



WELCOME !

October 25, 2021



Home Modification for Safety and Accessibility

Guest Speaker:

Alisa Brownlee ATP, CLIPP, CAPS, WSP

Assistive Technology Specialist

ALS Association-Greater Philadelphia Chapter

Assistive Technology Consultant

The ALS Association

The ALS Association

National Office-Care Services

Ph: 800-782-4747 cknoche@alsa-national.org

ALS[®]

ASSOCIATION

Making a Home Accessible and Safe for a Person with ALS

Alisa Brownlee, ATP, CLIPP, CAPS, WSP

Assistive Technology Specialist

National Office and Greater Philadelphia Chapter

abrownlee@alsa-national.org

Welcome

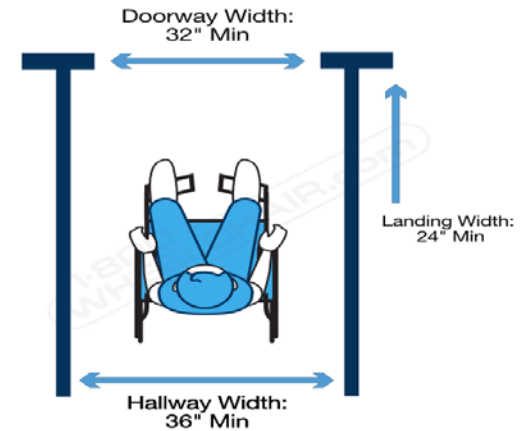
- I have no actual or potential conflict of interest in relation to this program/presentation
- I have no financial interest regarding any product I am including in this presentation
- I will share my slides – email me
 - abrownlee@alsa-national.org

About me

- Assistive Technology Professional
 - Specialty areas are communication, computer access, environmental controls, home modifications
 - Credentialed Assistive Technology Professional (ATP) through RESNA (Rehabilitation Engineering and Assistive Technology Society of North America)
 - Certified Living in Place Professional (CLIPP) through the Living in Place Institute
 - Certified Aging in Place (CAPS) through the National Association of Home Builders
 - Credentialed Wheelchair Service Provider (WSP) through the International Society of Wheelchair Professionals
 - Current RESNA Board Member
 - Current RESNA Faculty
- 25 years with the ALS Association
 - Greater Philadelphia Chapter
 - National Office

Virtual Visit Home Assessment – free service provided by the ALS Association

- Contact me if you are interested in a virtual home assessment
- Can be completed via Zoom, Facetime, Duo, or WhatsApp, Skype
- Have as many family members on the call as possible
- Initial discussion to address area of concern about the home
 - Virtual walk through of home
 - Have caregiver come to meeting prepared with a measuring tape and use it to measure doorways and hall width
- Important due to cost and psychological element of modifying home



Cost of modifying a home



\$3,000-
\$5,000



\$10,000-
\$20,000



\$10,000+



\$20,000-
\$25,000



\$40,000-
\$70,000



\$8,000-
\$12,000



\$30,000-
\$60,000



\$300+



\$300.00-
\$500.00



\$2,000-\$20,000



\$12,000-
\$25,000



\$3,000-
\$6,000



\$300.00-
\$1,000.00



\$25,000+

Decision Making

- Housing worldwide has not been designed or constructed to accommodate the needs of disabled people in terms of accessibility, safety, independence, and location
 - Less than 3.5% of current single-family homes have three of the most critical accessibility features
 - Zero step entrances, single floor living, wide hallways and doors
- Home Modifications
 - Is my house accessible?
 - Do I make permanent or temporary adaptations?
 - Am I SAFE with these adaptations? Is my caregiver SAFE?
 - Can I afford it?
 - The VA is the only organization that will reliably fund renovations
 - Out of pocket expense can be thousands
 - Will modifications raise my homeowners insurance?
 - Will modifications increase or decrease my home value?
 - Should I move?
- The person with ALS and their medical decisions are crucial when discussing home modifications
 - Financial decisions
 - Cost of modifications versus in home care

Psycho-Social Aspect of Modifying a Home

- Homes are a place of significant personal meaning
- Home modifications can often be viewed as the physical manifestation of ALS
- Clinicians and therapists want to strengthen the home as a place of personal and social meaning as well as improve safety and comfort for the person with ALS at home
- It's important for allied medical professionals as well as the person with ALS and their family to understand the person-environment relationship

<https://www.tandfonline.com/doi/full/10.1080/02763890802232048>

Home Environment

- The home environment is conceptualized as having 3 primary modes of experience
 - The physical home—consisting of the concrete raw materials and the design and layout of the dwelling
 - It refers to the space that can be measured and is shaped by function, culture and history
 - The social home—encompassing relationships with significant others, such as a spouse or family member, who may often inhabit the same physical environment and also includes those who may enter the home on occasion or exert an influence from outside the home such as relatives, neighbors, friends, and community networks
 - The personal home—being a place of self-expression, identity, and personal control; a central reference point in a person's life encapsulating feelings of familiarity, security, and belonging

Reluctance

- Home, as a physical, social, and personal experience, occurs within a temporal framework, reflecting the dynamic and changing nature of the meaning of home for individuals over time
- Peoples' relationships with their homes have histories, futures, recurrences, and rhythms that affect their current experience and meaning
- People with ALS often wants things to remain as “normal” as possible
 - Refuse to change their living environment to adapt to the disease
 - “I want things to be the same
 - I want thing to be a normal as possible
 - But they are NOT normal for the caregiver

Modifications should focus on safety

- Modifications may not be ideal aesthetically
 - May have to compromise
- Focus on SAFETY for both the person with ALS and their caregivers
- Consult with Occupational or Physical Therapists, Assistive Technology Professionals, Aging in Place Specialists, Chapter or Clinic Staff for assistance with home modifications



Most common obstacles

- Most common home obstacles are getting in/out of home and bathroom accessibility
- Other issues
 - Width of doors
 - Thresholds
 - Stairs
 - Rugs
 - Maneuvering Space

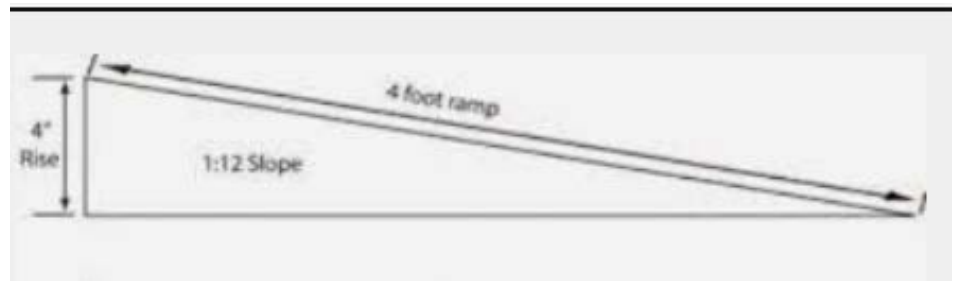


Entering and Exiting a Residence

Not every house is able to accommodate a ramp



Ramps



- Is my house rampable?
- For all ramps, whether permanent or temporary, the legal requirement is 1 to 12
 - For every inch of height in grad change, 12 inches of ramp length is required
 - Some areas in the US are allowing 1 to 7
- Ramp length should not exceed 30 feet of landings
- Ramp should not rise more than 30 inches
- Minimum width of a ramp is 36 inches
- Landings at top and bottom need to be as wide as the ramp (36")
- Need level/steady surface for exit of ramps

Wood versus Steel/Aluminum ramps

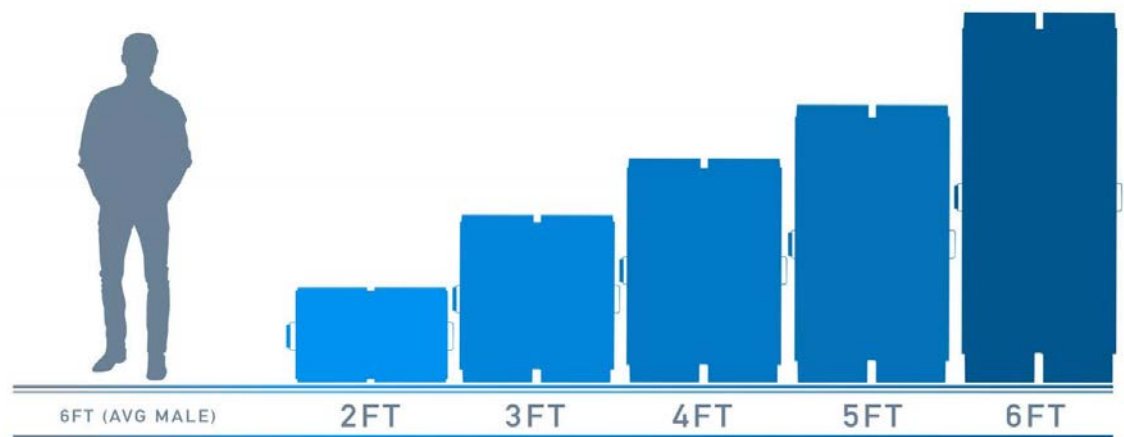
- Wood ramps are permanent
 - Can be more costly than steel/aluminum
 - Need a permit
 - Can reduce value of home
- Steel/Aluminum
 - Temporary
 - Can be easily removed



Suitcase and Roll Up Ramps



• SUITCASE AS SIZE CHART •



Threshold Ramps



Stair Lifts—Outside

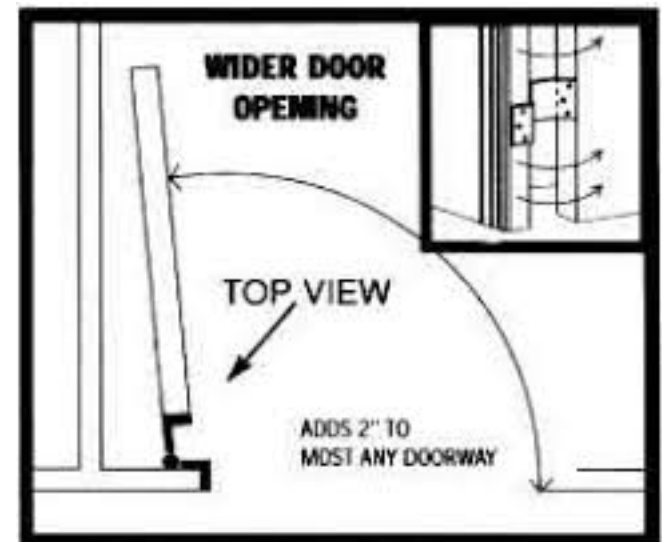


External Vertical Lifts



Doors

- Minimum door width is 32 inches
- Swing away hinges can give up to 1 ½ - 2 inches
- Depending on configuration, switching door swing may allow better access



Offset (or swing away) hinges



Bathroom Accessibility

Hazards of Bathrooms

- Most common location for fall injuries in the home was the bathroom, including when people are hurrying to the bathroom
- A National Institute on Aging statistic states that 80% of falls in the home happen in the bathroom
- Do not do transfers in the bathroom
 - Use rooms with space like living room/bedroom
- Try to avoid the bathroom at night, when alone, or when it is unsafe for person with ALS or their caregiver
 - Use a bedside commode, urinal (female and male) or condom cath



Bathrooms

- Ideal is to have an open concept bathroom



European Style (aka Wet Bath) Bathroom



Toilet Assistance

NO NO NO NO



EZ-ACCESS Tilt Toilet Lift Single Motor
Elongated Seat

Elevated Toilets and Toilevator



Bidets

- Can be added to existing toilets
- Not covered under insurance
- Approximately \$400+
- HUGE quality of life device

Bidets
can't
be
used
with
> > > >



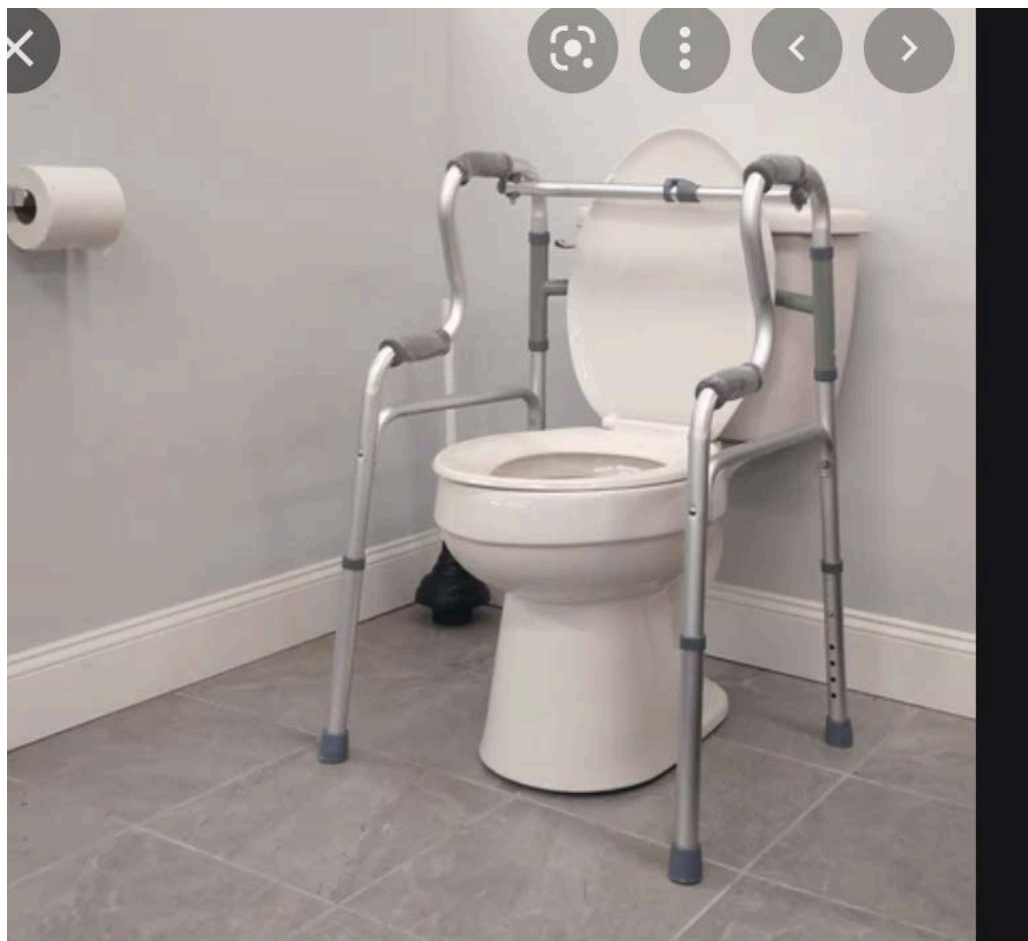
The Bidet: How It Changed My Life with ALS by David Rayl, a person with ALS

- *The biggest surprise to me was the benefits of adding a bidet during the master bathroom remodeling.*
- *My biggest focus for the master bathroom remodeling was to replace the existing tub and stand-up shower with one larger curbless shower and no tub. The everyday task that I dreaded the most in my old house was using the bathroom. This would be the worst part of my already hard ALS day. In my old house, using the toilet would require all my available energy and I would be exhausted for the next few hours. After my family and I moved into the new house, my most dreaded part of my day became very pleasurable. This was because of the new bidet feature added to the toilet. I had very low expectations and no clue on what to expect before using the bidet. I am surprised and amazed on how much cleaner I feel and how much less effort is required to use the toilet. The specific bidet features that I found to be most useful are adjustable water and drying temperatures. The cost of a very good bidet may be cost prohibitive for some (ours over \$500), but I feel that all the benefits it provides are worth the investment. I would recommend highly that every household has at least one bidet.*

Retractable Grab Bars



<https://www.wingits.com/>



Stander Pole



Starts at \$180.00

Using a Tub via a Tub Transfer Bench



Over the Toilet Sliding Tub Transfer Bench



Seat easily glides in and out of the tub,
and securely locks at each end of the sliding rails

Sliding Tub Transfer System







www.gamburd.com (888)902-2237

ALS
ASSOCIATION

• Shower assistance

NO NO NO>>



Shower Ramp
(available on
multiple sites
including
Amazon)



ASSOCIATION

Portable Showers



Fawssit



Shower Bay

Shower Bay



Fawssit



Transfer Devices

Patient Transfer Lifts



Hoyer Lifts

****Make sure you get the correct sling!**





Permanent or Portable

- **Lift System: (Permanent)**

- Permanently installed into ceiling joists.
- Track can be any length and can even have curves
- Great long term option as you could have track go all the way over toilet and shower/bath - depending on home design
- No posts to get in the way

- **2 Post Lift System: (Portable)**

- Portable
- Smaller track but not permanently installed into ceiling
- Typical installation is over a bed to transfer between bed, wheelchair and commode
- A second 2 post lift system could be installed in the living room to transfer into recliner chair. It is also possible to use the same electric motor for both which saves money but is less convenient.
- Great short term solution and is both easier and safer to use than hoist lifts.

- Source:
- Caringforagingparents.com

Ceiling Lifts

- What they are
 - Track mounted on the ceiling (or a portable system uses 2 posts to suspend the track) with a battery powered motor that lifts the senior in a sling.
- They allow the PALS to move between hospital bed, wheelchair and commode
- Others have a more extensive track going from bed to bathroom - over toilet and over bathtub
- This allows them to use the bathroom and to access a bathtub



Factors to consider for Ceiling Lifts

- Easy to use - Simple controls (some just have on/off and up/down - which is all you really need)
- Weight capacity - Make sure the PALS is within the weight capacity of the lift
- Long enough track - If it is a permanent track installed on the ceiling, make sure you have enough room beside bed to put wheelchair and commode
- If a 2 post lift - Make sure it has wide bases and the track is long enough to fit both bed and wheelchair (or commode) under
- Do you need this long term?
 - Permanently installed ceiling lifts take up less room than portable 2 post lifts.
- Does the PALS need to access the bathroom or can they sponge bathe in bed or have a bath/shower at a community bathing program?
- Where to put the lift?
 - In the existing bedroom or maybe convert the living room into a bedroom to allow more room or more social contact for person with ALS
 - Source:
 - Caringforagingparents.com



2 Post Portable Ceiling Lifts



Approximately
\$2,000



Portable Ceiling Lift



- Interior Stair Accessibility Options

Stair Glides—Inside

- Are only SAFE when someone has trunk support

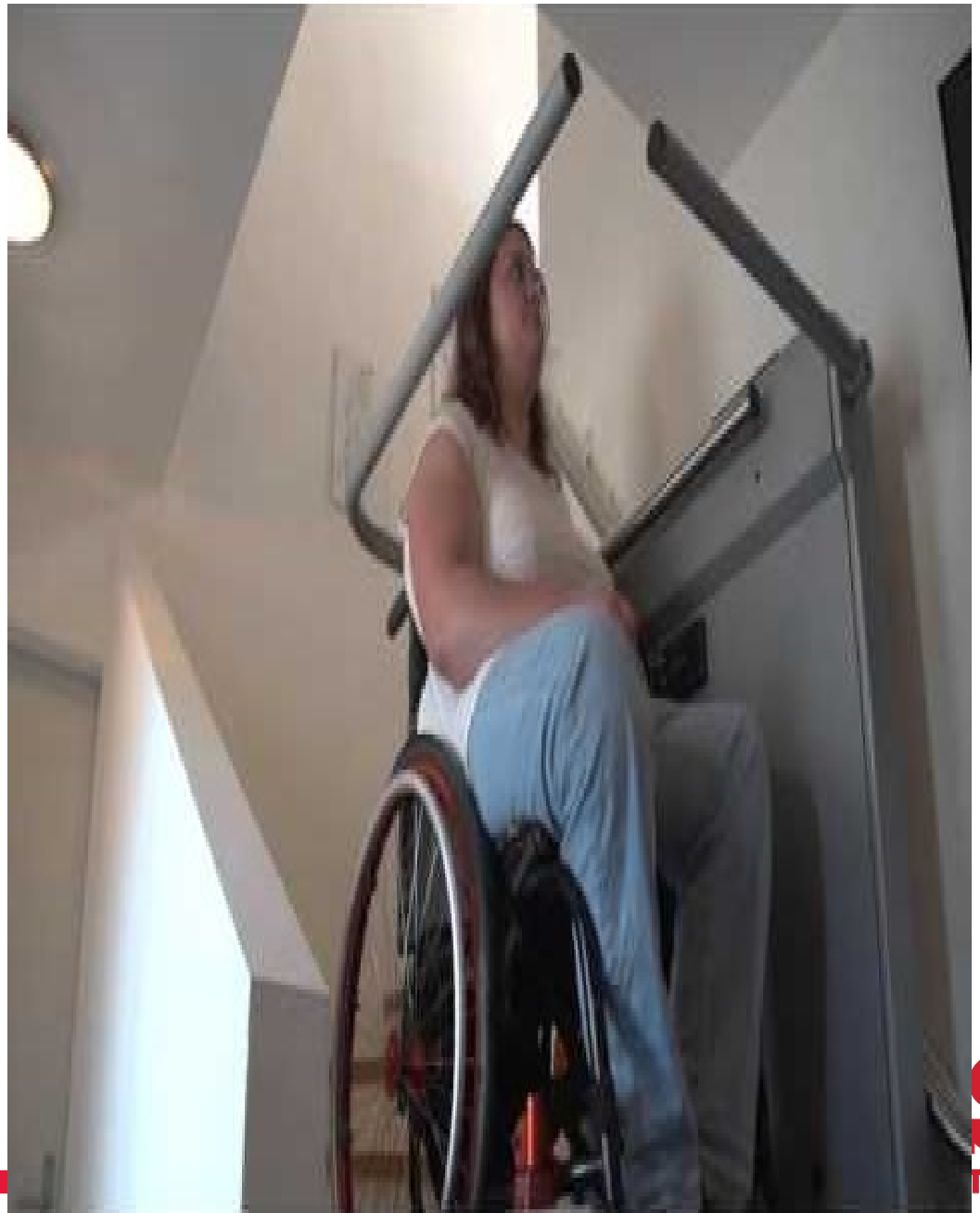


Curved stairs require
a custom stairglide --
start price of \$8,000



Straight shot stairs
start at \$3,000

Interior Stair Lifts



Elevators



Stair Climber



MOBILE STAIRLIFT

Instructional Video

Approximately
\$1,000.00



Assisted Wheelchair Climber



Approximately \$2,100

Emergency Evacuation Aide



Emergency Evacuation Chair



Go Bag



Content suggestions

- Copy of your Medical Insurance Cards
- Medical Card with ALS specific information
- Written list of phone numbers: doctors, pharmacy, and family contacts
- Written list of medications
- 7 days worth of medication
- Written directions on how to communicate with the person with ALS
- Letterboard
- Enteral Nutrition (for those with feeding tubes)
- Advance Directive
- Style/Serial number of medical devices
- Water
- Hand Sanitizer
- Wipes
- Sanitary Products
- Adult Diapers/Urinals
- Phone Charger / Ear Buds
- Socks
- Energy Bars
- Pen and paper
- Cash

References

- [Lund & Nygard, 2004](#)Lund, M. L. and Nygard, L. 2004. Occupational life in the home environment: The experiences of people with disabilities. *Canadian Journal of Occupational Therapy*, 71: 243–251. [\[Google Scholar\]](#); [Oswald & Wahl, 2005](#)Oswald, F. and Wahl, H. 2005. “Dimensions of the meaning of home in later life”. In *Home and identity in late life: International perspective*, Edited by: Rowles, G. D. and Chaudhury, H. D. New York: Springer Publishing Company Inc. [\[Google Scholar\]](#); [Sixsmith, 1986](#)Sixsmith, J. 1986. The meaning of home: An exploratory study of environmental experience. *Journal of Environmental Psychology*, 6: 281–298. [\[Crossref\]](#), [\[Google Scholar\]](#); [Smith, 1994](#)Smith, S. G. 1994. The essential qualities of a home. *Journal of Environmental Psychology*, 14: 31–46. [\[Crossref\]](#), [\[Web of Science @\]](#), [\[Google Scholar\]](#)).
- [2Sixsmith, 1986](#)Sixsmith, J. 1986. The meaning of home: An exploratory study of environmental experience. *Journal of Environmental Psychology*, 6: 281–298. [\[Crossref\]](#), [\[Google Scholar\]](#); [Steward, 2000](#)Steward, B. 2000. Living space: The changing meaning of home. *British Journal of Occupational Therapy*, 63: 105–110. [\[Google Scholar\]](#)).
- Miller RG, Jackson CE, Kasarskis EJ, et al. Practice parameter update: the care of the patient with amyotrophic lateral sclerosis: drug, nutritional, and respiratory therapies (an evidence-based review). *Neurology*. 2009;73(15):1218-1226.
- Miller RG, Jackson CE, Kasarskis EJ, et al. Practice parameter update: the care of the patient with amyotrophic lateral sclerosis: multidisciplinary care, symptom management, and cognitive/behavioral impairment (an evidence-based review). *Neurology*. 2009;73(15):1227-1233.
- Lewis M, Rushanan S. the role of physical therapy and occupational therapy in the treatment of amyotrophic lateral sclerosis. *NeuroRehabilitation*. 2007;22:451-461.
- Simmons Z. Management strategies for patients with amyotrophic lateral sclerosis from diagnosis through death. *Neurologist*. 2005;11(5):257-270
- Dunn, Haney McClain, & Youngstrom, 1998Dunn, W., Haney McClain, L. and Youngstrom, M. J.1998. “The ecology of human performance”. In *Willard and Spakeman's occupational therapy*, Edited by: Neistadt, M. E. and Crepeau, E. B.531–535. Philadelphia: Lippincott-Raven. [\[Google Scholar\]](#); Rubinstein, 1989Rubinstein, R. L. 1989. The home environments of older people: A description of the psychosocial processes linking person to place. *Journal of Gerontology: Social Sciences*, 44: 545–553. [\[Google Scholar\]](#); Sixsmith, 1986Sixsmith, J. 1986. The community networks (meaning of home: An exploratory study of environmental experience. *Journal of Environmental Psychology*, 6: 281–298. [\[Crossref\]](#), [\[Google Scholar\]](#)).
- [\(Depres, 1991](#)Depres, C. 1991. The meaning of home: Literature review and directions for future research and theoretical development. *Journal of Architectural and Planning Research*, 8: 96–115. [\[Web of Science @\]](#), [\[Google Scholar\]](#); [Dovey, 1985](#)Dovey, K. 1985. “Home and homelessness”. In *Home environments*, Edited by: Altman, I. and Werner, C. M. Vol. 8, 33–61. New York: Plenum Press. [\[Google Scholar\]](#); [Sixsmith, 1986](#)Sixsmith, J. 1986. The meaning of home: An exploratory study of environmental experience. *Journal of Environmental Psychology*, 6: 281–298. [\[Crossref\]](#), [\[Google Scholar\]](#)).
- Dovey, 1985Dovey, K. 1985. “Home and homelessness”. In *Home environments*, Edited by: Altman, I. and Werner, C. M. Vol. 8, 33–61. New York: Plenum Press. [\[Google Scholar\]](#); Werner et al., 1985Werner, C. M., Altman, I. and Oxley, D. 1985. “Temporal aspects of homes: A transactional perspective”. In *Home environments*, Edited by: Altman, I. and Werner, C. M. Vol. 8, 1–32. New York: Plenum Press. [\[Google Scholar\]](#)).
- Rubinstein, 1989Rubinstein, R. L. 1989. The home environments of older people: A description of the psychosocial processes linking person to place. *Journal of Gerontology: Social Sciences*, 44: 545–553. [\[Google Scholar\]](#); Sherman & Dacher, 2005Sherman, E. and Dacher, J. 2005. “Cherished objects and the home: Their meaning and roles in later life”. In *Home and identity in late life: International perspectives*, Edited by: Rowles, G. D. and Chaudhury, H. D. New York: Springer Publishing Company. [\[Google Scholar\]](#); Sixsmith & Sixsmith, 1991Sixsmith, A. J. and Sixsmith, J. A. 1991. Transitions in home experience in later life. *Journal of Architectural and Planning Research*, 8: 181–191. [\[Web of Science @\]](#), [\[Google Scholar\]](#)).
- Davison, Kendig, Stephens, & Merrill, 1993Davison, B., Kendig, H., Stephens, F. and Merrill, V.1993. “It's my place” -Older people talk about their homes, Canberra, , Australia: Australian Government Publishing Service. [\[Google Scholar\]](#)).

Resources

- National ALS Association
 - www.als.org
- Alisa Brownlee, ATP, CLIPP, CAPS, WSP
 - abrownlee@alsa-national.org
 - Twitter @alsassistivetec
 - Facebook: Alisa Brownlee ALS
 - LinkedIn: Alisa Brownlee
 - 215-631-1877