



# The Art and Practice of Planning

SERIES



## A TOOLKIT FOR CARE PARTNERS



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Parkinson & Movement Disorder Alliance

**KYOWA KIRIN**



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## Planning for the Future

**Planning for the future may be one of those tasks you put off** because it seems so daunting, requires conversations you aren't comfortable with, or you just can't think that far ahead. But taking the time to think through you and your loved one's future needs and how you'd like to direct them gives a sense of peace, builds confidence, and allows you and your loved one to have more control. While this is not a comprehensive guide to planning for the future, these key points will help you take that first step of thinking through what to do and a starting point on where to get the help and support you need.

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### TYPES OF PROFESSIONAL CAREGIVING SERVICES

**HOME CARE COMPANIONS** (*self-pay or Long Term Care (LTC) Insurance policy*): Provide supervision and companionship but are limited to the amount of hands-on assistances provided.

**HOME CARE AIDES** (*self-pay or LTC insurance policy*): Can assist with activities such as bathing, dressing and grooming, assist with walking, medication reminders, light housework and meal preparation, assistance with exercises.

**HOME HEALTH**  
This can be a nurse or a therapist like a physical therapist or occupational therapist who can provide treatment specific services that are short term. They are typically covered by Medicare or insurance but are time-limited and require an order by a physician.

**ADULT DAY CARE** (typically self-pay unless VA facility/benefits or LTC insurance policy): Facilities that offer respite care for care partners by providing loved ones a place to go where they can receive socialization, therapeutic activities and nutritional support.

# WHAT SHOULD YOU PLAN?

## A care plan for managing the changing needs of the disease over time

### Things to Consider:

- **Is your home able to accommodate things like medical equipment?** Are there stairs? Can you age-in-place? Do you have the ability to do home modifications?
- **As the care partner, what are your options should your loved one need more assistance?**
- **What level of care are you able to manage as the care partner?** Do you have any physical limitations of your own? Can you manage activities of daily living like bathing and dressing? If you live alone and are the person with the diagnosis, how would you like to see the management of your ADL's handled?
- **Finances for in-home or long-term care:** Do you have a Long Term Care policy? Do you have savings to supplement your care in the home through services such as home care aides? If your loved one (or you) need assisted living or nursing facility care, do you have the funds?

Do you have a plan as care partner for your loved one in the event you experience your own emergency?

- Consider seeing a financial planner.
- Prepare a budget.
- Create a plan and consistently review, revise as needed.

### Advanced Medical Directives:

This is a general term for documents that include a Living Will, instruction directive, healthcare power of attorney or health care proxy depending on your state. Each state has specific forms for these documents so make sure you have one the ones for every state you might need.

[Downloading Your State's Advance Directive | NHPCO](https://www.nhpco.org/advancedirective/)

<https://www.nhpco.org/advancedirective/>

- **LIVING WILL** A Living Will communicates your health care decisions and the types of treatments you would like or not like to receive when you are no longer able to express informed consent because of an illness or incapacity. These direct the level of care one would like in terms of life-sustaining treatments including nutrition and hydration when a person's condition is terminal.
- **DURABLE POWER OF ATTORNEY (DPOA)** This document names the person you trust to make decisions as you would for yourself in the event you are unable to speak, or no longer wish to, whether temporarily or permanently. Durable Power of Attorneys can be limited or general, depending on needs. Talk with your lawyer about the best options for you as there are different types depending on your specific needs.
- **MEDICAL POWER OF ATTORNEY (ALSO KNOWN AS A DURABLE POWER OF ATTORNEY FOR HEALTHCARE)** The person you appoint may be called: Health care agent, health care proxy, health care surrogate, attorney-in-fact, agent, or principal. They are legally bound to acting in your place when arranging care to your treatment preferences specific to medical decisions.

## Estate Planning:

- **FINANCIAL POWER OF ATTORNEY** (*also known as a durable power of attorney for Finances*) This person can handle simple tasks such as paying monthly bills and sorting mail to more complex tasks like watching over accounts, investments and filing tax returns.
- **WILL** Legal document that declares your final wishes of distribution of property and assets to others.
- **TRUST** Trusts are created to protect personal and financial assets on behalf of a beneficiary or beneficiaries. Trusts can be arranged in many ways and can specify exactly how and when the assets pass to the beneficiaries. Assets in a trust may also be able to pass outside of probate, saving time, court fees, and potentially reducing estate taxes as well.

## HOW DO YOU PLAN?

- Set a goal, write it down, check it off when done.
- Consider meeting with an Aging Life Care Manager
- Meet with your medical team social worker.
- Meet with an elder law attorney who can address your estate planning and advanced directive needs.
- Work with a financial planner who can assist with determining your goals and needs related to your care and your assets.



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## LONG-TERM CARE PLACEMENT OPTIONS

### CONTINUOUS CARE COMMUNITIES

(CCRCs) are retirement communities that offer independent living, assisted living, and nursing home care. This is typically self-pay or LTC insurance policy.

**ASSISTED LIVING FACILITY (ALF)** is a housing facility for those who cannot or choose to not live alone and may need assistance with some activities of daily living. This is self-pay or LTC insurance policy.

**NURSING FACILITY-SKILLED NURSING FACILITY (SNF)** is care provided following hospitalization for specific medical needs and is covered by Medicare and insurance. A nursing facility provides long-term custodial care and is typically self-pay or Medicaid.

## WHERE TO GO

*Aging Life Care Association Home*  
<https://www.aginglifecare.org>

*Eldercare Locator (acl.gov)*  
<https://eldercare.acl.gov/Public/Index.aspx>

*The National Association of Personal Financial Advisors | NAPFA*  
<https://www.napfa.org>

*Senior Benefits: Find Help Paying for Everyday Needs | BenefitsCheckUp*  
<https://www.benefitscheckup.org>

*VA.gov Home | Veterans Affairs*  
<https://www.va.gov>

*NAELA | National Academy of Elder Law*  
<https://www.naela.org/FindALawyer?>

*Home - PMD Alliance*  
<https://www.pmdalliance.org>



## Caregiver's Action Plan

It often helps to write down the tasks or goals you have in order to stay focused and organize your time better. For those things you have determined you need to do in order to better prepare yourself for the journey of caregiving, whether that is a practical task such as contacting an estate planner or a personal goal such as stress management, write your goals and tasks below and set a target date. Then when you can check something off your list, you will feel a sense of accomplishment and control.

<b>What I Need To Do</b>	<b>Action I Must Take To Do It</b> <small>(who to call, phone number)</small>	<b>Timeframe To Complete</b>	<b>Follow Up Needed?</b>	<b>Action Completed</b>

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## Temperature Check:

### Care Partner Burnout Assessment

Burnout is a real problem and can creep up on you. If you are feeling overwhelmed, anxious, grumpy, tired or isolated, you might be experiencing burnout. Take this quiz and see where you stand. Choose the number that most fits where you fall between the two extremes on the temperature scale.

	TRUE <most of the time				not at all>
1 I feel emotionally drained because of my caregiving duties.	1	2	3	4	5
2 I have developed a negative attitude.	1	2	3	4	5
3 I feel stressed out more often than not.	1	2	3	4	5
4 I have more medical problems as a result of being a caregiver.	1	2	3	4	5
5 I feel more depressed and/or anxious than before I became a caregiver.	1	2	3	4	5
6 I am not successful as a care partner/caregiver.	1	2	3	4	5
7 I have trouble sleeping at night.	1	2	3	4	5
8 I feel all alone. No one helps me.	1	2	3	4	5
9 I have trouble making time for myself and taking a break.	1	2	3	4	5
10 I feel trapped in my caregiving role.	1	2	3	4	5
11 I feel hopeless and as if there is no help for my situation.	1	2	3	4	5
12 I have become angry and frustrated and sometimes I take my anger/frustration out on the person I care for.	1	2	3	4	5

If you find the majority of your answers fall in the yellow to red zone, you may be in or near burnout and should speak to your health care provider, a professional counselor, join a support group, and begin asking for help. If you fall somewhere in the middle, take some steps now to ease your burden and protect yourself from burnout.

If you need assistance with obtaining help, speak to your medical team social worker or find a care manager who can help you develop a plan. Visit [aginglifecare.org](http://aginglifecare.org) for a care manager in your area.

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# Asking for Help

Caring for someone can add up to a lot of tasks and hours. In fact, a survey found that care partners spend up to 45 hours a week on caregiving tasks. And while many care partners want help, 81% feel guilty asking for it.

Creating a support system that works for your situation can help reduce stress and help during transitions in your loved one's care needs. If you live on your own without a built-in support system, then creating a plan will offer peace of mind and more control when more help is needed.

At some point in life, we all have had the challenge of asking, accepting, or even trying to provide another, with help but it is HARD. Some of challenges to seeing help can include:

## Guilt

Inability to release control

Uncomfortable asking

Fear of rejection/ or receiving a "no"

Do not know who to ask

Feeling like nobody wants to help

Don't want to be perceived as weak  
if you are the person with the disease.

You feel like it's your responsibility

They will not do it as well as you



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A survey conducted by Kyowa Kirin found that care partner's top four tasks they reported spending time on include:

92%

Providing emotional support to their loved one

81%

Managing doctor appointments

81%

Transportation to appointments

74%

Helping with memory

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## ● WHY YOU SHOULD ASK FOR HELP

Over time, the physical, emotional, and psychological toll of helping a loved-one without support can cause burnout which leads to exhaustion, stress, anxiety, depression, mood swings, sleeplessness, anger, frustration, and resentment followed by guilt.

### ***Additional factors that contribute to burnout can include:***

**ROLE CONFLICT:** conflicting demands and difficulty balancing the needs of your loved one, your job, family, friends, and yourself. This is often a significant challenge for adult children.

**ROLE CONFUSION:** the merging of your role as care partner and your relationship with your loved one. You may find you refer to yourself as “caregiver or care partner” instead of spouse, partner, or child.

**LACK OF MARGIN:** the gap between rest and exhaustion, a boundary that is built into your day where you have time to relax, unwind, and enjoy moments of freedom to do something you enjoy. Even if this is just a few minutes a day, many people find their margin has disappeared.

**UNREALISTIC EXPECTATIONS:** whether you place them on yourself, or they are demands placed by family members, not setting some boundaries on what you can and cannot do can increase your burden.

## ● WHEN TO ASK FOR HELP

Caregiving burnout is sneaky. Often by the time you realize you need help, you are already overwhelmed and the ability to make decisions and coping with challenges can be more difficult. Some people don't ask for help until they are in a crisis. Waiting to that point reduces the chances of having options. Not only will your loved one's needs continue to increase, but you will also have changing needs, abilities, and limits of your own to consider.

## ● HOW TO ASK FOR HELP

**MAKE A LIST/CALENDAR:** Make a list of tasks that would be helpful to you such as transportation, grocery shopping, chores, errands, walking the dog, or spending time visiting with your loved one while you rest or go do something for yourself. Keep it up to date and give people options. Post it and allow others to share it.

**CONSIDER WHO YOU ASK:** Some tasks can be addressed by friends, family, or volunteers and others might be better hired out.

**BE CLEAR:** Make a specific request and be clear in what you are asking for and give options, so they see that you are flexible.

**BUILD YOUR SUPPORT NETWORK:** There are some that might seem obvious like friends or family, but think outside the box about others who might be able to help. Are you involved in a church or synagogue that has a ministry that helps? Many communities have service organizations that provide support services to older adults. Check with your local Area Agency on Aging for a list. Some supports can be formal such as food delivery services, yard services, home care, adult day care, etc.

**SHOW YOUR GRATITUDE:** Saying thanks through cards, buying lunch or other ways of showing appreciation for the help others give goes a long way!

## ● TYPES OF SUPPORT

**FORMAL SUPPORT:** Provided by individuals or organizations that you either pay or are provided by a professional. Examples include: hired companion services or talking with a social worker.

**INFORMAL SUPPORT:** Support provided by people who are in your personal social network such as family, friends, neighbor, church, community, or support group.

## ● BUILDING YOUR TEAM (SUPPORT SYSTEM)

**FIRST STEPS:** If you haven't asked for help yet, there is no better time than the present. Think of something small to begin with and who you might ask.

What type of support do I need?

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What task(s) do I need help with?

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Who can I ask? Where can I get it?

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When am I asking? Set a time:

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**Don't forget to also plan for emergencies.**

If you happen to need help for yourself because you are sick or need hospitalization, who do you call (especially in the middle of the night) to be with your loved-one?



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NAME: \_\_\_\_\_ DATE OF BIRTH: \_\_\_\_\_

PHONE NUMBER: \_\_\_\_\_ EMAIL: \_\_\_\_\_

PHARMACY NAME: \_\_\_\_\_ PHARMACY PHONE NUMBER: \_\_\_\_\_

ALLERGIES TO MEDICATIONS: \_\_\_\_\_

APPROVED RELEASE OF INFORMATION (NAME AND PHONE): \_\_\_\_\_

Name of Medication	Description of Medication	Dosage	Number of Pills	As Needed	Time	Time	Time	Time	Time	Special Instructions	Purpose of Medication	Prescriber Name & Number	Pharmacy Name & Number

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## Communication Tool



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## What PMD Alliance is All About

We bring an arms-open, hand-in-hand, “Yes, and...!” mentality to every aspect of our work. We believe that no breakthrough exists in a vacuum, and no person with a movement disorder ever rides the wave of this journey alone.

We’re a partnership-based organization wholly devoted to exuding inspiration - for those with a movement disorder, their care partners, adult children and the ecosystem that supports us all. It’s about listening and engaging in a people-powered conversation. We will inspire you to take new leaps and strengthen your personal care team.

To our core, PMD Alliance believes that no one with a movement disorder truly thrives by him/herself. Going forward, movement and connections become like manna that nourishes your best life. Every day becomes a team effort, and we want to be part of your team in three ways: through in-person events, community-based support, and online opportunities.

Using our continuum of services and programs (based on the Movement Disorder Care and Support Ecosystem© - found on the last page), you will always be close to PMD Alliance and our free (yes, FREE!) resources, no matter the distance. With hundreds of programs designed just for you, we hope you take time to connect.

## How We Work

We see our job as providing tools (like this one), information, resources, and connections that give you easy access to information and inspiration. We want you to live with Parkinson’s, not for it, so our tools help you effectively focus on PD, then get on with living!

## What We Believe

People are more than their disease.  
Transparency is a cornerstone of trust.  
Partnership offers collective success.  
Sustainability is the essence of organizational health.  
Stretching and risk taking are imperatives.

## Connect with Us

[www.PMDAlliance.org](http://www.PMDAlliance.org) • [info@pmdalliance.org](mailto:info@pmdalliance.org)  
(800) 256-0966



# SYMPTOMS TOOL

*adapted from Bunch's Symptoms List*

**NAME:** \_\_\_\_\_

Nothing is more important than communication when navigating Parkinson disease. At first glance, this emPowered!® booklet may look like it's a symptoms checklist, but it's really much more. It's a tool to help families, loved ones, and physicians communicate effectively with each other. With clear communication, it's much easier to navigate the ups and downs and physicians can more effectively address your concerns.

It should take no more than 10 minutes to complete each use of this tool. We strongly encourage every person to complete the checklist separately (person with Parkinson's, care partner/spouse, adult children, family/ friends). Once completed, meet together and discuss what each of you have noticed. After completing your discussion, fill out the Snapshot Tool and forward it to your doctor. Everyone will be on the same page. Ideally, you will complete this tool quarterly and have shared discussions at those times.

## How to complete the tool

- + Review the various symptoms.
- + Place an **X** asterisk if you experience the listed symptom some of the time.
- + Place an **A** mark if you experience the listed symptom nearly all or all of the time.
- + Leave the box empty if you experience the listed symptom rarely, never, or it does not bother you.

The goal is to surface a handful of issues that present significant challenges impacting your quality of life. Care partners, your input is important too. Please fill out a separate document to identify which symptoms impact your quality of life or what concerns you the most.

Once each person has completed their list, sit down together and talk. When you recognize issues and challenges noted by one or more of you, it strengthens your "personal team" and improves your interaction with the rest of your care team.

**Effective communication is transformative!**

**Let's DO this!**

# ACTIVITIES OF DAILY LIVING (ADL)

Date    Date    Date    Date

Blank = rarely, never, or not bothersome • X = sometimes, somewhat bothersome  
A = frequently, always, very bothersome

				<b>Acid Reflux/Heartburn/Indigestion</b>
				<b>Appetite:</b> increased or reduced
				<b>Chewing/Choking:</b> difficulties keeping food moving toward the throat, aspirate food into lungs
				<b>Communication:</b> slow at finding/remembers the right word - Aphasia
				<b>Cramping/Burning/Pins &amp; Needles:</b> toes, legs, neck, etc -Dystonia
				<b>Daytime Sleepiness:</b> excessive - EDS/Somnolence
				<b> Drooling:</b> excessive saliva - Sialorrhea
				<b>Dry Mouth:</b> excessively dry, cheeks may 'stick' to your teeth - Xerostomia
				<b>Fatigue:</b> physical/mental weakness
				<b>Freezing in Position:</b> temporary, feet stuck to floor, hands won't release - Akinesia
				<b>Light Sensitivity:</b> pupillomotor, more sensitive to light - Photophobia
				<b>Nasal Draining:</b> unexplained, often in just one nostril
				<b>Numbness/Tingling:</b> generally arms and/or legs
				<b>Pain:</b> burning, scalding, stabbing, insects crawling on the skin
				<b>Sexual Dysfunction:</b> men & women, less desire for sex, lower testosterone levels
				<b>Sleep/Insomnia:</b> awoken often, can't fall/stay asleep
				<b>Sleep Apnea:</b> snoring/stoppage of breathing
				<b>Sleep Problems:</b> frequent awakening/early awakening
				<b>Smell - Loss of:</b> can diminish to zero - Anosmia/Hyposmia
				<b>Speaking:</b> soft or low volume - Hypophonia
				<b>Speech:</b> hesitant/monotone/slurred, difficult articulation - Dysarthria
				<b>Swallowing:</b> difficulty swallowing, risk of aspiration - Dysphagia
				<b>Sweating:</b> increased or excessive, "night sweats" - Hyperhidrosis
				<b>Temperature Sensitivity:</b> hot and/or cold
				<b>Thirst:</b> excessive/sporadic/constant and extreme "dry mouth" - Polydipsia
				<b>Turning/Rolling Over in Bed:</b> difficulty turning and moving in bed
				<b>Urination:</b> frequently, incontinence, urgency, frequently at night - Nocturia
				<b>Vision:</b> blurred/double, depth perception, dry eyes, eye strain, light sensitivity - Diplopia
				<b>Vivid Dreams:</b> may act out, may become dangerous to self or others
				<b>Writing Smaller:</b> difficult to read - Micrographia

**Other symptoms that I have questions or concerns about:**

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# MENTATION, BEHAVIOR, MOOD

Date    Date    Date    Date

Blank = rarely, never, or not bothersome • X = sometimes, somewhat bothersome  
A = frequently, always, very bothersome

Date	Date	Date	Date	
				<b>Aggression:</b> hostile or violent behaviors or attitudes toward others
				<b>Anxiety:</b> worry, concern, apprehension, angst
				<b>Apathy:</b> lack of interest (ennui), enthusiasm, concern
				<b>Cognitive Function:</b> diminished problem solving, decision making
				<b>Comprehension:</b> difficulty understanding
				<b>Delusions:</b> misconceptions, misbelief not backed by reality, faulty judgment
				<b>Dementia:</b> impaired mental ability impacting daily activities, memory and reasoning
				<b>Depression:</b> despondency, dejection
				<b>Fear:</b> alarm, panic, terror, fright, dread, distress
				<b>Frustration:</b> exasperation, annoyance, vexation, irritation
				<b>Grief:</b> deep sorrow, sadness, anguish, distress, heartache, woe, despair
				<b>Guilt:</b> sense of wrongdoing, misconduct, shame, regret
				<b>Hallucinations:</b> seeing/hearing/sensing something not present
				<b>Impulse Control:</b> compulsive spending, eating, sex, gambling, hoarding, etc
				<b>Inappropriate crying/laughing:</b> tearfulness, outbursts of laughter - Pseudobulbar Affect
				<b>Insecurity:</b> lack of confidence, self-doubt, nervousness, uncertainty
				<b>Internal Restlessness/Tremor:</b> difficult to sit still - Akathisia (not Dyskinesia)
				<b>Irritability:</b> short tempered, testy, ill humor
				<b>Memory Changes or Loss:</b> slower at recalling words/ideas
				<b>Mood Swings:</b> abrupt changes in temperament, emotional instability
				<b>Panic Attack:</b> acute and disabling anxiety
				<b>Self Esteem, (low):</b> less confidence in one's own worth or abilities, self respect
				<b>Sexual Desire (less):</b> lacking motivation, need, attraction, lust
				<b>Startle Easy:</b> very easily surprised - Hyperekplexia
				<b>Suspicious Thinking:</b> unfounded fears, distrust of others, conspiracy mindset - Paranoia
				<b>Thinking:</b> slow and deliberate, impaired - Bradyphrenia
				<b>Time Perception:</b> difficulty determining time spans
				<b>Worry:</b> overthinking, brood, panic, lose sleep, fret, stew

**Other symptoms that I have questions or concerns about:**

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# Motor

Date      Date      Date      Date

Blank = rarely, never, or not bothersome • X = sometimes, somewhat bothersome  
A = frequently, always, very bothersome

Date	Date	Date	Date	
				<b>Balance:</b> movement loss, falling backwards - Retropulsion/Dysequilibrium/Ataxia
				<b>Coordination:</b> less coordination, especially fine motor - Ataxia
				<b>Dyskinesia:</b> involuntary movements, twitches, jerks, twisting, rocking
				<b>Eyes:</b> dry, decreased blinking, difficulty opening, blurred vision
				<b>Facial Expression:</b> "masked face," no expression - Hypomimia
				<b>Foot and Toe Cramping:</b> painful cramping - Dystonia possible
				<b>Gait:</b> Freezing of Gait (FOG) - sudden inability to move legs, small steps, can't move forward
				<b>Muscle Jerks:</b> muscle jerks or spasms - Dystonia
				<b>Pill Rolling:</b> rubbing the thumb with the forefinger - Pill Rolling Tremor
				<b>Posture Instability:</b> hunched, stooped over, problems standing/walking
				<b>Restless Leg Syndromes (RLS) + Arms:</b> constant moving of limbs
				<b>Rigidity:</b> less range of motion of arms, legs, and torso - Akinesia
				<b>Rising from Seated Position:</b> difficulty getting up, not in balance
				<b>Slow Movement:</b> slowness or limited range of movement - Hypokinesia/Bradykinesia
				<b>Stiff Shoulder:</b> frozen or painful shoulder
				<b>Tremor (at rest):</b> arms, face, hands, head, jaw, legs, voice
				<b>Walking:</b> foot drag usually on one side - no arm swing, shuffle, slow, stiff
				<b>Weakness:</b> arms and legs - Generalized Asthenia

# Other Nonmotor

Date	Date	Date	Date	
				<b>Allergies:</b> increased number of allergies
				<b>Back Pain (lower):</b> pain from mild to severe aches, spasms
				<b>Blood Pressure (low):</b> BP drops when standing, dizzy, falls
				<b>Bowels:</b> incomplete elimination or absorption of nutrients, impaction
				<b>Breath:</b> shortness, shallow, panting, wheezing, hyperventilation - Dyspnea
				<b>Constipation:</b> bowel movement less than 3x/week or reduced frequency
				<b>Digestion:</b> difficulty fully digesting food - Gastroparesis
				<b>Dizziness, Fainting, Lightheadedness, Vertigo</b>
				<b>Edema:</b> swelling of legs, retention of excess water
				<b>Heart Palpitations:</b> heart races intermittently
				<b>Nausea, Queasiness, Vomiting:</b> with or without medication
				<b>Neurogenic Orthostatic Hypotension:</b> dizzy when standing
				<b>Punding:</b> continually taking something apart and putting it back together, repetitive
				<b>Skin:</b> dandruff, flaky, itchy, oily, rashes, red - Seborrhea, Shingles
				<b>Tearing:</b> excessive tearing for 20-40 seconds from only one eye or both

# LET'S TALK ABOUT IT

*Tips for communicating more effectively with your physician & medical team*

It's not unusual to be slightly uncomfortable when talking with your doctor. In fact, research shows that many patients are often afraid to share concerns with their physicians out of fear that they will be perceived as a complainer. The tips below can help you and your loved ones communicate more fully and comfortably with your care team.

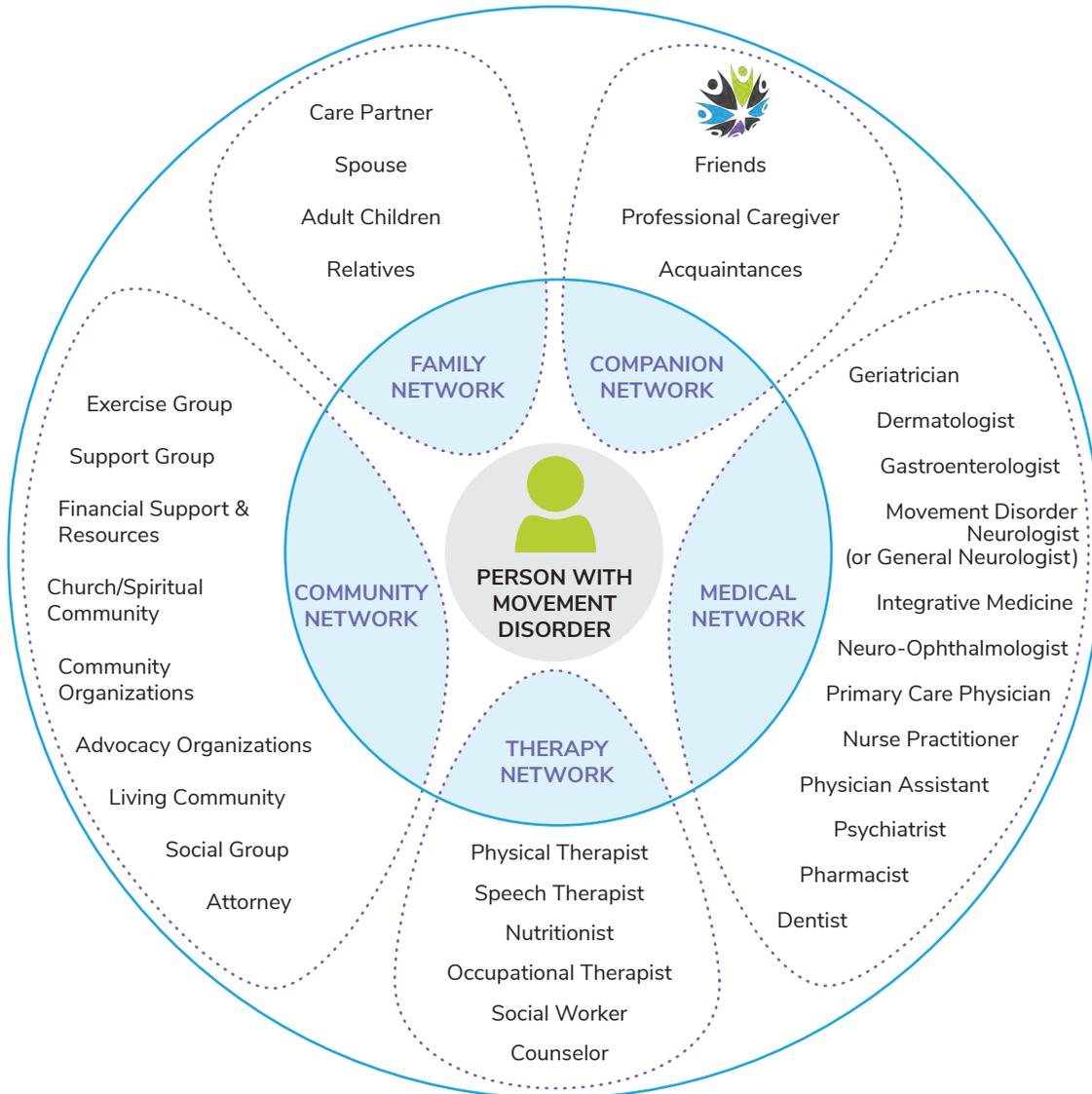
- + Most physicians find their greatest self-worth and value when they can help, but your doctor can't help you address issues that s/he doesn't know about. Telling the truth - good or bad - helps everyone get the most out of the visit, including your doctor.
- + Many people believe that their doctor will bring up all the issues that matter during an appointment. That may have been the case when a physician could spend 45 minutes or an hour with a patient, but it isn't the reality anymore. Doctors often need to rely on you to surface issues that they can then respond to.
- + Remember, it's a team effort. The person impacted by the disease, the care partner, adult children, and friends will all see different aspects of the disease. Getting and sharing input from a variety of sources can help a physician.
- + Synergy matters. It's important to develop a truthful, open connection with your physician. As in any long term relationship, trust and rapport make it easier to talk honestly to each other.
- + If you find it difficult to think of issues to talk about at your appointments, you can:
  1. Bring this booklet with you and use it as a talking guide.
  2. Make a copy of this booklet for your physician or ask the front desk staff to send the physician a note in advance of your appointment.
  3. Give a list of your concerns to the medical person that takes you to the exam room so your doctor is prepared when s/he comes in.
  4. Take notes while talking with the doctor. Later, when you want to recall the conversation, your notes will make it easier for everyone.
- + It's your health. You're in charge. You deserve reliable, trustworthy and responsive health care. Your part in that effort to openly share information about your condition, your concerns, your questions, and your goals.

## Some phrases to get the conversation started:

- + Since my last appointment, these are the top three to five issues that have impacted my quality of life . . .
- + My number one thought/feeling/experience over the last three months has been . . .
- + Since my last appointment, these are three ways I've tried to bring more quality to my life . . .
- + My biggest worry since my last appointment has been . . .

# MOVEMENT DISORDER CARE & SUPPORT ECOSYSTEM<sup>©</sup>

Parkinson & Movement Disorder Alliance (PMD Alliance), a nonprofit, independent organization, delivers high impact programs to the public, healthcare providers, and healthcare/residential facilities. With attention on the whole system, we re-ignite vitality, create resiliency, and strengthen connections.





## emPowered!® Communication Tool | Collective Snapshot

**Instructions:**

- Individually, complete the emPowered!® Communication Tool
- Discuss and review completed tool with your loved ones
- Fill out the Collective Snapshot with the compiled information
- Bring completed Collective Snapshot to your doctor's appointment

DATE FORM COMPLETED: (should be within 3 days of the appointment) \_\_\_\_\_

PATIENT NAME: \_\_\_\_\_ DATE OF BIRTH: \_\_\_\_\_

COMPLETED BY: \_\_\_\_\_ Patient \_\_\_\_\_ Care Partner \_\_\_\_\_ Other: \_\_\_\_\_

The following symptoms have **gotten worse** or create more problems in my life since my last appointment:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

The following symptoms have **gotten better** since my last appointment:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

If I could **change one symptom** or complication right now, because it's seriously impacting my wellbeing and quality of life, it would be:

\_\_\_\_\_  
\_\_\_\_\_

Something you should also know, or my most significant question is:

\_\_\_\_\_

# Creating a Personal Health Record



## WHY YOU SHOULD HAVE ONE:

A personal health record (PHR) is a file you create either electronically or in hard copy form that contains all the important records regarding your or your loved-one's health. The purpose of creating a personal health record is so you have all your medical history available in one place which will enable you to accurately share the details of your or your loved-one's medical history easily.

## PERSONAL HEALTH RECORD VS. PATIENT PORTALS

Many medical practices and healthcare systems now offer patient portals and personal health records that are tethered to the Electronic Health Record (EHR). Patient portals are secure online websites that give you access to personal health information (PHI) anywhere there is an internet connection using a password. These allow you to view summaries of visits, medications, request prescription renewals, view lab results and may also offer email with the healthcare team. The downside is when you have multiple providers that are not using the same portal and EHR system, which is where having your own PHR comes in handy.

## OPTIONS FOR CREATING A PERSONAL HEALTH RECORD:

- Save copies electronically all your records to your computer or a cloud-based program like Google Drive.
- Create a three-ring binder of all your information with divided sections.
- Use an online program or app on your computer, smartphone or tablet.

*\*many physician practices now offer portals but it is still a good idea to have copies saved elsewhere.*

Thank you to our annual partner:

**KYOWA KIRIN**



**PMD Alliance**  
Parkinson & Movement Disorder Alliance

 (800) 256-0966

 [info@pmdalliance.org](mailto:info@pmdalliance.org)

 [www.pmdalliance.org](http://www.pmdalliance.org)

# Creating a Personal Health Record

## WHAT A PERSONAL HEALTH RECORD SHOULD INCLUDE:

- Personal information including full name and date of birth.
- Blood type (if you know it)
- Emergency contacts
- Contact info for all healthcare providers
  - Including specialists, dentist, eye doctor, etc.
- Insurance information
  - Copy of card, prescription card, summary of insurance coverage including claims and EOB
  - Please note: medical bills often have errors and you should closely monitor your bill and compare against insurance claim.
- Medications with dosages, and prescriber name Including supplements
- Any allergies
- Important family history
- Last physical exam
- List of all significant illness, surgery, diagnoses
- Summary reports from recent doctor visits
- Test results, lab results, dental and eye records, and immunization records
- Notes section for appointments, contacts with insurance company, etc. This should also include your appointment snapshot document

www.



### WEB BASED TOOLS:

- Healthspek  
[www.healthspek.com](http://www.healthspek.com)
- MTBC PHR  
<https://phr.mtbc.com>



### SMARTPHONE APPS:

- Capzule PHR
- Tidy Health PHR
- talkPHR



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