

WORKSHEETS

One of the most important things you can do to live well with Parkinson's is take action. This section will help you identify what you need, determine which steps to take and track your progress. Additional copies of any of these worksheets can also be downloaded and printed out at [dpf.org/worksheets](https://www.dpf.org/worksheets).

There are three different kinds of interactive tools to help you develop greater awareness of your needs, learn self-care approaches to address specific symptoms and organize your thoughts so you are better prepared to make the most of your appointments with the various specialists on your wellness team about your care:

1.  **Wellness and lifestyle self-assessments.** Designed to help you evaluate your needs, set priorities and take positive steps toward living well with Parkinson's. There are also worksheets to help you track your progress so that you can see the effects over time of changes you've made and set new goals for the future.
 - a. Parkinson's Care Questionnaire
 - b. Goal Summary for Doctor Visits
 - c. Daily Medication Log
 - d. Overall Medication Log
 - e. Wellness Self-Assessment
 - f. Pre-Exercise Self-Assessment
 - g. Exercise Journal
 - h. Nutrition Self-Assessment
 - i. Parkinson's Psychosis Self-Assessment
 - j. Deep Brain Stimulation (DBS) Self-Assessment
 - k. Our Relationship Self-Assessment
 - l. Parkinson's Home Safety Checklist
 - m. Parkinson's Travel Checklist

2.  **Symptom checklists.** These worksheets encourage you to become more aware of how and when symptoms are problematic, offering recommendations for simple things you can do to minimize and manage symptoms. Completing these worksheets will also help you organize your needs and concerns so that you can clearly communicate them to your wellness team.
 - a. My Symptoms Worksheet
 - b. Bladder Worksheet
 - c. Cognitive Wellness Worksheet

- d. Constipation Worksheet
 - e. Dental Worksheet
 - f. Dyskinesia and “Off” Time Log
 - g. Emotional Wellness: Anxiety
 - h. Emotional Wellness: Depression
 - i. Fatigue Worksheet
 - j. Gait, Balance and Freezing Worksheet
 - k. Insomnia and Sleep Worksheet
 - l. Low Blood Pressure and Dizziness Worksheet
 - m. Speech and Communication Worksheet
 - n. Swallowing Worksheet
 - o. Sexual Dysfunction Worksheet
3.  **Medical information snapshots.** These documents are intended to organize important information about you for your wellness team, including specialists such as a DBS programmer, dentist or a hospital wellness team. The “Medical Summary for Your Doctor Appointment” worksheet is a one-page document that organizes the most important information about you for your doctor’s appointment. The “Prepare for Your Hospital Stay” worksheet collects all your current and essential Parkinson’s information into a single document for the doctors, nurses and aides that will be caring for you during your stay.
- a. Clinical Appointments Summary
 - b. Current Symptoms Summary
 - c. Wellness Team Contact Information
 - d. Medical Providers
 - e. DBS Medical History
 - f. Prepare for Your Hospital Stay
 - g. Medical Summary for Your Doctor Appointment
 - h. Medical Summary for Dentists

For your convenience, all of these resources can be downloaded and printed out at [dpf.org/worksheets](https://www.dpf.org/worksheets). Print additional copies for your wellness team as well as care partner to use, as he or she might have different observations that are important to bring up at appointments.

PARKINSON'S CARE QUESTIONNAIRE

Name: _____ Age: _____

Date of Birth: _____

Healthcare Provider Name: _____

What are your goals for this appointment?

List your current or most bothersome problems or symptoms:

Did you make the changes recommended during your last visit?

Were your last treatment changes helpful? Explain: _____



 **List any new medical problems or allergies since your last visit:** _____

Do you experience dyskinesia? (circle one) Yes / No

Do your medications wear “off” or stop working? (circle one) Yes / No

If yes, on average how long does each dose last? _____ hours

Have you had any falls since your last visit? (circle one) Yes / No

List any changes in your living arrangements: _____

List prescription refills you need: _____

Circle any problems that you had in the past month related to each specific area:

Movement

Tremor

Stiffness

Slowness

Imbalance

Walking Problems

Frequent Falling

Movement Freezing

Involuntary Movements

Muscle Spasm/Cramping

Other (Explain): _____

EVERY VICTORY COUNTS _____

Speech/Swallowing/Gastrointestinal

Speech Changes	Swallowing Problems	Drooling
Pneumonia	Weight Loss	Weight Gain
Aspiration	Nausea	Vomiting
Abdominal Pain	Facial Masking	

Other (Explain): _____

Bowel or Bladder/Autonomic/Other

Bladder Problems	Constipation	Diarrhea
Chills/Sweats	Fatigue	Leg Swelling
Dizziness/Lightheadedness	Fainting or Loss of Consciousness	
Sexual Dysfunction		

Other (Explain): _____

Cognitive/Behavioral

Anxiety	Depression	Apathy
Sleep Problems	Daytime Sleepiness	Fatigue
Memory Loss	Confusion	Hallucinations
Paranoia	Delusions	Mania

Impulsive Spending, Sex or Gambling
Executive Function Difficulties (planning, decision-making, etc.)
Sudden, Uncontrolled Sleep “Attacks”

Other (Explain): _____

Other

Fever	Chills	Hearing Loss
Headache	Joint Pain	Back Pain
Neck Pain	Palpitations	Chest Pain
Cough	Hearing Loss	Vision Change
Numbness/Tingling	Driving Challenges	

List any other concerns or problems that you have: _____

GOAL SUMMARY FOR DOCTOR VISITS

The best way to improve your health is by being an active participant. Complete this form during and between each visit with your Parkinson's doctor or other healthcare professionals on your wellness team. Record your action steps and progress between visits. Review your results with your wellness team at each visit.

My goals for today's visit (date) ____ / ____ / ____ are:

1. _____

2. _____

3. _____

Action steps I will take to meet these goals are:

1. _____





2.

3.

Progress I have made toward these goals:

1.

2.

3.



 *Obstacles or areas for improvement needed to reach these goals are:*

1. _____

2. _____

3. _____

MAKE A FILE FOR COPIES OF THIS AND OTHER FORMS TO REFER BACK TO AS MARKERS OF YOUR TREATMENT OVER TIME.

WELLNESS SELF-ASSESSMENT

Complete this self-assessment after reading the **Living Well Now** section.

For each section below, record two areas you would like to improve and steps you will take for improvement. For instance, if you have not seen your primary care physician in the past year for a yearly physical, this can be listed with the action step to make an appointment within the next month.

Then, pick the top three items (from any category) you listed that you would like to achieve in the next month.

General Healthcare

Check if Priority Item

This section focuses on general health items, such as preventative health screenings and blood pressure management.

1. Area of concern _____
Actions to take _____
2. Area of concern _____
Actions to take _____

Parkinson's Self-Care

Check if Priority Item

This section focuses on preparing for your doctor's visits, emergency and hospital stays. It can also include taking the steps to take charge of your medications and learning about specialists who can be on your wellness team.

1. Area of concern _____
Actions to take _____
2. Area of concern _____
Actions to take _____

Physical Exercise

Check if Priority Item

This section focuses on participation in exercise programs, improving symptoms such as pain, balance, decreased stamina and pursuing physical therapy.

1. Area of concern _____

Actions to take _____

2. Area of concern _____

Actions to take _____

Diet and Nutrition

Check if Priority Item

This section focuses on changes you would like to make in your diet.

1. Area of concern _____

Actions to take _____

2. Area of concern _____

Actions to take _____

Emotional Health

Check if Priority Item

This section focuses on treatment of depression, anxiety, apathy, stress reduction, relaxation, social engagement and spiritual growth.

1. Area of concern _____

Actions to take _____

2. Area of concern _____

Actions to take _____

PRE-EXERCISE SELF-ASSESSMENT

Pre-exercise screening is a process allowing a doctor to review your medical and exercise history and assess risk factors that may impact your health and safety when engaging in an exercise program. If you are not exercising now and wish to begin, your primary care physician may call for pre-exercise testing, especially if you have heart or lung disease, high blood pressure or diabetes. With a neurological condition like Parkinson's, pre-exercise screening should be completed by a family doctor, clinical exercise specialist, clinical exercise physiologist or cardiologist.

Before starting a new exercise program, talk with your Parkinson's doctor about whether there are any safety concerns that specifically relate to your situation. This worksheet will allow you to assess both motor and non-motor symptoms that can impact your exercise. Although exercise is essential to living well with Parkinson's, it is important to consider and discuss with your doctor before you start or change your exercise routine.

Use the space below to check and describe symptoms or concerns you have related to exercise, as well as to record any recommendations from your wellness team about these concerns.

Motor Symptoms

- Dystonia (muscle spasms) worsens before, during or after exercise.

Concern: _____

Recommendation: _____

Ask your physical therapist to test your walking and balance and recommend exercises to include, as well as any to avoid.

- Exercise seems to worsen my dyskinesia.

Concern: _____

Recommendation: _____

Inform your doctor and discuss how to address your symptoms. You may be more prone to muscle tears during bouts of uncontrolled dyskinesia.

- I'm unsure whether I should exercise when I am in an "off" state.

Concern: _____

Recommendation: _____

If your medications wear "off," ask your doctor if you should avoid exercising when medications are not working well. Typically, stiffness, slowness and walking are worse when the medications are wearing "off," which can increase risk of injury.



Non-Motor Symptoms

- I have difficulty falling or staying asleep.

Concern: _____

Recommendation: _____

Sleep problems can be improved with regular exercise, although avoid exercising close to bedtime. If you're taking sleep medications, ask your doctor if your medications can be reduced if exercise improves your sleep problems.

- Exercise-induced fatigue is a problem for me.

Concern: _____

Recommendation: _____

If fatigue is limiting your exercise plans, talk to your primary care doctor. Fatigue has many causes and may require an in-depth discussion to determine how to treat it.

- If my anxiety or depression symptoms improve with exercise, should I change my medications?

Concern: _____

Recommendation: _____

Exercise can have positive effects on emotional wellness. Ask your doctor whether mood control medications are still necessary if you are experiencing improvements as a result of exercise.

- I feel tired during the day, making it difficult to exercise.

Concern: _____

Recommendation: _____

Ask your doctor about ways to improve daytime sleepiness so that you can be more ready for exercise. You might need to plan exercise around times of day when you feel most alert and refreshed, as well as consider timing and nutrition of meals and snacks.

- Overactive bladder limits my ability to exercise.

Concern: _____

Recommendation: _____

Talk to your doctor if overactive bladder is limiting participation in exercise. Ask about minimum and maximum fluid intake per day for optimal hydration.

- Could my medications influence my blood pressure while exercising?

Concern: _____

Recommendation: _____

Talk to your doctor about whether the combination of your medications and exercise could alter your blood pressure. You might need to exercise at specific times of day to avoid either very low or high blood pressure.

- I have low or fluctuating blood pressure.

Concern: _____

Recommendation: _____

Low or fluctuating blood pressure can get worse if the intensity of your exercise is too much, so you may need to avoid certain exercises. Ask your doctor if your blood pressure is a concern to address when making your exercise plans.

- I have attention or concentration difficulties.

Concern: _____

Recommendation: _____

You might want to avoid complicated exercises and work individually with a trainer who can supervise you and keep you on task. Ask your doctor or physical therapist to determine whether your exercise program should be supervised.

- I experience cognition problems (sometimes or often).

Concern: _____

Recommendation: _____

Talk to your doctor about whether your cognitive health limits your exercise choices. For instance, you might not be able to swim alone or might need to use a treadmill only with supervision for safety.

Exercise Readiness

- I want to start a new exercise program.

Concern: _____

Recommendation: _____

Ask your doctor for a referral to see a physical therapist before starting a new exercise program.



Describe your current level of activity:

- I exercise regularly.
- I don't exercise regularly, but my lifestyle is somewhat active.
- I'm mostly sedentary.

What do you do to exercise or to stay active?

How often do you engage in physical activity?

What fitness concerns do you have?

- I want to increase my stamina and endurance.

Activities I'd like to improve through increased cardiovascular fitness:

- I want to get stronger.

Activities I'd like to perform better through increased strength:

- I want to be more flexible.

Activities or mobility I'd like to improve through increased flexibility and balance:

Notes:

EXERCISE JOURNAL

Use this journal to record your daily exercise activity. Download and print additional copies at dpf.org/worksheets to help you keep track of your progress over time.

Week of: _____

DAY		CARDIOVASCULAR	STRETCHING	STRENGTHENING	OTHER
Sunday	Activity				
	Duration				
Monday	Activity				
	Duration				
Tuesday	Activity				
	Duration				
Wednesday	Activity				
	Duration				
Thursday	Activity				
	Duration				
Friday	Activity				
	Duration				
Saturday	Activity				
	Duration				
<i>Example</i>	Activity	<i>Walked outdoors</i>	<i>Seated stretches, standing stretches</i>	<i>10 lunges, 5 arm raises with 1 lb. weights</i>	<i>Took stairs to second floor office instead of using elevator</i>
	Duration	<i>20 minutes</i>	<i>10 minutes a.m., 10 minutes p.m.</i>	<i>15 minutes</i>	<i>—</i>

WORKSHEETS AND RESOURCES

NUTRITION SELF-ASSESSMENT

Complete this self-assessment to determine what changes you can make in your diet to improve your wellness. Following these general guidelines can help you feel your best and address some common Parkinson's symptoms, such as constipation, fatigue, weight fluctuations and even various cognitive challenges. Refer to the "Diet and Nutrition" chapter in the **Living Well Now** section for detailed explanations of the nutrition information highlighted here. Be sure to discuss with your doctor and wellness team before making major changes to your diet.

See how your current diet stacks up with the recommendations below. If you can't check all the boxes in the first section, plan for what actions you will take to improve your basic nutrition. Which additional suggestions for optimal nutrition can you incorporate into your diet? Take a trip to your grocery store, local farmer's market or natural foods market to explore the possibilities. Make a list of new foods and supplements you'll incorporate into your diet. Exploring new flavors and cuisines can be fun!

GENERAL GUIDELINES

Daily Recommendations for Basic Nutrition

- Take a general multivitamin with calcium, phosphorous, vitamin B and D.
- Drink at least eight cups of fluid per day, including when you take your medication for general health and to avoid low blood pressure and constipation.
- Select healthy snacks such as fruits, nuts, yogurt, oats, milk or soy.
- Avoid processed foods high in sugar, "bad fats," unwanted chemicals and additives. These foods actually rob you of energy.
- Choose fresh, local and organic products if you can. This will increase the freshness, level of nutrients and limit pesticides or unnecessary additives.
- Be sure to consume adequate protein. Ask your doctor how much protein is right for you each day and when to best consume protein if you experience interactions with your medications.
- Avoid fad diets and supplements in high doses.

Additional Suggestions for Optimal Nutrition

- Consuming antioxidants is essential brain and heart health. See below for suggestions on antioxidants to include in your diet.

EVERY VICTORY COUNTS

- ▶ Add omega-3s into your diet. Salmon, halibut, tuna, walnuts, almonds, ground flaxseed and fish oil tablets are good choices for omega-3s.
- Aim for 20–30 grams of fiber daily from fruits, vegetables and wheat products to help with digestion and constipation.
- Discuss with your doctor if you experience weight gain or weight loss. Some medical conditions can cause weight changes.
- Determine whether you are getting adequate levels of calcium and vitamin D, which are important supplements for bone strength.
- Consult the “Constipation Worksheet” and “Low Blood Pressure or Dizziness Worksheet” for more specific information tailored to these problems.

ANTIOXIDANTS

The following high-nutrient foods are also high in antioxidants thought to be helpful in maintaining brain and heart health:

Vitamin C: green vegetables, tomatoes, strawberries, broccoli, citrus fruits and juices, apple juice, potatoes, kiwi, green, red and yellow peppers

Vitamin E: whole grains including brown rice, green vegetables, nuts, seeds, vegetable oils, wheat germ, papayas, avocados, sweet potatoes and peanut butter

Vitamin A (Carotenoids): sweet potatoes, carrots, tomatoes, kale, collard greens, apricots, cantaloupe, peaches, pumpkin, broccoli and pink grapefruit

Selenium: eggs, garlic, chicken, fish, grains, wheat germ and bran, Brazil nuts, shellfish and beans

Lignans: flaxseed and oil (omega-3 fatty oils), rye, oatmeal and barley

Flavonoids: soy, dark chocolate (70% cacao), red grapes, cranberries, green or white tea and pomegranate

Lycopene: watermelon, pink grapefruit and tomatoes

Lutein: spinach, kale, broccoli, kiwi, Brussels sprouts and other dark green vegetables

Recommended foods that are rich in antioxidants and offer other health benefits:

- Ground flaxseed (provides fiber, omega-3 fatty acids and lignan)
- Salmon (provides omega-3 fatty acids and selenium)
- Soy products (provide protein and good source of all the essential amino acids, calcium, zinc, iron, magnesium, phosphorus, omega-3 fatty acids, fiber and B vitamins)

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- Whole grains (provide B vitamins, vitamin E, iron and magnesium)
- Berries (provide vitamin C, folate, fiber and high antioxidant properties)
- Green vegetables (provide vitamin A and C, calcium and iron)

CoEnzyme Q10: A 2014 study did not show added benefit when used early in Parkinson's. However, CoQ10 has not been shown to be harmful. Discuss with your doctor before adding this supplement to your diet.

Antioxidant supplements are also available, but should not be used in place of a healthy diet. Speak with your doctor about appropriate choices and brands when taken into consideration with your current medications.

Make a list of items you will add to your regular diet:

- | | |
|----------|-----------|
| 1. _____ | 6. _____ |
| 2. _____ | 7. _____ |
| 3. _____ | 8. _____ |
| 4. _____ | 9. _____ |
| 5. _____ | 10. _____ |

PARKINSON'S PSYCHOSIS

SELF-ASSESSMENT

Sometimes Parkinson's itself or side effects of medications can change your perception of reality, resulting in Parkinson's psychosis. Parkinson's psychosis typically takes the form of hallucinations (experiencing things visually or otherwise that are not really there), delusions (a false belief or impression that you hold to firmly, even though it is irrational or illogical) or both. Some people are aware what they are experiencing is not actually real, while others are not.

Review the statements below together with your care partner and discuss with your doctor if you are experiencing any of the following:

For People Living with Parkinson's

- I've seen, heard or smelled things, such as people, animals or objects, that weren't actually there.
- I've had experiences, such as the vivid sensation of someone in the room with me or a brief vision of movement, when there was nothing actually there.
- I've looked at something and seen it appear briefly as something else. For example, words on a page appearing as insects.
- I've had beliefs or fears, such as my loved one abandoning me, being unfaithful or stealing from me.

For Care Partners and Family Members

- My loved one has seen things, heard things or felt things that weren't actually there.
- My loved one has experienced any false beliefs toward me or others, such as believing someone is stealing from them or that I'm being unfaithful.
- These false beliefs or visualizations have affected our daily lives.

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WORKSHEETS AND RESOURCES

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DEEP BRAIN STIMULATION (DBS) SELF-ASSESSMENT

DEFINING AND ASSESSING EXPECTATIONS

One of the most important discussions you can have with your doctor and your family before considering or undergoing DBS surgery is about defining realistic expectations. You should ask your doctor about how DBS will change **your** symptoms and motor function, not just about how DBS can help Parkinson's symptoms in general. Setting appropriate expectations before surgery can help pave the way for greater satisfaction with results in the many years that follow. Complete this self-assessment and use it to guide the discussion with your doctor and family.

What Parkinson's symptoms do you expect to be improved by DBS in order for you to be satisfied with the procedure outcome?

- | | |
|----------|----------|
| 1. _____ | 4. _____ |
| 2. _____ | 5. _____ |
| 3. _____ | 6. _____ |

Considering all your Parkinson's symptoms, place them in the appropriate categories below:

Symptoms That Improve with Medication
(most likely to respond to DBS)

Symptoms That Do Not Improve with Medication
(not likely to respond to DBS)

Other Bothersome Symptoms Not Listed
(discuss further with your doctor)



▶ The symptoms that respond favorably to Parkinson’s medications typically respond well to deep brain stimulation, with tremor being the exception. Even if tremor does not respond well to medications, it will typically respond well to stimulation. Stiffness, slowness, posture, gait shuffling and tremor generally improve noticeably with stimulation. People who have DBS typically experience more “on” time and less dyskinesia and “off” time, once the stimulation settings have been optimized.

Completing this worksheet can help guide you through the important process of determining whether DBS may be appropriate for you. Although each individual experiences varying symptoms and severity, understanding how your symptoms may or may not be managed by DBS is a key factor in determining whether or not you are a candidate for the surgery and whether the benefits you can reasonably expect merit undergoing the procedure.

Other questions to think about and to discuss with your doctor:

1. Do my Parkinson’s symptoms bother me enough to undergo brain surgery?
2. Do I understand the risks associated with the surgical implantation of the hardware?
3. Have I asked the surgeon about his/her specific rates of surgical complications?
4. Are my expectations reasonable enough to proceed with a DBS work-up?
5. Do I have any medical conditions that increase my risks of complications during DBS surgery?
6. Do I have adequate access to medical professionals that can adjust the stimulation settings once I have the implantation (helping with my maintenance over time)?
7. Are there any medical, environmental or exercise considerations after DBS?
8. How long will the implanted neurostimulator last?
9. How long will I need to take off work?
10. How long will I be restricted from driving?
11. What is the process leading up to surgery like?
12. What can I expect during the surgery?
13. What can I expect after surgery?

OUR RELATIONSHIP SELF-ASSESSMENT

Parkinson's can affect many of your relationships, especially with your partner. Communication is crucial: make time to talk openly and honestly with your partner about your relationship. Questions to consider as you have a candid conversation with your partner include:

What has changed in our relationship that we are reluctant to discuss?

What could I do to make the relationship stronger?

What am I doing that is causing unnecessary stress on the relationship?

What is working well?

What needs more attention?

Could we meet with a specialist for guidance?

EVERY VICTORY COUNTS

PARKINSON'S HOME SAFETY CHECKLIST

We frequently ask people with Parkinson's, occupational therapists, physical therapists and care partners some of the most instrumental changes people with Parkinson's can make to their home. We then put all the information we gathered together and created this checklist as a great starting point to help make your home a great place to live comfortably with Parkinson's. Sometimes the smallest changes can make the biggest difference when it comes to living well.

General Safety Guidelines

Implement these updates everywhere in the house.

- Decrease clutter. Place furniture so that you have wide walkways and can move around easily. Decreasing clutter in your physical space not only reduces tripping hazards but can also reduce freezing and mental clutter, allowing for greater focus and calm.
- Install lever handle door knobs instead of circular knobs for easier opening.
- Install grab bars throughout your home. (If possible, seek advice from an occupational therapist (OT) on proper placement first.)
- Make sure chairs in the house are stable (not on wheels), have arm rests and are the adequate seat height to make standing up and sitting down easier. (Your feet should be able to touch the floor and your legs and hips at about a 90 degree angle so you can stand easily.) Avoid purchasing sofas and arm chairs that are soft and low as they are difficult to get up from.
- If using a wheelchair or walker, always lock brakes after each use.
- Arrange your furniture to avoid multiple turns or maneuvers to access areas used every day as this is where you are most likely to fall.
- Be sure a communication system is in place and easily accessible in every room and hallway that you use. (This could be a phone, alarm button or medical alert necklace or bracelet.) This is important for people who are in the later stages of Parkinson's.
- Give 2-3 trusted individuals keys to your home in case you need them to come by, and let each of them know who is on your trusted list. Compile their contact information and share with each person if they're comfortable with that. Or use a lockbox and key, garage door remote code or a smart lock so you can offer people easy access to your home.
- Consider a doorbell that offers a camera view so you can see who is at the door.

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- Place the File of Life ([folife.org](https://www.folife.org)) notice outside your house and the information on the side of your refrigerator so that first responders can access it quickly and respect your wishes.
 - Consider getting a service dog that can help you with freezing of gait at home and elsewhere.
 - Consider in-home exercise equipment for exercise solutions in bad weather. Exercise can improve gait, movement and mental capacity throughout the day—even short bouts of 10-15 minutes can be helpful.
 - If you exercise at home, make sure you have plenty of space to do your exercises.
 - Request a visit from a physical therapist (PT) or occupational therapist (OT) who knows the ins and out of Parkinson's to address your needs and offer solutions.
 - Utilize voice activated music devices (Alexa, Google Home, etc.) to assist with ungluing from a freeze.
 - Be sure to remove or lock up all guns or other dangerous items so they are out of easy reach if you are experiencing hallucinations or delusions.

Lighting & Electrical Outlets

- Place lights so they are easily accessible.
- Make sure hallways and stairways are well-lit and use extra lighting to reduce shadows on steps.
- Use contrasting colors on light switch plates or get lighted switch plates to make finding switches easy in the dark.
- Put night lights in hallways between bedrooms and bathrooms.
- Get lamps that you can turn on with one touch or with sound.
- If possible, install all electrical outlets about waist high so you don't have to bend down to access them. If not practical, use power strips that are placed within easy reach.
- Put all electrical, extension and telephone cords out of the flow of foot traffic to reduce tripping hazards.

Floors

- Consider installing hardwood flooring and tile throughout your house. If you redo your floors, consider flooring that includes horizontal lines or contrasting grout colors to help with freezing.
- 

EVERY VICTORY COUNTS

- ▶ Change the paint color in rooms to lighter colors. It can give the illusion of more space and assist with freezing.
- Eliminate abrupt changes in surfaces (i.e. carpet to hardwood) because they can be a tripping hazard.
- Ensure there are handrails on both sides of all stairways (or areas with multiple steps) that run the full length of the stairs. Cueing may be needed to use the railing consistently.

Entryway & Stairs

- Install light switches (or motion sensors) at the top and bottom of the stairs and at every entryway.
- Put a piece of easy-to-see tape at the edge of each step to help with depth perception.
- Avoid distractions such as carrying on a conversation or carrying multiple objects while going up or down the stairs. Always keep one hand free to use the rail.
- Use painter's tape to mark proper foot placement for routine tasks or to guide foot placement through doorways and around corners that might otherwise cause freezing.

Bedrooms

- Make sure you can touch your feet to the floor when seated on your bed to make it easier to get in and out.
- Consider installing a side rail, a sturdy bedside table or a rope above the bed to assist with rolling and getting up.
- Put a bedside commode next to the bed. This is ideal if you struggle to move easily upon waking.
- Always have a bottle of water at the bedside to assist in raising your blood pressure in the morning if needed.
- Securely place blocks, bricks or other objects under the bed to slightly elevate the head of the bed and decrease the angle necessary to get out of the bed. This potentially decreases large drops in blood pressure with change in position from supine to sitting if you have neurogenic orthostatic hypotension (nOH).
- If you have REM Sleep Behavior Disorder, reduce safety hazards (secure bedside lamps, lock up any weapons, remove clutter) in case you act your dreams out at night or fall out of bed. (Consider sleeping in separate beds.)
- Consider putting a motion sensor in the bedroom with an alarm or light activation to alert your spouse if you get up in the middle of the night.

- 
- Consider using a satin sheet for your bottom sheet to make it easier to roll over.
 - Make the bed with loose and light sheets that can be taken off or layered depending on the temperature. (No heating blankets.) Or, just use a light down comforter instead of sheets and blankets to reduce the chance of getting caught up in multiple sheets.
 - Place a flashlight in the nightstand or within easy reach in case your power goes out.
 - Keep a telephone within easy reach of the bed.

Bathrooms

- Install grab bars near the toilet, tub and in the shower. (If possible, get help from a PT or OT on proper placement.)
- Ensure your toilet is at comfort height to make it easier to get up and down. (You can get a riser if you don't want to replace your toilet.)
- Install a stable, purpose-made seat or bench in your shower.
- Make sure all bathtubs, showers floors and exits from shower are non-slip. (Use aqua socks in public showers.)
- Install faucets that turn on and off with one touch.
- Make sure water temperature is consistent and not too hot.
- Make sure there is a phone or life alert button within easy reach of the shower, tub and toilet in case of an emergency. (Better yet, consider using a waterproof med alert device such as Revolar in the shower or tub.)

Kitchen

- Install faucets that turn on and off with one touch and can do hot/cold with one hand.
- Consider appliances that automatically turn off after a certain length of time in case you forget.
- Put frequently used items in easy to access locations so you don't have to bend or reach to get them. (No step stools or ladders!)
- Create prep stations with all of the supplies for a task within easy reach of the work space (i.e., a coffee station).
- Consider trading your ceramic and glass dishes for those made with melamine, a more durable substance that rarely breaks when dropped.

- ▶ Swap out large trash cans for smaller ones or ones with wheels to make it easier to take out the trash.
- Try “flicking fingers” periodically to help with tremor when performing kitchen tasks and eating.
- Purchase convenience foods that are pre-cut and washed to save time and limit the need to use sharp knives.
- Make opening jars easier by using a one-touch automatic jar opener.
- Use non-slip rubber matting to stabilize cutting boards, mixing bowls or dinnerware.

PARKINSON'S TRAVEL CHECKLIST

For the average person, traveling is a minor frustration. Security lines, delays, crowded airports and cramped and long lines at snack shops and restaurants are par for the course. However, if you're living with Parkinson's, those things aren't just frustrations, they can be so troublesome and aggravating to deal with that you choose to stay at home.

That's why we decided to reach out to our Davis Phinney Foundation Ambassadors, many of whom are avid travelers, to get their best tips for traveling with Parkinson's.

Planning

- Travel by train rather than plane when possible. Trains have more leg room and no TSA.
- Allow time for transfers when purchasing tickets. Changing planes or trains takes longer than you expect.
- Travel when you're at your best. For example, travel in the morning if that's when your medications offer the most symptom relief.
- Make packing lists and save them. You might have different lists for road trips, weekend getaways and international trips. Update your lists each time you travel.
- Pack early but check the weather right before you leave in case you need to adjust what you bring.
- Put all paperwork in an easy-access location. Consider including an emergency contact list with information about your medical providers and caregivers.
- Arrive at the airport early.

Medication Management

- Bring more than you need and know how to get more in a pinch.
- Store your medications in more than one location, including carry-on bags or on you if possible. Ask a travel partner to carry an extra dose.
- Set timers or alarms that remind you to take them on schedule.
- Plan a consistent schedule for taking your medication. For example, if you're going through multiple time zones, take your meds every four hours rather than at 1:00 and 5:00.
- Always carry a list of your medications with you and be ready to show them if asked. Be sure at least one set of your prescriptions are in Rx bottles with labels.

EVERY VICTORY COUNTS

- Get a letter from your doctor for liquid medications. TSA allows liquid medications above 3oz, but only with clear documentation. Keep these in your carry-on; not checked luggage.

Getting Around

- Carry a cane or walking stick, even if you think you don't need it. Stress often makes Parkinson's symptoms worse, and travel is stressful.
- Arrange for a wheelchair to get through the airport, which helps in crowds and unfamiliar places.
- Ask for help if you need it. If help is offered, take it. This includes having someone carry your bags, taking advantage of extra time allowed for boarding, having someone get food for you, etc.
- Take a disposable plastic grocery bag with you so you can sit on it on the plane. Plastic reduces friction which makes it much easier to get out of your chair.
- Practice getting in and out of your airplane seat (or any seat) before you go.

Communication

- Communicate clearly and frequently. "Nobody can read our cue cards so it's our job to let them know what's up." —Kathleen Kiddo
- Consider wearing or traveling with a card that says, "I've got Parkinson's and I need a bit more time and space. Thank you."

Clothes

- Pack light. You can usually find anything you forgot at your destination.
- Travel in comfortable clothing that's easy to get on and off in bathrooms.
- Wear knee-high compression socks for car and air travel to promote blood flow and reduce swelling.
- Bring a change of clothes in your carry-on bag.

Sleep and Rest

- Slow down and avoid overscheduling. Prioritize activities that are most important and conserve energy so you have it when it matters most.
- Time your travel so you can rest when you arrive at your destination. For travel with significant time change, take a 1-2 hour nap upon arrival. Assimilate into the routine of the time zone as soon as possible.

- 
- Bring a sleep mask and earplugs, and maybe an inflatable neck pillow for additional comfort.
 - Let your travel companion(s) know when you're too tired to do certain activities. Rest is important.

Food & Drink

- Keep food items at the ready to separate them at security.
- Fill your water bottle after security and between flights.
- Bring more snacks than you think you'll need on the plane in case of delay.

Exercise

- Stand up to stretch every 30-45 minutes while in transport.
- Consider bringing a jump rope for simple, light, portable, aerobic exercise.
- Continue practicing the activities that make you feel well whenever possible. Maintaining routine is important during vacation and for when you return home.

Miscellaneous

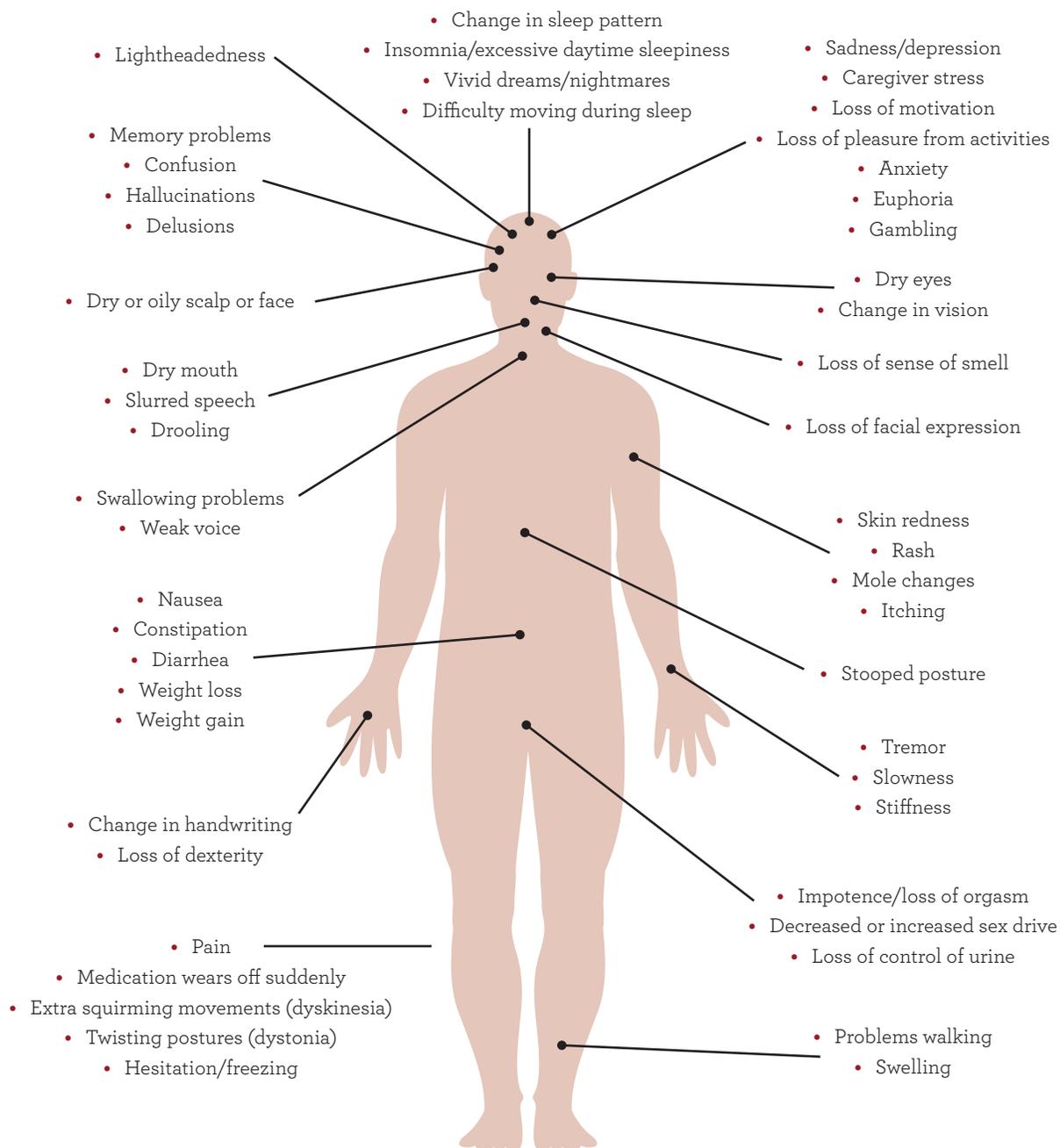
- Label loose objects with your name and cell number.
- Get a handicap placard.
- Check out the local Parkinson's offerings wherever you're travelling. If they don't have new skills to offer you, maybe you have skills to offer them.
- If you have DBS, bring the device wallet card from Medtronic (or alternate company). Security may ask for it. Tell them it's a "medical device" or say you have a pacemaker rather than explaining DBS. You can't go through the old-style security check machines or let them use wands to check you. Be prepared for a pat down.
- Travel with people who know you and can help with the unpredictability of Parkinson's.
- Maintain a sense of humor. Travel is difficult, but you'll get where you need to go eventually. "If you like to travel, then it's part of your living fully with Parkinson's."
—Jill Ater

EVERY VICTORY COUNTS

✓ MY SYMPTOMS WORKSHEET

Use this body map to circle symptoms or problem areas that you would like to discuss with your doctor or other member of your wellness team. While most of these are symptoms of Parkinson's itself, some are side effects of Parkinson's medications. On the next page, indicate how bothersome each symptom is for you.

Bring the worksheet to discuss with your doctor at your next appointment.



WORKSHEETS AND RESOURCES

Rate how each symptom or area of daily life bothers you by circling a number on a scale from 0 to 5.

0 = No Problem or No Concern

5 = Severe Problem or Biggest Concern

Anxiety	0	1	2	3	4	5
Bathing, Dressing	0	1	2	3	4	5
Bladder Problems	0	1	2	3	4	5
Chest Pain or Palpitations	0	1	2	3	4	5
Chills	0	1	2	3	4	5
Constipation	0	1	2	3	4	5
Cough or Sore Throat	0	1	2	3	4	5
Delusions	0	1	2	3	4	5
Depression	0	1	2	3	4	5
Double or Blurred Vision	0	1	2	3	4	5
Dyskinesia	0	1	2	3	4	5
Falls	0	1	2	3	4	5
Fatigue	0	1	2	3	4	5
Fine Motor Movement, like folding clothes or opening mail	0	1	2	3	4	5
Freezing	0	1	2	3	4	5
Hallucinations	0	1	2	3	4	5
Headache	0	1	2	3	4	5
Hearing Loss	0	1	2	3	4	5
Heartburn or Upset Stomach	0	1	2	3	4	5
Impulsivity	0	1	2	3	4	5
Joint Pain	0	1	2	3	4	5
Leg Swelling	0	1	2	3	4	5
Lightheadedness	0	1	2	3	4	5
Motivation	0	1	2	3	4	5

EVERY VICTORY COUNTS

0 = No Problem or No Concern

5 = Severe Problem or Biggest Concern

Muscle Spasm	0	1	2	3	4	5
Nausea/Vomiting	0	1	2	3	4	5
“Off” Time	0	1	2	3	4	5
Pain	0	1	2	3	4	5
Rash or Bruising	0	1	2	3	4	5
Rigidity	0	1	2	3	4	5
Seizures	0	1	2	3	4	5
Sexual Function	0	1	2	3	4	5
Sleep	0	1	2	3	4	5
Slowness of Movement	0	1	2	3	4	5
Speech	0	1	2	3	4	5
Swallowing	0	1	2	3	4	5
Sweating	0	1	2	3	4	5
Thinking	0	1	2	3	4	5
Tremor	0	1	2	3	4	5
Walking	0	1	2	3	4	5
Writing	0	1	2	3	4	5

BLADDER WORKSHEET

Bladder problems can occur as a result of how Parkinson's affects the nerves that control emptying the bladder. This can lead to an overactive bladder in people living with Parkinson's, and/or incontinence, the accidental or involuntary loss of control of urine or bowel movements. This can range from occasional minor leakage to complete loss of control of urine or bowel movements. Review this worksheet for ideas of changes you can make to improve bladder problems, checking those you can implement right now.

Dietary Changes

- Drink fluids for general health, but limit after 5:00 p.m. if you urinate frequently at night.

Lifestyle Changes

- Wear pads to reduce stress, anxiety and increase your freedom to go out.
- Be safe. Talk with an occupational therapist about safety measures to take at home, such as grab bars in the bathroom, night lights to illuminate your path at night, a bedside commode or urinals when appropriate.

Treatments

- See your doctor about abrupt changes in bladder control, since this could signal a bladder infection. Also, an abrupt decline in movement or thinking functions can be the first sign of a bladder infection.
- Physical therapy can help with pelvic floor exercises to improve incontinence.
- Occupational therapy can help with bladder therapy, bathroom and hygiene, as well as offer many safety techniques to reduce falls.
- Review bladder control with your doctor. Certain medical conditions affect bladder control. Some medications cause muscle weakness and can therefore weaken bladder control.
- A urologist can help if incontinence continues despite treatment.
- Be sure to tell your doctor if you have memory or thinking problems, as certain bladder control medications can worsen memory.

EVERY VICTORY COUNTS

COGNITIVE WELLNESS WORKSHEET

Thinking and processing can be improved in many enjoyable ways. Brain games, physical activity and social engagement all boost your brain health, which leads to increased cognitive wellness. Visit your community center, senior center or local community college to see what programs are available to you and your family. Many libraries, universities, school districts and online outlets also offer adult learning programs covering a wide range of interests. You can also ask your healthcare provider for a referral to an occupational, recreational, art, music or physical therapist for more focused cognitive wellness programs.

Make the commitment to schedule activities that challenge your brain into your routine. Choose things and people you enjoy, pace yourself and remember to have fun.

Increase Physical Activity

- Consult with a physical therapist to develop the best, safest exercise program for you.
- Exercise three to five times a week. Personal trainers can motivate and help you stick to your routine.
- Don't exercise alone: involve your family or a buddy, walk in the park, go to a group exercise class. Getting to know others in exercise classes can provide a sense of connection and accountability to go.
- Yoga and tai chi give extra benefits of relaxation and improve balance.
- Dance and music add fun, joy and allow creative expression.

Flex Your “Thinking Muscles”

- Read or listen to documentaries, and/or books on tape.
- Do brain teasers, such as video games, word games, sudoku or puzzles.
- Play cards. Bridge, poker, euchre or solitaire are some examples.

Engage Socially and Creatively

- Attend support groups.
- Take an art, music, drama, crafting or dancing class.
- Attend a poetry or book group.
- Join or organize your own coffee hour, dinner group or movie night.

CONSTIPATION WORKSHEET

Digestive health and specific problems, like constipation, can be improved through dietary and lifestyle changes. Check the items listed on this worksheet to indicate actions you can take to improve your constipation. Discuss any problems that may persist with your doctor.

Dietary Changes

- Drink at least eight cups of fluid per day.
- Be sure you are eating 20–30 grams of fiber per day. Good examples are prunes, pears, nuts, grains, ground flaxseed and bran.
- Eat a well-balanced diet with plenty of fruits, vegetables, multigrain breads and cereals. Eat smaller meals several times per day, rather than three large meals.
- Avoid high-sugar foods and snacks.
- Choose high-fiber bread (>5 grams fiber) instead of refined white or wheat bread.
- Try homeopathic herbal teas blended to help relieve constipation.
- Try drinking a caffeinated warm beverages with earlier meals, but avoid carbonated beverages if bloating is a problem.

Lifestyle Changes

- Exercise! At least take a walk daily, if possible. A physical therapist can help you get started with an exercise routine that's right for you.
- Try to maintain good posture while doing cardio or strengthening exercises.

Medication Recommendations

(Note: talk to your doctor before beginning)

- Stool softeners once or twice a day can help. You can also try a stool softener with a stimulant if you experience moderate to severe constipation.
- Glycolax powder (like Miralax) can be purchased over the counter and is very effective, has few side effects and can be used daily if needed.
- Consider taking once-a-day supplements, such as fish oil, flaxseed oil or magnesium.
- Avoid excessive use of fiber supplements such as Metamucil or Citrucel as they can sometimes worsen constipation and lead to obstruction.

EVERY VICTORY COUNTS

► Other Treatment

- Ask your doctor about medications you may be taking that can worsen constipation, such as amantadine, amitriptyline and sedatives.
- Consider seeing a gastroenterologist, a specialist who treats constipation.
- Occupational therapy can help establish a bowel routine or regimen.
- Ask your doctor for a nutrition consult if you need more help with dietary changes.

DENTAL WORKSHEET

Dental care is an integral part of living well with Parkinson's. Regular dental care can minimize your risk of experiencing pain and discomfort, but most importantly, it can reduce the risk of infection, which can be a significant stressor on the body when coupled with Parkinson's-related challenges.

Dietary Changes

- Choose a nutritious snack between meals like cheese, milk, plain yogurt, fruits, vegetables or nuts. Sugary snacks (like candy), soda and sticky food (like dried fruits) can put you at risk for cavities and other oral health problems.
- Citrus fruits and other acidic foods (like oranges, tomatoes and red meat) should be eaten as *part* of a meal instead of separately, since the acidity of these foods can have a negative effect on tooth enamel.
- Talk with your primary care physician about including cheese, milk, calcium-fortified tofu, leafy greens, almonds, meat, poultry, fish and eggs in meals. These have high calcium, nutrient and phosphorus levels and may assist in dental health but prevent medication absorption.
- Drink your daily intake of fluids to avoid dehydration and dry mouth.

Lifestyle Changes

- Schedule tooth brushing around medication "on" times.
- Replace your toothbrush or toothbrush bristles every 3-4 months, after you've been sick or when it starts to show signs of wear such as frayed bristles.
- Brush your teeth three times a day or after each meal for two minutes to remove sugars and food particles from your teeth.
- Floss daily. Instruments like a flossing proxy brush can help ease the process, or a care partner can assist.
- Use moisturizing mouth spray, non-alcohol based mouthwash, a fluoride rinse or oral swab brushes daily if you experience dry mouth or inflammation (common Parkinson's medication side effects).
- Use a wide handle toothbrush or add an adaptive device to facilitate easier grip on the toothbrush handle.
- Consider an electric, ultrasonic or specialty toothbrush to maximize brushing benefits.

EVERY VICTORY COUNTS

- ▶ Ask your dentist about using a biteguard if you have bruxism (grinding of teeth).
- Ask your dentist about prescription strength, topical stannous fluoride gel treatments and toothpastes, as these can be good preventative strategies.

Treatments

- Visit your dentist every 6 months for regular, short (45 minutes or less) check-ups.
- Complete the “Daily Medication Log” in this section, and bring it to your dental visit to address important risks of medication interactions during your dental appointment. Anesthesia and novocaine can cause increased sedation, imbalance or confusion.
- Schedule your appointments during your medications “on” time and when your dyskinesia is not generally bothersome.
- Ask to keep the dentist chair 45° incline or higher to enable comfortable swallowing.
- Request frequent suctioning to assist with saliva production and muscle weakness.
- Have your dentist or care partner assist you in and out of the dental chair to reduce the risk of a fall.
- Include your dentist in your wellness team, making sure they have an understanding of how Parkinson’s disease may affect your oral health.
- Collaborate with your dentist to determine a signal for discomfort; for example, put your hand up to signal you need a break or are having trouble swallowing.

Name: _____ Date: _____

- In the Medications row, place an **X** under the hour that you took your medicine; draw a line through the hours that you are asleep.
- In the Dyskinesia row, indicate the severity by entering the correct number. Use the guide below to determine which number is appropriate.
 - 0 = *No extra movement*
 - 1 = *Mild extra movement*
 - 2 = *Moderate movement*
 - 3 = *Severe disabling movement*
- In the “Off” row, indicate if you felt that your medicine is not working using the following guide.
 - 0 = *Feeling no symptoms*
 - 1 = *Mild tremor, stiffness or slowness without disability*
 - 2 = *Moderate tremor, stiffness or slowness, possibly requiring assistance*
 - 3 = *Severe tremor, stiffness or slowness requiring total assistance*

	am						pm						am											
TIME	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5
1. Medications (Place an X at the time of your dose)																								
2. Dyskinesia (See scale above)																								
3. “Off” (See scale above)																								

Keep this diary 3 days before your appointment and bring it with you.

EMOTIONAL WELLNESS: ANXIETY

Identify Triggers

- Keep a diary to identify triggers that worsen anxiety.

Some triggers I've identified are: _____

- Record times when anxiety is worse. For instance, anxiety can increase when medications wear "off."

I've noticed my anxiety is worse when: _____

Address Your Anxiety

- Talk with your doctor about treatment that can include medicine, relaxation techniques, counseling, mindfulness and coping strategies.
- Learn to breathe. Simple exercises consisting of 10-20 slow, steady deep breaths can be calming.

Reduce Stimulants

Avoid nicotine, diet or energy pills and caffeine.

Substance	Current Use	Goal for Reducing
Nicotine	_____ x week	_____ x week
Energy pills/drinks	_____ x week	_____ x week
Diet pills	_____ x week	_____ x week
Caffeine	_____ x week	_____ x week

Implement Relaxation Techniques

- Try breathing exercises, guided imagery, biofeedback, meditation or prayer. Many community, recreation and senior centers offer meditation or yoga classes. There are also many good books from which you can learn more about these techniques.
- Plan relaxation breaks during the day. Take a moment to take a breathe deeply, slowly inhaling and exhaling 10 times to prevent an anxiety attack (or to calm one in progress).
- Use soft or meditative music, or guided meditation or yoga videos to help you relax. Establish a quiet space at home for relaxation. Try using aromatherapy, soft lighting and soothing surroundings to help you relax.



WORKSHEETS AND RESOURCES



Change Your Habits

- Avoid taking on too many tasks or always saying “yes.” Maintain a routine, and prioritize chores and commitments by making lists. An occupational therapist can help with this.
- Exercise to help relieve tension. Gentle stretching helps relax the face, shoulders and back. Try yoga or tai chi.
- Talk about your feelings of stress or anxiety with loved ones. Consider sharing your observations about what triggers these feelings, and talk about how they can support your efforts to reduce stress and anxiety in your life.
- Take a moment for yourself. Try a soothing cup of tea; chamomile, lemon balm or valerian root may have anxiety-fighting benefits for some people.

EMOTIONAL WELLNESS: DEPRESSION

Identify Triggers

- Keep a diary to identify triggers or thoughts that worsen your mood. Record times when depression is worse. For instance, depression can worsen when medications wear “off.”

Some triggers I've identified are: _____

Address Depression

- Talk with your doctor about treatment. This can include medicine (such as antidepressants), counseling, cognitive behavioral therapy or relaxation techniques.
- Obtain a general medical examination. Some medications, thyroid disease, heart disease and illness can cause or worsen depression.
- Explore light therapy if you suffer from seasonal/winter depression.
- If you are currently taking antidepressants, closely monitor with your doctor. Some studies have found that antidepressants may exacerbate other Parkinson's symptoms.

Add Positive Energy

- Spend five minutes a day thinking about or visualizing life's pleasures or what you are grateful for, such as family, grandchildren, pets.
- Spend time to reflect on the beauty of the natural world around you.
- Volunteer. It can be uplifting and rewarding.
- Laugh with others. Watch comedies. Children and pets bring a smile.
- Dance, paint, sing, share memories with others around you.

Change Your Habits

- Eat a well-balanced diet. Consult the “Nutrition Self-Assessment” in this section for more ideas of how to improve your diet.
- Take medications as prescribed.
- Tend to sleep habits. Consult both the “Fatigue Worksheet” and the “Insomnia and Sleep Worksheet” in this section for tips to improve your sleep hygiene.

WORKSHEETS AND RESOURCES

Be Connected

- Attend classes, support groups, call a friend, join a positive chat group or a buddy program.
- Attend to your spiritual needs.

FATIGUE WORKSHEET

Complete this worksheet to determine if certain times of day or activities trigger your fatigue. Record observations you have about when you feel fatigued and what other things are happening when you do, and check the actions you can take right now to improve your energy.

I feel fatigued most often:

- Early morning
- Late morning
- Early afternoon
- Late afternoon
- Evening

My mood or emotional state seems to make me feel more fatigued.

How often does this occur? _____

Other situations I've noticed make me feel fatigued: _____

Lifestyle Changes

- Exercise to improve strength and endurance. This improves mood and reduces the energy required to do daily activities.
- Exercise when you feel good, such as when the effects of your medications are at their best. Pace yourself, though. Don't overdo it.
- Pay attention to your sleep habits. Use short naps (between 10 and 20 minutes) during the day, if needed. However, limit naps. Sleeping excessively during the day can actually increase your sleepiness and fatigue, as well as make it more difficult to sleep at night.
- Avoid post-lunch fatigue by keeping your mind active with games, puzzles or hobbies or taking a walk outside.



Dietary Changes

- Eat small, frequent meals instead of big, heavy meals. Don't skip breakfast. Be sure to get plenty of fluids.
- Snack on high-energy foods such as apples, oranges, pears, yogurt, walnuts, almonds, oats and whole-grain products. Avoid processed, high-sugar foods which can rob you of your energy.
- Caffeine can be helpful for midday fatigue or sleepiness if permitted by your doctor. Avoid caffeine after 3:00 p.m.
- See general dietary guidelines in the "Nutrition Self-Assessment" and in the "Diet and Nutrition" chapter in the **Living Well Now** section.

Treatment

- Take Parkinson's medications on time to avoid wearing "off."
- Avoid energy pills!
- See your doctor for a checkup. Anemia, malnutrition, sleep apnea, depression, thyroid and vitamin deficiencies can cause fatigue. Review your medications (prescription and over-the-counter) as some can cause fatigue and worsen daytime sleepiness.
- See an occupational therapist for energy conservation techniques and physical therapist or personal trainer for exercise guidance.
- Refer to the **Living Well Now** section for helpful tips on sleep, anxiety and depression. These are all problems that can reduce your energy levels.

GAIT, BALANCE AND FREEZING WORKSHEET

Many of the main motor symptoms of Parkinson’s—tremor, rigidity, stiffness and postural instability—can cause difficulties with walking and balance. Freezing, problems initiating movements that often results in feeling like your feet are glued to the floor, is especially common in the later stages of Parkinson’s. This worksheet provides ideas to help improve gait and balance and to manage freezing. Check the options you can begin to implement right now and be sure to discuss any continuing challenges with your doctor and wellness team.

Physical Exercise and Training

- Perform balance exercises every day, even before you think you need them. Consider it part of your routine, like brushing your teeth. Balance is critical for walking. You can always improve your balance, even if it seems perfect right now! For more specific balance exercises, see the “Balancing Life, Exercise and Function for Optimal Health” article in the “Complementary Therapies” chapter of the **Living Well Now** section.
- Exercise daily. Include stretching, strengthening and exercises to help you get out of a chair, stand straighter and walk farther.
- See a physical therapist who specializes in movement disorders to develop a home exercise program, even if you have one. Ask your PT when you should be re-evaluated. Do not wait for your doctor to initiate it – you can ask for it. See the “Why Exercise Matters” chapter in the **Living Well Now** section for more details about at-home exercises to improve gait, balance and freezing.
- Practice making wide U-turns rather than pivot turns to avoid falling.
- Use a walking aid if you need help walking. It will help you walk better, keep you safe and remain independent longer. Be sure you see your physical therapist to choose the correct cane or walker. Using the wrong one can actually cause falls!

Lifestyle and Good Habits

- Get in the habit of daily exercise. Five minutes of exercise daily is better than 20 minutes once a week.
- Establish a routine. Write your goals and expectations on a calendar.
- Try to time your exercise to the time of day you feel best, such as when your medications are working.

- 
- Exercise with a buddy. Everyone in your family can benefit. Consider a “balance night” devoted to balance games. You do not need fancy video games for this. Make up your own challenges. Keep safety first, though. It is a good idea to involve your physical therapist before beginning.
 - Avoid multitasking. Do one thing at a time. Avoid carrying multiple objects in both hands if you have trouble walking. This helps you focus on the task of walking if you have trouble.

Dietary Changes

- Dizziness and low blood pressure can cause weakness, fatigue, loss of consciousness and falls. See the “Low Blood Pressure and Dizziness Worksheet” as well as the and “Nutrition Self-Assessment” for additional treatment recommendations.
- Eat the high-energy foods explained in the “Diet and Nutrition” chapter in the **Living Well Now** section, rather than processed, high-sugar foods that rob you of your energy.

Treatment

- There is a tendency to blame difficulties solely on Parkinson’s, but there are many causes of walking and balance problems. Fatigue, heart and lung conditions, muscle weakness, stroke, inner-ear problems, peripheral neuropathy, joint pain and arthritis are all examples of conditions that occur more often as we age. Talk with your doctor to be sure that these potential other problems are treated.

Tips for Freezing

Freezing (feet stuck to the floor) occurs in crowded, small places. Often, the act of initiating movement, such as when you stand and begin walking, make a turn or with any stop and start of movement, prompts freezing.

- Learn to make wide “U-turns.” Avoid pivoting. If you use a walker, be sure your walker is the right type for freezing.
- See your physical therapist to review cueing strategies. Cueing from lasers, guided imagery, marching or even walking to the beat of a musical rhythm can help get you over or through a freezing spell. For instance, sing the first few lines of a common song like “Happy Birthday” in your head to help get “unstuck.”
- See your occupational therapist to review areas that cause you to freeze. Can crowded spaces be identified, such as bathrooms or closets? Can these areas be modified by removing clutter?

EVERY VICTORY COUNTS

- ▶ Experiment with flooring and shoes. Shoes with soft rubber soles are comfortable, but may “stick” to the floor. Different flooring textures, color changes and patterns can precipitate freezing, such as changing from tile to carpet.
- Experiment with putting tape on the floor, a step distance apart. This can serve as a visual cue to help you lift your legs to walk over and through a tight space or threshold.

INSOMNIA AND SLEEP WORKSHEET

Trouble falling asleep and staying asleep are very common in people living with Parkinson's. This worksheet provides a range of strategies for preparing your body for rest and for giving yourself the best possible sleep environment. Take a good look at your sleep routine using the list below. Note habits you'd like to change, and decide which recommendations you will incorporate into your routine in the future. Talk to your doctor about sleep concerns you may have, as well as strategies you've tried to improve your sleep.

Sleep Hygiene

- Remove TV, computers, tablets, cellphones and other technology devices from your bedroom. Keep the room dark and use night lights that can easily be turned on, such as motion-activated lights that will turn on when you walk to the bathroom.
- Establish a routine: go to bed and get up the same time each evening and morning.
- Avoid intense TV shows, video games or anxiety-provoking activities before bed. This is not the time to pay your bills! Try relaxing music, gentle stretching, aromatherapy, meditation and massage before bed.
- Avoid bright lights and screens at night. Many computers, tablets, smartphones and other devices have "blue light reduction" options you can either activate or download to reduce the impact of the specific light of computer screens that can keep you awake.

Dietary Changes

- Avoid stimulants such as caffeinated drinks after 3:00 p.m. Avoid alcohol completely or limit to one glass.
- Avoid heavy, starchy meals or snacks before bed. Try foods with tryptophan, such as poultry and milk.

Lifestyle Changes

- Take a warm bath to relax before bedtime.
- Limit catnaps during day to 10 to 20 minutes before 3:00 p.m.
- Avoid exercise at night, but do exercise daily.

▶ **Bed Comfort**

- Use silk or satin pajamas or sheets if you have trouble turning.
- Consider a sturdy, secure headboard that you can use to help turn over in bed.
- Examine your mattress. Has it seen better days?
- An occupational therapist can also help with bed comfort.

Treatment

- See your doctor to optimize motor control and Parkinson's medication.
- Depression, anxiety, pain, restless legs syndrome, vivid dreaming, incontinence and sleep apnea can be treated. Discuss with your doctor.
- A sleep study may be needed to diagnose sleep apnea if you snore.
- Sleep medications can cause daytime sleepiness, confusion and weakness. You may not need them if you develop good sleep habits.

LOW BLOOD PRESSURE AND DIZZINESS WORKSHEET

Dizziness or lightheadedness can occur as a direct symptom of Parkinson's or as a side effect of some Parkinson's medications. You can also experience lightheadedness if you do not drink enough fluids or restrict salt in your diet.

Parkinson's may lower your blood pressure, as can the medications used to treat the movement symptoms of Parkinson's. This worksheet provides helpful lifestyle changes you can make to address low blood pressure and dizziness. Check the changes you can make now, but be sure to discuss with your doctor to identify root causes and other potential solutions. For more information about how to address low blood pressure and dizziness, consult the "Neurogenic Orthostatic Hypotension (nOH) in Parkinson's" article in the **What You Need to Know About Parkinson's** section.

Dietary Changes

- Increase fluid intake to eight cups per day. Caffeine can help, but use in moderation. Sports drinks and salty drinks such as Gatorade or V8 are helpful, but may not be safe if you have diabetes, hypertension or heart disease. Check with your doctor before you make any changes.
- Get in the habit of drinking a full cup of water every time you take a dose of your medication.
- Avoid alcohol.
- Add salt to your diet if approved by your doctor.
- Eat small meals to avoid blood pressure drops that can occur after large meals.
- Reduce your consumption of high-glycemic carbohydrates, like white breads, rice and pastas, sugary juices, cereals and sweets.
- Increase your consumption of low-glycemic index carbohydrates, like whole-grain breads, rice and pasta, fruits and nuts.

Lifestyle Changes

- Elevate the head of your bed by 30° by placing blocks under the legs of your bed or getting a mattress that can be easily adjusted. Simply adding more pillows may not help.
- Stand slowly to give your blood pressure time to adjust to a change in position.



EVERY VICTORY COUNTS

- ▶ Wear compression stockings to help keep fluid in your blood vessels and reduce leg swelling.
- Avoid holding your breath or contracting your stomach muscles excessively when standing.

Treatment

- Review your medications with your doctor. Many medications, including Parkinson's medications, can reduce your blood pressure.
- Physical therapy can show you exercises that can reduce drops in blood pressure when standing, such as contracting your leg muscles before you stand.
- Talk to your doctor about medications to increase blood pressure if other measures are not helpful.
- If you take medications for high blood pressure, speak to your doctor about whether you still need them.
- Treat constipation, since straining may cause dizziness.

SPEECH AND COMMUNICATION WORKSHEET

Many people living with Parkinson's experience difficulties speaking and communicating. These challenges may show up as a quiet voice, unclear speech, trouble finding words or reduced facial expression. Review the worksheet below for ideas you can use to improve your speech and communication. Check the tips you plan to put into practice.

Speaking Tips

- Pace your words if you talk too fast.
- Begin talking by sitting up straight, taking a deep breath and opening your mouth.
- Singing is fun and helps keep your voice flexible and increases your breath support. Try karaoke or simply sing along to your favorite songs.
- Practice facial exercises like the sounds "ooh" and "ahh" with exaggeration in your mouth to reduce muscle stiffness.

Breathing Tips

- Open your chest by sitting up straight to allow for big, deep breaths. Breathing deeply helps increase your volume of speech.
- Practice deep breathing daily. Yoga, tai chi and meditation classes can all help you learn breathing exercises.

Communication Tips

- Improve communication with your care partner. A speech therapist and counselor can help with ideas such as active listening and other recommendations focused on staying engaged in communication and relationships, even when common verbal or non-verbal cues may be different because of Parkinson's.
- Get your hearing checked to ensure it is not impaired.
- Don't let conversation bypass you. If you are in a group setting, ask the group to pause, reminding them that you or your partner would like to speak and be heard!
- Use body language and hand gestures during a conversation to help tell your story, especially if your facial muscles do not express emotion like they used to.



EVERY VICTORY COUNTS

► **Treatment**

- Seek out a speech therapist early in the course of Parkinson's. A speech therapist with experience working with people living with Parkinson's can help keep your speech strong before there is a problem or work with you to improve speech with any change.

SWALLOWING WORKSHEET

Parkinson's can present a variety of problems related to swallowing, ranging from minor complaints when swallowing pills to severe difficulty chewing tough foods like steak and hard breads. Swallowing issues are important to address because of the potential risk of aspiration pneumonia, caused when saliva, liquids or food is breathed into the lungs instead of being swallowed into the esophagus and stomach. Many swallowing issues can be easily addressed with specific swallowing exercises and minor changes in diet. It is a good idea to consult with a licensed speech language pathologist to identify problem areas and improve swallowing ability through intentional exercises. The worksheet below provides changes to help with swallowing challenges; check those you can incorporate into your daily routine now.

Swallowing Tips

- Cut food into smaller pieces.
- Take smaller bites when eating.
- Avoid gulping, big sips when drinking.
- Avoid straws if you have a swallowing problem, as using a straw may promote choking.
- Alternate food with sips of fluid to help your swallowing tract remain clear. This is especially helpful if you have dry mouth.

Lifestyle Changes

- Don't eat when overly tired. Try to eat before you reach that point.
- Eat at the table. This helps avoid distractions, allowing you to focus on eating.
- Eat sitting straight. A chair at the table is better for posture than the couch or recliner.
- Don't stop going to restaurants if this is enjoyable to you. Call ahead to discuss your concerns. Typically a chef can prepare your meal to meet your needs. You can ask for a specific table if you are self-conscious. Early-bird specials are not only cheaper, they're often less crowded and less noisy!

Dietary Tips

- Avoid dry, flaky foods like cornbread, toast, rice or cake unless it is moist. Sauces and gravy help keep your food tasty and moist.
- Switch to thicker liquids. Thin liquids and water are often more difficult to swallow. Mix pills in applesauce or yogurt if you have trouble swallowing.
- Try eating papaya fruit or drinking papaya juice to thin your saliva if it feels too thick.
- Drink adequate fluids, but give yourself more time to do so.
- Whether you have too much saliva in your mouth or not enough, try sucking on small suckers, lemon candy or chewing gum. Although this creates more saliva, it will prompt you to swallow more frequently.
- Ask for a swallowing evaluation if you are coughing, drooling, feeling like you have trouble clearing your throat or swallowing pills, are changing your diet due to swallowing concerns or are losing weight.
- Always report changes in swallowing to your doctor.

SEXUAL DYSFUNCTION WORKSHEET

Many people with Parkinson's experience changes in their sexual activity, including low libido, increased sex drive and even hypersexuality, difficulty achieving orgasm or pain during intercourse. Sexual changes and dysfunction can be caused by Parkinson's or side effects of certain Parkinson's medications. This worksheet will provide questions you can ask different members of your wellness team to start a conversation about improving sexual dysfunction as well as adjustments that may help improve your intimacy.

Ask Your Primary Care Physician:

- Are there diagnostic tests appropriate for sexual dysfunction?
- Do I need a referral to a gynecologist or urologist?
- Are my other medications impacting my sexual life? If so, are there treatments for this?

Ask Your Parkinson's Doctor:

- Are any of my Parkinson's or Parkinson's-related medications contributing to sexual dysfunction or hypersexuality/impulsivity problems?
- Discuss anxiety, depression, insomnia, restless legs, bladder problems, constipation, fatigue, personality changes or movement-related problems that are impacting your relationship. Medications and physical therapy may be helpful to treat symptoms and maximize strength and flexibility.
- Ask for a referral to a trained counselor or neuropsychologist.
- Ask for a referral to a speech therapist if challenges communicating verbally are affecting your relationship.

Other Tips:

- Take your medications on time to feel your best.
- Exercise to build up stamina, reduce fatigue and stress.
- Eat a balanced diet to maximize your health — body, mind and brain.
- Drink appropriate amounts of fluids to reduce fatigue and maintain your blood pressure.
- Reserve together time for you and your partner to focus on emotional and physical closeness.
- Be as independent as possible. Set guidelines when you want help.

EVERY VICTORY COUNTS

- ▶ Show gratitude to your care partner, even the smallest of actions can make a huge impact.
- Set aside time each week to focus on your relationship.

CLINICAL APPOINTMENTS SUMMARY

TAKE ACTION AT YOUR HEALTHCARE APPOINTMENTS

This section is focused on helping you get the most out of your healthcare appointments. You will get more out of these appointments if you are ready for them. ***Preparing and organizing information for your wellness team is often overlooked, but is time well spent.***

A key element to taking action is having the information available that you and your wellness team will need to discuss. The worksheets that follow will help you organize your information and will need to be updated occasionally, sometimes before each visit.

Healthcare appointments are intended to encompass visits with all of the following healthcare providers on your wellness team:

- Doctor (primary care physician, neurologist, movement disorder specialist)
- Specialist (gynecologist, urologist, sleep specialist, physical therapist, speech and language pathologist, occupational therapist, recreational therapist, art therapist, music therapist)
- Alternative therapist (acupuncturist, chiropractor)
- Dentist
- Optometrist
- Social worker
- Emotional health specialist (counselor, psychologist, psychiatrist)
- Dietitian

As you update your information, file older worksheets in a specific location so that you and your wellness team can refer to them later as a measure of your progress over time.

GET THE MOST FROM YOUR APPOINTMENT

As you learn to communicate your needs and current status with the various members of your wellness team, you will help each specialist better understand what you are experiencing. When you provide detailed information, you help your team be in the best position to improve both your quality of care and your quality of life.

Many things can cause your healthcare appointments to be less than satisfying. In some instances, you might not remember important details about a visit, especially if you are anxious, are learning things for the first time or have hearing problems, multiple medical problems or memory difficulties. In addition, you may have difficulty expressing yourself, forget what you were going to say or be hesitant to ask questions. ***These are all common***

EVERY VICTORY COUNTS

 **experiences, even for people who do not have Parkinson's.** Utilizing the worksheets in this section will help you avoid these familiar pitfalls.

The following steps are provided to help optimize your time and enhance communication with your wellness team.

Step 1: Before Your Appointment

Write down your overarching goals for the appointment. It is very helpful to take some time and think about what is important to you. This will help you focus the appointment on your most pressing concerns.

- Complete the “Goal Summary for Doctor Visits” worksheet before your visit and bring a copy to share with your doctor.

Note specific questions and concerns before your visit. Sometimes you may forget to ask important questions during your healthcare appointment, so writing them down will remind you to ask.

- Prioritize your questions with the most important one first as you may not have the time to address everything in one visit.
- Allow space to write answers next to the question so you can refer to them later. It may also help to have your care partner or bring a friend or family member to the appointment with you to write the answers for you.
- If you are a care partner, your questions and concerns are important, too. Remember to add these to the list and be prepared to address them during the appointment.

Keep a record of any changes your doctor makes to your treatment for quick reference.

Some ways to keep good records include:

- Keeping a dedicated notebook for your healthcare visits.
- Completing the “Daily Medication Log” and showing this to all members of your wellness team before starting treatment. This will lower risk of medication interactions.
- In the “Overall Medication Log,” note how each medication you are currently taking or have taken affects you, being sure to mention any side effects you have experienced.
- Keeping copies of previous brain MRIs, CT scans and any other medical test or procedure you have had.
- Updating medical notes and contact information for current and previous healthcare providers (start by filling out the “Wellness Team Contact Information” sheet).



Step 2: Appointment Day

Maximize your time with your healthcare provider. Plan ahead, arrive early and complete forms accurately. These steps will save time for both you and your healthcare provider. Begin by asking your healthcare provider what information is needed from you. Ask questions that are important early during your appointment; don't wait until the end.

Complete the patient questionnaire forms provided by your healthcare provider. These forms can help improve communication, provide information for your record, allow your healthcare provider to spend more time on you and reduce errors and mistakes, especially when tracking your medications. Medications are a primary means of managing Parkinson's and accuracy can greatly affect how well your healthcare provider can control your symptoms.

If writing is difficult for you, ask your care partner or a family member or friend to assist you in completing the forms. In some cases, you might even be able to call and request the forms ahead of time, giving you more time to complete them at home before your appointment.

Remember these tips on the day of your appointment:

- Arrive at least 30 minutes early to complete any forms.
- Always bring a complete list of your medications (such as the “Daily Medication Log”) to reduce errors that can occur from one visit to the next. Do not use statements like, “no changes,” “same as last visit” or “the doctor knows what I am on.” This is how errors occur!
- Visit the restroom before the start of your appointment to ensure comfort throughout the visit.
- Ask for extra copies of forms for future visits. Store them with your records and complete them at home before your next appointment.
- Schedule your appointments during your medication “on” times. This will reduce symptoms during the appointment. In some cases, it may be beneficial to schedule appointments during your “off” periods. For example, your neurologist might benefit from seeing you when your medication is “off.” Talk with your doctor if you are unsure.
- Ask your doctor for permission to audio record your appointment for future reference.
- If applicable, bring your care partner with you to your appointment.

Ask questions and learn about your condition. To ensure a productive dialogue with your doctor, come prepared with questions you want to ask and note the answers. Important questions to ask include:

- What are the symptoms or problems that are related to my Parkinson's and what symptoms should I look for?
 - Do I need medication? If so, what should I expect medication to change or improve?
- 

EVERY VICTORY COUNTS

- 
- What are the most common side effects of the medication you are considering for me?
 - Are there any known drug interactions with over-the-counter medications?
 - What symptoms or side effects should be reported immediately?
 - How often should I make appointments? (Ask yourself how often you would like to see your doctor, then share this with them.)
 - Where can I find accurate and comprehensive information about my symptoms?
 - When should I see a physical therapist, occupational therapist, speech therapist, counselor or other specialist?

Step 3: After the Appointment

How often do you leave your healthcare appointment trying to remember what just happened?
Do you have trouble following through with your treatment plan?

The following suggestions will help you stay on track between appointments:

- Bring a care partner, family member or friend to write down instructions and help you keep track of your next steps.
- Complete the remaining sections of the form “Goal Summary for Clinic Visits.” You are more likely to follow through with changes if you review your goals and write down the action steps needed to get you there.
- Review the information in your “Goal Summary for Clinic Visits” with the other members of your wellness team to involve them in your treatment.
- Keep a journal or a calendar of your goals for the week and steps you have taken to reach them.

Between Appointments

- Keep a list of any changes that result from calls to your doctor about new symptoms experienced between appointments.
- Keep track of medication refill needs before you run out. Provide your pharmacy with your phone number, fax number and/or address for quicker refills.
- Keep a list of prior medicines that were tried and not effective or caused side effects so that they are not used again. You can do this in the “Overall Medication Log.”
- Review your goals written in the “Goal Summary for Doctor Visits” worksheet and update on your progress.
- Ask each healthcare professional on your wellness team what information is important for you to bring to each visit so that you can work together as a team.



Appointment Checklist

The following information will be helpful to you and your wellness team over time. The worksheets referenced in this section are intended for you to use to help organize your information and maximize the usefulness of your healthcare appointments.

- Complete your doctor's patient questionnaire, or use the "Parkinson's Care Questionnaire."
- Keep a list of medications to include name, strength, timing, generic or trade name. Consider using the "Daily Medication Log."
- Keep a list of all the medications you've tried over the course of living with Parkinson's, being sure to note side effects or reasons specific medications were discontinued. Consider using the "Overall Medication Log."
- Keep a list of all your treating healthcare professionals, including name, address and fax number. Consider using the "Wellness Team Contact Information."
- Keep a list of troublesome side effects to discuss with your doctor. Consider using the "My Symptoms Worksheet."

Remember to bring the following on appointment day:

- Updated "Daily Medication Log."
- Updated "My Symptoms Worksheet."
- Updated "Goal Summary for Doctor Visits" assessment.
- Updated "Current Symptoms Summary."
- Updated "Parkinson's Care Questionnaire."
- Updated "Dental Worksheet" and "Medical Summary for Dentists" if visiting a dental provider.
- List of questions to ask before your visit.

These steps require some effort on your part. They will, however, save time in the long run and most importantly, help you obtain the greatest possible benefit from your healthcare appointments.

CURRENT SYMPTOMS SUMMARY

Name: _____ Date: _____

This document will summarize your problems or concerns, improving your team's understanding of you and your Parkinson's and helping them to effectively tailor your treatment.

I have trouble in the following areas that may be affected by my treatment, hospital stay or procedure:

Motor Problems

- Balance problems
- Communication and speech difficulties
- Dyskinesia - uncontrollable movements usually caused by medication
- Dystonia - involuntary muscle spasm, contraction leading to pain, flexion or twisting movements
- Freezing of gait or motor initiation problems (feet stuck to floor)
- "On/off" fluctuations - periods of time when my medications are "on" that I can move better and when my medications are "off" and I have difficulty moving. "Off" periods usually happen as my medication is wearing "off." To reduce this problem, **I must have my Parkinson's medications on time.**
- Swallowing problems

Non-Motor Problems

- Anxiety
- Apathy or trouble self-initiating tasks
- Bladder problems
- Constipation
- Depression



- Cognitive problems
 - Memory problems or mild thinking difficulties
 - Dementia
 - Hallucinations or sensitivity to hallucinations with certain medications
- Drooling
- Excessive sweating or chills
- Fatigue
- Impulsivity problems
- Loss of smell or loss of appetite
- Pain in these areas: _____
- Sleep problems
 - Trouble staying asleep
 - Restless legs syndrome
 - Periodic limb movement disorder: repetitive movements, typically of the legs and feet
 - Sleep apnea
 - REM sleep behavior disorder: vivid, active, physical dreaming
 - Daytime sleepiness
- Sensations such as tingling, aches, pain, cold hands/feet
- Sexual dysfunction
- Vision problems

WELLNESS TEAM CONTACT INFORMATION

Primary Care Physician

Name: _____

Address: _____

Phone: _____ Fax: _____

Neurologist

Name: _____

Address: _____

Phone: _____ Fax: _____

Other Provider _____ **Specialty:** _____

Name: _____

Address: _____

Phone: _____ Fax: _____

Other Provider _____ **Specialty:** _____

Name: _____

Address: _____

Phone: _____ Fax: _____

Other Provider _____ **Specialty:** _____

Name: _____

Address: _____

Phone: _____ Fax: _____

MEDICAL PROVIDERS

Primary Care Physician

DBS Programmer

Primary Urgent Care

Neurologist

Alternate Urgent Care

Optometrist/Ophthalmologist

Emergency

Dentist/Oral Surgeon

EVERY VICTORY COUNTS

DBS MEDICAL HISTORY

NO: Diathermy, Lithotripsy MRI or Ultrasound. Medical Consent Required.

PATIENT HISTORY

Name: _____ DOB: _____

Address: _____

Type of Residence: _____ Phone: _____

Marital Status: _____ Work Status: _____

Occupation (if employed): _____

Activity Level: Sedentary Moderately Active Very Active

Smoker: No Yes, Current Previous

Allergies (*check for YES*):

Aspirin Codeine Penicillin Local Anesthetics Acrylic Latex Metal

PATIENT PROGRAMMER

Device: _____ Manufacturer Contact: _____

Neurologist Contact: _____ Programmer Contact: _____

MEDICATIONS

NAME	DOSAGE	FREQUENCY	STRENGTH





PHYSICIANS

TYPE	DOCTOR NAME	HOSPITAL / CLINIC	ADDRESS CITY, STATE, ZIP	PHONE
Primary Care Physician				
Neurologist				
DBS Programmer				
DBS Surgeon				
Optometrist/Ophthalmologist				
Dentist				
Oral Surgeon				
OTHER				



MEDICAL INSURANCE

PRE-AUTHORIZATION

Claim #: _____

Entitled to: _____

Insurance Company: _____

Employee ID #: _____

Group Name: _____

Group Policy #: _____

Claim Inquiries: _____

EMERGENCY CONTACTS

Name: _____

Relationship: _____

Home Phone: _____

Cell Phone: _____

Name: _____

Relationship: _____

Home Phone: _____

Cell Phone: _____

Name: _____

Relationship: _____

Home Phone: _____

Cell Phone: _____

IMMUNIZATIONS AND PREVENTATIVE SCREENINGS

TYPE	DATE
Flu	
Pneumonia	
Tetanus	
Hepatitis B	
Shingles	
Gardasil	

TYPE	DATE
Colonoscopy	
EKG	
Echocardiogram	
Eye Exam	
Physical Exam	
Neurology Exam	



SURGICAL HISTORY

SURGICAL PROCEDURE	REASON FOR SURGERY	DATE	SURGEON NAME	HOSPITAL	CITY, STATE

EVERY VICTORY COUNTS

PREPARE FOR YOUR HOSPITAL STAY

BRING THE FOLLOWING INFORMATION WITH YOU:

Make copies of your completed “Daily Medication Log” to give to your nurses and doctors. Remember to update this each time your medications are changed.

List of Medications You Should Not Have

Common anti-hallucination and anti-nausea medications can worsen movement. Both nausea and hallucinations can occur with certain medications and during illness.

Note: This is not a complete list of medications to avoid. If you have questions about other medications, ask your pharmacist or doctor.

Anti-Hallucination Medications to Avoid

Note: The anti-hallucination medications Pimavanserin (Nuplazid), Quetiapine (Seroquel) or Clozapine (Clozaril) can be used for hallucinations and psychosis. The following should be avoided:

- Aripiprazole (Abilify)
- Chlorpromazine (Thorazine)
- Flufenazine (Prolixin)
- Haloperidol (Haldol)
- Molindone (Moban)
- Perphenazine (Trilafon)
- Perphenazine and amitriptyline (Triavil)
- Risperidone (Risperdol)
- Thioridazine (Mellaril)
- Thiothixene (Navane)

Anti-Nausea Medications to Avoid

- Metoclopramide (Reglan)
- Phenothiazine (Compazine)
- Promethazine (Phenergan)



Medications to Avoid if You Are on Rasagiline (Azilect) or Selegiline (Eldepryl)

- Pain medications meperidine (Demerol), tramadol (Ultram) and methadone
- Antispasmodic medication (Flexeril)
- Dextromethorphan (cold medication) and ciprofloxacin (antibiotic)

Note: This is not a complete list of medications to avoid. If you have questions about other medications, ask your pharmacist or doctor.

If you have DBS: Bring the name and contact number for your neurologist, DBS programmer and device manufacturer, along with a document of tests, medications and procedures that require medical consent from your neurologist. Consider using the “DBS Medical History” form to collect and share this information.

Bring copies of the “Current Symptoms Summary,” as certain symptoms such as swallowing, dizziness, constipation and confusion could worsen in the hospital and these symptoms could influence your treatment decisions.

Inform Hospital Staff

- Highlight your need for medications on time.
- Discuss what you can do when the medications are “on” and when they are “off,” so that they are aware of any potential changes in your movement. This is an opportunity to reinforce the need to get your medications on time.
- Describe your dyskinesia and freezing episodes and when they occur, as these symptoms may be unfamiliar to your hospital treatment team.

What to Ask for During Your Hospitalization

- Physical therapy, occupational therapy, speech/swallowing therapy, especially if you have trouble with balance, swallowing and general mobility.
- Chaplain services or social work consult for support of you or loved ones.

What to Know or Ask Before Discharge

- Have your neurologist and primary care physician been notified of your condition while in the hospital?
- When should you see your primary care physician?
- Should you get additional rehabilitation such as physical therapy?
- What important tests, procedures or new diagnosis have you had?
- What medications have been changed and why?
- How do you get a copy of the hospital records sent to your doctor?

▶ **Advanced Directives**

The following advanced directives ensure that your rights and personal wishes are respected in the event of a medical emergency or change in your health status in which you are unable to make decisions for yourself. Many options are available to help you determine these, and each document should be reviewed by your attorney to ensure your wishes are accurately recorded. Check with the department of health in your state or country for additional guidance.

Medical Power of Attorney: This document gives a designated person the power to make medical decisions for you in the event that you are incapacitated and unable to do so.

Durable Power of Attorney: This document gives a designated person the power to make certain legal, financial and disability decisions for you in the event that you are incapacitated and unable to do so.

Living Will or Healthcare Directive: This is a written document that specifies what type of medical treatment you desire if you become incapacitated.

It is a good idea to also bring a signed statement identifying a friend or family member who your doctors can talk to about your treatment.

Summary of Hospital Document Checklist

- Bring “Daily Medication Log”
- List of medications to avoid
- Bring “Current Symptoms Summary”
- Advanced directives
- Bring “DBS Medical History” (if applicable)

MEDICAL SUMMARY FOR YOUR DOCTOR APPOINTMENT

List your top three goals or concerns for your next doctor’s appointment:

Note: You may wish to review the “Current Symptoms Summary” and “My Symptoms” worksheets to identify and help set these priority goals.

1. _____
2. _____
3. _____

Describe any treatment changes you have made since your last visit and how they have affected your symptoms:

List any new medical problems, allergies or hospitalizations since your last visit:

1. _____
2. _____
3. _____

Review the “Daily Medication Log” and “Overall Medication Log” to discuss any side effects of your medications.

MEDICAL SUMMARY FOR DENTISTS

Bring the following information to your dentist to inform them of Parkinson's-specific dental issues and modification tips.¹

About Parkinson's

- Parkinson's is a progressive, neurodegenerative movement disorder.
- Primary motor symptoms include rigidity, tremor, slow movement, postural instability, difficulty speaking, decreased facial expression and weakness of face and throat muscles.
- Primary non-motor symptoms include loss of smell, sleep disturbances, depression, excessive saliva, anxiety and cognitive issues.
- Parkinson's medication side effects commonly include dry mouth, low blood pressure, dizziness, confusion, nausea and an "on/off" cycle, when medication ebbs and flows in its effectiveness.

Communication

- Allow additional time for responses, as difficulty speaking and mild cognitive impairments can lead to a longer lead time in responding. Include the care partner (if present) in the discussion to ensure all information being understood is accurate.
 - Collaborate with your patient to determine a signal for discomfort – for example, the patient may put his or her hand up to signal they need a break or are having trouble swallowing. Decreased facial expression can make it difficult to express discomfort in the chair.
- ! Ask your patient what medications they are currently taking to reduce the likelihood of interactions with numbing medications or anesthesia.**

Treatments

- Use more frequent suction during cleaning, as the cough reflex may not be as strong.
- Offer an intraoral rubber bite block, as Parkinson's patients may have difficulty keeping their mouth open, managing saliva or restricting head and tongue movements.
- Use an aspirator tip placed under a rubber dam and stabilized by an assistant. This will assist the patient in managing saliva and protecting airways from the higher risk of aspiration.

¹ Friedlander, A. H., Mahler, M., Norman, K. M., Ettinger, R. L. (2009). Parkinson Disease: Systemic and orofacial manifestations, medical and dental management. *The Journal of the American Dental Association*, 140(6), 658-669.

- Look for excessive loss of tooth structure; Parkinson's tremors of the orofacial musculature and the use of levodopa medication may cause bruxism.
- Utilize glass ionomers and resin-modified glass ionomers.
- Keep the dental chair at an incline of 45° or higher to enable comfortable swallowing.
- The dental chair should be raised and lowered slowly to allow the patient to adapt to the position and prevent syncope episodes.
- Help your patient in and out of the dental chair slowly to reduce the likelihood of falls. Encourage them to sit up in the chair, plant their feet on the ground, stand up slowly and walk out of the room – pausing for around 20 seconds between each transition.

❗ Ask your patient if they have had Deep Brain Stimulation surgery.

Medications and Interactions

- If a patient is taking MAO-B inhibitors (selegiline, rasagiline), avoid meperidine (Demerol), tramadol (Rybix, Ryzolt, Ultram), droperidol (Inapsine), methadone (Dolophine, Methadose), propoxyphene (Darvon, PP-Cap), cyclobenzaprine (Amrix, Fexmid, Flexeril) and halothane (Fluothane).
- Administer no more than 0.05mg of epinephrine per 30-minute period, with careful aspiration to avoid intravascular administration.
- Be careful when using local anesthetic agents containing epinephrine in patients being treated with levodopa and entacapone, because these patients may experience an exaggerated effect on blood pressure and heart rate.

Deep Brain Stimulation (DBS) Therapy

- Patients should have a complete dental checkup and treatment prior to DBS surgery.

❗ Ask your patient if they have had Deep Brain Stimulation surgery. If the answer is yes:

- Do not use diathermy (therapeutic ultrasound), as it is contraindicated and may lead to coma or death.
- Ultrasonic cleaning that uses air and water will not interact with the device.
- X-ray use is not contraindicated.
- Laser technology use should be reviewed with the DBS device manufacturer.
- Any electrical or magnetic device near the head, neck or chest should be approved for use by the device manufacturer.
- Device labeling does not require pre-medication with antibiotics for dental treatment

EVERY VICTORY COUNTS