

Step by Step Plan for Living with INTENT

Intent (noun): to be focused, purposeful, and deliberate

Managing Parkinson's can feel like a full-time job.

Although there are many helpful tips and resources to improve your quality of life, it can be overwhelming to organize them into manageable steps.

Review each tip below and indicate with a whether you are already using INTENT or you need to use MORE INTENT. Write "N/A" if this is a tip that you don't need.

Topics

| Seek the Best Medical Care |
|------------------------------|
| Manage Your Medications |
| Enroll in Physical Therapy |
| Enroll in SPEAK OUT! Therapy |
| Reduce Fall Risk |
| Keep Your Mind Sharp |
| Improve Social Communication |
| Promote Good Sleeping Habits |
| Reduce Stress |

| | Resources and Suggestions | Already doing with INTENT | Needs more INTENT |
|-------------------------------|---|---------------------------------|-------------------------|
| Seek the Best Medical Care | Create a "Medical Binder" that includes your medical history, notes from appointments, and physician business cards. Put the most current information in front. | | |
| | Each year, review your list of emergency contacts. Inform all your physicians of any new information. | | |
| | Add your Emergency Contacts to your cell phone: ICE -First Name-Last Name (<u>I</u> n <u>C</u> ase of <u>E</u> mergency). | | |
| | Seek treatment from a movement disorder specialist. If there is not one in your area, find a neurologist with a high caseload of Parkinson's patients. | | |
| | Check with friends at local Parkinson's Support Groups for referrals. | | |
| | Find a knowledgeable and attentive primary care physician whose clinical staff is accessible and responsive to calls and emails. | | |

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| Seek the Best Medical Care | Seek a second opinion when you are dissatisfied or uncertain about the medical advice you have received. | | |
| | Prior to each doctor's appointment, make a list of concerns and questions you want to discuss. | | |
| | Bring your Care Partner (family member or close friend) to every doctor's visit to take notes and listen with INTENT. | | |
| | After each doctor's appointment, sit down with your Care Partner and review the notes from the appointment. Complete follow-up tasks. | | |
| | Keep physician names, phone numbers, and addresses current in your cell phone AND your Care Partner's cell phone. Delete old contacts in your phone. Save old medical contacts in your "medical binder." | | |
| | Watch Parkinson Voice Project's lecture on "Strategies for Building Your Parkinson's Care Team" presented by Connie Carpenter Phinney: https://parkinsonvoiceproject.org/education/lectures/ | | |

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| Manage Your | Use only one pharmacy for all your medications. | | |
| Medications | Find an accessible and personable pharmacist who is knowledgeable about Parkinson's. | | |
| | Make an appointment with your pharmacist to review all your medications, vitamins, and supplements. | | |
| | Tell your pharmacist about pills that are challenging to swallow. Ask if the pills can be cut in half, crushed, or if they come in a different form that would be easier to swallow (e.g., gummies). | | |
| | Find a pharmacy that has convenient hours of operation and delivers. | | |
| | Ask your pharmacy to print a list of your medications for you. Compare their list to your list and update as needed. | | |
| | Keep an updated list of your medications in your purse or wallet. | | |

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| Manage Your Medications | Take a photo of your medication list with your phone and save it. When you update your medication list, be sure to delete the old photo. | | |
| | Coordinate medication schedules with your meals. Ask your movement disorder specialist if you need to be concerned about your PD medications and protein OR interactions with other foods or drinks. | | |
| | Use medication reminders to stay on schedule (e.g., pill box, phone app). | | |
| | If your medications aren't working well, keep a journal for 1-2 weeks. Share this journal with your neurologist to help adjust your medications. Keep track of medication times, foods consumed, symptoms throughout the day, sleep, stress, and daily activities. Is there a correlation between how your medications work and these factors? | | |
| | Watch Parkinson Voice Project's lecture on "Pharmacological Management of Parkinson's" presented by Amie Taggart Blaszczyk, Pharm.D., CGP, BCPS, FASCP: https://parkinsonvoiceproject.org/education/lectures/ | | |

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| Enroll in Physical | Schedule a Physical Therapy Evaluation with a physical therapist who specializes in Parkinson's. | | |
| Therapy | Enroll in Physical Therapy and complete daily home exercises. | | |
| | Set up an exercise space or room in your home. Gather the supplies or equipment you need to exercise with INTENT. | | |
| | After you complete individual physical therapy, continue exercising every day. Add 20-30 minutes of exercise to your daily calendar. Keep this time sacred. Schedule other appointments around your physical exercise. | | |

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| Enroll in Physical | Join a weekly group for additional exercise and motivation. Be open to trying new types of exercise (e.g., Tai Chi, dancing, boxing). | | |
| Therapy | Schedule a re-evaluation with your physical therapist every three to six months. Re-enroll in physical therapy as needed. Continue this treatment plan forever for best results. | | |
| | Watch Parkinson Voice Project's lecture on "Parkinson's Disease Wellness, Recovery, and Physical Therapy" presented by Becky Farley, PhD, MS, PT: https://parkinsonvoiceproject.org/education/lectures/ | | |

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| Enroll in SPEAK OUT! | Schedule a SPEAK OUT! Evaluation with a speech-language pathologist who has completed training with Parkinson Voice Project. | | |
| Therapy | Watch Parkinson Voice Project's "What is Parkinson's?" Video: ParkinsonVoiceProject.org | | |
| | Enroll in SPEAK OUT! Therapy and complete daily home speech exercises. | | |
| | Complete Extra SPEAK OUT! Activities using your SPEAK OUT! Workbook or the SPEAK OUT! eLibrary (e.g., photo, word, math, problem-solving flashcards). | | |

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| Enroll in SPEAK OUT! | Set up a space in your home to complete your daily SPEAK OUT! Exercises. | | |
| Therapy | After you complete individual SPEAK OUT! Therapy, continue exercising your speech and swallowing muscles every day. Participate in Parkinson Voice Project's online "Parkinson's Speech Exercises:" ParkinsonVoiceProject.org | | |
| | Participate in a weekly SPEAK OUT! Therapy group for added motivation. | | |
| | Schedule a SPEAK OUT! Refresher with your speech-language pathologist every 3-6 months. Re-enroll in SPEAK OUT! Therapy as needed. Continue this treatment plan forever for best results. | | |

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| Reduce Fall Risk | Schedule a Physical Therapy Evaluation with a physical therapist who specializes in Parkinson's (see above section about Physical Therapy). | | |
| | Schedule an Occupational Therapy Evaluation with "Home Assessment" by an Occupational Therapist who specializes in Parkinson's. | | |
| | Enroll in Occupational Therapy to improve activities of daily living (e.g., dressing, bathing). Complete daily home exercises. | | |
| | Recognize your limitations, and ask for help. | | |

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| Reduce Fall | Avoid carrying items while walking. | | |
| Risk | If an assistive device (e.g., cane) has been recommended, use it. | | |
| | Add grab bars in the shower, by the toilet, and other areas of your home, as reccommended. | | |
| | When getting up from a chair or bed, take a moment to get steady before walking. | | |

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| Reduce Fall Risk | Eliminate throw rugs from your home, especially in the kitchen and bathrooms. | | |
| | Add night lights to hallways and bathrooms. | | |
| | Post reminders to "Walk with INTENT" in key places around your home. | | |
| | If you experience "freezing" while walking, try stepping backward first, then forward. You can try rocking side to side, humming a patriotic march, or counting while walking. You can also "stop and reset"- in other words, when you start to freeze, stop walking, reset and then "walk with INTENT!" | | |

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| Reduce Fall Risk | To minimize freezing in doorways, keep your head up and always look "beyond the door." | | |
| | Wear clothing with a pocket so you always have your phone in case you need to call for help. | | |
| | Watch Parkinson Voice Project's lecture on "Parkinson's as an Occupation" presented by Dr. Michelle Holloway: https://parkinsonvoiceproject.org/education/lectures/ | | |

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| Keep Your Mind Sharp | Read aloud each day for 5 minutes. Read from a book, a magazine, a newspaper, or even read your email aloud. | | |
| | Complete cognitive activities aloud that improve thinking speed and word-finding: name items in categories; spell words forward and backward; make up sentences with words; describe photos from a magazine or family album; recite mathematical equations. | | |
| | Play card games and board games with family or friends. | | |
| | Complete crossword puzzles, Scrabble, or other word games. It would be more effective if you say each word aloud as you play. | | |
| | Complete Extra SPEAK OUT! Activities using your SPEAK OUT! Workbook or the SPEAK OUT! eLibrary (e.g., photo, word, math, problem-solving flashcards). | | |
| | Watch Parkinson Voice Project's lecture on "Neuropsychological Testing and Cognitive Challenges in Parkinson's" presented by Richard L. Fulbright, PhD: https://parkinsonvoiceproject.org/education/lectures/ | | |

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| Improve Social Communication | Warm up your voice for 5-10 minutes prior to social engagements (e.g., doctor's appointments, parties, church, dining out). | | |
| | Each time you say something, speak with INTENT. | | |
| | Make good eye contact with whom you are speaking. | | |
| | Turn off distractions when conversing with others (e.g., television). | | |
| | Dine out on days when restaurants are not as crowded. | | |
| | When dining out, call ahead and request a quiet table away from the kitchen, restrooms, or heavy traffic areas. | | |
| | When dining out, order food that is easier to manipulate, so you can concentrate more on speaking with INTENT (e.g., lasagna instead of spaghetti; enchiladas instead of tacos). | | |
| | Post reminders to "Speak with INTENT' in key places at home. | | |

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| Promote Good Sleeping Habits | Establish a relaxing bedtime routine (e.g., pajamas, soothing lights and music, meditation or prayer). | | |
| | Avoid watching news/controversial TV shows before bedtime. | | |
| | Keep your bedroom for sleep, not paying bills or other daily tasks. | | |
| | Replace old mattresses, pillows, and bed sheets. | | |
| | Keep the temperature cool in your bedroom. | | |
| | Use a sound machine or other soothing app to quiet your mind. | | |
| | Wear soft, comfortable pajamas. | | |
| | Talk to your doctor if you have trouble falling asleep, staying asleep, or experience combative behavior during the night (e.g., acting out your dreams). | | |
| | Consult with a sleep disorder specialist as needed. | | |

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| Reduce Stress | A good day begins the night before. Review your schedule. Prepare your clothes, snacks, and medications. | | |
| | Keep a calendar and keep track of exercise, appointments, and daily tasks all in one place. Develop a routine and stick to it. | | |
| | Assign a set location for common objects such as medications, keys, wallet, glasses, mail, bills, etc. | | |
| | Organize medications 2-4 weeks at a time using a pill organizer | | |
| | Say "no" to activities or requests that interfere with you caring for yourself OR that don't bring you joy. | | |
| | Recycle junk mail as soon as it arrives. | | |
| | Take time to create and label files for important documents (whether these are paper files or files on your computer). | | |
| | Remove clutter from your home. This includes any items you don't need or items that don't bring you joy. Seek help from a family member, friend, or professional organizer. | | |

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| Reduce Stress | Organize the contacts in your phone and keep them up-to-date (include family members, physicians, therapists and other important contacts). | | |
| | Develop a grateful mindset: say "thank you" often; keep a gratitude journal; write a kind note each week; call a family member or friend to express your gratitude each week; count your blessings. | | |
| | Watch Parkinson Voice Project's lecture on "Live Your Best Life with Parkinson's" presented by Tim Hague, Sr. https://parkinsonvoiceproject.org/education/lectures/ | | |



ParkinsonVoiceProject.org

