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OT and ALS: Treatments, Goals and Management

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About me

- OT for 20 years, 10 with ALS
- AOTA Board Certified in Physical Rehabilitation
- RESNA Certified Assistive Technology Practitioner and Seating and Mobility Specialist
- Published articles, book chapters on OT and ALS
- Speak locally, nationally and internationally about ALS

Objectives

- Discuss OT treatments for persons with ALS
- Goal writing, samples
- Adaptive equipment and techniques
- Sample ideas

continued™
ALS quick overview

- Affects brain and spinal cord motor neurons
- UMN and LMN signs have to be present
- Diagnosis of exclusion
- Voluntary muscles affected including swallowing and breathing
- 3-5 year life expectancy but often varies
- Cognition/behavior affected in over 50%
- Can start anywhere, progress anywhere
- Generally fatal, unless consider PEG, vent

OT treatment for ALS

- Function for ADLs, maintain independence
- Lots of adaptive techniques and equipment
- Power mobility
- Accessing home and community
- ROM, pain management
- Safe exercise in early stages

OT Treatment- Function for ADLs

- Toileting
  - Bidet information
  - Long handled wiper
  - Bedside commode
- Bathing
  - Shower seat or tub bench
  - Long handled bendable sponge
  - Pump bottles for shampoo and liquid soap
- Dressing
  - Hemi dressing techniques
  - Velcro for buttons
  - Dressing stick
OT Treatment - Function for ADLs
- Eating
  - Feeding cuff
  - Portable arm support
  - Pizza cutter
- Grooming
  - Cylindrical foam on make-up brushes
  - Set up grooming station at kitchen table
  - Electric toothbrush
- Meal Prep
  - Pre-open all water/juice bottles, smaller containers
  - Packaged, prepped meals
  - Rolling cart

OT Treatment - Adaptation
- Adaptive techniques
  - Rolling to side to get out of bed easier
  - Use of pliers to pinch a ketchup packet
  - Use of dressing stick to pull out laundry
- Adaptive equipment
  - Teach to use a sock aide, shoehorn, elastic laces
  - Seat belt pull use
  - Reacher
- Leisure skills
  - Turning pages of a book and use of an easel to hold book
  - Increasing grip on a golf club with Velcro
  - Gardening from a large pot or raised garden

OT Treatment - Power mobility
- Encourage client to get OT/PT wheelchair eval with experienced clinicians
- Tap loaner equipment closets
- Top VA when appropriate
- At least 3 power features - tilt, recline, power legs, and power seat would be nice
- Upgraded electronics, long term flexibility
- Beware of getting a transport chair, manual wheelchair or basic power wheelchair with insurance money
- Walker, lift chair, commode BEFORE power wheelchair

continued
OT Treatment- Home and Community Access

- Home safety
  - Rugs, lights, obstacles
  - Ramp or lift
  - Safe, correct angle
- Wider doorways
  - 36” if possible
- Bathroom adaptations
  - Roll in shower, wall mounted sink, higher toilet with bidet
- Use of bus/transport systems
- Tapping into community resources
  - Independent Living, churches, civic groups, clubs

OT Treatment- ROM, Pain management

- Teach safe and functional ROM to client and caregivers
  - Is full ROM necessary??
- Gentle pain management
  - Ice or heat, massage, Ultrasound
- Incorporate daily stretching into all aspects of day
- Splinting
  - Giv Mohr sling
  - Progressive resting hand splint
  - Spring splints for finger joints

OT Treatment- Safe exercise

- No “feel the burn”
- Not if under 3/5 strength
- Aerobic more important
- Watch tiring out muscles for functional tasks
- Is it important to them?
- Fatigue
- Sometimes daily routine enough exercise
Therapy

- Often serial therapy - short sessions to solve problems
- Therapy is often non-traditional
- Can be home or community based
- Get in contact with clinics/loan closets in your area for resources
- Can be therapy in Hospice/Palliative care as well

OT Goals

- Maximize engagement in meaningful occupations
- Prevent secondary complications
  - Decubitus ulcers, contractures, pain, injury
- Medication mgmt.
- Energy conservation/Work simplification
- Maximize quality of life
- Cognitive/behavioral strategies
- Teach strategies to self-manage effects of disease process/Coping strategies
- Teach caregivers safe and effective ways to provide assistance

Goal Setting

- Goals set in small increments
- Generally little to no improvement in strength or fine motor skills. Focus on function/ADL’s.
- Ask the patient about needs and wants
- Be creative
- Adaptive equipment use
- Patient and family education
- Improve function and safety
Treatment/Goal Ideas

- Eating, grooming, dressing, bathing, toileting
- Emergency access to phone/door, safety
- SROM, AROM, AAROM
- Adaptive techniques and equipment use
- Energy conservation, work simplification
- Set up/transfers to toilet, bath, bed
- Leisure
- IADL's
- Writing, holding books, computer access, phone access
- School/work tasks
- Positioning, bed/chair set up

Sample Goals:

- Client will improve ability to use adaptive dressing equipment during dressing program to modified independent within 4 weeks.
- Client will perform AROM in all joints and planes with supervision from family within 2 weeks.
- Client will use a medication reminder strategy to properly take medication with modified independence after 3 weeks.
- Client and family will employ safety strategies for alerting and phone use within 4 weeks to improve overall safety at home.
- Client will improve ability to use typing aide and speech to text program for communication and safety management to modified independence within 4 weeks.
- Client will access home environment with power wheelchair for ADLs with independence within 2 weeks.
- Client will transfer safely to tub bench for bathing with min A from family within 3 weeks.

Adaptive Equipment

- Small items: button hook, elastic shoelaces, long handled sponge, typing aide, long handled brush, Dycem, pliers, key turner, dressing stick, reacher
- Made items: razor holder, figure 8 splint, thumb opposition splint
- Larger items: furniture risers, book stands, leg lifter
- Electronic items: on-screen keyboard, X-10, power wheelchair mouse, switch adapted alerting system
- Unusual items: mobile arm support, ergo rest, bottom wiper, bidet seat
- Equipment: Transfer tub bench, shower seat, rolling shower commode chair, 3:1 commode, toilet seat riser, toilet safety frame, hospital bed, hoist lift
- Look for loaners from ALSA, MDA
Commercially available gadgets:
- Mattress Genie
- Drink aide
- Power wheelchair mouse emulator
- Mealtime Partners drink assists
- Mobile arm supports

www.jaecoorthopedic.com
www.drink-aide.com
www.mealtimepartners.com

Commercially available gadgets
- Drink holder for wheelchair
  - Fisher Price
- Inspection mirror
  - www.pattersonmedical.com

Commercially available options
- Stylus option
  - RJ Cooper
- Wireless Doorbell
Existing and New Equipment

- Portable shower
- The FAWSsit- standard and reclining

Typing Aids & Stylus Options

- etsy "shapedad" styli
- Low cost homemade options
  - One way valve drink holder
  - Toetroller

Low cost homemade options
Low cost options

- Kaykare Double Arm Sling

Low Cost Alternatives

- Rubber twist ties

Low or No-Cost Alternatives

- Slippery satin fabric seat covers, headrest covers and bed sheets
- One-way valve straws
- 3M Adhesive dots and tacky strips
Low cost alternatives
- Electric razor strap
- Suspenders

Custom Modifications
- iPad and iPhone holders
- Flat laser pointer mounted to headband for communication
- Adaptive Clothing
  - Snaps
  - Velcro
  - Buttless pants

Client and Caregiver Inventions
- PVC Bedrail
- Backpack head holder
Client inventions

- Drink Holders
- Wheelchair drawers
- Bathroom adaptations

Client/Therapist Adaptations

iPad use when need hands to type as communication device

Conclusions:

- ALS and therapy are possible together
- Focus on client goals
- Encourage your clients’ creativity
- Communicate with therapists at a multidisciplinary center
- Have “trash” and “tools” to create
- Think outside the box!
References


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