



Resource Guide

MS Coalition Resource Guide

Written by: MS Coalition

Consortium of Multiple Sclerosis Centers
Multiple Sclerosis Association of America
Multiple Sclerosis Foundation

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The logo features a stylized globe icon on the left, composed of several curved lines representing latitude and longitude. To the right of the globe, the text "MS" is written in a large, bold, sans-serif font. Below "MS", the word "Coalition" is written in a smaller, bold, sans-serif font. At the bottom, the words "Resource Guide" are written in a bold, italicized, sans-serif font.

MS
Coalition
Resource Guide

MISSION – The Multiple Sclerosis Coalition is an affiliation of independent MS organizations dedicated to the enhancement of the quality of life of all those affected by multiple sclerosis. The Coalition’s mission is to increase opportunities for cooperation, and provide greater opportunity to leverage the effective use of resources for the benefit of the MS community.

PURPOSE – This Resource Guide is to offer information to support professionals, like you, who care for patients and families with multiple sclerosis. Oftentimes in your capacity as a health care professional, patients share information about themselves and their families beyond the immediate scope of your work.

Hopefully some of the information provided herein will assist you in recognizing when a referral is necessary to link a patient with needed services. It is our intent that this Guide will help to identify the resources available to support your efforts to achieve the best possible quality of life for your patients and their families affected by multiple sclerosis.

REFERRAL TO A MENTAL HEALTH PROFESSIONAL

SEEKING SUPPORT – Psychiatrists, psychologists, and licensed social workers can all assist MS patients and families with individualized mental health care. Patients need a professional who is both aware of their needs and sensitive to their cultural backgrounds. An understanding of MS and the complexities of the health system are also important. Patients need to feel that they are respectfully treated and, above all, that personal information is kept absolutely private and confidential.

Patients can check with their primary care physician or family doctor for referral information. Employee assistance programs are another possible resource, as is one's personal health insurance plan. Wellness centers represent another option; community mental health service programs yet another. Joining a local support group may be another good idea. Patients should be instructed to investigate a counselor as well as a support group to determine whether or not the group or counselor will assist them in meeting goals. Support groups and counselors vary. If the patient attends a support group, or seeks a counselor who is not appropriate, the results can be perceived by the patient as another way they are failing to cope and successfully manage their disease.

Other mental health service sources include local universities or teaching hospitals and physician referral services. Consulting with the school psychologist or another member of the Child Study Team can be yet another excellent resource for mental health support services.

WHEN TO REFER – Consider initiating a referral to a mental health professional or service when your patient demonstrates signs of:

- Depression
- Poor coping patterns
- Signs of family disruption
- Issues of abuse/neglect
- Poor adherence patterns
- Self destructive thoughts or behaviors
- Problems in relationships with significant others
- Eating disorders (not physically caused by MS)
- Substance abuse
- Anxiety

Please note: The professional should be experienced in multiple sclerosis or other chronic illness/disability.

DEPRESSION – The National Institute of Mental Health describes depression as a serious medical illness; it is not something that you have made up in your head. Depression is far more than just feeling “down in the dumps” or “blue” for a few days. It’s feeling “down” and “low,” and hopeless for weeks at a time.

National Institute of Mental Health (NIMH)

1-301-443-4513

www.nimh.nih.gov

Signs and Symptoms of Depression (From National Institute of Mental Health)

- Persistent sad, anxious or “empty” mood
- Feelings of hopelessness, pessimism
- Feelings of guilt, worthlessness, helplessness
- Loss of interest or pleasure in hobbies and activities that were once cherished and enjoyed
- Thoughts of suicide

Additional Resources:

The National Alliance for the Mentally Ill

1-800-950-6264

www.nami.org

NAMI is a nonprofit organization dedicated to the eradication of mental illnesses including schizophrenia, bipolar disorder, major depressive disorder, obsessive-compulsive disorder, panic and severe anxiety disorders, autism and developmental disorders, attention deficit/hyperactivity disorder, and other severe and persistent mental illnesses that affect the brain.

American Psychiatric Foundation

www.psychfoundation.org

The American Psychiatric Association suggests the following warning signs for **teens** which include:

- Angry or aggressive behaviors
- Poor concentration, can't focus
- Increased tardiness or absences from school
- Withdrawn, lack of friends
- Anxious, worried

Other warning signs of mental health problems in **teens** include:

- Marked change in school performance, sleeping and/or eating habits
- Inability to cope with problems and daily activities
- Many physical complaints
- Sexual acting out
- Depression shown by sustained, prolonged negative mood and attitude, often accompanied by poor appetite, difficulty sleeping or thoughts of death
- Abuse of alcohol or drugs
- Intense fear of becoming obese with no relationship to actual body weight, purging food or restricting eating
- Persistent nightmares
- Threats of self harm or harm to others
- Violence toward pets or animals
- Self-injury or self-destructive behavior
- Frequent outburst of anger or aggression
- Threats to runaway
- Aggressive or non-aggressive consistent violation of the rights of others, opposition to authority, truancy, thefts, or vandalism
- Strange thoughts, feelings, and unusual behavior.

(Excerpt from "Fact for Families" American Academy of Child and Adolescent Psychiatry (AACAP))

The American Academy of Child and Adolescent Psychiatry notes that if problems persist over an extended period of time, and especially if others involved in the child's life are concerned, consultation with a mental health professional, child/adolescent psychiatrist or other clinician specifically trained to work with teens may be helpful.

SUICIDE PREVENTION

SUICIDE AND MS – Studies have shown that the risk of suicide is 7.5 times higher among individuals with MS than in the general population. Upon diagnosis, patients need to be carefully assessed for symptoms of depression, as well as evidence of depression within their family.

If you are concerned that someone is considering suicide, it is extremely important for the person to receive early, quality treatment from a specially trained mental health care professional. The best thing to do is to help that person find treatment. Be supportive and reassuring that successful treatment is possible.

(From the Depression and Bi-Polar Support Alliance)

Depression and Bi-Polar Support Alliance

1-800-826-3632

www.dbsalliance.org

According to the Depression and Bi-Polar Support Alliance, if someone is threatening to take his or her life:

- Remind the person there is help and hope. Don't try to handle the crisis alone.
- Take the person seriously. Stay calm and let the person know you are willing to listen.
- Involve other people. Don't try to handle the crisis alone or put yourself in danger.
- Get help from a suicide hotline, or call 911 if necessary.
- Contact the person's family and a psychiatrist, therapist, or others who are trained to help.
- Express concern. Ask direct questions and listen. Try to find out if the person has a specific plan.
- Be understanding, not judgmental. Remind the person that suicide is a permanent solution to a temporary problem.
- Never promise confidentiality. You may need to speak to the person's doctor in order to protect him or her.
- If possible, don't leave the person alone until you are sure he or she is in the care of professionals.

Other Resources:

American Foundation for Suicide Prevention
1-888-333-2377
www.afsp.org

The mission of the American Foundation for Suicide Prevention is dedicated to funding research, developing prevention initiatives and offering educational programs and conferences for survivors, mental health professionals, physicians and the general public.

Yellow Ribbon Suicide Prevention Program
PO Box 644
Westminster, CO 80036-0644
1-303-429-3530
www.ncsp.org

The Yellow Ribbon Suicide Prevention Program is a community based outreach program of Light for Life Foundation International. Yellow Ribbon offers a program that teaches about the internal nature of depression and loneliness.

National Hopeline Network
1-800-SUICIDE (1-800-784-2433)

CHILD ABUSE AND NEGLECT

The American Psychological Association states that parents and caretakers don't always know that they are being abusive or neglectful toward their children. Few adults actually intend to hurt or neglect their children. The effects of child abuse can last a lifetime. An abused or neglected child needs help right away. Is a child you know being abused or neglected?

American Psychological Association
1-800-374-2721
www.apa.org

Warning Signs of Child Abuse and Neglect (from the American Psychological Association)

Warning signs of maltreatment include a child who has or demonstrates:

- Cuts and bruises
- Broken bones or internal injuries
- Burns
- Constant hunger and thirst
- Lack of interest in surroundings
- Dirty hair or skin, frequent diaper rash
- Lack of supervision
- Pain, bruising or bleeding in the genitals
- More knowledge about sex than is normal for the child's age
- Hard-to-believe stories about how accidents occurred

How Can We End Abuse and Neglect?

The American Psychological Association suggests that sometimes people are afraid to report child abuse or neglect because they do not want to break up a family. When you report abuse or neglect, you could be saving that child's life. The goal of stopping child abuse and neglect is to keep children safe. Part of keeping children safe is finding help for the adults who have hurt them. Adults who have abused or neglected a child have many places to turn for help, including:

- The child's doctor
- Local health and social service departments
- Hospitals and community centers
- Psychologists, counselors, and social workers
- Religious groups and institutions

What Should I Do if I Suspect a Child Is Being Hurt or Is at Risk?

The American Psychological Association suggests that you report your suspicions immediately to your local, county, or state child abuse protection agency. Many agencies accept anonymous calls, if you are leery about giving your name.

Who Must Report Abuse and Neglect? (from the American Psychological Association)

In every state, the following people are required by law to report suspected child abuse or neglect:

- Doctors
- Nurses
- Dentists

- Mental health professionals
- Social workers
- Teachers and education professionals
- Day care workers
- Law enforcement personnel

In some states, clergy, foster parents, attorneys, and camp counselors also are required to report abuse. In approximately 20 states, any person who suspects child abuse or neglect is required to report it.

When you make a report, the agency will make a judgment about how serious the situation is. If necessary, a child protection worker will visit the family to see whether abuse or neglect has occurred and to determine what needs to be done. The goals of child protection are to: Stop the abuse, give needed services to the family, and help the family to become safe and loving. Each state has a child welfare organization to respond to the needs of children and families.

Where to Go for Help

County or State Child Welfare Organization

Obtain the telephone contact number for your state's reporting hotline.

American Humane Association

63 Inverness Drive East

Englewood, CO 80112-5117

1-303-792-9900

www.americanhumane.org

Child Help USA

15757 North 78th Street

Scottsdale, AZ 85260

1-800-4-A-CHILD

www.childhelpusa.org

American Bar Association Center on Children and the Law

740 15th Street NW, 9th Floor

Washington, DC 20005-1009

1-202-662-1720

www.abanet.org/child

American Professional Society on the Abuse of Children
407 South Dearborn, Suite 1300
Chicago, IL 60605
1-312-554-0166
www.apsac.org

Family Violence and Sexual Assault Institute
1121 East S.E. Loop 323, Suite 130
Tyler, Texas 75701
1-903-534-5100

National Clearinghouse on Child Abuse and Neglect Information
332 S. Michigan Avenue, Suite 1600
Chicago, IL 60604-4357
1-312-663-3520
1-800 Children
www.childabuse.org

National Organization for Victim Assistance
1730 Park Road NW
Washington, DC 20010
1-800-TRY-NOVA
www.trynova.org

Rape, Abuse and Incest National Network
635B Pennsylvania Avenue SE
Washington, DC 20003
1-800-656-HOPE
www.rainn.org

SUBSTANCE ABUSE

National resources include:

United States Department of Health and Human Services
Substance Abuse/Mental Health Services Administration (SAMHSA)
SAMHSA's mission is to build resilience and facilitate recovery for people with
or at risk for substance abuse and mental illness.

1-800-662-HELP (1-800-662-4357)
SAMHSA has a treatment facility locator
www.samhsa.gov

DOMESTIC VIOLENCE

National resources include:

National Coalition Against Domestic Violence

The mission of the National Coalition Against Domestic Violence is to organize for collective power by advancing transformative thinking and leadership of communities and individuals working to end the violence in our lives.

1-800-799-SAFE (7233)
Immediate assistance dial 911
www.ncadv.org

PARENTS WITH DISABILITIES

National Resource Center for Parents with Disabilities (Through the Looking Glass):

Through the Looking Glass is the first national center for parents with disabilities, funded by the National Institute of Disability and Rehabilitation Research, US Department of Education.

The mission of Through the Looking Glass is to empower parents and potential parents with disabilities by disseminating disability-appropriate information regarding parenting to parents, disability advocates, and legal, medical, intervention and social services providers. The center's overall goal is to increase information and support more disability-appropriate resources for parents with disabilities and their children throughout the US.

Through the Looking Glass
1-800-644-2666
www.lookingglass.org

ABOUT CARE PARTNERS – “The differing emotional experiences of the care partner and the care recipient sometimes require outside help to fully understand and get both persons’ emotional needs met. Speaking with a professional, friends, support groups, or calling a hotline for support are excellent ways to get help.” (Excerpt from “Caring for a Loved One,” MSAA’s magazine, *The Motivator*, Spring, 2004. Please find the entire article at www.msaa.com.)

Care Partner Resources

National Family
Caregivers Association
1-800-896-3650
www.thefamilycaregiver.org

Well Spouse Foundation
1-800-838-0879
www.wellspouse.org

Resources

Avonex Support Line
(Biogen)
1-800-456-2255
www.avonex.com

Rebif MS Lifelines
(Serono/Pfizer)
1-877-447-3243
www.ms lifelines.com

Betaseron Pathways Program
(Berlex)
1-800-788-1467
www.ms pathways.com

Novantrone MS Lifelines
(Serono/Pfizer)
1-877-447-3243
www.novantrone.com

Copaxone Shared Solutions
(Teva Neuroscience)
1-800-887-8100
www.sharedsolutions.com

Other National Resources

US Government Medicare
1-800-633-4227
www.medicare.gov

Social Security Administration
1-800-772-1213
www.socialsecurity.gov

ADA Helpline, Equal Employment
Opportunity Commission
1-800-669-4000
www.ada.gov

Job Accommodation Network
1-800-526-7234
www.jan.wvu.edu

National Institute of Neurological
Disease and Stroke
1-800-352-9424
www.ninds.nih.gov

Multiple Sclerosis Organizations

Consortium of Multiple
Sclerosis Centers
1-201-837-0727
www.mscares.org

International Organization of
Multiple Sclerosis Nurses (IOMSN)
1-201-837-9241
www.iomsn.org

Multiple Sclerosis Association
of America
1-800-532-7667
www.msaa.com

Multiple Sclerosis Foundation
1-888-673-6287
www.msfocus.org

National Multiple Sclerosis Society
1-800-344-4867
www.nmss.org

LACTRIMS (Latin American
Committee for the Treatment
and Research in Multiple Sclerosis)
www.lactrims.com

