are listed in the first document in the publications section on Treatment Considerations (<http://www.immed.org/>). Ask your physician if certain supplements may interfere with medications that you are currently taking.

4. Lipid Replacement Therapy is important for fatigue and mitochondrial function. The Institute for Molecular Medicine has conducted several clinical trials on the use of Lipid Replacement Therapy to reduce fatigue and restore mitochondrial function, which is important for general health and recovery from chronic illnesses. Publications on this topic using NTFactor and other lipid replacement products can be found in the publications section of Treatment Considerations (<http://www.immed.org/>).

5. Antibiotics have helped patients. Although Morgellons is not caused by bacteria alone, bacterial co-infections are extremely likely with this condition. Patients have benefited from tetracyclines, such as doxycycline, along with other antibiotics. Many MD patients test positive for Lyme Disease, caused by *Borrelia b.*, *Mycoplasma* spp., among other infections (*Chlamydia pneumoniae*, . Thus an antibiotic regimen has proved useful to suppress system wide signs and symptoms and neurological problems. Some patients have also used anti-parasitic medications.

6. Some Natural Remedies are useful. These are often the same as those used in patients with Chronic Fatigue Syndrome or Fibromyalgia Syndrome and can be found in the first document in the publications section on Treatment Considerations (<http://www.immed.org/>). In addition, green coffee extract (<http://vitanetonline.com>) has been reported as useful. Ask your physician if certain supplements may interfere with medications that you are currently taking.

7. Probiotics are a requirement for recovery from chronic illnesses. These are important in restoring gut flora and helping with digestion and maintenance of the gastrointestinal system. Some are listed in the first document in the publications section on Treatment Considerations (<http://www.immed.org/>).

8. Pain and sleep medications will help you sleep if relaxation activities are insufficient.

9. Ample pure water is essential. It is important to keep hydrated with bottled water.

10. Eliminate alcohol, caffeinated products and excess sugar from your diet. These interfere with the therapy and generally make your condition worse.

11. Remove biofilm (optional). Foreign matrix material under the skin can be slowly broken up with agents that dissolve biomatrix, such as formed by bacteria or parasites. These matrix materials protect the microorganism from immune attack and drug treatment, so their removal is thought to help patients with conditions of foreign biofilm and infections. Metal and salt chelators, such as EDTA, have been used to break up biofilm, and a useful and safe product for this is Detoxamin EDTA suppositories (www.detoxamin.com) used every other night.

Once you have begun to follow the general dietary recommendations, it's time to consider some specific recommendations for Morgellons. This condition should be considered contagious, although this has not been proven, it may be capable of spreading to family members and pets. It should be considered parasitic, but a known parasite has not been identified in Morgellons. Worm-like forms have been removed from lesions, but their role in the illness has not been confirmed. They may contribute to the sensation of insects crawling under the skin. It may also involve other co-infections, such as Lyme *Borrelia b.*, *Mycoplasma* species or other bacterial infections. It may also involve fungal co-infections. Morgellons affects multiple organs and tissues, and there is no simple, single treatment that is effective.

The Second Consideration is that there are important hygienic suggestions that must be followed. Please consider following the suggestions below.

1. Clean everything with strong cleaners, such as Pinesol or Lysol. If you have a dishwasher, use this to wash and sanitize personal items. Clean surfaces and even door knobs with Pinesol or other cleaners.

2. Wash clothes daily with detergent and bleach. Linens, pillowcases, mattress covers and sheets should be changed and cleaned daily. Flannel is a comfortable alternative. Use Borax with detergent in the wash.

3. Try to keep as dry as possible. Moisture appears to worsen the condition. Use baths only to clean the skin lesions and then only with sea salt, Epsom salt with medicated soap. Moisture control in containers around the house and air purifiers help keep the environment dry. Also, try to keep autos, yard, garage, etc. as dry as possible.

4. Do not use lotions or perfumes; instead, use acne products for skin treatments. Lotions or perfumes tend to spread the condition to uninvolved areas. Instead, use Neutrogena Rapid Clear acne treatment pads, Isotrex gel topical acne treatment (containing isotretinoin, <http://www.walgreens.com/>). Hand sanitizer gels should be used when removing debris in sores. Medicated soaps should be used, or soaps such as Dead Sea salt soap for acne or Dettol bar soap (<http://www.carbolicsoap.com/dettol>).

5. Keep hair away from your body, even when washing your hair, and shampoo with Dawn dishwashing detergent or a medicated shampoo. If you can't use medicated shampoo, try Tresemmé Deep Cleansing Shampoo with vitamin C and conditioner or Jojoba Shampoo plus conditioner (Millcreek botanicals, <http://www.millcreekbotanicals.com/>). At night a thickening spray can be used, such as made by Pantene. Avoid contact hair with others to minimize chance of spreading the condition.

6. Use latex gloves if your hands are infected, and do not touch uninfected skin with your bare hands. Use Zim's Advanced Wound Care gel (<http://www.bizrate.com/>) or Dr. Bonner's Hemp Lavender or Hemp Peppermint soap for washing exposed skin (<http://www.drbronner.com/>).

7. Treat pets, if necessary, because they can contract the condition. Medicate with anti-parasites and antibiotics, if necessary.

8. Remove carpets, if necessary, and maintain a clean, dry environment. Change air filters often.

Patients diagnosed with bacterial co-infections should be treated with antibiotics. For the types of intracellular bacterial co-infections found in Morgellons patients, long-term antibiotics are usually necessary. In addition, patients with fungal co-infections should be treated with anti-fungal drugs. The Institute for Molecular Medicine has posted some information on antibiotics, anti-virals and anti-fungal drugs. These are prescribed by a physician. They are listed in the first document in the publications section on Treatment Considerations (<http://www.immed.org/>). Ask your physician if certain antimicrobials may interfere with medications that you are currently taking.

Next is a list some of some common commercial products that will help. Keep in mind, however, they may not work for everyone. You may have to come up with a mix that will work well for your needs. There is no known cure for Morgellons, so these are only suggestions that could help improve your condition.

1. Directly treat skin sores with a Calamine spray (Band-Aid, <http://www.amazon.com/>). Leave the product on as long as possible, and do not rub it into the skin. Also, colloidal silver can be used directly on lesions. Betadine antiseptic solution is a good broad-spectrum antiseptic (<http://www.brucemedical.com/>) and hand (gel) sanitizers can be used on sores and keep hands clean.

2. Skin can be treated with acne products or medicated soaps. Some examples are Sapoderm soap (<http://shopping.ninemsn.com.au/>), Dettol soap (www.amazon.com) oatmeal soap, Clear Skin for acne and especially African Black Soap by Nubian Heritage (<http://www.iherb.com/>). Combinations of Dettol and African Black Soap are helpful. Do not rub your skin—lather and rinse. Use towels only once, and then wash them. Hand (gel) sanitizers can be used to keep skin clean. After cleaning, a lotion or cream containing vitamin C should be applied, especially at bedtime, or a lotion containing cranberry seed oil (<http://www.fruitessentials.com/>).

3. Cover open skin sores with a loose bandage (Band-Aid, decompression strips, Hytape surgical tape, etc.) and keep them dry.

4. Remove any fibrous or worm-like material with an alcohol-treated tweezers and use facial tissues. Do not contaminate other skin areas with materials removed from your skin and use hand (gel) sanitizers after removing debris to keep skin clean and sanitized.

5. Treat sinus problems with a cold medication, such as Dristan, Allerest, Actifed, etc. Do not use nasal sprays.

6. Treat skin and muscle pain. A variety of pain products and muscle relaxers are available, such as Advil PM, Doan's backache nighttime, Loratab or Flexril.

7. If you have trouble breathing, try a bronchodilator such as Primatene Mist (<http://www.primatene-mist.us.com/>).

8. Avoid mucous build-up. Using decongestants, bronchodilators and expectorants (mucous thinners), such as Actifed, NyQuil Sinus, Primatene Tablets or Mucinex (<http://www.mucinex.com>), keeps mucous from building up in the throat and lungs.

9. Examine feet often and treat shoes and feet to prevent foot problems.

10. Keep your nails short and clean. Often anti-fungals are necessary.

11. Make sure that your eyes are clear and clean. Eye drops, such as Zaditor or Naphcon A are available at local drug stores, and can be used to keep eyes clear.

11. Clean your ears. Use Hylands Earache drops to remove particles from ears (<http://www.walgreens.com/>)

13. Baths must be carefully considered. Fill tub with very hot water and add 2 cups of Epsom salt or magnesium sulfate or Dead Sea salt with White Tea Bath Leaves (<http://www.webvitamins.com/>) and immerse for 10-20 minutes to open pores (without getting your hair wet). Then add 3 16 oz bottles of 3% hydrogen peroxide and continue soaking until the water begins to cool. Rinse before drying.

14. Women have special needs because of periods and other problems. Yeast infections are common, and Betadine iodine douches (<http://www.brucemedical.com/>) and Monistat vaginal cream are useful. Also, women are prone to bone loss, and bone-building products should be considered.

There are websites where information on Morgellons and related conditions is shared by patients, such as <http://www.skinparasites.com/>, <http://www.lymebusters.com/>, <http://www.biologyonline.org/> , <http://www.morgellons-research.org/morgellons/>

There are also sites where good antiseptic products can be obtained: <http://www.mfasco.com/>

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