

Muscular Dystrophy and Other Neuromuscular Diseases

Psychosocial Issues

**Leon I. Charash
Robert E. Lovelace, MD, FRCP
Claire F. Leach, MSW
Dr. Austin H. Kutscher
Rabbi Jacob Goldberg
David Price Roye, Jr., MD
Editors**



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and Other
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Jill C. Crabtree
Editor for the Foundation of Thanatology

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Muscular Dystrophy and Other Neuromuscular Diseases: Psychosocial Issues

CONTENTS

Preface	1
<i>Ronald J. Schenkenberger</i>	
SECTION I: PSYCHOSOCIAL ASPECTS OF NEUROMUSCULAR DISORDERS	
Impact of Illness on Lifestyle	3
<i>Lisa B. Schwartz</i>	
<i>Patricia A. Devine</i>	
<i>Clyde B. Schechter</i>	
<i>Adam N. Bender</i>	
Methods	4
Results	6
Discussion	14
Conclusion	18
Living with Amyotrophic Lateral Sclerosis (ALS)	23
<i>Richard F. Mayer</i>	
Clinical Material	25
Results	25
Discussion	29
Summary	30
Family Response to Duchenne Muscular Dystrophy	31
<i>Jessica Robins Miller</i>	
Diagnosis	33
Cessation of Ambulation	35
Adolescence	36
Late Stage of the Disease	37

Tasks for Adjustment	38
Challenges	40
Psychosocial Issues and Case Management in Myotonic Muscular Dystrophy	43
<i>Marcia Sirotkin-Roses</i>	
Muscular Dystrophy: Assessing the Impact of a Diseased State	63
<i>Michael K. Bartalos</i>	
Human Interactions	64
The Impact of Disease on the Individual	65
The Impact of Illness on "Significant Others"	66
The Impact of Illness on Health Care Personnel	68
Responding to the Total Needs of the Patient	69
Epilogue	71
Emotional Stress and Multiple Sclerosis	75
<i>Bruce L. Danto</i>	
Literature Review	75
Case Illustrations	79
Discussion	86
Living with Multiple Sclerosis: The Gradual Transition	89
<i>Florence E. Selder</i>	
<i>Kathleen A. Breunig</i>	
Subjects	90
Life Transition Theory	90
Getting the Diagnosis	91
Living with the Disease	93
Uncertainty	93
Managing the Disease	95
Comparative Testing	97
Making Meaning	98
Depression and Adjustment in Friedreich's Ataxia	99
<i>Michael A. Nigro</i>	
<i>Patti L. Peterson</i>	

Charcot-Marie-Tooth Disease: Disorder or Syndrome?	103
<i>Robert E. Lovelace</i>	
What Is It?	103
The Name	103
How Disabling?	104
Age of Onset	104
How is CMT Inherited?	104
Diagnosis	105
Treatment and Cure	106
Research	107
Psychosocial Aspects of Charcot-Marie-Tooth Disease in Childhood	109
<i>Linda Phillips Goldfarb</i>	
<i>Howard K. Shapiro</i>	
Psychosocial Aspects of Charcot-Marie-Tooth Disease in the Adult Patient	125
<i>Howard K. Shapiro</i>	
<i>Linda Phillips Goldfarb</i>	
Charcot-Marie-Tooth Disease and the Family: Psychosocial Aspects	143
<i>Ann Lee Beyer</i>	
<i>Teresa Daino</i>	
The Parent	145
The Child	146
Concerns of Parents	148
Impact on the Family	149
Encouraging Children to Develop Other Abilities	149
Thoughts of Not Having Children or Limiting the Family	149
Expenses	150
Relationship with Spouse	150
Talking About CMT Within the Family	151
Lack of Information About CMT	151
Feelings of Loss	151
Family Adjustment to CMT	152
Discussion	152

Helping Patients Cope with Acute Loss of Neuromuscular Function **155**

Ramaswamy Viswanathan

Stressors Associated with Neuromuscular Dysfunction 155

How Patients Can Be Helped to Cope 157

Case Illustrations 159

Grief Management by Spouses of Neuromuscular Disease Patients **165**

Peggy Reubens

Variations in Grief Management 166

The Couple as a System 169

Whose Hell Is Hotter—Yours or Mine? **171**

Ed Gallagher

SECTION II: CLINICAL AND RESEARCH CONSIDERATIONS

Rehabilitation Concerns in Late-Stage, Ventilator-Dependent Muscular Dystrophy Patients **173**

Agatha P. Colbert

Francis J. Curran

Onset of Respiratory Failure 175

Clinical Course 178

Other Medical Complications 179

Functional Considerations in Seating and Mobility 181

Conclusion 182

The Ventilator Support of Patients with Neuromuscular Disorders **185**

Colin D. Hall

James F. Howard, Jr.

James F. Donohue

A Note on Researcher Bias in Working with Terminally Ill Children **193**

Richard A. Witte

Seated Thanks to William Carlos Williams	199
<i>Ed Gallagher</i>	

SECTION III: IMPORTANCE OF SOCIAL SUPPORT

ALS Support Groups: An Update	201
<i>Claire F. Leach</i>	

Sponsorship	202
Using the Network	204
Choosing the Variables	204
Formats: What Do They Look Like?	215
Summary	218
Conclusion	220

Comprehensive Care for ALS Patients and Families	227
<i>Bonnie Sutter</i>	
<i>Edward Dick</i>	

China's Care of the Disabled	233
<i>Dennis Ryan</i>	

Hoping Strategies for the Amyotrophic Lateral Sclerosis Patient	239
<i>Tae-Sook Kim</i>	

Introduction	239
1. Environmental Conditions	241
2. Inventory of the Assets and Abilities Attributed to ALS	242
3. Growth Forces	243
4. Group Comparison	243
5. Consensual Validation of Feelings	244
6. Personal Responsibility	244
7. Avoiding Negative Possibilities	245
8. "If . . . Then" Conditional Events	245
9. Speculative Coercion of Reality	245
10. Future Possibilities (Someday, Something)	246
11. Truism	246
12. Hope Commendation	246
13. Testimonial	247
14. The Unpromising Future	247
Summary	249

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ABOUT THE EDITORS

Leon I. Charash is Chairman of the Medical Advisory Committee of the Muscular Dystrophy Association, Incorporated. He is also Associate Professor of Pediatrics at Cornell University Medical Center in New York City.

Robert E. Lovelace, MD, FRCP, is Professor of Neurology at the College of Physicians and Surgeons, Columbia University in New York, New York, where he has worked for over twenty-seven years as a faculty member and a practicing neurologist. He is also Co-Director of the Muscular Dystrophy Clinic at Columbia-Presbyterian Medical Center in New York City.

Claire F. Leach is Clinical Social Worker in the Department of Neurology of the Nassau County Medical Center in East Meadow, New York.

Austin H. Kutscher, PhD, is President of The Foundation of Thanatology and Professor of Dentistry (in Psychiatry) at the College of Physicians and Surgeons of Columbia University in New York City. His clinical and teaching activities have focused on psychosocial aspects of life-threatening illness and bereavement; cancer diagnosis, therapy, and management; and pharmacotherapeutics.

Rabbi Jacob Goldberg is Director of the Commission on Pastoral Bereavement Counseling and also Assistant Professor for Bereavement Counseling at the Wurzweiler School of Social Work at Yeshiva University in New York City.

David Price Royce, Jr., MD, is Assistant Professor of Clinical Orthopedic Surgery in the Department of Orthopedic Surgery of the College of Physicians and Surgeons at Columbia University in New York City.

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Preface

Life has many challenges, and dealing with the difficulties imposed by a chronic disability is certainly a tremendous one. The news of the diagnosis of a severe medical problem often comes as a great shock to the patient as well as family members. Not only are there feelings of guilt, fear, blame, and stress, which exact a toll in family relationships, but the prospect of living with a chronic progressive physical disability may lead to a good deal of anxiety, doubts, and questions—which cry out for resolution.

Often efforts are made to seek opinion after opinion in the hope that someone will disprove the diagnosis and alleviate the fears and dread of a progressive illness. When such efforts fail to secure a less dire diagnosis, a sense of intense aloneness may engulf the entire family. But they are not alone. There are many concerned professionals who care deeply and are prepared to offer their support and professional guidance.

This text reports on the findings of professionals who, over the years, have developed strategies for maintaining the psychosocial well-being of youngsters and adults with chronic, progressive neuromuscular disorders, as well as that of family members. The Muscular Dystrophy Association is pleased to have been of assistance in the publication of this important book.

Ronald J. Schenkenberger

Ronald J. Schenkenberger is Director of Patient and Community Services, Muscular Dystrophy Association, New York, NY.

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SECTION I: PSYCHOSOCIAL ASPECTS OF NEUROMUSCULAR DISORDERS

Impact of Illness on Lifestyle

Lisa B. Schwartz
Patricia A. Devine
Clyde B. Schechter
Adam N. Bender

The percentage of our population with chronic and terminal illness is on the rise, largely due to increasing numbers of elderly and advances in medical technology and chemotherapy (Forsyth, Delaney, and Gresham 1984; Wilson and Drury 1984). Cost containment is now a major issue in the health arena, causing a shift in treatment from long-term hospital stays

Lisa B. Schwartz, MD, is affiliated with the Department of Neurology; Patricia A. Devine, MD, is affiliated with the Neuromuscular Clinic; Clyde B. Schechter, MD, is Assistant Professor of Community Medicine; and Adam N. Bender, MD, is Associate Professor of Neurology and Director of the Neuromuscular Clinic and Laboratory, all at Mount Sinai Hospital and Medical Center, New York, NY 10029.

This work was submitted in partial fulfillment of the clerkship requirements in Community Medicine while Patricia Devine and Lisa Schwartz were third-year students at Mount Sinai School of Medicine.

The authors wish to thank Virginia Walther, CSW, for help with this investigation.

to ambulatory care. As a result, there is a need to reevaluate whether the psychosocial needs of the chronically and terminally ill are being met within this changing system.

The purpose of this study is to explore the similarities and differences between patients with myasthenia gravis (MG), a chronic disease, and amyotrophic lateral sclerosis (ALS), a terminal disease. Both are neuromuscular diseases characterized by muscle weakness, and both can lead to difficulty in talking and swallowing as well as to difficulty in breathing, life on a respirator, and death (Muscular Dystrophy Association 1984, 1986; Myasthenia Gravis Foundation 1985; Sivak, Gipson, and Hanson 1982; Charles 1985). The similarity of these two diseases led Mulder, Lambert and Eaton in 1959 to address the issue of confusion of the two diagnoses in their article "Myasthenic Syndrome in Patients with Amyotrophic Lateral Sclerosis." This internal consistency makes these two diseases ideal in studying the larger hypothesis since MG is treatable and ALS is not.

MG is an autoimmune disease caused by a reduction in the number of functioning acetylcholine receptors in the muscle endplate (Myasthenia Gravis Foundation 1985, 1986). This causes abnormal neuromuscular transmission and results in voluntary muscle fatigue, ptosis, and diplopia. It most commonly affects women of childbearing age and men in their fifth decade (Myasthenia Gravis Foundation 1985). The treatment of MG includes anticholinesterase agents, thymectomy, steroids and other immunosuppressive drugs, and plasmapheresis (Muscular Dystrophy Association 1986; Myasthenia Gravis Foundation 1986).

ALS is a disease of unknown etiology in which the upper and lower motor neurons gradually disintegrate, resulting in progressive atrophy of the muscle cells they innervate (Muscular Dystrophy Association 1984). Muscular atrophy, paralysis, fasciculations, hyperreflexia, emotional incontinence, and relentless progression are characteristic (Myasthenia Gravis Foundation 1985; Udaka et al. 1984). It occurs more commonly in men (1.5 male:1.0 female) with the average age of onset 57 years old. Fifty percent of all ALS patients die within three years of onset (Janiszewski, Caroscio, and Wisham 1983).

METHODS

In order to evaluate the differences in the impact on lifestyle of a treatable diagnosis versus an untreatable one, a cross-sectional survey design was utilized. The study population was composed of 19 ALS and 19 MG patients from the respective clinics at Mount Sinai Medical Center, which

is a national center for ALS and a regional center for MG. Twenty-two questionnaires were distributed to ALS patients and 20 to MG patients; 39 were completed for a response rate of 93%. Three ALS patients dropped out.

Almost all the instruments in this study have already been used and extensively pretested where their validity and reliability have been established (Wallston et al. 1976; Billings and Moos 1981; Brown, Rawlinson, and Hilles 1981; Schipper and Levitt 1985; Spitzer et al. 1981). The survey form contained a total of eight sections of fill-in, multiple choice and yes/no questions:

1. *Demographics.* This included date of birth, sex, race, marital status, education, occupation, income, and date of diagnosis.

2. *Severity of Illness.* The patient rated his concept of illness severity as compared to the physician's assessment. Swallowing and breathing difficulties were included because these are common manifestations of very advanced stages in both illnesses.

3. *Coping Styles.* This was adapted from the Billings and Moos (1981) coping response items. Included are three methods of coping and two foci of coping categories. Coping methods consisted of active cognitive (AC) coping (6 items), including attempts to manage one's appraisal of the stressfulness of the event; active behavioral (AB) coping (6 items), referring to overt behavioral attempts to deal directly with the problem and its effects; and avoidance coping (5 items), referring to attempts to avoid actively confronting the problem or to indirectly reduce emotional tension by eating or smoking more. Coping foci consisted of problem-focused (PF) coping (6 items), including attempts to modify or eliminate the sources of stress through one's own behavior; and emotion-focused (EF) coping (11 items), including behavioral or cognitive responses whose primary function is to manage the emotional consequences of stressors and to help maintain one's emotional equilibrium (Billings and Moos 1981).

4. *Life Satisfaction, Perceived Health and Social Activity.* Brown et al. (1981) proposed a life satisfaction model where they compared coronary artery disease with chronic obstructive pulmonary disease patients. Life satisfaction, perceived health, and social activity were each measured by a 9-Rung Cantril Ladder, which is an equal-interval, self-anchoring scale.

5. *Multidimensional Health Locus of Control (MHLC).* MHLC is an 18-item Likert-type instrument developed by Wallston et al. and based on Rotter's social learning theory (Wallston et al. 1976; Wallston and Wallston 1978). It consists of subscales reflecting three dimensions: whether the patients think (1) they have control over their health (internal LOC); (2) their health is determined by powerful others (external LOC); or (3)

their health is a matter of luck (chance LOC). Items are scored on a six-point scale and answers are totaled as three separate scores (McFarlane et al. 1980).

6. *Psychosocial Well-Being*. This section explored social life, family relations, friendships, recreation, religious activities, and psychological well-being. Seven out of the 14 questions (4, 5, 10, 11, 12, 13 and 14) were adapted from the Functional Living Index for Cancer (FLIC) (Schipper and Levitt 1985) (see Table 1). FLIC is a 22-item survey that utilizes the Likert Scale. The polarities of the questions were alternated in FLIC. We modified this by arranging all negative polarities on the left side and positive polarities on the right side since Corney and Clare's (1985) pilot study on the Social Problem Questionnaire showed that alternating directions causes confusion. Questions 6, 7 and 8 were adapted from Ware, who emphasized the importance of social factors in conceptualizing disease impact (Ware 1984; Holahan and Moos 1981). Questions 2, 3 and 9 were innovative questions.

7. *Public and Body Image*. This section examined distorted body image and lack of privacy, two changes often found in chronic and terminal illness according to Purtilo (1976). It consisted of three yes/no questions: (1) Since the diagnosis, do you ever find yourself hesitating to look in the mirror? (2) When you go out in public, do you feel like people are staring at you? and (3) If yes, has this caused you to avoid public places? The last two questions compared type of diagnosis and public image.

8. *Quality of Life (QOL)*. QOL of the two groups was compared by using the "Q-L INDEX" developed by Spitzer et al. (1981). The Q-L INDEX consists of five distinct item groups including activity, daily living, health, support, and outlook. Each item is scored on a 0-2 point scale giving a total score of 0-10.

RESULTS

The mean age was greater for ALS (61.91) than for MG (53.59) whereas the standard deviation was greater for MG than for ALS patients (Table 2). This age difference was taken into account in the analysis by comparing age-specific scores of the 15 MG patients 40 years old or older with the ALS group for all lifestyle variables. A younger subgroup could not be compared since a younger age group did not exist for ALS. There were also some discrepancies in the distribution of perceived illness severity between the two groups (Table 3). There was a small subgroup that regarded their illness as mild, and they were equally represented in the two diseases. Ratios of moderate and advanced were reversed in the two

Table 1 PSYCHOSOCIAL WELL-BEING

Please circle the number that you feel best describes you on each of the scales below.

1. What was your initial reaction to your diagnosis?
1 2 3 4 5 6 7
rejection acceptance
2. How long after you were told your diagnosis did you tell your family and friends?
1 2 3 4 5 6 7
long time short time
3. Rate whether this has drawn you and your family closer together or further apart.
1 2 3 4 5 6 7
further closer
apart together
4. Rate in your opinion how disruptive your disease has been to those closest to you.
1 2 3 4 5 6 7
totally no
disruptive disruption
5. Rate how willing you are to see and spend time with your friends.
1 2 3 4 5 6 7
unwilling very willing
6. Since your diagnosis, has the number of your friends changed?
1 2 3 4 5 6 7
decreased increased
a lot a lot
7. Since your diagnosis, has the frequency of visits with friends and relatives changed?
1 2 3 4 5 6 7
decreased increased
a lot a lot

TABLE 1 (continued)

8. Since your diagnosis, has the number of club and organizational memberships changed?	1	2	3	4	5	6	7	increased a lot
9. Since your diagnosis, has the frequency of your attendance at religious services changed?	1	2	3	4	5	6	7	increased a lot
10. Rate your ability to maintain your usual recreational or leisure activities.	1	2	3	4	5	6	7	increased a lot
11. How much time do you spend thinking about your illness?	1	2	3	4	5	6	7	able
12. How well are you coping with everyday stress?	1	2	3	4	5	6	7	never
13. Rate how often you feel discouraged about your life.	1	2	3	4	5	6	7	very well
14. Rate the degree to which you are frightened of the future.	1	2	3	4	5	6	7	never
15. Rate the degree to which you are frightened of the future.	1	2	3	4	5	6	7	not 'afraid

TABLE 2 - AGE, SEX AND NUMBER OF YEARS SINCE DIAGNOSIS

	<u>AGE</u> ($\bar{x} \pm SD$)	<u>SEX</u> (%)		<u># years since diagnosis</u> ($\bar{x} \pm SD$)
		<u>MALE</u>	<u>FEMALE</u>	
ALS-all	61.91 $\pm$ 8.79	52.6	47.4	2.85 $\pm$ 1.85
MG- all	53.59 $\pm$ 16.84	31.6	68.4	10.37 $\pm$ 8.066
MG $\geq$ 40y.o	59.33 $\pm$ 13.85			

TABLE 3 - PERCEIVED ILLNESS SEVERITY (%)

	<u>EARLY</u>	<u>MODERATE</u>	<u>ADVANCED</u>
ALS	15.8(3)	31.6(6)	52.6(10)
MG	15.8(3)	52.6(10)	31.6(6)

groups, and for this reason moderate and severe patients were compared separately. Some differences were noted in sex and years since diagnosis (Table 2). The ratio of males to females in MG was 0.46 whereas it was 1.11 in ALS. For this reason, the data was reanalyzed to control for sex by comparing sex-specific scores for all lifestyle variables. The mean number of years since diagnosis was greater for MG (Table 2). This could not be controlled for since there were only six MG patients in contrast to 18 ALS patients that were diagnosed five years ago or less. Race, marital status, income, and education were distributed relatively equally between the two groups (Tables 4-7). There was no relationship between the type of diagnosis and changes in employment status by Chi Square Analysis ($X^2 = 0.786$, $X^2 = 1.39$; NS).

Coping styles used by the two groups revealed a mean AC score that was greater for MG (68.40) than ALS (60.52) and a mean AB score that was greater for ALS (86.84) than MG (67.53). However, only the AB category was significant ($T = 2.719$, $p < 0.05$). The magnitude of the relationship remained the same when controlling for age, illness severity, and sex, however only the age-specific scores remained statistically significant ($T = 2.381$, $p < 0.05$). The lack of statistical significance probably reflects small sample size. MG and ALS patients both tended to be problem-focused (14/19 MG and 17/19 ALS) in dealing with their illness. Multiple T-tests were used to analyze these data due to small sample size. For this reason, these results must be applied with caution since the use of multiple T-tests increases the Type 1 error and the nominal significance level of 0.05 is not preserved.

Nonparametric Mann-Whitney U statistic was used to analyze the Cantril Ladder results for life satisfaction (LS), perceived health (PH), and social activity (SA). The MG median scores (7 for LS, 5 for PH, and 10 for SA) were higher than the ALS median scores (4 for LS, 4 for PH, and 1 for SA) in all three areas. For all three parameters there was a statistically significant association with type of diagnosis (Table 8). The strongest association was with social activity ($p < 0.025$). The relationship was

TABLE 4 - RACE (%)

<u>RACE</u>	<u>MG</u>	<u>ALS</u>
Caucasian	42.11 (8)	52.63 (10)
Asian	0	0
Black	36.84 (7)	36.84 (7)
Spanish American	15.79 (3)	0
Other	5.26 (1)	10.53 (2)

TABLE 5 - MARITAL STATUS

	<u>CURRENT</u>		<u>BEFORE DIAGNOSIS</u>	
	<u>MC</u>	<u>ALS</u>	<u>MC</u>	<u>ALS</u>
Married	11	13	11	14
Widowed	4	1	1	1
Separated	0	3	1	2
Divorced	1	2	1	2
Single*	3	0	5	0

* (never married)

maintained when controlling for severity of illness, age, and sex, with the loss of statistical significance only for the moderate illness group, probably because the small sample size had a greater effect.

In internal LOC, the mean score was significantly higher for myasthenics than for ALS patients ($T = 2.445$, $p < 0.05$). The relationship was strongest in the advanced group ($T = 2.165$, $p < 0.05$). Age did not diminish the relationship ($T = 2.117$, $p < 0.05$). The magnitude of the relationship remained the same when controlling for sex, however the statistical significance of sex-specific scores was diminished, probably due to small sample size.

The myasthenic group scored significantly higher than the ALS patients in psychosocial functioning measured with the Likert scale ($P < 0.01$) (Table 9). The magnitude of all the relationships was upheld when controlling for age, sex, and severity of illness, although the moderate illness group failed to reach statistical significance and statistical significance was diminished in the male-specific group. Again, this was probably due to small sample size.

Fisher's Exact Probability test was applied to the public and body image

TABLE 6 - EDUCATION (%)

	<u>MG</u>	<u>ALS</u>
<9th Grade	21.05(4)	21.05(4)
10th Grade	5.26(1)	0
11th Grade	0	0
12th Grade	36.84(7)	26.32(5)
Vocational	10.53(2)	5.26(1)
Some College	21.05(4)	26.32(5)
College Graduate	5.26(1)	5.26(1)
Master's Degree	0	15.79(3)
Doctorate Degree	0	0

TABLE 7 - INCOME (%)

	<u>MG</u>	<u>ALS</u>
<\$5,000	15.79(3)	21.05(4)
\$5,000-10,000	42.11(8)	36.84(7)
\$11,000-20,000	21.05(4)	10.53(2)
\$21,000-30,000	10.53(2)	10.53(2)
>\$30,000	10.53(2)	21.05(4)