

How can I help my loved one?

Glenn Schweitzer's article on "The Mighty" sums it up pretty well.

1. Accept your powerlessness
2. Take time to learn about their illness
3. Be with them but give them space when they need it
4. Validate their pain
5. Don't get frustrated

You can read the article here:

<https://themighty.com/2015/07/how-to-support-a-loved-one-with-a-chronic-or-invisible-illness/>

Sources

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About Mixed Connective Tissue Disease

MCTD is an autoimmune disease which occurs when a person's immune system decides to ramp up and instead of fighting an unknown enemy, it decides to attack itself. It was first noted in 1972 by Sharp et al. and describes a combination of symptoms from three connective tissue diseases; Systemic Lupus Erythematosus (SLE), Scleroderma and Polymyositis. Two additional diseases, Rheumatoid Arthritis and Sjogren's Disease, may also contribute their symptoms to the overall clinical picture. The sharing of symptoms in this manner is known as "overlap." These five are considered "overlap" diseases.

What is Connective Tissue?

Connective tissue is the fibrous tissue that makes up the framework of the body. As the immune system attacks these tissues, they become inflamed causing soreness, pain and in some instances damage to the organs.

Who does MCTD affect?

MCTD occurs in people worldwide and in all races. The female to male ratio has been reported as high as 9:1. The age of onset varies on different research but appears to range from 5 to 80 years with the average age of onset at 37 years. The peak onset however being during the teens and twenties.



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- Raynaud's Phenomenon is often the first symptom and precedes the rest by many months or years, occurring in 85% of patients
- General feeling of being unwell
- Swollen fingers or hands, "Sausage Fingers"
- Muscle and joint pains
- Muscle weakness, usually proximal, with or without tenderness
- Rashes, similar to rashes of Lupus ("Butterfly" or Malar Rash) and Dermatomyositis. Red or brown patches may appear over the knuckles, violet colored eyelids (Heliotrope Rash)
- Difficulty swallowing

Diagnosis

MCTD is often not diagnosed until after a long and exhaustive period of trial and error with physicians, medications, therapies and testing.

The final diagnosis can be a double edged sword of finally getting an answer but not being happy about what you hear. As a loved one, friend, co-worker or employer, please know that this diagnosis is not given out readily. It is real, the symptoms, though often subjective and variable, are real and the challenges daunting.

Complications

- Pulmonary Hypertension (High blood pressure in the pulmonary arteries) is the main cause of death in MCTD
- Interstitial Lung Disease (scarring in the lung)
- Heart Disease, Pericarditis, enlarged heart
- Kidney Disease (occurs in 25%)
- Digestive tract damage
- Iron Deficiency Anemia (occurs in 75%)
- Other Anemia, Leukopenia (occurs 30-40%)
- Hearing loss (can occur in up to 50%)
- Trigeminal Sensory Neuralgia (5th cranial nerve)

Treatment

The prescribed treatment will depend on the severity of the illness and symptoms at the time of the first visit with the Rheumatologist keeping in mind such factors as coexisting conditions and allergies. Thereafter, it is dependent on the course of the disease, how well the person is responding to current treatment and whether they are experiencing any side effects.

Medications commonly used include:

Antimalarials

Example: Plaquenil (hydroxychloroquine).

NSAIDs-nonsteroidal anti-inflammatory drugs

Example: Advil (Ibuprofen), Naproxen (Aleve), Celebrex, Voltaren

Steroids

Example: Hydrocortisone, prednisone, dexamethasone, triamcinolone

Disease-Modifying Antirheumatic Drugs (DMARDs)

Example: Trexall (methotrexate), Arava (leflunomide) Imuran (azathioprine)

Prognosis

Looking at the above complications is pretty frightening. Keep in mind that of all the people diagnosed with this disease, 13% *may* develop severe complications in 6-12 years. The other 87% will manage their disease with medication and lifestyle changes.