



# Home Modifications for People with ALS

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# Welcome

- I have no financial disclosures regarding affiliation with any electronic device(s) or DME company

# 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
- 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
    - Are their hard limits for the patient and caregiver?

# 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>

# Age of Person can increase the impact of Home Mods

- Older people order and manipulate the home environment to both accommodate increasing limitations and be representative of themselves and their lives, with memories and home often inextricably linked
- Older people have a clear relationship between the physical environment they inhabit and their feelings of belonging
  - Not necessarily tied to legal ownership or long occupation
- Older people diagnosed with ALS may have already made some modifications

# 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

# 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

# Ramps – what you don't want



# Not every house is able to accommodate a ramp



# Ramps

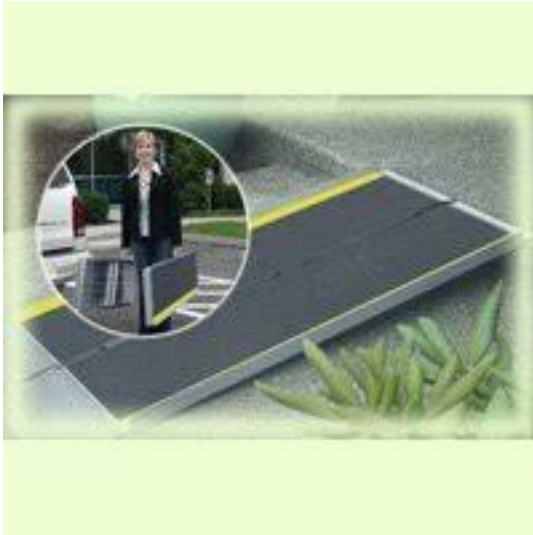
- Is my house rampable?
- For all ramps, whether permanent or temporary, the legal requirement is 1 to 12
  - For every inch of height in grad change, 12 inches of ramp length is required
  - Some areas in the US are allowing 1 to 7
- Ramp length should not exceed 30 feet of landings
- Ramp should not 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

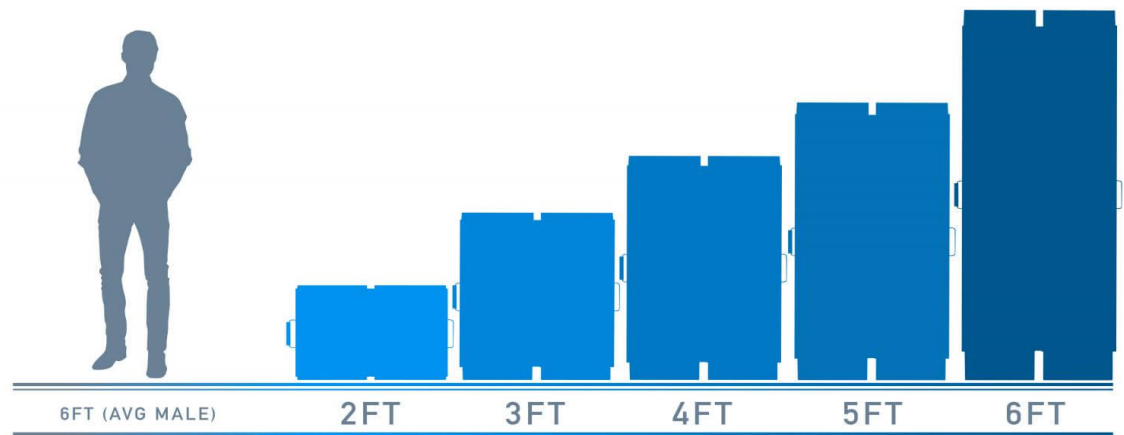
- Wood ramps are permanent
  - Can be more costly than steel/aluminum
  - Need a permit
  - Can reduce value of home
- Steel/Aluminum
  - Temporary
  - Can be easily removed



# Suitcase Ramps



## • SUITCASE AS SIZE CHART •

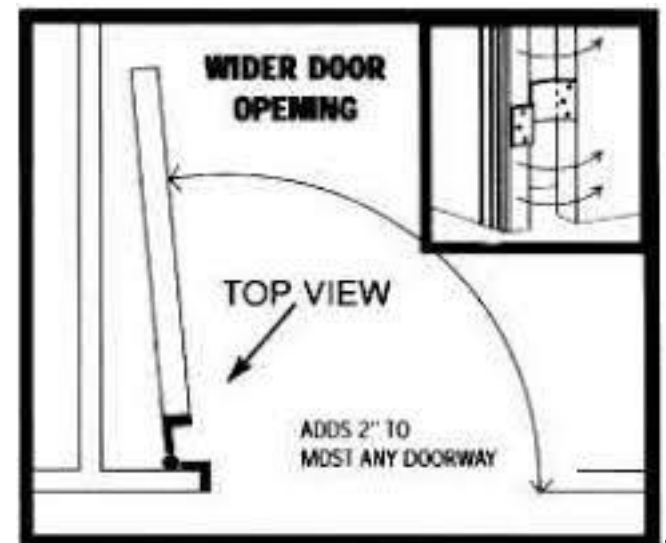


# Stair Lifts—Outside



# 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



# Threshold Ramps



# Toilet Assistance

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NO NO NO NO



# 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  
>>>>



# Bathrooms

- Ideal is to have an open concept bathroom



# Using a Tub via a Tub Transfer Bench



Tub Sliding System



# Tub Transfer System



•  
**Shower assistance**

NO NO NO>>



**ASSOCIATION**

# Portable Showers



Fawssit



Shower Bay

# 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](http://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.
- Some people just use a simple 2 post portable system over their bed to transfer between 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](http://Caringforagingparents.com)

# Stair Glides—Inside

- Are only SAFE when someone has trunk support except for lift



# Interior Stair Lifts



# Elevators



# External Vertical Lifts



# Emergency Transport Systems

- Calling for help is great, but how does a person with a disability get out of a house, apartment, tall building, etc...?
- \$500-\$3,000
- Tarps \$29.00



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# Resources

- National ALS Association
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- Alisa Brownlee
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