



# MOTIVATE PD

A Guide to Purposeful, Healthy Living for  
People with Parkinson's Disease

# Table of Contents

About the Authors.....	3
Welcome to Motivate PD!.....	4
What is Occupational Therapy?.....	5
<b>Part I: Activities</b> .....	6
Activities of Daily Living.....	9
Leisure (Physical Activities).....	11
Leisure (Hobbies + Other Interests).....	16
Social Activities.....	18
<b>Part II: Think Like an OT</b> .....	23
Identify Problems, Brainstorm Solutions.....	24
Setting Goals.....	26
Tracking Your Progress.....	28
<b>Part III: Optional Resources</b> .....	30
Acknowledgements.....	34
References.....	35



# About The Authors



**Lani Silverstone, OT/s** is an Entry-Level Occupational Therapy Doctoral candidate at Tufts University. She pursued her Bachelor of Arts in Biopsychology, Cognition, and Neuroscience with a minor in Medical Anthropology at the University of Michigan. Her clinical interests include geriatric care, stroke and brain injury, and the influences of virtual reality on rehabilitation outcomes. She has seen firsthand what it means to live with PD through her own family members, and through her involvement in PD organizations in the Boston area including Spaulding PD Dance and Tufts Dance for Parkinson's. She has clinical experience working with older adults in a variety of settings including post-acute care, long-term memory care, and daytime activity programs. In her free time, she enjoys cooking, rock climbing, practicing yoga, and hiking with friends.



**Linda Tickle-Degnen, OTR, PhD, FAOTA** is a Professor of Occupational Therapy Emerita at Tufts University. Her work focuses on physical, mental, and social health effects of daily life activities in the home and community. In her fifty-year career, she has provided occupational therapy to people with disabling health conditions, conducted research studies to better understand how to promote health across the lifespan, and taught healthcare practitioners how to provide the best possible care to their clients. Over the last two decades, her work has focused primarily on Parkinson's disease. She has given innumerable talks to people with Parkinson's, their caregivers, and health care practitioners across the world. She values listening to people in the Parkinson's community to learn their own perspectives and strategies on how best to cope, manage day-to-day living, and promote their wellness. In her free time, she enjoys practicing yoga, painting, hiking, and visiting with her two sons.

# Welcome to MOTIVATE PD!

**MOTIVATE PD** is an occupational therapy-based manual that is written for, and informed by, people with Parkinson's disease (PD) in the New England area and beyond.

This manual is based on the core belief that human beings thrive when they are able to do things that give them meaning and purpose on a daily basis. **The goal of this manual is to help you live and thrive with PD by continuing to participate in meaningful home and community activities over time.**

We hope that these pages empower you to:

- **Reflect** on what activities bring you joy and purpose
- **Identify** strategies to access these activities over time
- **Make a plan** to work towards your future goals



While these suggestions are meant to serve a wide range of abilities and interests, **you are the expert in your own life.** Feel free to try out whatever suggestions feel most feasible, safe, and accessible to you.

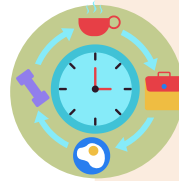
# What is Occupational Therapy?

- **Occupational Therapy (OT) is a healthcare profession that focuses on your ability to do the things you want and need to do.**
- “Occupations” are any activities that occupy your time, such as self-care (ie. brushing your teeth, getting dressed), chores, employment, or leisure.
- OTs help you identify your strengths, social supports, and other available resources to help you access and adapt activities that are meaningful to you.

## Looking for an OT in your area?

- Talk to your neurologist or primary care provider
- Call your local rehabilitation center
- Contact the [APDA Information and Referral Center](#) to be connected to an OT near you

## What can OTs help you with?



### Strategies for Everyday Living

Adapt your daily routines to fit your changing needs, from completing simple self-care tasks to more complex tasks like managing medications and driving.



### Strategies for Health Management

Understand, monitor, and manage your health daily, like keeping track of appointments and communicating with your neurologist.



### Functional Strength + Mobility

Maximize your balance, strength, endurance, and safety while navigating your home and community.



### Cognitive Strategies

Learn tricks to help your memory and problem-solving skills when completing everyday tasks.



# PART I: ACTIVITIES

# What Are Activities?

**“Activities” are any tasks that are central to your daily life.** Activities vary from person to person based on culture, upbringing, interests, resources, and life circumstances. Your activity participation also changes depending on your needs over time.

In this manual, we will talk about the following activity categories:

- **Activities of Daily Living:** what you *need* to do to support your daily living, from self-care to paying the bills or going grocery shopping.
- **Leisure Activities:** what you *choose* to do, that bring you pleasure and satisfaction. This includes more energy-demanding activities like physical exercise, or more relaxing activities like reading or watching TV.
- **Social Activities:** what you do to stay connected with your loved ones and broader community.



## Activities Are Social

**Human beings are social creatures.** Many of your daily activities are social in nature, and involve connecting with people in your social circle. Even if you live alone, simple chores like going to the pharmacy requires interacting with others.

# Why Are Activities So Important?

Regular engagement in everyday activities not only improves and protects your physical health; it also supports your mental, emotional, and social well-being.

- **Biological**

- Increases physical health
- Protects + enhances cognition
- Improves balance, endurance, and mobility
- May slow down progression of PD symptoms

- **Psychological**

- Enhances sense of identity and purpose
- Increases mood and overall mental health
- Increases life satisfaction

- **Social**

- Expands social networks and support
- Increased independence
- Prevents loneliness

(Baum & Edwards, 2008; Buchman et al., 2009; Kipnis et al., 2022; Tickle-Degnen et al., 2010; Tickle-Degnen et. al, 2020)



“

“I stay mindful that this is a unique journey for each person with Parkinson’s, but we choose to have hope and work on quality of life. Each day is a new opportunity to make a small step forward.”

*-Denise, Person with PD*

”



# Activities of Daily Living

**Activities of Daily Living (ADLs)** are things you *need* to do to support your daily life, such as:

- Self-care (ie. brushing your teeth, getting dressed)
- Employment
- Grocery shopping
- Washing dishes
- Doing laundry
- Taking out the trash
- Going to the doctor or therapy
- Yard maintenance
- Getting a haircut
- Cooking meals
- Driving
- Paying bills
- Household maintenance
- Caring for others (ie. kids, grandkids, pets)

ADLs require us to think and move! **Even if you don't have a lot of time for leisure, staying engaged in everyday activities is a great way to exercise your body and brain.**

(Baum & Edwards, 2008; Foster et al., 2021; Tickle-Degnen & Gunnerly, 2013-2019; Tickle-Degnen et al., 2022)



“

“We do all our own landscaping, and house cleaning...One of the things they advocate for Parkinson's is to do household chores, to do work around the house, to keep in motion. And so I do that.”

-Paul, Person with PD

”

# ADLs: Tips and Tricks



## Take Your Time

- Even if an activity takes you longer to complete, it is still worth doing – especially if it is an activity that is meaningful to you.
  - Slow down your pace
  - Take frequent breaks
  - Split up the activity over multiple days

“

“This past winter, I did my own snow blowing...[If I feel pain or fatigue], I have to sit down and rest a little bit... I try to push myself...[or], I'll just rake a little bit slower.”

*-Lou, Person with PD*

”



## Prioritize Tasks

- Save your energy for the activities that you most enjoy doing, and find easier solutions for the ones that you don't. For example, if you are finding it hard to cook meals:
  - **Simplify:** buy pre-cut vegetables at the store
  - **Modify:** cut vegetables while seated
  - **Plan:** Pick 1 day/week to complete one big meal prep; freeze your meals and simply heat them up throughout the week.



## Ask-Receive-Give

- Collaborate with others in your household, apartment complex, or neighborhood about who does what tasks.
- Exchange one of your strengths for someone else's strengths in your social circle
  - For example: “I'll mow your lawn if you help me change this lightbulb”

# Leisure: Physical Activities

**Physical activities include anything you do that gets your body moving.** The intensity of physical activities can be adapted depending on what your body needs.

Some examples include:

- Aerobic Exercise
- Swimming
- Playing a team sport
- Yoga/Pilates/Stretching
- Tai Chi
- Golf
- Tennis or other raquet sports
- Bowling
- Boxing
- Woodworking
- Hiking or Camping
- Walking
- Bicycling
- Canoeing/Boating
- Fishing/Hunting
- Gardening



“

“Try your best to think positive. And try to stay active as much as you can...The absolute worst thing to do is to sit here and just say, ‘Well, last week I didn’t do this, now I can’t do it anymore.’”

–Sam, Person with PD

”

# Physical Activities: Tips + Tricks

## Move with Others

- Did you know that doing physical activities with other people has even more health benefits than exercising alone?
- Research shows that moving with peers increases:
  - Mood and continued motivation
  - Endurance
  - Rhythm and speed of movement
  - Physical support and safety
  - External cues (signals in the environment that help you move)

“

“Whether you have Parkinson’s or not, the times that I’ve been most effective exercising on a consistent basis is when I was doing it with somebody else.”

*-Rodrigo, Person with PD*

”

## Listen to Your Body

- When you are living with a chronic condition, every day might feel and look a little different -- and that is okay.
- If an activity is feeling especially tiring or challenging, here are some ways to modify:
  - **Adjust the activity or level of support** you need to help you find success
    - ie. taking frequent breaks, doing things seated
  - **Talk to your occupational or physical therapist** about what adaptive equipment they might recommend.
  - **Take a rest day!** There is power in conserving your energy and trying again tomorrow

“

“Listen to your body, in terms of what you're able to do, and not able to do, and work with it. But, stay engaged...and keep moving.”

*-Charlotte, Person with PD*

”

# Physical Activities: Tips + Tricks

## Take a PD Movement Class

- Find your community with these PD movement classes! Here are a few options that offer classes in-person, online, and on-demand:

	<b>Rock Steady Boxing</b>	Boxing
	<b>Dance for PD</b>	Dance
	<b>Parkinson's Fitness</b>	Various (Strength, Balance, Yoga, + More)
	<b>American Parkinson's Disease Association (APDA)</b>	Various (Yoga, Tai Chi, Cycling, + More)

“I enrolled in **Rock Steady Boxing** classes...you not only exercise, but you are also introduced to a gigantic support group. This was an important strategic decision in my Parkinson's journey and has made the biggest impact in my life.”  
-Denise, Person with PD”



Illustration credit: Randall Pearson. See Kipnis et al., 2022 for full citation.

# Spotlight: Dance for Parkinson's

Dancing nurtures all aspects of body, mind, and soul, including:

- **Physical:** Posture, strength, flexibility, coordination, balance, gait/mobility
- **Cognitive:** Sequencing, rhythm, processing directions
- **Psychological:** Mood, motivation, purpose, identity
- **Social:** Sense of community, support, connection

## Dance for PD

**Dance for PD** is an organization that blends various dance styles and uses the fundamentals of dance, such as balance, sequencing, and rhythm, to promote social connection and self-expression. The class is for dancers of all levels and experience.

*How to join:*

- Check out [danceforpd.org](https://danceforpd.org) to find online, in-person, and on-demand dance classes.
- Or, take a picture of the QR code on p. 33 to access on your phone.

“

“The focus is not illness; it is living. It is self-expression, human connection, beauty, love. It's magic.”

-Dance for PD participant

”



Photo Credit: <https://danceforparkinsons.org/>

# Let's Talk About Mobility

Many people with PD experience mobility challenges that might make it harder to get out of the house, such as:

- Shuffling (taking small steps)
- Trouble turning
- Freezing (feeling like your limbs are stuck)
- Retropulsion (feeling like you are falling backwards)
- Slower speed
- Unsteady balance

Some creative tricks that people use to get moving:

- Playing music and stepping to the beat of the song
- Counting out loud or in your head
- Reminding yourself to keep your “nose over toes”
- Pushing off a steady object to get moving (ie. a wall)
- Focusing less on the destination
- Taking the indirect route (ie. walking in a half-circle or “weaving” rather than in a straight line)

## Meet Pamela Quinn



**Pamela Quinn** is a professional dancer and PD Coach who has had Parkinson's disease for over 25 years. Her website, **PD Movement Lab**, offers a wide range of strategies and resources to live and thrive with PD including:

- Funny and engaging videos on how to manage physical aspects of PD
- Interviews with PD outliers
- Blog posts
- Gaitkeeping: an online course that teaches you how to maintain/improve your gait
- Choreography performed by people with PD
- Free on-demand dance classes

# Leisure: Hobbies + Other Interests

**Leisure activities** are ways to occupy your time that can bring you joy and relaxation, such as:

- Watching a sports game
- Going to a museum, movie, concert, or play
- Sewing, hand crafts, or needlework
- Table games (eg. puzzles, cards, bingo)
- Drawing/painting
- Interior decorating
- Collecting (eg. stamps, coins)
- Photography
- Playing a musical instrument
- Reading (books, magazines, newspaper)
- Singing in a choir or group
- Creative writing/journaling
- Bird watching
- Watching television
- Listening to music
- Sitting and thinking
- Doing crossword or sudoku puzzles



“

“I’m a weaver... it’s my favorite pastime. I’ve been a weaver for about 30 years and I still feel like I’m a beginner... I always start my day [with] at least half an hour of weaving... it’s a good way to start [the day] because...[you] let yourself wake up gradually doing something you love”

*-Mary, Person with PD*

”



# Leisure: Tips + Tricks

## Join A Hobby Group

- Joining groups in your community is a great way to connect with others who have similar interests.
  - **Contact your local University** to see if they offer discounted classes for older adults
  - **Check out your local library** to learn about free activity offerings (ie. book clubs, book exchanges, technology classes, film showings, chess clubs, lectures, and more)
  - **Teach somebody else a skill** that you are good at



## Bring Your Interests to You

- Have friends over for a game, card, or craft night
- Start a book club over video call
- Look into adaptive tools that can help you participate in hobbies you love (ie. adaptive card-holders, weighted tools)
- *Not sure where to begin?*
  - Try out Paint by Number or Diamond Painting kits
  - Start a small indoor herb garden and watch your plants grow



# Social Activities

**Staying connected with other people is one of the most important things you can do for your health.**

Social activities include:

- Travelling
- Going to parties, potlucks, or family events
- Entertaining at your home
- Going to children's or grandchildren's activities
- Talking on the telephone
- Visiting with friends
- Eating at a restaurant
- Going to a place of worship
- Dancing
- Volunteering
- Being with a spouse or partner
- Storytelling or playing games with children



“

“...[I like to] walk with my friends...play Words With Friends...[my partner and I] have a lot of friends and family around, too, so we are often entertaining...”

*-Lila, Person with PD*

”

# Social Activities: Tips + Tricks

## Tune Into Your PD Community

- Connect to your **local APDA chapter** to find events near you
- Check out these National PD events:
  - **Dance for Parkinson's**
  - **Parkinson's Revolution**
  - **APDA Optimism Walk**
  - **Michael J. Fox Unity Walk**
- Check out these online PD communities to connect with others living with PD, and be part of a network of support.
  - **PD Conversations**
  - **Parkinson's Buddy Network**
  - **Parkinson's Disease Support Group**
- **Other ideas:**
  - Sign up for a PD research study
  - Create your own PD Fundraiser through the APDA Fundraising Campaign or Team Fox

“

“...I have been active in a local young-onset [PD] support group. I have also found support in numerous friends online through PD websites...So many of my PD friends give me hope. They inspire me when I talk to them, and I learn how to cope with PD.”

*-Judy, Person with PD*

”



<https://www.michaeljfox.org/unitywalk>

# Social Activities: Tips + Tricks (Ctd.)

Research shows that we thrive most when we experience a balance of giving *and* receiving support. This is called **social exchange**.

## Receive

- Looking for more companionship and/or support?
  - **LifePath Phone Pals** matches you with someone to talk about your interests, hobbies, and life experiences over the phone.
  - **FriendshipWorks** offers visiting services, social events, pet therapy, and other social supports.
  - **Little Brothers Friends of the Elderly** offers companionship for older adults who have limited access to transportation, language barriers to navigate, and few family members or friends nearby.

## Give

- Many people with PD share that helping others allows them to step out of the role of “patient” and into the role of “helper,” “healer,” “loved one,” and “friend.”
- Some ideas:
  - Volunteer at a local soup kitchen, museum, animal shelter, hospital, or library
  - Offer to take care of a pet
  - Give emotional support to a friend
  - Read to your grandkids or kids at a local school
  - Donate any available resources to a cause you care about (ie. money, clothes, books)

“

“[I read] to first and second graders in a local school...reading aloud gives me the opportunity to project my voice and practice my breathing. The enthusiastic response of 6 and 7 year olds spurs me forward again.”

—Joan, Person with PD

”

# Navigating Relationships with PD

If you are looking for more support regarding navigating relationships with PD, the following resources might help:

- **The Parkinson's Podcast: Love, Relationships, and Parkinson's**
- Check out this article by Allison Smith about dating and intimacy with Parkinson's disease:
  - **My Advice On Dating After a Parkinson's Disease Diagnosis**

## Is self-consciousness keeping you from socializing?

- Stigma, or embarrassment, is a common experience for people with PD. Folks have shared the following strategies:
  - Educate people about PD
  - Break the ice with humor (ie. "Well, I've always been a mover and a shaker")
  - Connect with others who have PD



“

“We shouldn't have to worry about making other people feel comfortable about the things that we can't change...PD is a part of you...anyone who cannot see past the disease, doesn't deserve your time.”

-Allison Smith

”

# Let's Talk About Mental Health

Mental health can be a barrier to participating in the activities you enjoy. You are not alone. While engaging in activities can be great for your mental health, here are some other ways people with PD choose to cope:

## Find a Professional You Trust

“I was introduced to a psychiatrist who assisted in returning to me the strength of spirit needed to resume football coaching and traveling...[he] helped me understand the mental aspects of Parkinson's disease”

—Kermit, Person with PD



## Find A Grounding Practice

“Family and faith are an important support for me. I constantly look at the screen saver photo of my granddaughters...my faith uplifts me...Whatever the outcome, I do not walk this path alone.”

—Sandra, Person with PD



## Stay in the Moment

“Don't let the fear of tomorrow ruin your today. we don't know what's going to happen in the future, [so] don't make today bad thinking that tomorrow is going to be bad. Make today good, so that when tomorrow comes, if it is bad, you can look back at a great life.”

—Paul, Person with PD



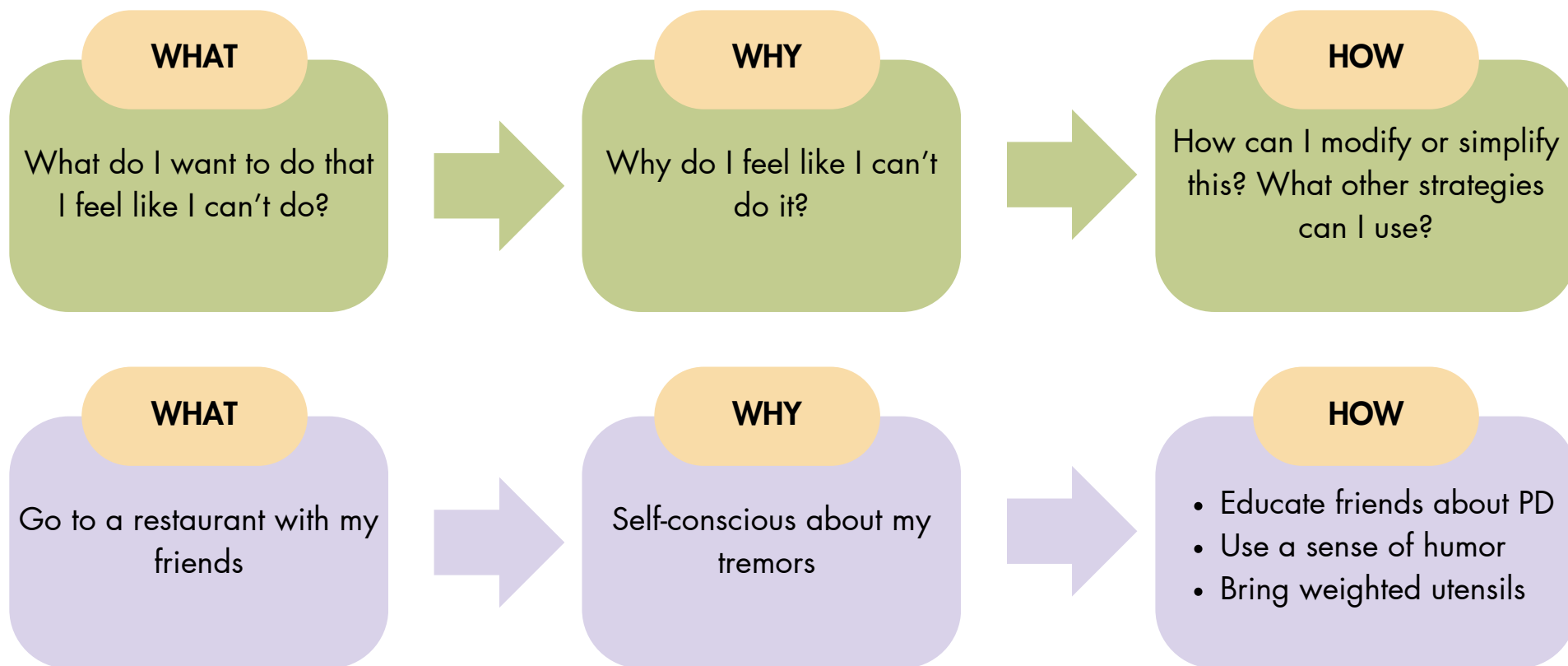


# PART II: THINK LIKE AN OT

# Identify Problems, Brainstorm Solutions

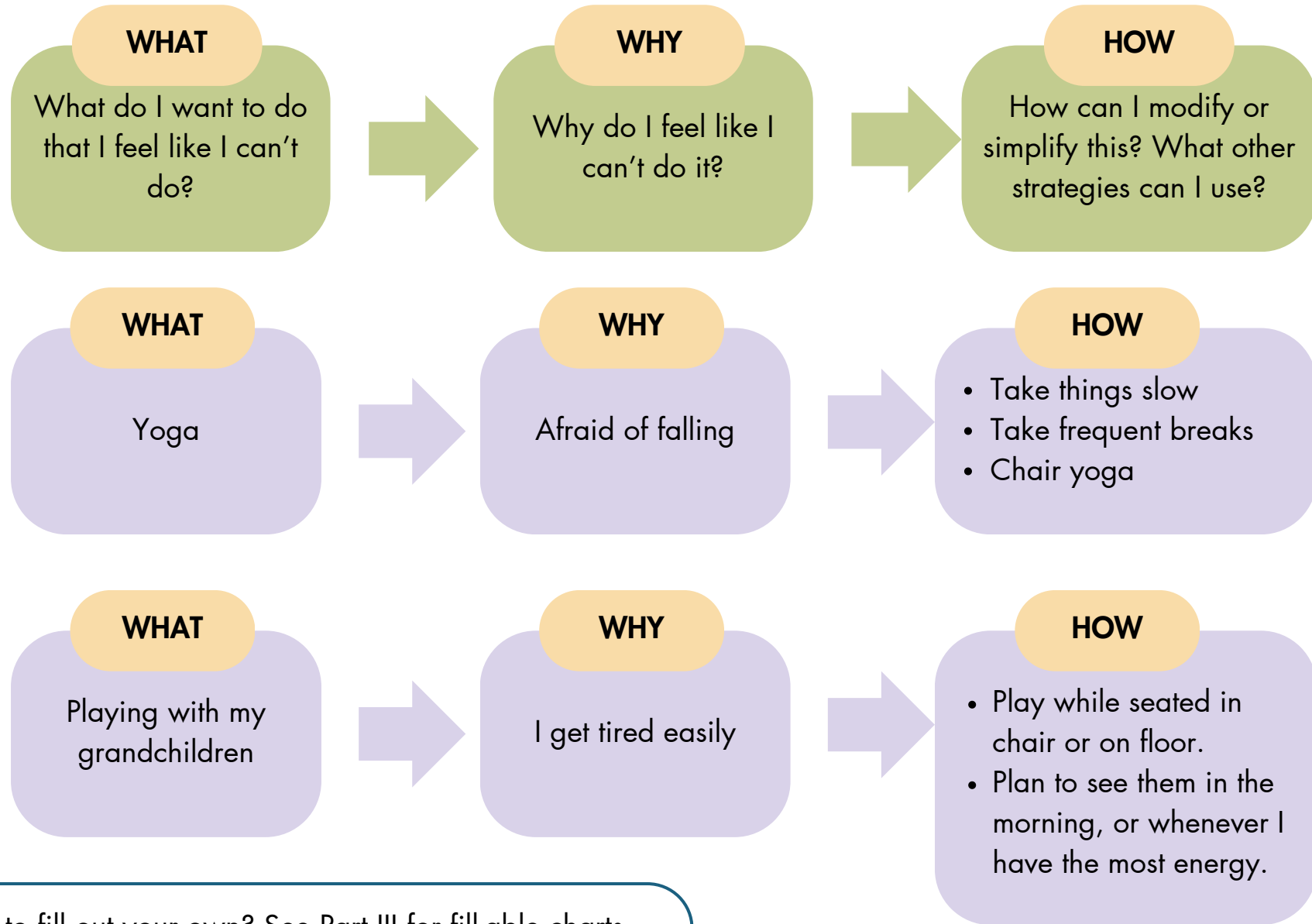
OTs help you come up with ways to make your valued activities possible. Once you identify what might be holding you back from doing the things you enjoy, you can brainstorm creative solutions that will empower you to take action.

This simple process can be useful whenever you are feeling “stuck,” or confronted by challenges in your everyday life. Refer to the purple boxes to see some examples.





# Identify Problems, Brainstorm Solutions: More Examples



Want to fill out your own? See Part III for fill-able charts.

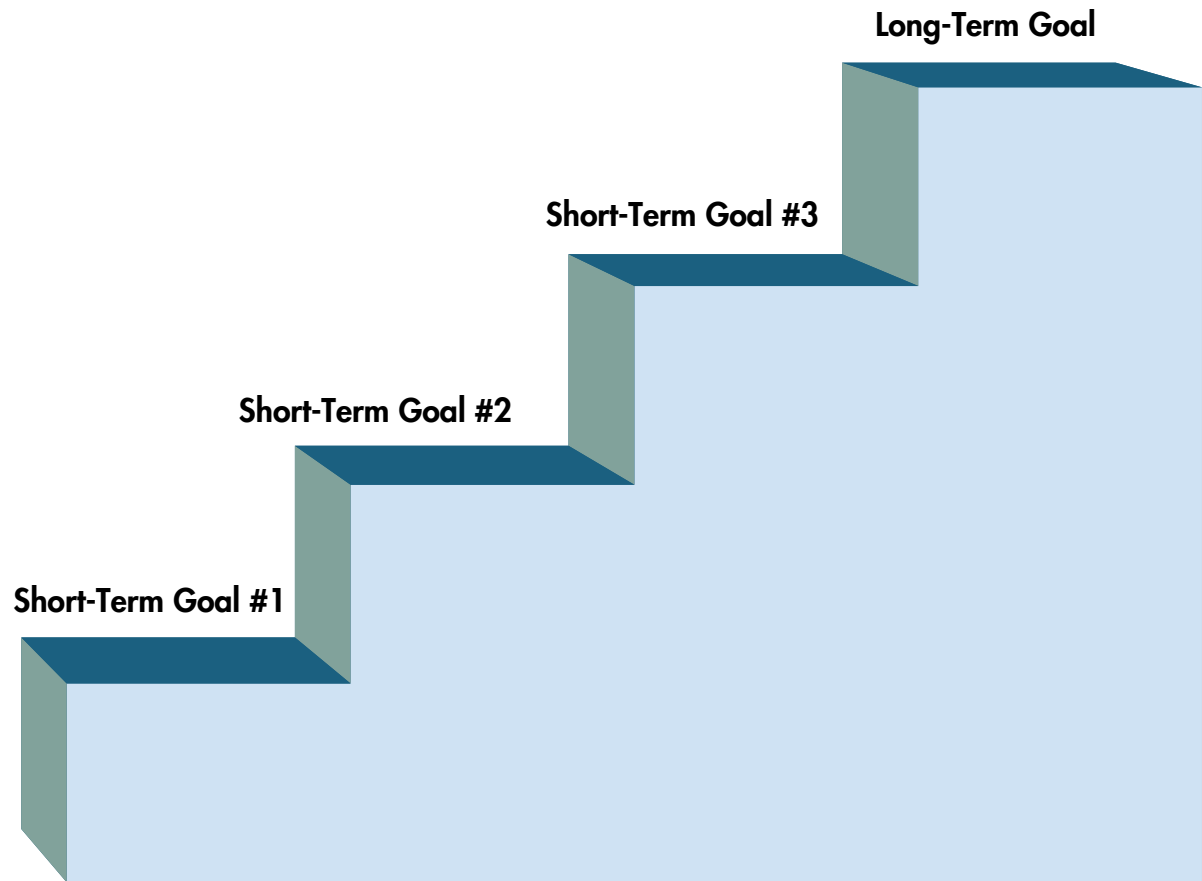
# Setting Goals

If you want to go a step further, you might consider setting some concrete goals. OTs create goals to help you visualize your future and take actionable steps to get there.

- **Long-Term Goal:** A big aspiration that takes a long time, or a lot of individual steps, to complete.
- **Short-Term Goal:** A smaller step you can take to reach your long-term aspiration; something you can feasibly do today or this week.

**Once you've created a long-term goal, think about all the smaller steps that you will need to do reach it.** Then focus on three things you can *realistically* do today or this week.

Want to fill out your own? See Part III for fill-able charts.



# Setting Goals: Example

## Short-Term Goal #1:

Find a dance class near  
me on the Dance for  
Parkinson's website

## Short-Term Goal #2:

Figure out logistics for  
getting there

## Short-Term Goal #3:

Take an online class  
first to see what it  
feels like

## Long-Term Goal:

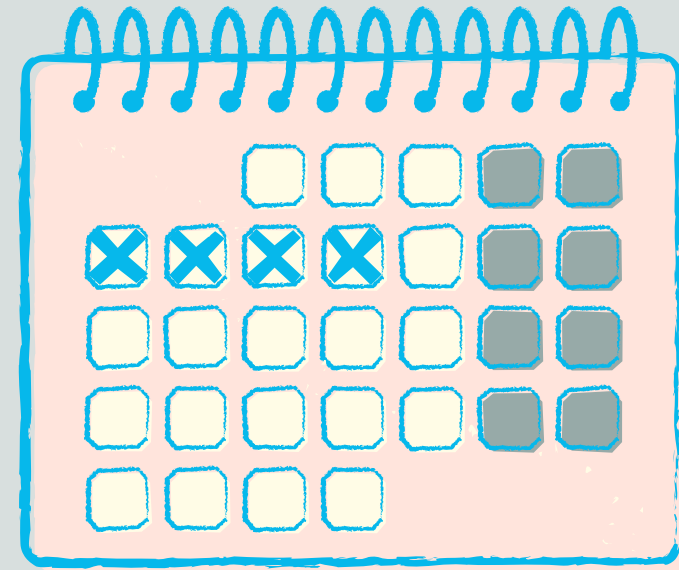
To bring dance back  
into my life

# Tracking Your Progress

Keeping track of your successes, no matter how small, can help you stay motivated over time. There are plenty of ways to do this – use any method that works best for you.

Some ideas:

- **Fill out a weekly “Track Your Progress” sheet** (see an example on the next page)
- **Put a sticker or check mark on your calendar** every time you did something that worked towards your long-term goal
- **Share your progress** with someone else
- **Keep a video or audio diary** of your progress
- **Celebrate the small wins!**
  - Give yourself a reward or have a little dance party every time you reach a small milestone



“...Seeing all the days you have [done a small step] on a day you’re not feeling up for it can help remind you that you are much closer to your overall goal than you were before and keep you motivated” (Travis, 2023)

# Track Your Progress: Example

Want to fill out your own? See Part III for fill-able charts.

Date: 04 / 05 / 24

Long-Term Goal: To bring dance back into my life

## What did I do this week?

- Found a dance class near me
- Figured out how long it will take to get there
- Asked a friend to carpool with me

## How do I feel?

- Excited!
- Proud of myself
- \_\_\_\_\_

## What do I still need to do?

- Take an online dance class this weekend
- Go to an in-person class next week
- \_\_\_\_\_

## Any changes I'd like to make to my long-term goal?

◦ Yes:

No

**Remember -- there are many ways to engage with these resources.** Choose the option that works best for you.

Some ideas:

- Make an audio or video diary
- Discuss with someone else
- Have a friend or loved one write your answers for you
- Recreate these pages on a larger piece of craft paper



## Part III: Optional Resources

# Identify Problems, Brainstorm Solutions

**WHAT**

What do I want to do that I feel like I can't do?

**WHY**

Why do I feel like I can't do it?

**HOW**

How can I modify or simplify this? What other strategies can I use?

**WHAT**

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**WHY**

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**HOW**

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# Setting Goals

Long-Term Goal:

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Short-Term Goal #3:

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Short-Term Goal #2:

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Short-Term Goal #1:

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# Tracking Your Progress

Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

Long-Term Goal: \_\_\_\_\_

**What did I do this week?**

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

**How do I feel?**

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

**What do I still need to do?**

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

**Any changes I'd like to make to my long-term goal?**

◦ **Yes:**

\_\_\_\_\_

◦ **No**

# Thank You!

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## But Wait, There's More!



Take a picture of the QR code above to access additional resources such as podcasts, movie + book recommendations, blog posts, and more! Or type in this link to your web browser: [linktr.ee/motivatepd](https://linktr.ee/motivatepd)



**Any questions or comments about this manual?**

Please e-mail Lani Silverstone at [lani.silverstone122@gmail.com](mailto:lani.silverstone122@gmail.com)

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