Understanding Interventions and Assessments for Individuals with ALS

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WROTSS 2020

Objectives

Examine	Key interventions for proactive care in the treatment and care for an individual with ALS
Identify	Assessments and diagnosis specific questionnaires used for individuals with ALS
Describe	Multidisciplinary collaborations between OT and other practitioners on a clinic team

Amyotrophic Lateral Sclerosis (ALS)

- Motor Neuron Disease
- Progressive degeneration of motor neurons
- Estimated 14,000 - 15,000 Americans have ALS
- Ages: 55 – 75 years old

- Military Veterans
  - 1.5 - 2 x more likely to develop ALS
- Sporadic = 90%
- Familial = 5-10%
  - C9ORF72
  - SOD1

(ALS Fact Sheet, 2019)

ALS: What are the symptoms?

- Muscle weakness
  - Upper and lower extremities, neck, or diaphragm
- Fatigue
- Muscle cramps
- Muscle atrophy
- Fasciculation
  - Upper and lower extremities
  - Shoulders
  - Tongue
- Impaired speech and swallow
- Spasticity

(ALS Fact Sheet, 2019)


Hope

“We may look as if we carry on with our lives as before.

We may even have times of joy and happiness.

Everything may seem “normal”.

But THIS, “Emptiness” is how we all feel…all the time.” John Maddox


ME
ALS


ME
ALS

Diagnostic Delay

- Median delay in diagnosis 14 months
  - Prognosis 3-5 years
- Inappropriate therapies
- Delayed use of life extending medication
- Delayed referrals to rehabilitative services

Therefore, timing of recommendations for equipment is important.

(Kiernen et al., 2011)

Rehabilitation interventions

- Maximize patient function
- Increase safety
- Increase independence
- Improve quality of life
- Recommendations for appropriate durable medical equipment and adaptive equipment
- Proactive and preventative care

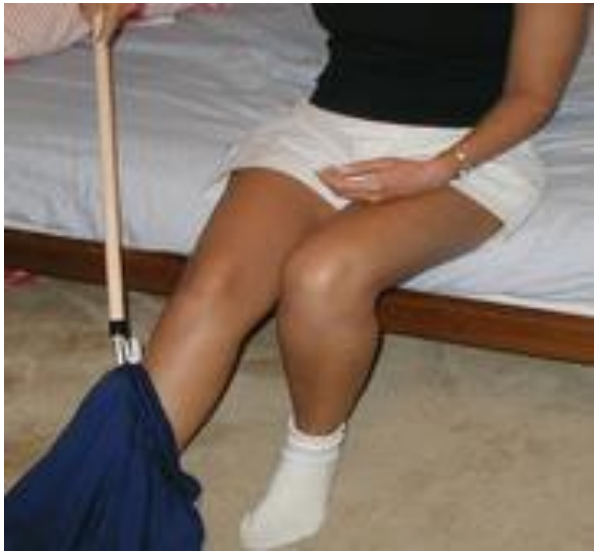
(Majmudar et al., 2014)

Interventions

- Energy conservation
- Moderate Exercise
- Adaptive devices
- DME
- Orthotics/splinting
- Wheelchairs

- Multidisciplinary program
  - 30% longer survival than general care
- Palliative care
- Telemedicine
- Preparatory methods

(Arbesman and Sheard, 2014)

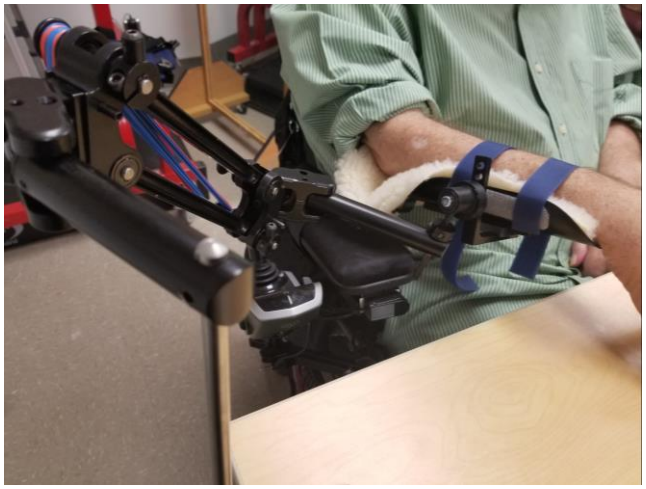



Brush
Comb
Groom Hair
Without
Straining

Additional Recommendations

Mobile Arm Support

Despite the cost, design limitations, fitting, and adjustment time, therapists and consumers are frequently willing to overlook these obstacles in their efforts to maximize functional use of the UEs.



(Haworth et al ., 1978.;Yasuda et al., 1984; Atkins et al., 2008)

Orthotic/Splinting

Assessments

Non-standardized

- Range of Motion (ROM)
- Manual Muscle Testing (MMT)
- Modified Ashworth Scale (MAS)
- Observation

Others

- Interest checklist
- COPM
- Fatigue severity scale
- Coordination: Diadochokinesis

Assessments

Common Assessments

- Functional Independence Measure (FIM)9-hole peg test
- Box and blocks
- DASH or Quick Dash
- Dynamometer
- Pinch gauge

ALS specific Assessments

- ALS Functional Rating Scale Revised (ALS-FRS-R)
- ALS Specific Quality of Life – Revised (ALSSQOL-R)

(Felgoise, 2011; Gordon, et al., 2004; Hudak, 1996; Ng, et al., 2007; Mathiowetz, 1985)

ALS Functional Rating Scale – Revised

ALS-FRS-R

- 12 questions
- Score ranges from 0 – 48
- No training required
- Approximately 10 minutes to administer
- Assess Gross and Fine motor skills
- Reliable and valid
- Interpretation: The higher the score the more function is retained
- No cost

(Cederbaum et al., 1997)

ALS-FRS-R: Measures

- Speech
- Salivation
- Swallowing
- Handwriting
- Cutting food and handling utensils (with or without gastrostomy)
- Dressing and hygiene
- Turning in bed and adjusting bed clothes
- Walking
- Climbing stairs
- Breathing


ALS Neurologist
ALS Association Chapter Liaison
Social Worker
Speech Language Pathologist
Registered Dietician
Occupational Therapist
Physical Therapist
Respiratory Therapist
Mental Health Professional
Nursing Professional
Person with ALS

Multidisciplinary Clinic Benefits

- Improved QoL
- Improved mental health
- Improved social functioning
- Improved survival

(Driskell et al., 2019)

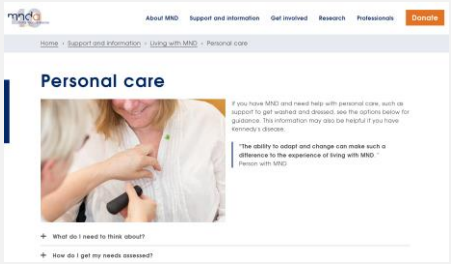
Multidisciplinary Collaborations

- Respiratory equipment modification
- Speech device recommendation
  - Hand function
  - Adaptive equipment and switch training
- Adaptive equipment per modified diet
- Leisure exploration to decrease feelings of isolation
- Power wheelchair evaluation and recommendation

Additional Resources

TEAM 37 GLEASON

ALS ASSOCIATION



- ALS Association
  - Support Group
  - Loaner closet
  - OT Manual
- Motor Neuron Disease Association(MNDA)
- ALS/MND Multidisciplinary Clinic
- MD Association
- Team Gleason

Daily Activities Made Easier for People with Amyotrophic Lateral Sclerosis (ALS)

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“The course of ALS provides distinct opportunities for occupational therapy practitioners to be involved in the nontraditional practice areas.”

(Arbesman & Sheard, 2014)

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Thank you…

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