

Muscular Dystrophy Association Motor Neuron Disease Clinic

At
The University of Utah
Department of Neurology

SUPPORT

Having support when you have ALS is very important. Support comes in many different forms. We would like to discuss several of these in this handout.

Spouse and Family

Spouse and family are usually the most important support because they know you better than anyone else. They are there for you most of the time. It is important to talk to your spouse and family about your feelings and needs. Sometimes family is left out to “spare” them. However, in our experience, most family members want to be involved. Sometimes setting aside specific time to talk is useful.

Friends and Neighbors

Your outer circle of friends can also be very supportive. Especially so if you need assistance with physical things. Friends and neighbors can also help indirectly by helping your spouse and family.

Church and Clergy

Religious faith can be very important. They can be especially helpful when working to make sense of a disorder such as ALS. Going to church is good for many people. When this is not possible, having visits by clergy can help continue this relationship.

National Associations

There are several national associations that can provide information about ALS. We recommend that you register with both of them.

Muscular Dystrophy Association

The Muscular Dystrophy Association is interested in 43 different nerve and muscle disorders. ALS is one primary focus. Accordingly, MDA supports basic science research on ALS and also sponsors this clinic. We encourage you to register with them. When you register, you will receive a monthly newsletter outlining new information about ALS. You will also receive a bimonthly magazine called Quest that provides general information, some of which can be helpful.

The MDA national office phone number is: 800 572 1717

The Utah MDA phone number is: 801 278 6200

The Idaho MDA phone number is: 208 327 0107

The MDA ALS web site is: als.mdausa.org

The Spanish MDA web site is: www.mdaenespanol.org

ALS Association

The ALS Association focuses only on ALS. They also support basic science and clinical research on ALS. We also encourage you to register with them. When you register, you will receive a bimonthly newsletter also outlining new information about ALS.

The ALS Association national office phone number is: 818 880 9007

The ALS Association web site is: www.alsa.org

ALS Support Groups

Local support groups can be the best source of experienced support. Every support group has people who have been where you will be going, and they can make the way less frightening. Some patients and spouses are reluctant to go to a support group, fearing “what they will see”. In our experience, support groups are not grim; there is humor and friendship as well as support.

Support groups usually meet monthly. At some meetings there are talks by experts in a particular field, such as physical therapists, occupational therapists, speech therapists or attorneys, to provide you with detailed information. At other meetings, the group breaks up into smaller groups, one consisting of patients and the other consisting of caregivers. This gives each a chance to discuss particular issues without offending the other.

Please consider attending a support group! There are two in the Salt Lake vicinity and one in Boise, Idaho.

Salt Lake City

All Saints Church: 1700 South and Foothill Blvd
6:00 PM, the first Tuesday of every month
Please call David Ricketts for more information 801 278 6200

Roy

Roy Public Library: 5396 South 2300 East
6:00 PM, the third Thursday of every month
Please call Dennis George for more information 801 498 7798

Boise

Please contact the MDA office in Boise: for more information 208 327 0107.

Motor Neuron Disease Clinic

Please consider the clinic as one of your supports. We are always available by telephone. We will always make a clinic appointment.

Please contact Barbara Miano at 801.585.6052