

ALS Association
MA Chapter
75 McNeil Way, Suite 202
Dedham, MA 02026

Patient & Caregiver Services

• **Telephone Consultation & Referral**

Consultation is available through a toll free line. Callers speak to a knowledgeable person who knows what it means to cope with ALS and who has access to updated information.

• **Initial Home Visits**

Initial home visits are conducted by professionals and may focus on educational and adjustment issues.

• **Case Management Consultations**

Consultations may be done via the phone or in the Resource Center in our Dedham office. Professionals will help patients and family members identify their needs and options and teach them how to use resources more efficiently and effectively.

• **Newly Diagnosed Patients and Family Meetings**

Newly diagnosed patients, along with their families, meet at our Resource Center to discuss their concerns and needs and to learn more about the disease.

• **The Peter and Terry Wise Resource Center-Lending Library**

The center provides materials to patients, caregivers and professionals on a loan-out basis. Books, videos and articles cover such topics as symptom management, legal and financial issues, diet and nutrition, insurance coverage and psychological issues.

• **Resource Guide**

Each family is provided with a free resource guide. The guide was developed to help families negotiate the complex system of health, social, legal and financial issues and to become more familiar with the services and educational materials that ALSA provides.

• **The June Eisenberg Memorial Support Group Program**

Support groups for patients and caregivers are excellent forums for sharing information and receiving emotional support. They include speakers who focus on all aspects of the disease. They are not “group therapy.” There is no psychological jargon or probing into one’s personal life. Each group is led by 2 qualified professionals including social workers, nurses and psychologists.

• **The Mel Kornbliet Memorial Equipment Loan Program**

Durable medical equipment is provided at no cost to patients with no insurance or limited coverage. Equipment includes wheelchairs, commodes, hooyer lifts, walkers, etc.

• **Augmentative Communication Program**

Augmentative communication equipment such as links and lightwriters are provided at no cost to patients who have lost the ability to speak. Evaluation and training can be arranged.

- **Respite Program**

Funding for short-term respite to relieve family caregivers. The Respite Program may provide some funding for home health care (nurses and aides), a short stay in a nursing home or rehabilitation hospital or an adult day health program.

- **Children's Program**

The Children's Fund can provide partial financial assistance to ALS patients who have children. The fund will cover such programs as daycare, preschool, after school community programs, summer camp and mental health counseling.

- **Buddy Program**

Families are matched up with former caregivers. The buddies are trained volunteers who know how it feels to watch someone you love and care for cope with ALS. They can help and inform patients and family members about ALS, offer insight and helpful tips on disease management, provide the latest information on resources and research or lend an ear or hand when things get tough.

- **Grief and Bereavement Support**

Families are followed via telephone calls, written correspondence and home visits.

- **"Living With ALS" Symposium**

The conference brings together leading researchers and expert practitioners who focus on research updates and disease management.

- **"Quality of Life Day" Programs**

Each year a program is developed for patients and family members that will help enhance their daily living.

- **The Gordon T. Heald ALS Fund**

The fund offers financial aid to those PALS who need additional support. Funding may cover the cost of durable medical equipment, services, heat, groceries or whatever one needs.

- **Public Education and Awareness**

We provide speakers to schools, civic organizations and community groups explaining the affects of the disease and how to become involved in the cause to find a cure. Our professional staff provides in-service presentations and continuing education for health care agencies serving ALS patients regarding the nature of the disease, its care and treatment, psychosocial issues, etc.

- **Advocacy**

ALSA works with state and national officials to sponsor legislation that benefits ALS families. We collaborate with ALS and Neuromuscular Clinics to ensure that patients and family members learn about their rights and the services that the ALSA provides.

- **Research**

We offer an up-to-date listing of current research trials that are being conducted locally and nationally. ALSA funds many investigator initiated research projects and continuing research grants.

- **Website**

Both the national office (alsa.org) and the MA Chapter (als-ma.org) maintain websites replete with information.

