



**Barrow**  
Neurological Institute

Neuro-Rehabilitation  
Center

# Transitioning from Hospital to Home:

A Resource for Persons Who Are Newly Diagnosed With a  
Rare Neurological Disease



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**No Disclosures**



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***Every Person's Journey is  
Different and that is Okay***



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# Four Core Issues of Returning Home

Physical Environment

The Physical Experience

Entering the Medical System

The Emotional Experience



# The Physical Environment: Preparing to Return to Your Home

## Mobility and Movement

- Creating Paths around furniture
- Preparing for carpet, smooth floors, and transitions
- Doorway challenges
- Showers, Bathing, and Toileting
- Navigating around pets and children

## Special Equipment

- Manual or Power Wheelchairs
- Hospital Beds
- Walking Aids
- Shower and Tub Equipment
  
- IV stands
- Other Medical Devices



# The Physical Experience

## Common Challenges

- FATIGUE
- Muscle Weakness and Paresis
- Poor Coordination
- Visual Challenges
- Balance Problems
- SPASTICITY/SPASMS
- Change in How you Get Around

## Potential Solutions

- Pacing yourself and scheduling rest periods and breaks
- Consistency with your prescribed exercise plan from your Therapists
- Magnifiers and Programs on your technology
- Go slow and don't fight your muscles
- Have patience with yourself and understand that you have a new learning curve for now



# Entering the Medical System as an Outpatient

## Medical Specialists and Appointments

- Your life may feel like one big medical visit
- Specialists, Specialists, and Specialists
- Getting to your appointments
- Keeping your calendar up to date- always take it with you!
- Outpatient Therapy feels different than Inpatient Therapy

## Medications and Treatments

- Oral medications
- Infusions
- Insurance covers what?
- Giving your Physicians and Therapists honest feedback on how you are doing



# The Emotional Experience

## The Mind and Body Challenges

- Fear
- Worry
- Insomnia
- Fatigue
- Uncertainty
- Frustration

## Helpful Changes

- Deep Breathing creates relaxation and better airflow
- Guided meditation provides a calming experience for your mind and body
- Mental Health Professionals provide guidance and an environment of safety for you to address your feelings
- Pace yourself and make time for resting- this helps the body and the mind
- Reduce stress and stressful situations to aid your recovery and healing



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