

Late Stage Accommodations: Options for HD Caregivers

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Ac*com*mo*date

1. To make room for: to hold without crowding or inconvenience
2. To make fit, suitable
3. To give consideration to: allow for
4. To bring into agreement
5. To provide with something desired, needed, or suited

To make room for, to hold without crowding or inconvenience

The Physical Environment

- Minimize items, clear clutter
- Flooring considerations
- Padding
 - Nightstands & beds
 - tables
 - rounded corners
- Auto-faucets Toilets!
- Protective gear
 - soft helmets
 - elbow & knee pads
 - geri-sleeves
 - hip protectors

To fit, suitable
Mobility/Positioning

- Beds
 - Hi-lo electric beds ;perimeter mattresses
 - Floor pads
 - Floor beds
 - Side rails must use caution! (None used since 1997)
- Seating
 - Introducing (and re-introducing) the wheelchair
 - Adaptations to wheelchair (anti -tip bars, auto-lock breaks, Dyscem, wedge and pummel cushion)
 - Seat belts/thigh belts. Positioning or Restraint?
 - Use Extreme Caution & DOCUMENT!
 - Other types of chairs
 - Walkers, canes

To Give Consideration to: Allow for
Respect/Dignity

“It still me in here!”

- Include the person with HD in the conversation
- Allow time for delayed response (slower processing)
Be Patient!
- Offer choices but not too many. Keep it Simple!
- Respect the choice that has been made

To Give Consideration to, Allow for Eating and Swallowing

- Watch for coughing, choking with solids or Liquids
- May need to alter the diet ie: Chop, puree or thicken
- May have food quirks !
- Encourage calories & supplements ie: Ensure, Boost
- Discussions about Tube Feeding

To bring into agreement
Letting Go/Acceptance

- Past ,Present and Future- Joy for the moment
 - Keep things in perspective
- Conscious letting go (different than giving up)
- Hygiene Changes
- Clothing: Keep it Simple
- Incontinence
- Sleeping patterns
- Mobility
- Social/leisure involvement

To bring into agreement Working Together as a Team

Your Team may include:

- The person with HD
- Family/guardians
- Doctors
- Nursing
- Dietician
- Social Service
- Rehab: OT, PT and Speech
- Support group
- Friends
- Volunteers

To provide something desired, needed or suited

Behaviors and Medications

Some common behaviors:

- Obsessive
- Aggression verbal and or physical
- Self Focused Preception
- Delusions, psychosis

Non pharmlological approaches should be tried first

Pick your battles

Medications may help and can improve the quality of life for all.

Be open to discussion with MD's

To provide something desired, needed or suited

End of Life

- Have discussions early that will help guide you
- Provide comfort
 - Medications
 - Pleasure Food
 - Lots of TLC
 - Respect decisions
- In home services may be needed ie: Home health
- May need to consider placement options
- Hospice and Palliative care

To provide something desired, needed or suited

Care giver Support

- Remember you are NOT alone!
- Enlist help of others, Remember your “Team”
- Take care of your self!

Phrases to remember:

Try to keep perspective

This too shall pass

It is ALL small stuff

Joy for the moment