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Toolkit for Living Supports after Brain Injury

Working Toward a Thriving Day

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Physical: Break down TASKs

leave more TIME



expect fatigue more easily

- may show up as behavior, pain, or emotions, etc.

add a 5-30 minute buffer for for tasks and responses

identify mobility or living aids and technology

ASK how to help



don't assume helplessness

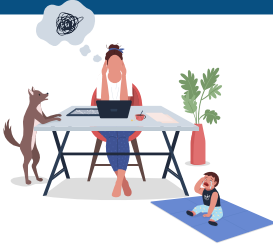
- treat like an adult (not a child)
- start with universal supports

encourage advocacy and speaking up for one's needs
(even if not sure how)

break down and build up skills slowly

- stop with increase in symptoms
-

reflect on SURROUNDINGS



prevent overstimulation (i.e. noise, light, movement, color)

use headphones, borders, ear plugs, sunglasses, adjusted
light (i.e. darker or natural)

meet in quiet spaces or request repositioning for less
stimulation

KEEP IT SMALL & concrete



ask for help with paperwork or excess screen time (fill out
with them, complete verbally, etc.)

request/give examples, visual metaphors, or 1-2 options
(yes/no, this/that)

take/offer breaks with smaller chunks of activity time (10
minutes for every 30 minutes to 1 hour)



Processing: Take it SLOW

shift your SPEECH



expect having to repeat yourself & ask for repetition

add pauses and ask for/give time to respond

ask questions over giving demands

summarize what you heard back

let them LEAD



ask to repeat back what's understood (not just, "Do you understand?")

- "let's go through that again together"
- "tell me what you heard from that?"

have them review the steps of a process

- "What's next?" "Where could we look?"
 - avoid always telling what to do
 - help problem-solve
-

OPTIMIZE conversations



avoid switching back and forth between ideas

keep an agenda for meetings with a maximum of 3 ideas at a time

look or keep aware for signs of fatigue and recommend breaks or movement

use cues before directives (look, point, the person's name)

WRITE it down



encourage habit of documenting information multiple times

use checklists, alerts, reminders, or automated processes using technology

ask for/give written handouts or email summary with next steps, contacts, etc.



Memory: Stick to the SAME

STEP by STEP



present new information in small chunks/steps

review information from last interaction before beginning a new one

give information in a step-by-step manner (one at a time)

ASSIST with strategies



follow a set routine, connect associations to form habits, and develop low- and high-energy systems

adapt the environment, including a consistent, visual schedule

set up or request reminders & follow-up emails for calls, meetings, & appointments

MANAGE consistency



set up consistent meetings (same time, place)

- give plenty notice for changes

encourage blocking time on the calendar with an accompanying alert

- brain dump your list of To-Dos and spread out through the week

use a timer to help get started

ENCOURAGE learning



text, pictures, labels, & designated spaces

- keep important items in view

use planners, calendars, notebooks, checklists, alarms, and reminders to help track activities

rehearse and practice steps (don't assume) and demonstrate expectations



Communicate: Use RAMPS

REACTIONS matter

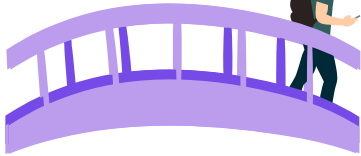


others' communication patterns act as a model

- nonverbal, posture, tone, volume, emotion
- encourage hope over helplessness

reflect on and help own successes, emphasize progress, encourage hope, and help track goals (use video/ picture)

ACT as a bridge



avoid finishing thoughts with word-finding trouble (unless frustrated)

- have them repeat full sentence after completion

ask questions to help them process information

- describe, point, cue beginning sound, etc.

summarize key ideas before train of thought was lost

use different METHODS



writing & drawing/pictures, recording audio or video

writing key words in a conversation

yes/ no questions or limited choices

communication boards, augmented devices, or apps

have PATIENCE and SIMPLIFY



plan for additional time in groups, meetings, and transitions

help determine triggers or unmet needs for behavioral communication (outbursts)

respectfully redirect to topic if going off on tangents or retelling ("let's go back to..")

ask to avoid jargon or clinical wording and focus on the important information

summarize the action steps or key ideas



Behavior: Be a PARTNER

connect to PRESENT



redirect thoughts or perseveration

- encourage breaks, movement, and use of calming music/sounds
- progressing muscle relaxation and deep breaths
- 3 things you see, 2 you hear, 1 you smell/touch
- use weighted, cold, or fidget/sensory objects

ACT as a facilitator



avoid trying to control the person or project what you would do in situations

ask what can you add or remove from the situation or in your communication style

encourage autonomy (focus on strengths and building off of previous gains)

help reframe/redirect energy to positive thoughts/action

REFLECT & validate



help label strong emotions: hurt, mad, sad, stressed, depressed, lonely, etc.

- "It sounds like..."
- "What I'm hearing is..."

acknowledge experiences with trauma, abuse, and brain injury symptoms

determine want for change to connect to goals and unmet needs (don't let professionals dictate care/goals)

give TIME to process



give clear expectations but expect adjustment period

assign tasks for all involved in care (follow through on your objectives, build trust)

practice guided problem-solving safe solutions, ask questions, discuss pros and cons to allow making choices



Behavior: Be a PARTNER

make NEXT STEPS concrete



build off strengths and goals

- "What has/ hasn't worked for you in the past?" "Where do you want to be?"

process what could have been done differently or worst case scenarios if overly worried

- question over-generalization or catastrophizing

create a written action plan and follow-up strategies (check in regularly)

EDUCATE risks & coping



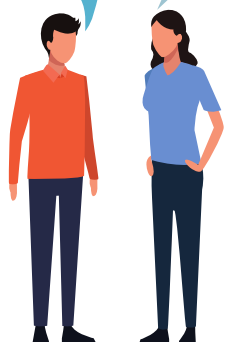
alcohol & drugs after injury

- stronger effects, lower tolerance, and risk for overdose and seizures
- disrupt balance and lower inhibition
- affect social relationships and mood negatively when effects wear off
- make challenges after brain injury even worse (i.e. memory, vision, movement)

seek out professional aid and assistive therapies

- help with coping, harm reduction, dependence concerns, and setting up strategies for long-term wellness

RESPOND directly



don't ignore inappropriate behavior

consider frame of mind (angry, depressed, fearful) and functions of an emotion or behavior

avoid arguing or trying to reason at the height of emotion/crisis

emphasize and praise the behaviors you want to increase (rather than shaming the wrong behaviors or saying "don't")



Health & Getting Diagnosed

What to Expect

What to Consider

Examples

Medical & Diagnostic Supports	Emergency Supports
Focus on different specialties of physical and medical care • Often fast-paced & symptoms-focused (headaches/pain, seizures, weakness, dizziness, vision, etc.)	Focus on medical stability and reduce other complications • bleeding, swelling, bruising, penetrating, broken bones • treatment depends on injury severity
Mild injuries or multiple concussions may not be easily seen on brain scans despite existing symptoms	Available in behavioral or mental health crisis to help with stabilization (psychosis, suicidality, severe mood swings, etc.)
• Primary Care Physician (PCP) • Federally Qualified Health Center (FQHC) • Neurologist and Physiatrist • Functional Neurologist • Neuro-psychologist • Neuro-Ophthalmologist	• Emergency Medical Services (EMS) • Emergency Department (ED) & Urgent Care • Concussion Clinics • Intensive Care Unit (ICU) • Acute Hospital or Medical Center • Behavioral Health or Crisis Clinic

Notes



Getting Better & More Involved

What to Expect

What to Consider

Examples

Rehabilitation Supports	Mental Health Supports	Day & Living Supports
Includes evaluation, assessment, and exercises to improve function (modality of rehab differs) movement, speech, daily living skills, cognition, etc.	Focus on emotion, feeling, & adjustment related to distress of mental health different specializations, remote options, and certifications	Group-based, outside of the home useful for social skills, life-skills, meaningful activity, self-esteem, and productivity
Inpatient, outpatient, or home options insurance and funding may be a significant limit	Peer-groups or support groups may be an informal space to help people feel like they are not alone	Provide support related to job or education preparation, interviewing, and maintaining
- Physical & Occupational Therapy - Speech & Cognitive Therapies - Music & Art Therapies - Recreation & Animal-Assisted Therapies - Aquatic & Vestibular Therapy	- Counselors & Social Workers - Support or Peer-Led Group - Assertive Community Treatment (ACT) - Substance Use Specialist - Neuro-Psychiatrist & Pharmacist	- Adult Day Programs & Clubhouses - Community Rehabilitation Programs (CRPs) - Recreation, Allied Health, or Interest Groups - Vocational Rehabilitation (VR) - Job Coaching & Supported Employment

Notes

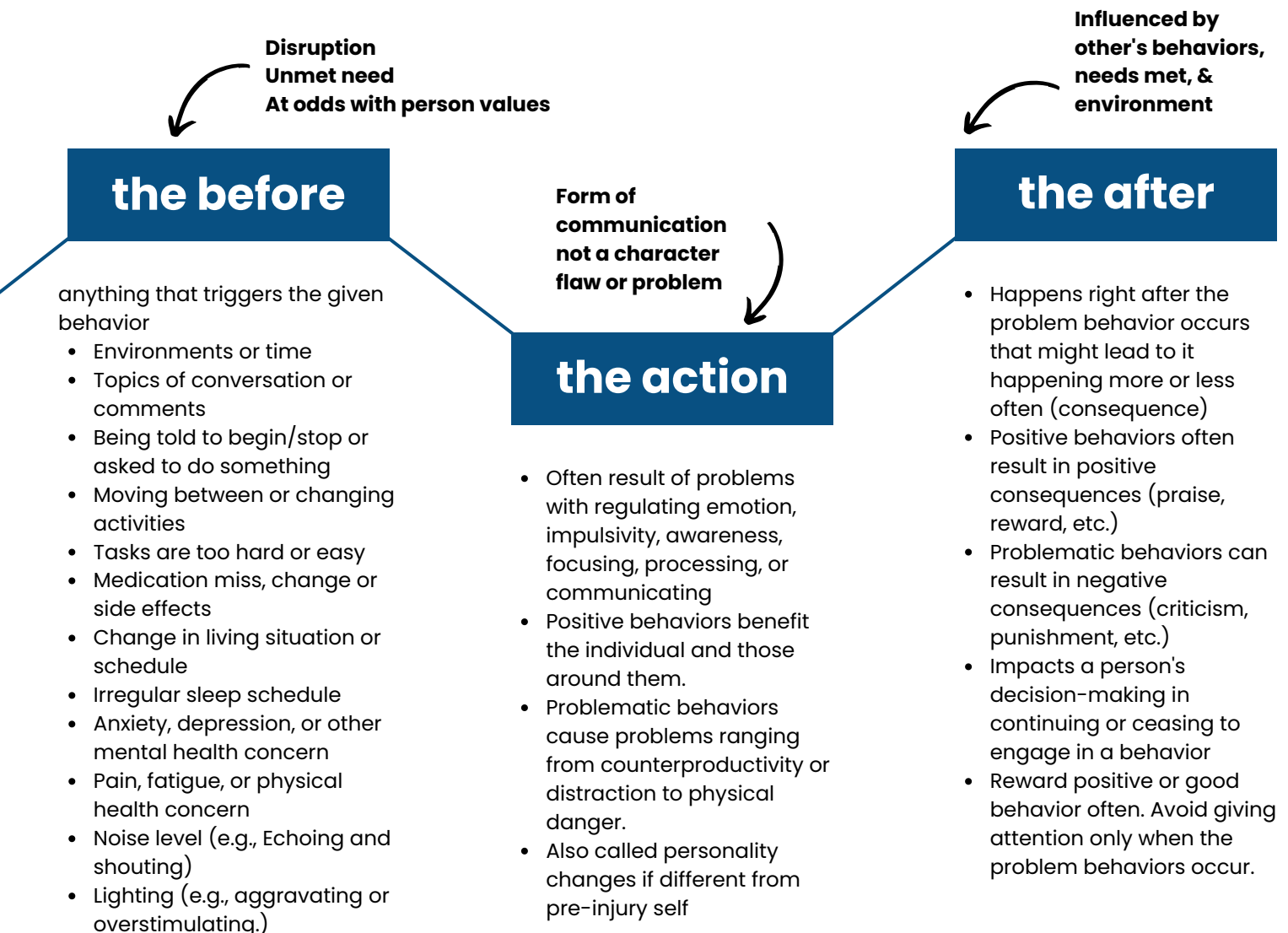


Getting Ahead & Having Help

	Home & Personal Care Supports	Residential & Daily Management	Assistance & Advocacy Supports
What to Expect	Support & supervision with participation in daily living - eating, bathing, positioning, dressing - recreation, transportation - groceries, chores, laundry, cleaning	Living supports for acquiring and retaining life skills for independence striving to avoid improper placement that does not focus of growth and rehab	Helpful connection to and access to appropriate services - Special Needs Trusts, ABLE Accounts - Guardian of the Person vs. Estate - TBI Medicaid Waiver
What to Consider	Respite vouchers and options are available for short-time relief to both carers and individuals with brain injury	Different levels of care available depending on insurance as well as medical, cognitive, and behavioral support needs	If calling 911 for support, request a Crisis Intervention Team (CIT) Officer trained about disability
Examples	- Non-medical Companion Care - Respite Care - Medical Home Health	- Supported Apartments - Group Homes - Alternative Family Living (AFL) - Assisted/Supported Living - Skilled Nursing Facilities (SNFs) - Neuro-behavioral Health Units	- Guardianship & Lawyers - Case or Care Management - State & Medicaid Services - Local Management Entities & Tailored Plans

Notes

Values, Unmet Needs & Behavior



Behavioral Communication Check In

- ☐ Who is or is not present before the problem behavior happens?
- ☐ Where does the problem behavior take place?
- ☐ What items (e.g., television, video game, cell phone) are present or absent just before the problem behavior takes place?
- ☐ What events took place before the problem behavior occurred?
- ☐ What time of day does the problem behavior happen?
- ☐ Is there a root cause or unmet need related to the behavior?

- ☐ What does the behavior look like?
- ☐ How often does the behavior happen?
- ☐ How long does the behavior last?
- ☐ How intense is the behavior?

- ☐ What happened right after the problem behavior?
- ☐ How did people react?
- ☐ Did the person get something from the behavior? For example, did they get attention (either good or bad)?
- ☐ Was something taken away or avoided because of the behavior?
- ☐ Did the environment change because of the behavior? For example, did the person leave a situation or place?

Behavioral Communication Check In

the before

the action

the after



SECURITY & SAFETY

Fear of unknown, uncomfortable with change

Prefer similar spaces and schedules with a systematic agenda

Prepare for transition time, give clear expectations, provide visual reminders, and offer words of encouragement

Check the box if this sounds like you:

☐

I don't feel comfortable with changes in my schedule.

☐

I prefer to be in places I know and have been to already.

☐

I get upset if someone tries to rush me if I haven't finished something.

☐

I prefer to understand each step in the process rather than "winging" it.

☐

I prefer to perfect things I've already done, than to try new things.



PURPOSE & MEANING

Experience boredom, sensory-deprivation, or feel useless easily

Prefer concrete and larger goals that feel important TO them (not just FOR them)

Identify opportunities for independence or helping others, and give ownership to all success

Check the box if this sounds like you:

☐

I prefer every day to be different, rather than the same thing.

☐

I like to feel needed and a part of something larger than myself.

☐

If I stay in the same place too long, I tend to feel restless.

☐

I dislike feeling useless, like just a number or a cog in a wheel.

☐

I prefer to work towards something, help others, and have responsibilities.



WELL-BEING

Physical or mental wellness impacts experience (fatigue, pain, hunger, etc.)

Incorporate learning, growth, relaxation and developing positive habits to identify stressors

Remove stressors and extra stimulation, encourage regular check-ins and prompt breaks

Check the box if this sounds like you:

☐

How I feel greatly impacts my daily routine (for example, when I feel bad, nothing seems to get done or sometimes I treat others poorly).

☐

I have a hard time feeling relaxed or calm most of the time.

☐

My emotions feel like they control me, instead of me controlling them.

☐

I get tired more easily but have a hard time stopping or taking breaks.

☐

My body never feels like it is healthy or at 100% (I have pain, heaviness, weakness, nausea, dizziness, etc.).



AUTONOMY & CONTROL

Afraid to ask for help and strive for independence

Respond poorly to being told what to do or not being involved with decisions

Give responsibility or tasks to take ownership, avoid scolding or lecturing, give choices, and ask questions to guide change ("what might you do differently?")

Check the box if this sounds like you:

☐

I get very angry if someone tries to treat me like a child or tell me what to do.

☐

I like to feel in control of what I do and how I do it.

☐

I prefer to make my own choices and be asked my opinion, rather than others making decisions for me.

☐

I dislike being lectured at, scolded, or just told about what I'm doing wrong all the time.

☐

I prefer to take charge and show my capabilities around others.



SOCIAL CONNECTION

Feel lonely, fear isolation, wanting to keep busy or be around other people

Look to engage in groups or activities to create a community (sports, social, spiritual, etc.)

Schedule regular visits, focus on creating quality social experiences, seek peer-support over professional

Check the box if this sounds like you:

☐

I prefer to be around people and feel recharged in social spaces.

☐

I like to attend social groups based on my interests or support needs.

☐

I prefer to keep busy and don't like being by myself.

☐

I feel lonely most of the time, which makes me sad.

☐

I would rather talk with someone similar to me for help than a professional.



EMOTIONAL REGULATION

Experience extremes related to mood (anger, sadness, happiness, etc.)

Meet the person where they are with flexibility and redirection to something creative or productive

Change environment, expect fatigue and give time to recover from mood episodes, and validate emotion (not behavior)

Check the box if this sounds like you:

☐

I feel like my moods so jump quickly, I cannot control them.

☐

When I feel down, I get stuck and not sure how to move forward to feel better.

☐

I feel drained and need hours or days to rest from my moods.

☐

I constantly feel like people cannot understand me or they judge me without knowing me.

☐

I feel guilty when I take my mood out on other people or when I can't remember that they happened.

Coping with Distress

Connect

- ☐ Squeeze a stress ball or use a fidget object (spinner, popper, etc.)
- ☐ Sip a cup of tea or warm drink
- ☐ Cross your thumbs against your chest, lightly tapping your hands one at a time
- ☐ Use a cold washcloth or ice pack to hold against your chest
- ☐ Lay or sit under a weighted blanket/object
- ☐ Smell something fragrant (candle, soap, lotion, flowers, baked goods)
- ☐ Close your eyes and practice a quick deep breathing exercise, meditate, or visualize
- ☐ Take a walk, yoga, simple stretches, or other exercise

Enjoy

- ☐ Listen to a podcast or audiobook
- ☐ Read a book, magazine, article, or story
- ☐ Take photos or look at pictures you like, places you'd want to go
- ☐ Play games, work on puzzles, or hobby
- ☐ Watch videos or movies
- ☐ Sing to, listen to, dance to, or play music
- ☐ Visit local spots or get out into nature (hike, lakes, beach, parks, museums)
- ☐ Take a warm bath, get a massage, brush your hair, do skin care, massage face, brush face
- ☐ Pet, spend time, or take care of animals
- ☐ Talk to someone (support group or trusted person)

Coping with Distress

Reflect

- ☐ Find a quiet, dark, comfortable space to be alone for a few minutes
- ☐ Get outside or sit by a sunny window for at least five minutes
- ☐ Write down at least 3 things you are grateful for
- ☐ Look up tasty meals you're interested in cooking or places you'd like to visit
- ☐ Practice positive affirmations or words of encouragement to yourself: "I am strong, I am worthy, I am whole, I am safe."
- ☐ Listen to ambient, nature, or calming sounds/music
- ☐ Take a break or replace social media/ phone time with another activity
- ☐ Take a walk, yoga, simple stretches, or other exercise

Create

- ☐ Give back (i.e. volunteering, donating, picking up litter)
- ☐ Write (i.e. journaling, children's book, creative writing, contributing to a blog or newsletter)
- ☐ Make (i.e. woodworking, artwork, cooking, scrapbooking, jewelry, crafting)
- ☐ Cook/bake an item you enjoy and savor the texture, smell, and flavors
- ☐ Do a task you've been putting off or create a to-do list
- ☐ Clean, declutter, or organize a space
- ☐ Garden, plant, or landscape
- ☐ Decorate a space
- ☐ Make a grocery list

Relaxation Strategies

Take 5

- Pause for a moment. Take a five deep breaths and pay attention to your breath flowing in and out.
- Look around and notice five things you can see.
- Listen carefully and notice five things you can hear.
- Notice five things you can feel in contact with your body— the air on your face, your feet on the floor, your back against the chair.
- Take a five more deep breaths and pay attention to your breath flowing in and out.
- Finish by thinking of or writing down 5 things you are grateful for.

4-7-8 Breathing

- Exhale completely through your mouth. You can add the visualization of blowing up a balloon.
- Close your mouth and inhale quietly through your nose to a mental count of 4 seconds.
- Hold your breath for a count of 7 seconds.
- Exhale completely through your mouth to a count of 8 seconds.
- Now inhale again and repeat the cycle three more times for a total of four breaths.

Relaxation Strategies

Muscle Relaxation

- Lie comfortably on the floor/in bed. Take a few deep breaths in and out.
- As you breathe in for about 3-5 seconds, tense or squeeze the muscles in just your toes.
- Breathe in and tense your ankles and calf muscles. Breathe out, release the tension in your ankles/calves.
- Work your way up your body. Tense each muscle group:
 - your thighs
 - your butt
 - your belly/core
 - your chest
 - your shoulders (lift toward your ears)
 - your biceps & forearms
 - your wrists & fingers
 - your face (scrunch your face tight) & forehead (move eyebrows up)
- Take a few deep breaths in and out. Let your body feel slack.

Breath Counting

Gently close your eyes and take a few deep breaths. Then let the breath come naturally without trying to control it.

- To begin, count 1 to yourself as you exhale.
- The next time you exhale, count 2, and so on up to 5.
- Then begin a new cycle, counting "one" on the next exhalation.

Diaphragmatic or Belly Breathing

- Begin by breathing into your belly rather than your chest. It may help put your hand on your stomach so you can feel it rise and fall. You can lie down or sit up.
- Take a deep breath and hold it for a few seconds before releasing it.
- Continue this pattern for 5 to 10 minutes.

Relaxation Strategies

Body Scan

- Sit or lie comfortably on the chair, floor, or bed. Take a few deep breaths.
- Pay attention to each part of the body for a period of time, just listening to your body and identifying how that body part feels.
- the face and head, over the shoulders, down the arms, and torso, through the pelvis and to the legs/feet.
- Identify areas of tension and with each breath out, use your breath to expel or release the negative tension outside of your body.
- Added visualization:
 - With each breath the stress moves outside your body collecting as a cloud. With each breath out, imagining the cloud moving further away.
 - Imagine the areas of tension or pain melting like ice or like sand through a vent. It starts losing it's shape and you're no longer having to hold it together in that place.
 - Imagine with each breath in a beam of positive light is filling up those areas of tension or pain. You start to feel lighter, like floating in the air.
 - Sit or lie comfortably on the chair, floor, or bed. Take a few deep breaths in and out.

Sample Schedule: Keeping Active after Brain Injury

	Daily Schedule						
	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
8am	Wake Up	Wake Up	Wake Up	Wake Up	Wake Up	Wake Up	Wake Up
9am	Morning Routine	Morning Routine	Morning Routine	Morning Routine	Morning Routine	Morning Routine	Morning Routine
10am	 Cognitive Enrichment	 Skill Building	 Mental Enrichment	 Cognitive Enrichment	 Skill Building	 Cognitive Enrichment	 Mental Enrichment
11am							
12pm	Lunch	Lunch	Lunch	Lunch	Lunch	Lunch	Lunch
1pm	 Physical Enrichment	 Social Enrichment	 Physical Enrichment	 Music or Art Enrichment	 Physical Enrichment	 Social Enrichment	 Physical, Music, or Art Enrichment
2pm							
3pm	Rest & Snack	Rest & Snack	Rest & Snack	Rest & Snack	Rest & Snack	Rest & Snack	Rest & Snack
4pm	 Life Skills	 Life Skills	 Review Goals	 Life Skills	 Group Activity	 Group Meeting	 Schedule & Planning
5pm							
6pm	Dinner	Dinner	Dinner	Dinner	Dinner	Dinner	Dinner
7pm	 Relaxing, Hobbies	 Relaxing, Hobbies	 Relaxing, Hobbies	 Relaxing, Hobbies	 Relaxing, Hobbies	 Relaxing, Hobbies	 Relaxing, Hobbies
8pm							
9pm	Evening Routine	Evening Routine	Evening Routine	Evening Routine	Evening Routine	Evening Routine	Evening Routine
10pm	Sleep	Sleep	Sleep	Sleep	Sleep	Sleep	Sleep

Schedule: Descriptions & Ideas

◀ Life Skills

- ☐ Cleaning
- ☐ Organizing/Arranging Items
- ☐ Laundry
- ☐ Budgeting
- ☐ Sweeping/ Vacuuming
- ☐ Dusting
- ☐ Home Repairs/Improvement
- ☐ Clipping coupons
- ☐ Reading the mail
- ☐ Paying bills
- ☐ Keeping records
- ☐ Meal preparation
- ☐ Meal planning
- ☐ Washing dishes
- ☐ Making the bed or tidying
- ☐ Grocery shopping

◀ Review Goals

- ☐ Improve tolerance to busy settings
- ☐ Get a job
- ☐ Get back to driving
- ☐ Improve stamina, walking, movement
- ☐ Live independently
- ☐ Improve mood and emotional response
- ☐ Improve social communication & relationships
- ☐ Improve memory
- ☐ Be able to read or write
- ☐ Not be so distracted
- ☐ Not get lost in new places
- ☐ Get my math skills back
- ☐ Be able to take care of myself
- ☐ Be able to follow directions
- ☐ Remember to take my medication

◀ Group Activity

- ☐ Community outing
- ☐ Movie Night
- ☐ Themed Cooking Night
- ☐ Dress up/Costume Party
- ☐ Music & Dancing
- ☐ Trivia Questions
- ☐ Book Club
- ☐
- ☐
- ☐
- ☐
- ☐
- ☐
- ☐
- ☐

◀ Group Meeting

- ☐ Settling conflict
- ☐ Voting on schedule or upcoming events
- ☐ Determining meals
- ☐ Distributing chores/roles
- ☐ Sharing ideas
- ☐ Picking community outings
- ☐ Planning outings
- ☐
- ☐
- ☐

◀ Schedule & Planning

- ☐ Reviewing the week's schedule
- ☐ Choosing activities
- ☐ Determining breaks
- ☐ Adjusting for appointments/meetings

Schedule: Descriptions & Ideas

◀ Morning Routine



- ☐ Brush Teeth
- ☐ Take Medicine
- ☐ Read News/Social Media
- ☐ Go to the Bathroom
- ☐ Take a Shower
- ☐ Wash face/skin care
- ☐ Unload dishwasher
- ☐ Feed animal/pet
- ☐ Walk animal/pet
- ☐ Have a relaxing drink
- ☐ Make Breakfast
- ☐ Eat Breakfast
- ☐ Watch TV/Videos
- ☐ Review schedule for the day
- ☐ Mindfulness, Meditation
- ☐ Daily Wellness Check-in

◀ Evening Routine



- ☐ Brush Teeth
- ☐ Take Medicine
- ☐ Read News/Social Media
- ☐ Go to the Bathroom
- ☐ Take a Shower
- ☐ Wash face/skin care
- ☐ Load dishwasher
- ☐ Feed animal/pet
- ☐ Walk animal/pet
- ☐ Have a relaxing drink
- ☐ Watch TV/Videos
- ☐ Check locks
- ☐ Turn off lights
- ☐ Review tomorrow's schedule
- ☐ Mindfulness, Meditation, Stretching
- ☐ Set alarms

◀ Cognitive Enrichment



- ☐ Word or Memory Games
- ☐ Scavenger Hunt
- ☐ Puzzles
- ☐ Bingo
- ☐ Jenga or board games
- ☐ Video games
- ☐ Sorting or Matching Activities
- ☐ Playing cards, dominoes, or dice
- ☐ Knitting or sewing
- ☐ Gardening
- ☐ Museums
- ☐ Art gallery
- ☐ Historic locations
- ☐ Writing/Typing, Reading
- ☐ Making lists

◀ Physical Enrichment



- ☐ Adaptive sports
- ☐ Swimming
- ☐ Dancing
- ☐ Gym classes
- ☐ Online exercise videos
- ☐ Yoga
- ☐ Tai-Chi
- ☐ Stretching with resistance bands
- ☐ Walking
- ☐ Running Clubs
- ☐ Lifting Weights
- ☐ Balloon Volleying or Dribbling Balls
- ☐ Thera-putty, play-dough, silly putty, slime
- ☐ Pinching clothespins or sorting coins
- ☐ Moving boxes/organizing

Schedule: Descriptions & Ideas

◀ Skill Building



- ☐ Physical Therapy Exercises
- ☐ Occupational Therapy Exercises
- ☐ Speech Therapy Exercises
- ☐ Social Skills Training
- ☐ Learning a Language
- ☐ Expanding Mental stamina
- ☐ Volunteer work
- ☐ Reading
- ☐ Typing
- ☐ Life Skills Worksheets
- ☐ Medication Management Activity
- ☐ Watching educational videos
- ☐ Book Club
- ☐ Cooking/baking
- ☐ Travel training
- ☐ Activity-based or Learning Club

◀ Mental Enrichment



- ☐ Counseling
- ☐ Mindful Coloring
- ☐ Mindfulness or meditation
- ☐ Painting (fingers, brushes, cups, etc.)
- ☐ Journaling
- ☐ Pet/animal therapy
- ☐ Support group
- ☐ Spiritual meetings or praying
- ☐ Finding/Sharing inspirational words
- ☐ Cultural connectivity
- ☐ Getting a massage, manicure, or self-care
- ☐ Reminiscing activities
- ☐ Guided imagery
- ☐ Sensory activity (bubbles, sand, water, etc.)
- ☐ Using smells (candles, herbs, flowers, essential oils, etc.)

◀ Music or Art Enrichment



- ☐ Name that Song
- ☐ Read Aloud
- ☐ Sing-Along or Karaoke
- ☐ Crafts
- ☐ Scrapbooking
- ☐ Making Mood Boards
- ☐ Legos or Building Materials
- ☐ Concerts or Music Video Viewing
- ☐ Themed Events
- ☐ Watching Musicals/Movies
- ☐ Making cards or ornaments
- ☐ Learn a dance
- ☐ Playing instruments
- ☐ Music or Art Therapy
- ☐ Drumming

◀ Social Enrichment



- ☐ Creating or joining clubs
- ☐ Visiting social spaces (parks, mall, local events, restaurant, State fair, carnival, etc.)
- ☐ Video calls with family/friends
- ☐ Texting or calling
- ☐ Social video games
- ☐ Social media groups
- ☐ Coffee or lunch dates
- ☐ Trivia groups
- ☐ Storytelling or "show and tell" for adults
- ☐ Getting a haircut
- ☐ Role Play or Rehearse Social Situations
- ☐ Cooperative board games
- ☐ Read-Aloud
- ☐ Visiting animals (farm, aquarium, pet store, zoo, animal shelter, bird-watching, etc.)

Personal Care: Checklist

◀ Hygiene & Dressing



**I Don't
Need Help**

**I Need
Some Help**

**I Need Help
All the Time**

Tooth brushing

Bathing/ showering

Shaving

Brushing hair

Makeup and skin care

Using the bathroom

Knowing when to use the bathroom

Trimming or painting nails

Using deodorant & fragrances

Choosing clothes

Dressing

I worry about being able to:

I want to get better at:

A year from now I want to be able to:

Others can help me by:

Personal Care: Checklist

◀ Health Care



**I Don't
Need Help**

**I Need
Some Help**

**I Need Help
All the Time**

Taking medications

Remembering medications

First aid for cuts or injuries

Setting up doctor appointments

Movement & exercise

Getting tired easily

Getting good sleep

Reducing or responding to pain

Acknowledging new symptoms

Reducing smoking, drinking alcohol,
or using drugs

I worry about being able to:

I want to get better at:

A year from now I want to be able to:

Others can help me by:

Personal Care: Checklist

◀ Cooking & Eating



**I Don't
Need Help**

**I Need
Some Help**

**I Need Help
All the Time**

Using the stove or oven

Cutting or chopping

Planning meals

Preparing Meals

Storing leftovers

Eating & snacking

Grocery shopping

Making healthy decisions

Drinking water and staying hydrated

Washing or unloading dishes

I worry about being able to:

I want to get better at:

A year from now I want to be able to:

Others can help me by:

Personal Care: Checklist

◀ Maintenance, Safety, & Care



**I Don't
Need Help**

**I Need
Some Help**

**I Need Help
All the Time**

Remembering and paying bills

Managing money & budgeting

Managing my time

Washing clothes

Folding clothes

Putting away clothes

Cleaning (disinfect, vacuum, sweep, mop)

Organization & avoiding clutter

Modifying the space for accessibility

Turning locks & off lights/fans

I worry about being able to:

I want to get better at:

A year from now I want to be able to:

Others can help me by:



Personal Care: Checklist

◀ Growth & Awareness



**I Don't
Need Help**

**I Need
Some Help**

**I Need Help
All the Time**

Speaking up for what I need

Asking for help

Solving problems and making decisions

Getting started or keep motivated

Awareness of strengths and limitations

Identifying emotions & positive coping

Practicing relaxation strategies & self-care

Creating and sticking to habits

Building self-esteem & confidence

Finding purpose & meaning

I worry about being able to:

I want to get better at:

A year from now I want to be able to:

Others can help me by:



Personal Care: Checklist



Community Access



**I Don't
Need Help**

**I Need
Some Help**

**I Need Help
All the Time**

Getting places, transportation, & driving

Going to busy places (restaurant, concerts)

Connecting to helpful services & supports

Adjusting services or events

Participating in what I like (sports, religion)

Connecting with others & socializing

Feeling independent

Go to work, school, or volunteer

Build relationships (family, friends or
romantic, etc.)

I worry about being able to:

I want to get better at:

A year from now I want to be able to:

Others can help me by:



Personal Care: Strategies

Hygiene & Dressing



- ☐ Tooth brushing
- ☐ Bathing/ showering
- ☐ Shaving
- ☐ Brushing hair
- ☐ Makeup and skin care
- ☐ Using the bathroom
- ☐ Knowing when to use the bathroom
- ☐ Trimming or painting nails
- ☐ Using deodorant & fragrances
- ☐ Choosing clothes
- ☐ Dressing

- Break process into small steps
- Relate tasks to goals
- Address sensitivities to certain textures, tastes, smells, etc.
- Use checklists and create routine (add one new habit at a time, partnering to old)
- Use apps, social stories, worksheets, or workbooks
- Investigate video or picture modeling

Health Care



- ☐ Taking medications
- ☐ Remembering medications
- ☐ First aid for cuts or injuries
- ☐ Setting up doctor appointments
- ☐ Movement & exercise
- ☐ Getting tired easily
- ☐ Getting good sleep
- ☐ Reducing or responding to pain
- ☐ Acknowledging new symptoms
- ☐ Reducing smoking, drinking alcohol, or using drugs

- Keep a record of medications
- Ask about interactions with other medicines, vitamins, and foods
- Write down any changes in symptoms and when they occur
- Use pill boxes
- Use apps or reoccurring reminders
- Develop a routine for sleep
- Get regular exercise – scaling or adjusting as needed

Cooking & Eating



- ☐ Using the stove or oven
- ☐ Cutting or chopping
- ☐ Planning meals
- ☐ Preparing Meals
- ☐ Storing leftovers
- ☐ Eating & snacking
- ☐ Grocery shopping
- ☐ Making healthy decisions
- ☐ Drinking water and staying hydrated
- ☐ Washing or unloading dishes

- Pre-measure ingredients, crockpot meals, overnight preparation, and use frozen or pre-cut or cooked options
- Rest as needed, keep a stool nearby
- Assess kitchen or organization design for accessibility
- Utilize adaptive equipment, Lazy Susan's, push carts, & cutting boards
- Utilize online shopping options
- Label drawers with extra storage containers for categorizing objects



Personal Care: Strategies

◀ Maintenance, Safety, & Care



- ☐ Remembering and paying bills
- ☐ Managing money & budgeting
- ☐ Managing my time
- ☐ Washing clothes
- ☐ Folding clothes
- ☐ Putting away clothes
- ☐ Cleaning (disinfect, vacuum, sweep, mop)
- ☐ Organization & avoiding clutter
- ☐ Modifying the space for accessibility
- ☐ Turning locks & off lights/fans

- Investigate home modification resources or Smart Home technology
- Use alarms and reminders for bill reminders with a checklist
- Utilize non-medical home care
- Create a chore list and schedule with checklists with each step (include pictures, words, and/or videos)
- Have list of people to contact for questions or assistance

◀ Growth & Awareness



- ☐ Speaking up for what I need
- ☐ Asking for help
- ☐ Solving problems and making decisions
- ☐ Getting started or keep motivated
- ☐ Awareness of strengths and limitations
- ☐ Identifying emotions & positive coping
- ☐ Practicing relaxation strategies & self-care
- ☐ Creating and sticking to habits
- ☐ Building self-esteem & confidence
- ☐ Finding purpose & meaning

- Discuss goals, strengths, and areas to work on (to address motivation)
- Develop a support network to help with identifying a problem, who to contact, and what next steps to take
- Use block time scheduling, with use of visual timers or reminders
- Seek support groups (online & in-person), counseling, and interest groups to help with wellness

◀ Community Access



- ☐ Getting places, transportation, & driving
- ☐ Going to busy places
- ☐ Connecting to helpful services & supports
- ☐ Adjusting services or events
- ☐ Participating in what I like
- ☐ Connecting with others & socializing
- ☐ Feeling independent
- ☐ Go to work, school, or volunteer
- ☐ Build relationships (family, friends or romantic, etc.)

- Investigate travel training, vehicle modifications, or disability transport
- Assess eligibility for a community guide service
- Evaluate hobbies, interests, and community groups
- Connect with group/activity leaders to educate and advocate
- Contact a local independent living center for resources or training



Personal Care: Checklist

What's Important TO me:

hopes, dreams, likes, dislikes, places, interests

What's Important FOR me:

what is needed to keep me safe and healthy

What does success mean to me? What does it look like?

What are my long term goals? Where do I want to be in 6 months, 1 year, or longer?

What skills are needed to achieve these goals? Where am I now in these skills?

What habits can I work toward improving these skills?

WRAP Memory Strategies



WRITE IT

- Write everything down (use a notepad or notebook)
- Create to-do lists
- Use visual calendars or a planner
- Keep all information in one place



REPEAT IT

- Repeat and rehearse new information
- After explained, practice again
- Schedule time during the day to practice for a couple days



ASSOCIATE IT

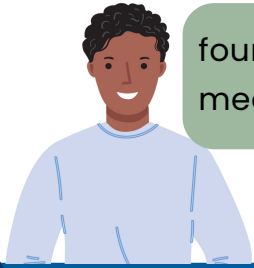
- Associate the new with the old
- Partner previous habits with new
- Group like things together
- Be creative
- Use songs, acronyms, or pictures



PICTURE IT

- Make a picture in your head
- Visualize the details (color, shape, sounds)
- Where is it typically found
- Where did you last interact or use it

Word-Finding Strategies



four legs, ears,
meows... a cat!



CIRCUMLOCUTION

- talking around the word
- describing it



not a dog,
but a... cat!



ASSOCIATION

- pairing with something similar
- giving clues or hints



feline, kitty...
oh a cat!



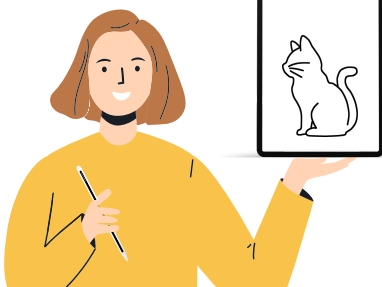
SYNONYM

- something that is like it or similar
- write synonyms into a search engine on a smart device



GESTURE

- using your hands or body to describe
- point to it if nearby



DRAW

- write or draw a picture
- find a picture online



DELAY

- wait a few minutes, go back later
- replay key conversation points

What I Needed the Most

I am not stupid, I am wounded. You don't need to raise your voice. Please respect me.	Stimulate my brain when I have any energy to learn something new, but know that a small amount may wear me out quickly.
Come close, speak slowly, and enunciate clearly.	Use age-appropriate educational toys and books to teach me.
Repeat yourself—assume I know nothing and start from the beginning, over and over.	Introduce me to the world kinesthetically. Let me feel everything. Teach me with monkey-see, monkey-do behavior.
Be as patient with me the 20th time you teach me something, as you were the first.	Trust that I am trying—just not with your skill level or on your schedule.
Approach me with an open heart and slow your energy down. Take your time. I may want you to think I understand more than I really do.	Ask me multiple-choice questions. Avoid Yes/No questions. Ask me questions with specific answers. Allow me time to hunt for an answer.
Be aware of what your body language and facial expressions are communicating to me.	Do not assess my cognitive ability by how fast I can think. Trust that my brain can always continue to learn.
Make eye contact with me. I am in here—come find me. Encourage me.	Speak to me directly, not about me to others.
Honor the healing power of sleep.	Cheer me on. Expect me to recover completely, even if it takes twenty years!
Touch me appropriately, with the care of a newborn, and connect with me.	Break all actions down into smaller steps of action.
Protect my energy. No talk radio, TV, or nervous visitors! Keep visitation brief (5 minutes).	Look for what obstacles prevent me from succeeding on a task.

What I Needed the Most, Continued

Clarify for me what the next level or step is so I know what I am working toward.	Keep me familiar with my family, friends, and loving support. Build a collage wall of cards and photos that I can see. Label them so I can review them
Remember that have to be proficient at one level of function before I can move on to the next level.	Create a healing team for me. Send word out to everyone so they can send me love. Keep them updated of my condition and ask them to do specific things to support me-like visualize me being able to swallow with ease or rocking my body up into a sitting position.
Celebrate all of my little successes. They inspire me.	Love me for who I am today. Don't hold me to being the person I was before. I have a different brain now.
Please don't finish my sentences for me or fill in words I can't find. I need to work my brain.	Be protective of me but do not stand in the way of my progress.
If I can't find an old memory, make it a point to create a new one.	Show me old video footage of me doing things to remind me about how I spoke, walked, and gestured.
Focus on what I can do rather than on what I cannot do. Avoid thinking anything is impossible.	Remember that my medications probably make me feel tired, as well as mask my ability to know what it feels like to be me.
Introduce me to my old life. Don't assume that because I cannot play like I used to play that I won't continue to enjoy music or an instrument, etc.	Remember that in the absence of some functions, I have gained other abilities.



◀ Where I want to live:

- ☐ with my family, such as:
- ☐ alone in my own house or apartment
- ☐ with roommate's in a house or apartment
- ☐ in house or apartment with caregivers to provide supervision
- ☐ in a supported apartment community designed for people with disabilities
- ☐ in a group home with several other people and hired caregivers
- ☐ another place, like:
- ☐ I don't know right now

▶ Where I am Now:

How do I feel about my current living arrangement?

What works well for me right now?

What would I like to have that I don't have right now in my living space?

What will make me feel good about my living space and the people who will help me?

What do I need to be successful in a new and different place? How do I feel about moving?



◀ Living with Others: Considerations

Here are some of the things that I do and are important to me in a living partner:

Me	Them	Eating Habits
☐	☐	Likes to share food
☐	☐	Does not like to share food
☐	☐	Cooks own meals
☐	☐	Cooks for others
☐	☐	Requires special diets
☐	☐	Eats with their mouth full
☐	☐	Cleans up after themselves
☐	☐	Other:

Me	Them	Interests
☐	☐	Enjoys sports, like:
☐	☐	Enjoys playing games, like:
☐	☐	Likes art
☐	☐	Likes music, like:
☐	☐	Likes to read
☐	☐	Enjoys being outdoors
☐	☐	Likes gardening
☐	☐	Likes to exercise
☐	☐	Watches TV and movies, like:
☐	☐	Other:



◀ Living with Others: Considerations

Here are some of the things that I do and are important to me in a living partner:

Me	Them	Sleeping Habits
☐	☐	Goes to bed and wakes up early
☐	☐	Goes to bed and wakes up late
☐	☐	Needs noise to fall asleep
☐	☐	Prefers the cold to sleep
☐	☐	Prefers the heat to sleep
☐	☐	Wakes up during the night
☐	☐	Doesn't sleep walk or snores
☐	☐	Takes daytime naps
☐	☐	Other:

Me	Them	Socialization
☐	☐	Needs quiet or alone time
☐	☐	Like to spend time with others
☐	☐	Enjoys parties
☐	☐	Enjoys inviting people over
☐	☐	Likes to share their things
☐	☐	Likes to go out
☐	☐	Prefers to stay in
☐	☐	Prefers living with same gender
☐	☐	Prefers living with someone from same race or ethnic group
☐	☐	Other:



◀ Living with Others: Considerations

Here are some of the things that I do and are important to me in a living partner:

Me	Them	Personal Behaviors and Temperament
☐	☐	Forgiving after argument
☐	☐	Can talk about things that are bothering them
☐	☐	When upset, does not get physical
☐	☐	Feelings get hurt easily
☐	☐	Likes to share belongings
☐	☐	Likes to help by doing things
☐	☐	Laughs a lot, has sense of humor
☐	☐	Gets sad often
☐	☐	Worries a lot
☐	☐	Is more outgoing
☐	☐	Is more shy/reserved
☐	☐	Borrows things frequently
☐	☐	Likes their area neat and tidy
☐	☐	Is more disorganized and okay with clutter
☐	☐	Enjoys hugs or okay with being appropriately touched
☐	☐	Smokes to relieve stress
☐	☐	Enjoys dressing up
☐	☐	Prefers more casual/lounge attire
☐	☐	Like and okay with pets, like:
☐	☐	Other:



◀ Living with Others: Communicating with Others

You may be interacting with people of different strengths and abilities. It's important that everyone feel welcome, respected, and at home. Below are some strategies related to specific disabilities that may help when living with others.

Trouble with vision or cannot see well



- Offer your help if you think it is needed, but don't be surprised if the person would rather do it themselves. If you are uncertain how to help, ask the one who needs assistance.
- When addressing a person who is blind, it is helpful to call them by name or touch them gently on the arm.
- Do not touch the person's guide dog, glasses, or cane without permission.
- Let the person hold on to you just above the elbow versus you holding or grabbing them.
- Use specific, directional language such as "to your left" or "directly behind you" rather than "it's over here."
- When walking into a room or talking in a group, identify yourself by saying your name.



◀ Living with Others: Communicating with Others

You may be interacting with people of different strengths and abilities. It's important that everyone feel welcome, respected, and at home. Below are some strategies related to specific disabilities that may help when living with others.



Trouble with language or cannot speak well

- Get the person's attention before you speak. Say their name first.
- Reduce background noise or distractions (noise, excess lights, movement, etc.).
Look for quieter spaces and turn off the radio or TV.
- Use simple communication, but keep it adult. Don't speak louder and don't talk down to the person. Use yes/no or limited choices instead of open-ended questions.
- Use and encourage different communication techniques: writing, drawing, gestures (pointing or describing). You can use paper and a pen to write down key words, or draw diagrams or pictures to support understanding.
- Give the person time to respond. Count to 10 in your head before repeating or rephrasing.
- Avoid finishing their sentences or overly correcting language errors. If they're having difficulty finding the right word, prompt them – ask them to describe the word, think of a similar word, try to visualize it, think of the sound the word starts with, try to write the word, use gestures, or point to an object.

◀ Living with Others: Communicating with Others

You may be interacting with people of different strengths and abilities. It's important that everyone feel welcome, respected, and at home. Below are some strategies related to specific disabilities that may help when living with others.



Trouble with hearing or cannot hear well

- Don't avoid talking to them and prevent isolation. Get attention with a wave of the hand, a tap on the shoulder, or other signal. With difficulty, enjoy each other's company in other ways (watch TV, listen to music, play cards or reading).
- Speak clearly and slowly, but without exaggerating your lip movements or shouting (shouting may distort sound).
- Give the person time to understand and respond. Look directly at the person and speak expressively. Don't assume everyone can read your lips, but they may be able to understand more from your facial expressions.
- Be flexible. If difficulty understanding what you are saying, rephrase your statement rather than repeating. If difficulty persists, write it down.
- Keep background noise at a minimum—turn off the TV, step away from others who are talking. Seek good lighting. Keep hands away from your face when speaking.
- When an interpreter accompanies a person, speak to the person rather than to the interpreter.

◀ Living with Others: Communicating with Others

You may be interacting with people of different strengths and abilities. It's important that everyone feel welcome, respected, and at home. Below are some strategies related to specific disabilities that may help when living with others.

Trouble with mental health or regulating emotions



- Allow having personal space in the room. Don't invade their space without permission, touch them, stand over them, or get too close. Don't block the doorway, have an exit plan if the situation escalates and you don't feel safe.
- Establish a structured and regular daily routine. Be predictable. Be consistent. Do not say you will do something and then change your mind. Give plenty of notice for changes that occur in schedule or activity.
- Offer praise continually. If their hair is combed after three days of not doing so, comment on how nice their hair looks. Ignore the negative and praise the positive.
- Avoid over-stimulation (lots of noise, lights, movement, crowds, etc.). Feeling confused or demanding mental activities can be exhausting. Prompt taking breaks, proper rest, and relaxation strategies to reduce stress and tension.
- Respect feelings by asking questions or validating their experience. Saying, "You're fine," "Cheer up, " or "There's nothing to worry about" will get you nowhere. Likewise, don't make it about you by drawing comparisons that may make their situation feel minimized. Allow the person to feel by saying something like, "It's all right if you feel worried. Just sit here by me for awhile." You can redirect to more positive activities, like being creative, moving the body, or spending time outside.

◀ Living with Others: Communicating with Others

You may be interacting with people of different strengths and abilities. It's important that everyone feel welcome, respected, and at home. Below are some strategies related to specific disabilities that may help when living with others.



Trouble with memory, attention, or keeping track of thoughts

- The person may be confused and fearful. Use a calm voice and be reassuring. The person is trying to make sense of the environment. Do not argue with the person. It would be better to reassure the person that everything is all right. Redirect them to doing something more positive.
- Treat each person as an individual with talents and abilities deserving of respect and dignity. Individuals can usually tell if they are being talked down to like a child, which can make the situation worse.
- Pictures and written descriptions can be useful records of things that have happened. Encourage using a diary, journal or calendar to record events and conversations.
- Give simple answers to questions and repeat them as often as needed. You can also write the answer down so that the person has a note of it. It won't help to tell them that they have heard the information before.
- If the person can't remember whether they have done something or not, try to give context to your question and include prompts. For example, 'It must be a while since you ate breakfast, are you hungry?' rather than 'Have you had breakfast?'.

◀ Living with Others: Communicating with Others



Trouble with memory, attention, or keeping track of thoughts

- If the person is struggling to find a word, give them enough time to say what they are trying to say. Feeling under pressure can make it more difficult.
- If you are not sure what the person is trying to tell you, consider the context of what they are saying. This may give you clues about the word they are looking for.
- If the person doesn't understand a word you are using, try using prompts, cues and context to help with naming items. The person may recognize an object and what it is used for, even if they can't remember what it is called.
- If the person is struggling to remember someone's name, try to find tactful ways to remind them without highlighting that they have forgotten – for example, 'Here's your friend, Elena'.
- Consider using a 'memory book' or 'memory box' with photos and brief information on people (such as their name and the story of how the person knows them). The person can then refer to this if they want to.
- Help the person to perform tasks by breaking them down into smaller, simpler steps. It can help to write short instructions and place them nearby.
- Consider the time of day when the person is usually more able to concentrate and try to schedule tasks for these times.

◀ Living with Others: Communicating with Others



Trouble with memory, attention, or keeping track of thoughts

- Make sure that items that the person uses regularly are clearly visible to them. Make tasks easier by putting out the items the person will need– for example, place tea bags and a mug near the kettle.
- Use reminders, such as sticky notes or a wall calendar, for one-off tasks. Set up more permanent reminders for regular tasks – for example, put up a sign by the front door to remind the person to take their keys and wallet if they leave the house.
- Assistive technology devices can help reduce danger or manage everyday activities – for example, electronic pill boxes can remind the person to take daily medication. Talk to an occupational therapist about coping strategies and suitable devices for help with day-to-day tasks.
- If the person gets lost when going out alone, consider going out with them, or arranging for someone else to do so. Make sure the person has a form of communication (i.e. mobile phone or GPS) and some form of identification when they go out, as well as contact numbers of people they know well.
- If the person is happy to, it can help if other people who live nearby are told about the person's difficulties. People like neighbors and local shopkeepers may be able to help if the person gets lost.

◀ Living with Others: Communicating with Others



Trouble with memory, attention, or keeping track of thoughts

- If the person is recalling a home that they used to live in, speak with them about this other home, and what it means for them. This may help them to place it in the past.
- Reassure the person that they are safe if they ask to go home, and encourage them to talk about their feelings. Asking questions like ‘What do you like about your home?’ may help you understand what they need to feel comfortable.
- Make sure that the person is surrounded with familiar items that will help them feel at home.
- Keep a reminder of the current home address somewhere visible to remind the person of where they are. If the person forgets the layout of the home, try putting up signs to help them find the bathroom, kitchen and other rooms they use regularly.



Dining Room

Place to sit & eat food



Pantry

Place to find food



Bathroom

Place to pee, poop, shower, or wash hands



Laundry

Place to wash clothes



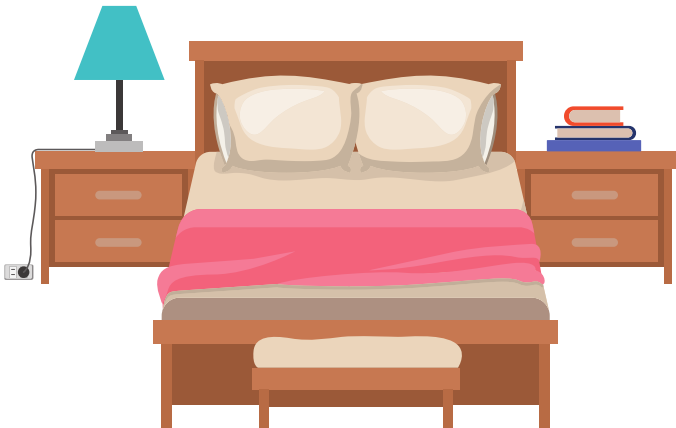
Garden

Place to plant & grow
items



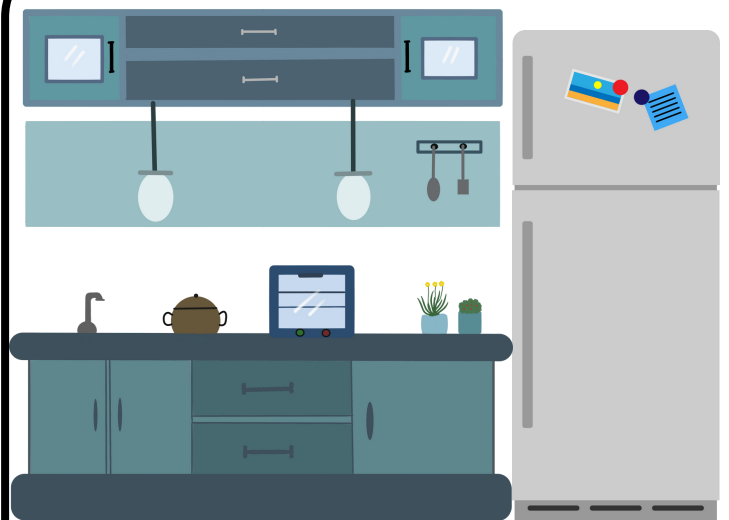
Living Room

Place to lounge & relax



Bedroom

Place to sleep & relax



Kitchen

Place to cook &
prepare food



Closet

Place to store items



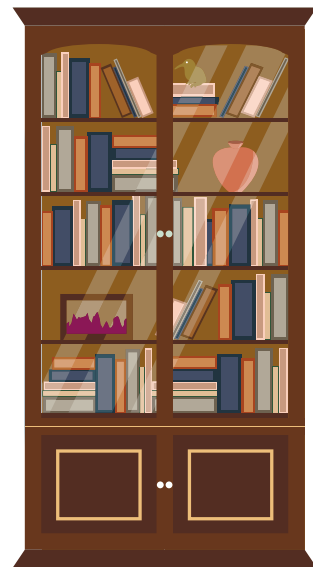
Garage

Place to store items



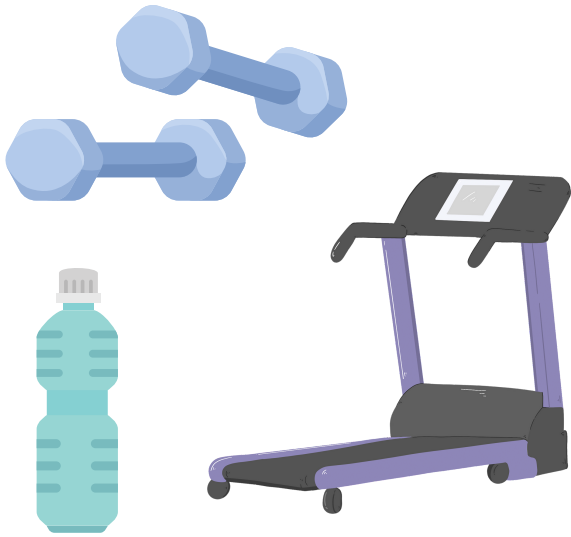
Office

Place to organize or
do work



Library

Place to read & think



Gym

Place to move your
body & exercise



Game Room

Place to have fun



Basement

Place to store items



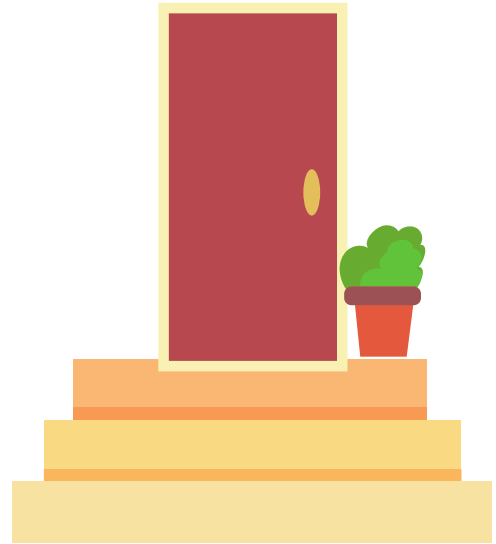
Sunroom/ Porch

Place to relax



Music Room

Place to play, dance, or listen to music



Exit Door

Place to leave or enter



Therapy Room

Place to work towards goals



Stop

This room is off limits, please ask someone for access

◀ Living with Others: Communicating with Others

You may be interacting with people of different strengths and abilities. It's important that everyone feel welcome, respected, and at home. Below are some strategies related to specific disabilities that may help when living with others.

Trouble with movement or uses a wheelchair, cane, or device

- Always ask the person if they would like assistance before you help.
- Be respectful. A person's wheelchair, cane, or mobility device is part of one's body space and should be treated with respect. Don't hang or lean on it unless you have permission. When a person transfers out of the wheelchair to a chair, toilet, car or other object, do not move the wheelchair out of reaching distance.
- Be careful not to exclude the person from conversations. Speak directly to the person and if the conversation lasts more than a few minutes, sit down or kneel to get yourself on the same level as the person in the wheelchair.
- Give clear instruction. Include distance, weather conditions, and physical obstacles which may hinder travel.
- Wheelchair use doesn't mean confinement. Be aware that persons who use wheelchairs are not confined or bound to them. Some persons who use a wheelchair for mobility can walk. Be aware of the person's capabilities.
- Wheelchair use is not a tragedy, as it provides freedom allows the person to move about independently. Structural barriers in public places create some inconveniences if not wheelchair accessible (including heavy doors).

◀ Living with Others: Service Settings

The Person's or a Relative's Home

- If the person with brain injury is returning home, alterations may need to be made (i.e. ramps, accessible bathroom/kitchen, wider doorways, handrails, home modifications) by contractors, engineers, or accessibility experts.
- Specific loans and state, federal, or community financial assistance may aid in modifications after brain injury.
- A combination of community-based services, home health, and outpatient rehabilitation can be beneficial to living with family

Home Health Services

- Home Health allows the same level of medical attention you'd expect from a hospital but in your home.
- Non-medical care is also available to assist with housekeeping, laundry, meal preparation, transportation, conversation, bathing, grooming and dressing.
- Can be provided through Home Health Care agencies, Medicare, Medicaid, and in some cases private health insurance.

Supported or Independent Living Programs

- For people who are capable of living on their own or with a roommate with some support, such as assistance with budgeting, grocery shopping, household maintenance, health/safety monitoring.
- Provided in the individual's own home or apartment or supervised apartment housing program.

A Group Home

- Provide 24-hour personal care and habilitation to help develop self-help skills, gain work experience, and participate in community activities.
- Medicaid homes are licensed and monitored by the North Carolina Division of Health Service Regulation (DHSR).
- Typically serve 3-6 individuals per home with single or shared bedrooms.

◀ Living with Others: Service Settings

Alternative Family Living (AFL)

- A person with an intellectual or developmental disability resides with an individual or family other than their own to receive habilitative care.
- Typically an expensive service and available only to NC Innovations (1915C Medicaid Waiver) recipients.
- Homes must be licensed if serving a child or more than 1 adult.

Long-term Care Residential Services

- Supported in-patient housing program designed for long-term living ranging in size (20-100+ residents).
- Provide food, 24-hour supervision, social activity programs, with some offering employment and/or case management.
- May have rehabilitation therapies built in to schedules provided by allied health professionals (i.e. physical, speech).
- Few neurobehavioral options available with locked housing, particularly for individuals with state/federal supports living in North Carolina.
- Some offer tiered housing support depending on need, giving the option to move to a less restrictive environment if care needs change (i.e. supervised apartments or group home settings).

Assisted Living Facilities

- Offers help with daily care, but not as much help as a nursing home provides.
- Range in size (25-120+ residents) and levels of care.
- Residents live in their own apartments or rooms, sharing common areas.
- Access to many services, including up to three meals a day; assistance with personal care; help with medications, housekeeping, and laundry.
- 24-hour supervision, security, and on-site staff; and social and recreational activities.

◀ Living with Others: Service Settings

Skilled Nursing Facility (SNF)

- Provides nursing care 24 hours a day, help with meals and personal hygiene, physical & social activity, and medication storage and dispensing.
- Can be longer-term housing or a shorter-term option for recovery and healing after hospital care (i.e. injury, illness, or surgery).
- May or may not have full access to rehabilitation therapies or specialized medical intervention (i.e. ventilator care).

Intermediate Care Facility (ICF)

- Funded by Medicaid to serve individuals with intensive medical or behavioral needs with more supports than a typical group home offers, but less than skilled nursing level of care.
- Range in resident size (6-30+) with overnight supervision provided.
- In addition to personal care and habilitation, specialized therapies and active treatment must be provided.

◀ Living with Others: Observing & Monitoring

You get to know a person by spending time with him or her and learning what is usual for them. Early identification of changes in an individual's daily routines, behavior, ways of communicating, appearance, general manner or mood, or physical health can save his or her life.

Physical Health



- **Skin:** Redness, cut, swelling, rash, slow-healing wounds.
 - For individuals with limited mobility, keep skin dry and change positions every two hours to prevent pressure sores.



- **Eyes:** Redness, yellow or green drainage, swelling of the eyelid, excessive tearing, or the individual reports pain, burning, or changes in vision (spots, blurry, cross-eyed, double, etc.).
 - Problems with vision may present as headaches, dizziness, nausea, or trouble with balance. Rehabilitation or specialized prism glasses may be helpful.



- **Ears:** Pulling at ear, ringing in the ears, redness, fever, diminished hearing, and drainage from the ear canal, the individual reports dizziness, pain, or loss of hearing.



- **Nose:** Runny discharge (clear, cloudy, colored), rubbing of nose, sores, or bloody nose, loss of smell.



- **Mouth and throat:** Refusing to eat, redness, white patches at the back of the throat, hoarse voice, fever or skin rash, toothache, facial or gum swelling, gum bleeding, fever, individual reports pain when swallowing.
 - Dysphagia is a swallowing disorder that may occur after brain injury.



- **Muscles and bones:** Inability to move a leg or an arm that the individual could previously move, stiffness, limited range of motion, individual reports pain in the arms, legs, back.
 - Warning signs of injury that require medical attention: swelling, joint deformity, pain or tenderness, decreased range of motion (including spasticity or contractures), different gait (how they walk, dragging feet, etc.) or numbness or tingling that could lead to falls.

◀ Living with Others: Observing & Monitoring

Physical Health



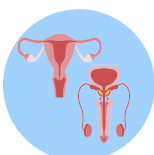
- **Heart and blood vessels:** Numb or cold hands or feet, swelling of ankles, arms, or legs, chest pain, shortness of breath.
 - Deep Vein Thrombosis (DVT) occurs with a blood clot forming in deep tissues, typically the leg. This clot could break off and settle somewhere else in the body, including the lungs causing Pulmonary Embolism (PE).
 - Orthostatic hypotension, or disruptions in blood pressure, may occur as a person changes positions - such as sitting to standing, or vice versa. The person may feel dizzy or even faint if changing positions too quickly.



- **Breathing (lungs):** Chest pain, cough, phlegm (mucous), shortness of breath or wheezing, fever, rash, stiff neck, headache, chills, nasal congestion, individual reports pain in nose or teeth, dizziness.
 - Disruptions in breathing may occur while sleeping, called sleep apnea. The person may snore loudly, stop breathing during sleep or gasping for air, have a dry mouth, morning headache, difficulty staying asleep (insomnia) or feeling awake during the day.



- **Abdomen, bowel, and bladder:** abdominal pain, bloating, vomiting, loose stools or diarrhea, constipation, fever, bad smelling breath or urine, difficult, painful and/or burning urination, changes in urine color (cloudy, bloody, or dark), nausea, pain on one or both sides of the mid-back, chills.
 - Urinary tract infections (UTIs) can be common with people with brain injury. They may experience pain and frequent urge to pee. This may present as agitation or behavioral communication.
 - Incontinence can occur after brain injury due to changes in signals sent from the brain to eliminate waste/urine. Creating an emptying routine can help rebuild those signals. Some may require a catheter that should be intermittently placed, as opposed to indwelling, to prevent infection.



- **Reproductive & Sexual health:**
 - Vaginal discharge, itching, unusual odor, burning, lower abdomen pain, changes in menstrual cycle, such as change in frequency, length, and flow.
 - Discharge from penis, pain, itching, redness, burning.
 - Disruptions in hormones, arousal, sensation, sensitivity, or sexual interest

◀ Living with Others: Observing & Monitoring

Changes in Mental or Emotional Status



- **Behavior & Emotions:** acting aggressively toward self or others (hitting, kicking, yelling, throwing, etc.), more or less active than usual, disruptive in groups, using excessive profanity or inappropriate language, impatient or irritated quickly, overly impacted by changes in schedule or expectations, only concerned about single point of view, personality changes, lack of emotion or fluctuating emotions.
 - Understand that there are often emotions behind the action of behaviors and thoughts behind the emotions. Validate the emotional experience without reinforcing the behavior. Remain calm, be patient, model behavior, and redirect energy to something more positive.



- **Ways of communicating:** stops talking, withdrawn, garbled, slurred, slowed, or unclear speech, trouble finding words, inserting inappropriate words or topics, tangents, interrupting, or changes in tone/volume.
 - Changes in communication could relate to pain, being tired, or feeling overloaded mentally. Remove or reduce distractions (noise, patterns, light, movement, etc.) in the environment to allow for rest. Give directives or action items one at a time (not all at once).



- **Appearance:** lost interest in activities, taking less care in appearance (hair, clothes, skin, makeup, facial hair, etc.), disruption in hygiene.
 - Avoid projecting how a person should look on others based on society standards. However, if you notice significant changes in someone's appearance, it could be an indication of mental health or energy changes.



- **Family/social relationships:** may act distant or afraid, inappropriate comments on social media, change in typical posting content, obsession or overuse of computer/phone or social media.
 - Keep aware if someone interacting with the person appears to be causing emotional distress. If you notice any signs of drug activity, or verbal or physical abuse, inform your supervisor immediately. Use caution, as individuals may be at risk for abuse or being taken advantage of financially or for other gains.

The Rancho Los Amigos Scale

TOTAL ASSISTANCE (LEVEL 1-3)

Reflection: What would it be like to have a normal day and then have no control of your actions?

- In a persistent vegetative state, seems to be in a deep sleep
- Might open eyes or respond inconsistently to movement, noises, pain, or touch
- No purposeful movement or sounds (posturing, stiffness, moaning)

MAXIMAL ASSISTANCE & AGITATION (LEVEL 4)

Reflection: Imagine every noise, movement, light, color feeling like a thousand bees buzzing in your brain.

- Increased awareness but limited understanding or processing
- Purposeful attempts to remove restraints or tubes or crawl out of bed (safety concerns)
- Limited attention for motor activities such as sitting, reaching and walking
- Agitation as a response to overstimulation
- Mood swings, crying out, screaming, sexual behavior, or exhibiting aggression (hitting, waving, cussing)
- Fight or flight (heightened physical/autonomic response)
- Incoherent or out-of-place vocalizations, wrong or mixed up words, non-sensical
- Limited cooperation with treatment

MAXIMAL ASSISTANCE & CONFUSED (LEVEL 5)

Reflection: What if you had more control over your thoughts but they felt all mixed up, like one moment of time slips into the next

- Agitated with overstimulation
- Confusion, lack of memory/new learning, and not oriented to person, place or time
- Can perform previously learned tasks with structure and cues provided
- Short attention span & brief socialization
- Struggle with goal directed, problem solving, self-monitoring behavior
- Inappropriate use of objects, communication, or confabulation

The Rancho Los Amigos Scale

MODERATE ASSISTANCE (LEVEL 6)

Reflection: What if you could start to feel in control of your life and body but everyone kept telling you "no"?

- Help with problem solving for task completion, continue supervision of familiar tasks, and assist for new learning
- Unaware of disabilities and safety risks
- Follows simple instruction with improvement in recall/memory
 - i.e. memory aids, reinforcement of visible schedule (expectations)
- More appropriate responses though may appear automatic or repetitive (same answers every time), and may appear self-centered

MINIMAL ASSISTANCE (LEVEL 7)

- Oriented to person and place, within familiar environments (less with time)
- Poor memory, planning, social skills, & awareness of limitations
- Expanded capacity for daily routines and for new learning
- Ritualistic and focus on automatic habits
 - Able to attend to highly familiar tasks in a non-distraction environment for at least 30 minutes with minimal assist to complete tasks
- Might appear unrealistic, risky decision-making, trouble concerning safety, overestimating abilities, unaware of others or social appropriateness, labeled as oppositional or uncooperative, and unrealistic planning for the future or thinking of consequences

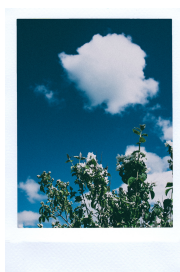
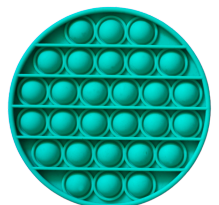
STAND BY ASSISTANCE (LEVEL 8+)

- Consistently oriented to person, place and time
- Independently completes familiar tasks for 1 hour with distractions
- Able to recall events, uses assistive memory devices, carries out familiar routines with stand-by assistance and can modify when needed with minimal assistance
- Aware of and acknowledges impairments and disabilities when they interfere with task completion but requires stand-by assistance to take action
- Thinks about consequences of a decision or action (with assistance), can overestimate or underestimate abilities, acknowledges others' needs and feelings, some disruption in mood (depressed, low frustration tolerance/easily angered, and argumentative), and may appear self-centered
- Recognizes inappropriate social behavior and takes corrective action with minimal assistance

Promoting Autonomy with Severe Brain injury

Sensory Stimulation Kits

- Functional, safe materials to stimulate the senses (sight, smell, taste, touch, hearing)
- Involve family & friends (not all at once - limit groups)
- Choose meaningful & important objects to the person
- Give down time & space out treatment
- Remove any noxious stimulant
- Place objects in the person's hands. Use objects with pleasant tactile sensations and different textures such as soft toys, silk scarves or books.



Considerations



Skin: Redness, cut, swelling, rash, slow-healing wounds.

- For individuals with limited mobility, keep skin dry and change positions every two hours to prevent pressure sores.



Muscles and bones: Inability to move a leg or an arm that the individual could previously move, stiffness, limited range of motion, individual reports pain in the arms, legs, back.

- Warning signs of injury that require medical attention: swelling, joint deformity, pain or tenderness, decreased range of motion (including spasticity or contractures), different gait (how they walk, dragging feet, etc.) or numbness or tingling that could lead to falls.
- Flaccidity requires supported joints (pillows, lap trays, soft neck collar, etc.).
- Spasticity requires early intervention (serial casting, exercises, medications, baclofen pump, etc.).
- Assist with following range of motion program.



Nutrition & hydration: Calorie needs increase 150% for proper recovery.

- Develop consistent bowel & bladder program.
- Note coughing, weight change, or avoidance as possible trouble swallowing (dysphagia).



Breathing: Remove mucus from airway or clean trache tube.

- Medications to regulate breathing patterns and stimulate brain stem activity.
- Listen for labored breathing, coughing, or choking.
 - Aspiration is when something enters your airway or lungs by accident.
- Breathing exercises to strengthen chest muscles and increase function.



Seizures: May have movement, lip smacking, or staring.

- Loosen tight clothing (neck).
- Assist/prevent falling.
- Turn the head to the side and don't put anything in the person's mouth.
- Call 911 if lasts longer than 3-5 minutes with no relief or continuous seizure activity.

Considerations



Discomfort: could cause behavioral communication

- Pain, infection
- Soiled Diaper
- Recently tube fed
- Cognitive overload
- Autonomic storming or dysautonomia (sweating, rapid heart, restless, dilated pupils)



Bowel Incontinence:

- Avoid continuous tube feeding (opt for bolus feeding).
- Add fiber or adjust formula thickness.
- Track and address C. diff concerns.
- Medications and suppositories to help soften or release.
- Time administration after eating.
- Use a toilet or bedside commode over a bed pan (gravity).



Bladder Incontinence:

- Catheters can cause infection, noxious stimulation, or be pulled out.
- Opt for external options or intermittent catheterization.
- Timed voiding (every 2-3 hours).
 - Be consistent & promote routine (all staff).
- May not be able to verbalize (wiggles, removing clothes, restless).



Wheelchair Positioning:

- Hips/pelvis: Bottom all the way back in chair, centered within confines of the wheelchair, knees even, and top of pelvis should be level (left even with right)
- Trunk or chest: Positioned in the middle of the backrest without leaning to one side
- Head: Positioned in the middle, not leaning to one side, headrest at the base of the head
- Legs and feet: Thighs should be straight, knees level with hips, and feet should make full contact on footplate
- Arms: Adequate armrest height to meet and support the elbow and forearm (not too high and not too low)



Total Assistance (Level 1-3)

ENGAGE & STIMULATE

- Talk with individuals in a calm, slow, normal voice about familiar or important topics to them
- Play music they would enjoy for short periods (5-10 min)
- Turn off or lower the lights
- Perform range of motion exercises
- Engage in “automatic” behaviors like scratching the skin or crossing/uncrossing the legs

PROVIDE STRUCTURE & PRACTICE STRATEGIES

- Offer small commands (i.e. "Close your eyes," "squeeze my hand," "raise your arm," "show me your teeth")
- Give one direction at a time and allow plenty of time for the response
- Avoid too much stimulation at once by having only two visitors at a time (take turns or rotate)

WITH MORE ALERTNESS, START SLOW AND SIMPLE

- Start a simple routine (such as washing their face)
- Ask questions with "yes" or "no" answers
- Designate a system with head nods, blinks, or gestures
- Act slowly and speak softly to avoid overstimulation

Early Stages Treatment Goals



- Increase arousal & stimulation
- Be aware for signs of agitation



- Prevent sensory deprivation & overload
- short bursts of 10-20 min



- Increase consistency and appropriateness of responses
- Develop a routine
 - Couple activities to promote rest



- Prevent medical complications (skin, injury, lungs, heart, etc.)
- Be aware of medication side effects

Maximal Assistance & Agitated or Confused (Levels 4-5)

PROVIDE EXTERNAL STRUCTURE AND SAFETY

- Reduce stimulation & medication
- Falls prevention & safety measures
- Be flexible with schedule/staff based on agitation
- Use other ways of communication (head movements or finger tapping)
- Give only one choice of food at a time and let them do as much for themselves

SLOWLY ENGAGE & BE FLEXIBLE IN SUPPORT

- Ask to try simple tasks (brushing teeth or washing face), place objects within reach
- Work in a quiet environment with no distractions
- Move slowly, repeat statements, don't argue at height of agitation
- Avoid startling them, especially when you wake them up from sleep

DON'T TAKE THINGS PERSONALLY

- Scary and overwhelming for family & friends to see change in personality & behavior
- Support, reassure, & encourage respite (it's not personal or a character flaw)
- It's okay if you need to walk away for a little to calm yourself
- Take a few deep breaths
- Avoid reactive behavior or communication

Agitated & Confused Stages Treatment Goals



Control stimulation

- Give consistent routine
- Provide rest periods
- Limit treatment time
- Avoid new learning



Ensure safety for person, family, and staff

- Staff continuity can help to identify triggers and reduce confusion



Expect personality differences and inappropriate behavior

- Avoid judgement
- Allow personal space
- Provide orientation & redirection (more positive)



Maximize good behavior, minimizing bad behavior

- Develop behavior treatment plan
- Reinforce good behavior

Moderate & Minimal Assistance (Levels 6-7)

ASSIST IN MEMORY & PROBLEM-SOLVING

- Go over information about family, friends, or the injury
 - Use photo albums, hang pictures, show videos, flashcards, etc.
- Help recall instead of always giving answers
 - Ask questions and if the correct answer is not given, provide some clues
 - Demonstrate or have them go over the steps again, talking through it

PROVIDE EXTERNAL STRUCTURE/ CUES

- Simple, concrete & one-step direction, offer reminders, and expect repetition
- Encourage writing information down & making to-do lists
- Create a structured schedule and routine with rest periods
- Reduce distractions (i.e. TV, patterns, movement, extra objects) when learning
- Limit activities (bathing, dressing, feeding, etc.) to 30 min, supervising and giving redirection as needed
- Avoid multi-tasking - you may need to prompt rest or down-time

ENGAGE, REDIRECT & PRAISE

- Engage in simple ball or simple card games to have fun and work on cognition
- Kissing, hugging or stroking may be confused as sexual messages
 - Gently tell them that this is not appropriate and practice alternatives for affection (limit physical contact to pat on the shoulder, fist bump, hand shake)
- Give praise and encouragement for positive interactions or behavior
- Acknowledge that learning and tasks may be slower
- Offer calm and gentle feedback on-the-spot

Recovery Stages Treatment Goals



- Increase the time left unsupervised
- Ensure proper safety measures



- Consistency for all staff
- Using strategies and keeping routines
 - May be able to work around staff



- Expand attention & distraction tolerance
- Provide less cueing and incorporate new learning



- Encourage independence and community involvement
- Connect to social or support groups



Brain Injury Related Services

RESPITE CARE



WHO

Caregivers: Caregiving can be the most *rewarding* time in your life, and it can also be the most *challenging* time in your life. It is important to remember that in order to care for those loved ones that are in need of your caregiving, you must first take care of yourself.

WHAT

Respite Care is designed to give you, as a caregiver, a break and to build some independence for the care receiver. That break is provided by a person or an agency that you and your loved one is comfortable with in allowing you and your loved one time apart.

WHY

There are many benefits to Respite Care

■ Family Unit

- More time spent together
- Improved relationship quality with other family members
- Improved relationship with, and better able to relate to, the care recipient
- Ability to live 'a more ordinary life'

■ Caregiver

- Have time for everyday activities, like sleeping or running errands, and for taking care of own health
- More time to spend with other family members, or friends
- Freedom to do something for themselves, like visit friends or read a book
- Better overall physical and emotional health
- Reduced stress, exhaustion, and anxiety
- Feeling a 'sense of renewal' or relief

■ Care Recipient

- Meaningful, and potentially new, experiences
- Greater independence by spending time away from the caregiver
- Socialization and keeping active (depending on activities during respite time)
- Improved interactions with caregiver (because caregiver is less stressed)
- Increased happiness and self-esteem
- Improved physical and mental health

There are available options for respite care depending on eligibility criteria and individual needs. Options include:

The Family Caregiver Support Program:

- Helps eligible caregivers address challenges related to providing 24-hour care.
- Provides services including respite care, information about services and supports, training to assist caregivers to improve their caregiving skills, individual and family counseling, and other services to complement the care provided by caregivers.

Home and Community Based Services (HCBS):

- Offers a variety of services and support, including respite, that allow individuals to stay in their homes.
- Services are offered through several programs with varying functional and financial eligibility criteria.

To find out more information regarding respite care and these programs, contact the Michigan Alliance for Families

www.michiganallianceforfamilies.org/respite/

or speak with your therapist about available resources in your area!