ALS: A QUICK GUIDE FOR OCCUPATIONAL THERAPISTS (OTs)

INTRODUCTION TO ALS

Centre de réadaptation STAN CASSIDY Centre for Rehabilitation
Towards Independence / Vers l'autonomie

Your role as the OT

Maximize comfort, increase and maintain function and prepare clients and caregivers for future needs with a high priority placed on patient's goal and objectives.

Progression of decline

Wide variation, from slow to rapid.
Median survival at age of diagnosis:
>60 = 2.4 years
<40 = 8.7 years
10% live over 10 years

Types

- Sporadic
- Familial
- Bulbar (affects speech, swallowing first)

Primary Lateral Sclerosis (PLS)

Similar functional outcomes to ALS but slower progression and higher tone.

Functional implications

- Arm function
- Mobility
- ADLs/IADLs
- Communication
- Sleep/Fatigue
- Cognition impairment in 50%

Initial assessment

What information should I gather in the first session?

- Type of ALS and time since diagnosis
- Current level of function (including presence/absence of pain) and goals
- Supports in place, social environment
- Home accessibility
- Potential equipment needs

Treatment frequency

Clients should be seen a minimum of every 3 months initially, but this may increase depending on the speed of progression. Options for appointments can be in person, through video or phone as well as a community outreach to their home.

Emphasize planning ahead...

We have found that clients have difficulties planning ahead when the functional decline they are planning for is not yet visible. It is important to be **supportive yet clear** with clients and emphasize things may progress quickly. It may be a good idea to present the options without encouraging clients to make decisions within the same session. This way the client can be made aware of their options and take the time necessary to think about it before the next session. These suggestions will help decrease their fears and anxiety. Providing written summary of discussion and options will help client feel less overwhelmed.

Pictures are for illustrative purposes only

General principles: Energy conservation

- Emphasize sitting when doing functional tasks
- Take breaks during task
- Perform high–energy tasks when client has more energy
- Determine which tasks can be accomplished by someone else and/or with assistance
- Prop arms on counter top to reduce arm effort
- For high emotional fatigue, it is important to include activities they enjoy each day
- For high cognitive fatigue, it is important to break tasks requiring high concentration into small parts with breaks

Feeding

- **Table height:** If trouble with shoulder flexion, use over bed–table. Increase height to chest and place arms on table
- Large–handled utensils
- Built–up handles using foam
- Universal cuff
- Rocker knife, pizza cutter, plate guard, dycem
- Travel mugs
- If arm/hand weakness, use a lightweight cup or a nosey cup

Bathing

- Sponge bath may be easier than full bath
- Grab bars for the shower/bath and non-slip mats
- Shower chair or tub transfer bench
- Handheld shower
- Long-handled sponge/loofah
- If the progression is slow and patient wants to bath, an Aquatech/Neptune style bath lift might be considered
- If the patient's progression is slow, consider a wheel-in shower or installing a track lift above their bath
- If weak trunk and neck, consider reclining shower chair with foot and head support on wheels, such as:

Raz-AT Commode

Toileting

- If accessibility is barrier, consider commode by bed or urinal
- Female urinal (camping stores)
- Install grab-bars/versa frame
- Raised toilet seat/high toilet
- Dignity apron – have a client use an apron to maintain privacy with toileting
- Add bidet to existing toilet for independence with cleaning. Can be purchased at Costco, Home Depot, Amazon or medical suppliers, online stores such as Canadianbathrooms.com

6800U Bidet seat

Pictures are for illustrative purposes only

Ook Cocoon by Umano Medical

Sleep

- Consider type of clothing for easier movement in bed
- Bed rails
- Leg lifter
- Wedges/foam for in-bed positioning
- Consider height of bed
- M-rail/Smart rail/Arco rail (to assist with transfers)

Mattress

- Foam, static or alternating air and gel
- Consider mobility of client in bed when selecting mattress

Hospital bed benefits

- Encourages independence with bed mobility and assists with managing pressure depending on mattress
- Assists with transfers
- Facilitates breathing
- Supports bed mobility
- Adjustability allows for pain management

Dressing

- Aids: buttonhook with built–up handle, dressing stick, zipper ring
- Consider sitting to dress for safety and energy
- Loose clothing, elastic waistband, Velcro, elastic shoelaces
- Pay attention to fabrics: nylon is much easier than fleece

Grooming

- Electric razors

Oral care

- Electric toothbrush: consider lightweight device
- Height–adjustable table to prop arms on if needed
- If suction machine is available consider using suction toothbrush
- Tongue scraper
- Perform oral care 2–3 times/day even when not eating
- Can use chlorhexidine to clean mouth. This requires a doctor's prescription

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ORTHOTIC DEVICES

Head and neck support in wheelchair and bed

Vista Collar

Headmaster Collar

	PROS	CONS
Vista collar	More rigid for increased support and most popular. Pads are moisture-wicking and replaceable. Adjustable heights.	One size fits all (6 sizes in one), more obtrusive appearance.
Soft collar	If client cannot tolerate rigid collar.	Provides less support, less durable.
Headmaster collar	Breathable, firm support. Many sizes and colours available. Easy to clean, more subtle appearance.	Harder to adjust – minimal adjustments are possible by bending the collar. May need pad over collarbone.

Shoulder support: Prevent subluxation and pain

- To be worn when ambulating
- Try different options, some are more cumbersome
- Some clients find kinesiotaping helpful initially
- Other shoulder supports: https://www.neurorehabdirectory.com/product-category/shoulder-subluxation-sling
  - Rolyan Custom Hemi Arm Sling
  - Rolyan MFC Unilateral Shoulder Orthosis
  - Wilmer Orthosis
- In sitting:
  - Use a breastfeeding pillow to support arm/shoulder when:
    - Sitting in bed or recliner
    - Travelling in car
    - Using electronics and while reading

Photo courtesy of Ottobock

Hands

- Resting hand splint: to maintain ROM and prevent contractures
- Restorative hand splint has better compliance than custom-molded due to softness
- Wrist splint can help with grasp
- Thumb spica splint can be used when muscle wasting is apparent in thenar eminence to assist with grasp

Feet

- Consult physiotherapist for appropriate recommendations for gait
- Dictus band raises foot after toe-off and reduces risk of tripping
- Night splint: to prevent foot drop at night, maintain ROM for wheelchair positioning, prevent pressure sores and contractures, and improve ambulation

Dictus Band

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Mobility

- Four-wheeled walker with seat for early ambulation needs
- Dictus or AFO for foot drop prevention (see orthotic devices on page 5)
- Refer to physiotherapy to maximize muscle function, decrease pain and address mobility
- Early power chair prescription or lightweight manual wheelchair is recommended. Some clients may choose a manual tilt wheelchair over a power wheelchair

Which wheelchair?

Consider

1) Progression of disease and level of function
   - Early: consider transport wheelchair or lightweight manual chair to get to and from appointments
   - Initiate power mobility prescription when client is still ambulating but has fatigue issues and can't ambulate long distances
2) Insurance/funding
   - **Private Insurance**
     - This process takes time. Start process early
   - **ALS Society**
     - Check with provincial organization for available funding
   - **Government funding**
   - **Veteran Affairs**
3) Home accessibility
4) Transportation needs

Recommended features of a power wheelchair:

- Tilt
- Recline
- Elevating leg rests
- Bluetooth controls
- Power elevate (facilitates transfers)
- Vent tray
- Consider ordering head controls at the same time as joystick
- If needed consult specialty seating

Patient transfer devices

- Stand-pivot
- EZ-Turn II Disc
- Sliding board transfer
- Superpole with horizontal bar
- Grab bars
- Lift chair
- Track lift
- Hoyer lift

Home environment: *Move or modify*? What to consider

- Access to home
- Access to bathroom
- Can they be wheeled in the shower?
- Stairs: can they set up on one floor?
- Paved driveway
- Types of flooring
- Social environment: who does the client live with?
  - If primary caregiver is partner and partner has limited mobility or function, moving to accessible home may be a feasible option for the long–term
  - If client lives alone with a part-time caregiver and only minimal adjustments need to be done to the home, staying at home may be less complicated and less of an emotional adjustment
  - Discuss with client the option of long-term care. Some clients may feel more comfortable with the idea of keeping home modifications to a minimum. They may prefer to plan for a transition to a long-term care facility later on. They may want to think about a hospice
  - At some point patients should be linked with the palliative team

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Porch lift/ramp

- For ramp information: https://www.cmhc-schl.gc.ca/odpub/pdf/65023.pdf
- Ramp = more cleaning in the winter

Porch lift

- Clients may be wary of installing a porch lift outside of their home or in their garage, especially if they are still able to transfer without it

Other modes of transportation

- Adapted car or van – refer to adaptive/van specialist
- Assess if there is accessible transportation in the area
  - May be cheaper option than adapting vehicle
- If a used adapted van is found, consult with adaptive driving to ensure appropriate vehicle is purchased

Assistive technology

Consult your assistive technology services in your province

Ways to control a tablet, smartphone or computer

- Built in accessibility options
- Alternative mice (head mouse, mouth joystick, trackballs, trackpads, etc.)
- Software options
- Switch control
  - Buddy button
  - Ultra Light
  - Proximity
  - Pillow

Alert systems

- Cellphone, intercom, baby monitor, portable doorbell, or pager system

Tech to control the environment

- Door security
- Lights
- Climate control
- Smart plugs

Tech for activities of daily living and instrumental activities of daily living

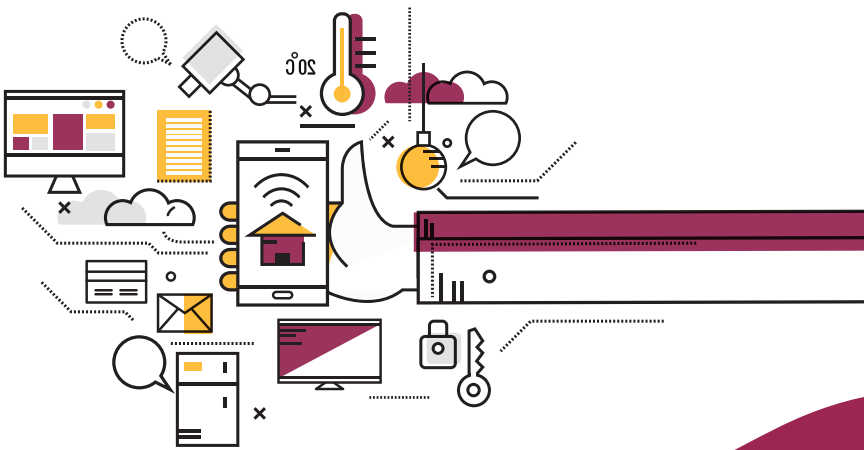
- Online banking
- Shopping
- Medication reminders
- Auto toothpaste dispenser

Tech for leisure

- Streaming
- Gaming
- Reading
- Wellbeing
- Entertainment

Tech for communication

- Texting
- Social media
- Saving memories
- Videocalls
- Communication software
- Voice amplifier, for when speech is well-pronounced but may be lacking in volume – with a Speech Language Pathologist



This is not an exhaustive or comprehensive list and it will continue to change as products and technology change.
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