MS Support Groups, Community Resources, and Caregiver Information, Alternative/Complimentary Treatments, Future Treatments

Possible Assessment Components
- MS Quality of Life Inventory (MSQLI)
- Patient Interview
- Home Evaluation

Support Groups
- Provide a place to:
  - listen and encourage one another
  - Share challenges and victories
  - Learn coping skills
  - Share ideas and resources
  - Participate in social activities, outings, educational events

- Support groups can be found through local hospitals, churches, community centers, and internet resources.
  - Moving On with MS: 2nd Saturday, 10:00 AM
    Mercy San Juan Physicians Plaza
    6555 Coyle Ave.
    Carmichael
    (916) 349-1324
  - MS Support Group: 2nd Wednesday, 2:00 pm
    Kaiser Permanente
    6600 Bruceville Rd.
    South Sacramento
    (916) 688-2674

  - Additional local support groups: [http://www.deloro.org/resultspage.asp](http://www.deloro.org/resultspage.asp)
    Del Oro is a local non-profit organization for caregivers resources that has a list of available support groups for individuals who are caregivers and individuals with diagnosis such as MS.

- Classes:
  - Exercise groups
  - Community college classes

Resources
  - *The MSF Cooling Program* offers a variety of items, free of charge, including: Cooling vests, Neckties, Wristbands, Bandanas, Work collars, Skull-pads, Baseball hats
- MSF Homecare Assistance Grant Program: [www.msfocus.org/programs_patientsvc_homecare.php](http://www.msfocus.org/programs_patientsvc_homecare.php)
- Serves as a liaison between the patient and the local resources. If resources aren’t available, direct support can be provided including: home care, therapy visits, respite care, and assistance getting home from the hospital.

- Find additional MSF resources at: [http://www.msfocus.org/programs_services.php](http://www.msfocus.org/programs_services.php)

- Barrier-free home
  - Can also search [http://www.barrierfreehome.com](http://www.barrierfreehome.com) for homes and apartments for the mobility-impaired

- Transportation
  - Sacramento Regional Transit District (RT) provides fully accessible fixed-route service in the greater Sacramento area. Seniors and individuals with disabilities can ride RT at a reduced fare.
  - ADA Paratransit service is door-to-door, shared-ride transportation for individuals whose disabilities or health conditions prevent them from using Regional Transit's (RT) bus and light-rail system.

**Financial Considerations**

- SMUD: SMUD's Medical Equipment Discount (MED) Rate
  - Can save more than 30 percent on your electric bill every month.
- PG&E: Medical Baseline Allowance
  - Get additional quantities of energy at the lowest (baseline) price for residential customers. A California-licenced physician must certify that a full time resident of the household has been diagnosed with Multiple Sclerosis.
- MSF Assistive Technology Program: [www.msfocus.org/programs_patientsvc_equip.php](http://www.msfocus.org/programs_patientsvc_equip.php)
  - Provides assistive technology products, help locate a products, or helps with funding for a wide range of devices including: Aids for Daily Living, Communication Devices, Computers and Computer Aids, Environmental Control Systems, Architectural and Vehicle Modifications, Orthotics, Seating, Positioning and Mobility Devices, Aids for Vision and Hearing, Cooling Aids
- Financial Planning

**Occupational Assistance**
• MS Workplace: [http://www.msworkplace.com](http://www.msworkplace.com)
  - provides MS-specific career advice, workplace tips, and job postings for
    the MS community. MS Workplace addresses the common challenges that
    people living with MS can face related to work, providing expert advice
    and linking them to jobs across the country that may be appropriate and
    fulfilling.

**Caregiver Information**

• Support groups
  - Caregiver Support Group: 4th Monday, 12:00 Noon
    2391 St. Marks Way.
    Sacramento
    (916) 483-7848
  - Additional support groups: [http://www.deloro.org/resultspage.asp](http://www.deloro.org/resultspage.asp)

**Internet Resources**

• MS Association of America: [http://www.msassociation.org](http://www.msassociation.org)
• National MS Society: [http://www.nationalmssociety.org/index.aspx](http://www.nationalmssociety.org/index.aspx)
• Multiple Sclerosis Foundation: [http://www.msfocus.org/index.php](http://www.msfocus.org/index.php)
• MS Workplace: [http://www.msworkplace.com](http://www.msworkplace.com)

The following supplemental information has been added by:
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**Future Disease Modifying Treatments**
There is significant research including clinical trials for new medications in the
treatment of MS that have not yet been approved by the FDA. A few of the new
drugs include cladribine, fingolimod, and clofazimine. Most of the drugs being
researched including the above mentioned are immunosuppressive agents that
prevent damage to the nervous system.

**Alternative/Complimentary Treatment**
There are *many* alternative treatments for MS. Most of the CAM ‘s
(complementary and alternative medicine) for MS have not been supported with
sufficient clinical evidence to support efficacy, and safety. If you are interested in
all of the CAM’s used the book *Complimentary and Alternative Medicine and
Multiple Sclerosis* by Allen C. Bowling MD, PhD takes a comprehensive look at
the various treatments practiced.

**Dietary changes/Supplements**

*High pH Therapy/Alkaline Therapy* involves the dietary intake of foods rich in alkaline
minerals such fruits and vegetables or supplements such as Cesium Chloride to improve
immunity. Some believe that a diet high in acidic producing foods (meat, grain, sugars)
disrupts the body’s inherent pH, and promotes the excretion of essential minerals therefore making a person more susceptible to illness.

*Bioflavonoids* are pigments from plants especially citrus fruits that have been recently discovered to possess many therapeutic properties. In the CNS they are believed to elicit effects such as protecting the tissue of the CNS from autoimmune attacks, and strengthening the BBB (blood brain barrier).

**Reference**


**Vitamin D absorption** through sunlight or diet has been linked to optimal operation and health of the CNS and the immune system.

**Reference**


**Prokarin Patch**

A transdermal patch containing histamine-2 and caffeine. The histamine is believed to increase bloodflow in brain, improve nerve conduction velocity, stimulate myelin, and suppress the immune system. The caffeine is believed to accentuate the effect of the histamine. Supported by EDMS Research started by Elaine Delack a Nurse diagnosed with MS in the 1980’s. The use of prokarin patches is very controversial. In 2002 the National Multiple Sclerosis society published a dispute against the conclusion of a 2002 EDMS study. Proponets of the prescription patch believe that it has the following benefits:

- Increased tolerance to heat
- Better sleep
- Decrease in body pain
- Decrease in fatigue, Increase in energy
- Increased tolerance to stress
- Improvement in motor function or sensory function
Improved bladder function
Improvement in balance
Better speech
Improvement in vision

Herbal Treatments

-Pingfu Tang: Pingfu Tang is an original Chinese herbal formula in which many of its ingredients strengthen the immune system function, regulate metabolism, improve blood circulation, and increases the action of neuroendocrine regulation, as well as protecting the construction and function of the adrenal cortex during the administration of corticosteroids. In this study Pingfu Tang significantly reduced the annual relapse rate of MS from 1.07 times to 0.01 times, which is lower than that in the control group (1.01)

Cannabis Based Medicine: Along with the many symptoms that MS patient's have to manage central pain is one symptom in which as many as 32% of patients regard pain as their most severe symptom describing it as "frequent, disabling and inadequately managed symptom". Central pain is a by product of a primary lesion or dysfunction of the CNS in which nonparoxysmal extremity pain occurs that can be described as burning, aching, pricking, stabbing, squeezing and painful extremity spasms.

References


Bee Sting Therapy

Bee Venom: Bee sting therapy is increasingly used to treat patients with MS in the belief that it can stabilize or ameliorate the disease. In this trial treatment with bee venom in patients with relapsing multiple sclerosis did not reduce disease activity, disability, or fatigue and did not improve quality of life.

References

Magnetic Field Therapy

BEMER (Bio-Electro-Magnetic-Energy-Regulation) Therapy: Fatigue is a symptom that many MS patients have to manage on a daily basis. Currently, researchers are exploring CAM's in an attempt to improve fatigue in MS patients with forms of magnetic field therapy. A pilot study by Piatkowski et al. demonstrated improved fatigue levels in MS patients. The researchers hypothesized this improvement on factors such as energy metabolism, oxygen supply, and microcirculation. As a result of this pilot study's uncertainties, trials with more patients and longer duration are required to describe and understand any long term effects.

References


*** all of the above information and resources may be helpful in managing and living with MS in the early, middle, and late stages.