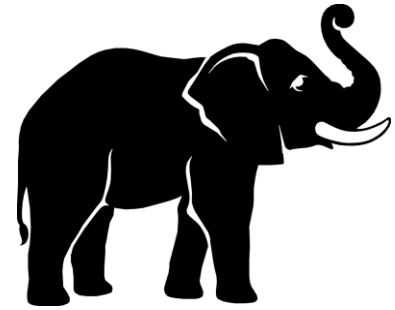


# How To Eat An Elephant

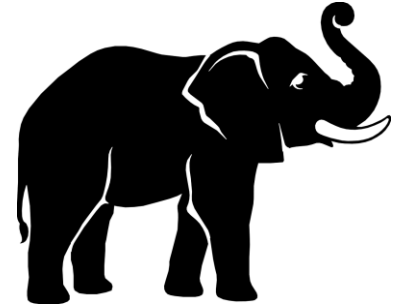
# How To Eat An Elephant



My husband, CW, was finally diagnosed with Parkinson's disease in 1999, after 2 years, seeing 5 doctors, and receiving 5 different diagnoses.

After CW's Parkinson's diagnosis, we realized that we needed to manage the "elephant" of having multiple medical specialists, medical providers, medical services, etc.

This is how we learned by trial and error to manage our own elephant journey.



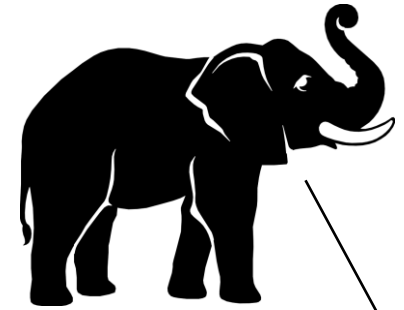
**Question:**

How do you eat an elephant?

**Answer:**

One bite at a time.

# Our Elephant



## **On-Going**

Family Doctor / Internal Medicine

Neurologist

Neurologist / Movement Disorders – PD  
Specialists

Cardiovascular / Cardiologist

Endocrinologist

Urologist

Lab

Pharmacist

Dentist

Orthopedic surgeon

Ophthalmologist

Dermatologist

**ER Staff**

## **Therapy**

Speech Pathologist

Speech Therapist

Physical Therapist

Occupational Therapist

## **Surgery**

Neuro-Surgeons

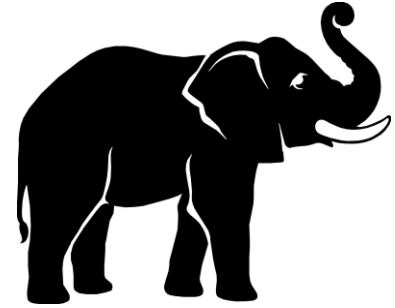
Surgeon - Gasterology

Anesthesiologists

Hospital/Ward Pharmacist

Ward Nurses & Staff

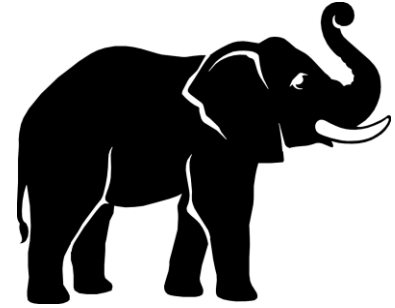
# It Is All About - You



No Matter Wherever You Are -- Do You Have The Following Information Easily Available In Case Of an Emergency?

- Your name, address, telephone number
- ICE (In Case of Emergency) - Your next of kin or Contact Name(s) – Have you put this information in your cell phone's contact list?
- Do you have the ID cards for your Medical & Hospital Insurance Information (Medicare, Medicaid, Private Insurance) and Prescription Insurance?

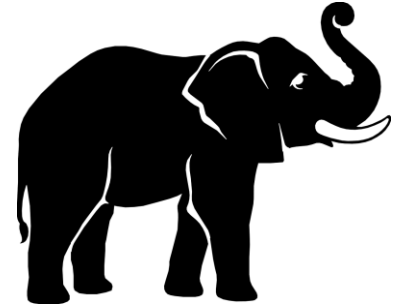
# More All About – You



Do You Have A Summary of Your Medical History and Information

- Current Rx/medications summary, who prescribed them and for what illness/symptom
- Medical / Surgical / Procedures History – A list of the dates of any illnesses, what was the illness/injury, attending doctor, where at, and any comment or other information
- A list of your current doctor's name, address, phone #, specialty
- Your Blood Type
- A list of your Allergies versus Side Effects
- A list of any injections (e.g., Flu, Pneumonia, Tetanus) and the date when last taken

# It Is All Legalese - or - Not

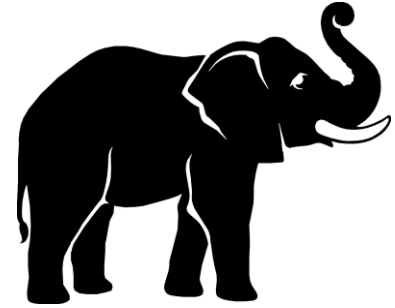


- Health Care Power of Attorney
- Living Will
- Advanced Directives
- DNR (Do Not Resuscitate directions)
- HIPAA (Health Insurance Portability and Accountability)
- Funeral Wishes
- Obituary Draft

Who else knows where all these documents are?

Do you have a copy of all your legal paperwork in your car(s) and / or in your suitcase / purse when you travel?

# Lists Are Your Friend

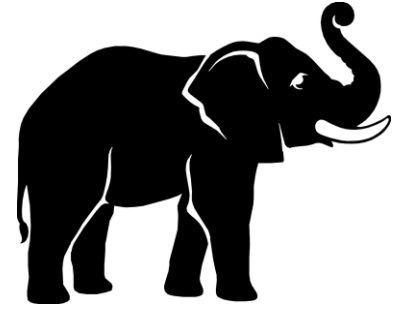


## Examples Of Lists You May Want To Make & Keep

- Your medical history & information
- Your medications – prescription and over-the-counter
- Your doctor visit questions – put most important ones first
- Any medical problems and concerns – identify those that you think are or may be Parkinson related
- Things you need to research or understand – medical terms, etc.
- Action items of what you need to do and when
- Action items of what someone should have done and when
- What information that should flow/pass to all of your medical professionals / providers / services (your team members)



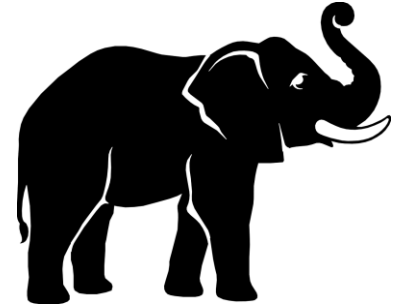
# Electronic Devices and You



PC's – Laptops – Netbooks – Tablets / iPads – Phones

- Create your lists, records, or any other type of documents
- Speech recognition is available (speech-to-text and text-to-speech). Examples are Dragon, Word, or apps like Speak Up and Speech4Good
- Ability to do research – Google – PDF (Parkinson's Disease Foundation) – NPF (National Parkinson's Foundation) – MJF (Michael J. Fox Foundation) – NIH (National Institute of Health) – and of course the Columbia Parkinson's Support Group website.
- Warning – Be Careful - There is some false, erroneous, and incorrect information on the internet.
- Apps – Some examples are: PocketRx – WebMD – PD Toolkit – PD Central - Medscape

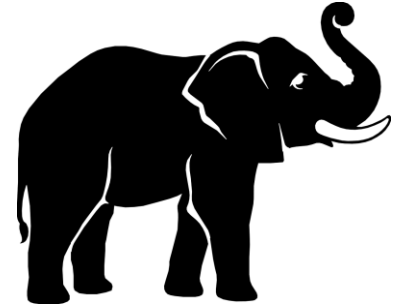
# Symptoms — Listen to your body



Keep specific data and information — in a notebook or on an electronic device

- When did it first begin
- Where is the symptom happening — location on your body
- How do you feel — be very specific
- What do you think caused this
- What makes it better or worse — provoking events
- Do you have a high/low temperature

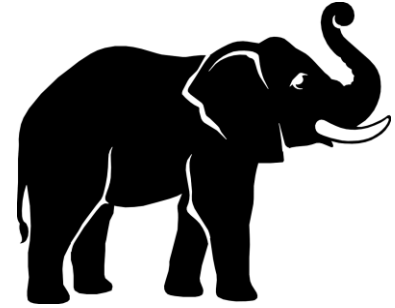
# Symptoms — Listen to your body (continued)



## **Keep specific data and information – in a notebook or on an electronic device**

- Timing – how often does it happen – duration / how long does it last
- Pain (scale of 1 to 10) – type of pain, intensity, where
- Unusual other body reactions
- What medications are you taking – Rx and Over-The-Counter including herbs – When and How much
- Does it happen before, during, or after you eat
- What things have you tried doing to treat the problem – have they made a difference

# Game Plan



Have a game plan before you see any doctor

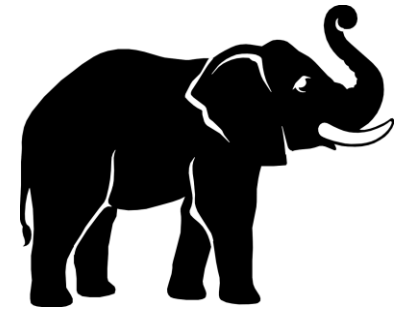
**What are your expectations for your doctor visit? What do you want to happen from your visit?**

**New doctor? Check them out before your visit – for example**

- Find out their qualifications and education – Are they Board Certified?
- Are they Hospitalists – Do they have hospital privileges
- Do they have any complaints filed against them
- What is their track record – How many surgeries vs surgical problems
- How long have they been practicing

**After each doctor's visit, do a postmortem** - Review the visit in your notebook. Did your visit meet your expectations? Now is the time to start a list of questions for the next visit.

# When You See A Doctor

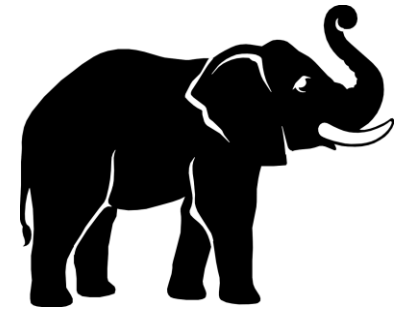


## Things to take with you to the doctor's office

- Your elephant notebook all about you and your medical journey
- For every a doctor visit have someone go with you – spouse, significant other, friend, neighbor, etc. They are to listen, take notes, and make sure all your questions are covered – using your elephant notebook
- Symptom Information List
- Medical History / Information List
- Current/Previous Test Results (These an be sent ahead of time, or you can carry copy with you)
- Insurance information cards
- Drivers License or picture ID

# When You See A Doctor

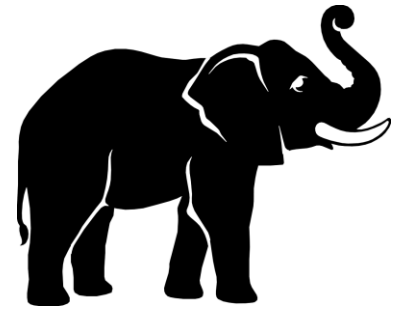
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## Things to take with you to the doctor's office

- Drivers License or picture ID
- List of Prescription/medication/OTC/herb information – (Note: Some specialists/doctors require seeing the actual bottles/containers)
- List of questions you want answered, with most important item listed first in case you don't get through the whole list
- Bring copies of legal documents – Living Will, Medical Power of Attorney, and don't forget about putting who can have access to your information on the HIPPA forms
- **Reminder** - don't forget the Buddy System - **always** have someone go with you to listen, take notes, and make sure all your questions are covered – use your notebook

# It Is All About Your Team's Communication



**Be assertive** about requesting that all your doctors involved, must communicate with each other.

**Team communication is critical.** It is important to find out early in the game, that everyone on your team is willing to work together with each other, and with you on any PD issues, or any other aspects of your medical care.

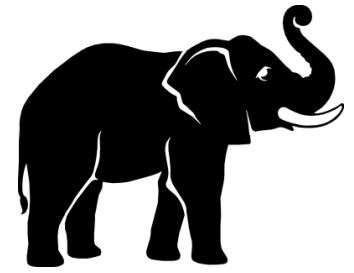
**You may need to “train” your doctors.** Let them know that team communication is very important to you. Remind the team members often about keeping all the other members up-to-date.

**Test if communication is really happening.** Ask each team member during your visit with them if they have received your “xyz” tests and any notes from the other members. Ask them “What do you think about the test results?”

**Bring extra copies of test results with you.** If the team member did not get the results, then give them extra copies of the test results you brought with you.

**If anyone is not a team player.** Perhaps you need to get another team member!

# Testing – Testing - Testing



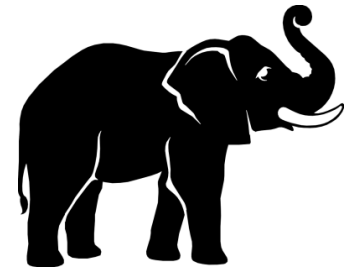
Your Doctor orders some tests -- Ask the doctor questions and have your Buddy write the doctor's responses in your elephant notebook

- Why do I need this test?
- What does this test measure?
- What could happen if I don't have the test?
- Are there any alternative tests?
- Will my insurance pay for the test – how much?
- How accurate is the test?
- How frequently does this test show false positives (the test shows a problem that doesn't exist) and false negatives (the test says there's no problem, but there is)?



# Testing – Testing – Testing

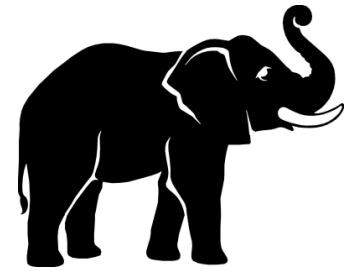
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**Your Doctor orders some tests -- Ask the doctor questions and have your Buddy write the doctor's responses in your elephant notebook**

- How is the test performed?
- What kind of pain or discomfort involved?
- What can go wrong during the test?
- How should I prepare for the test?
- How will I feel after the test and how soon can I get back to normal?
- When will I get the results and what are the ideal results we want to see?
- What's the next step after the testing?

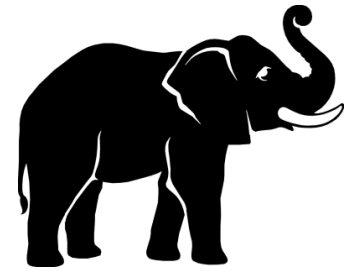
# Test Results



- You should look at all the test results and verify that the information about “you” is consistent and true!
- When the doctor reviews the results with you, your Buddy should write down any information in your elephant notebook

Don't hesitate to ask the doctor to spell any words you don't know

- Get copies of everything - For your own files !!!
- Have copies of the test results sent to all of the other doctors on your team – including your family doctor – and your regular specialists (i.e., neurologists)
- Warning! Use the internet with “caution” when you research what the test results means



# Opinions – Everyone Has One

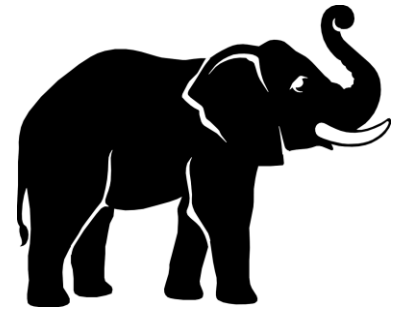
If you don't feel comfortable about your doctor visit, test results, diagnosis, etc., etc. -- get 2<sup>nd</sup> or 3<sup>rd</sup> or as many opinions as you need to feel confident.

This applies to even if you don't feel comfortable or confident any member of your team. Get someone else.

Remember, you are the customer. You are paying to get the best medical care for you. It is your life!

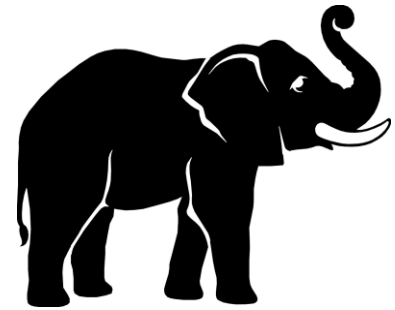
It is better to be safe than sorry!

# General Comments



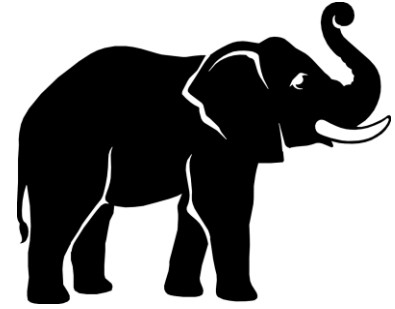
- PD patients can react very differently (in dangerous, even in fatal ways) to drugs used to treat PD in conjunction with other "common" drugs such as those used for anesthesia, pain, blood pressure, heart, and others. Always research any side effects for all your medications – prescriptions, over-the-counter, vitamins, etc. Develop a relationship with your pharmacist, they can be one of your best resources.
- Our support group recommends PD patients to see a Movement Disorder PD specialist; because they see many PD patients under a wide variety of conditions. They will be more likely to know what may be causing a particular symptom or problem. They also know about any new research, procedures, medications, etc.
- A PD patient may require the amount and timing of PD medications be adjusted due to a number of variables – PD keeps progressing – patient ages – etc.

# General Comments



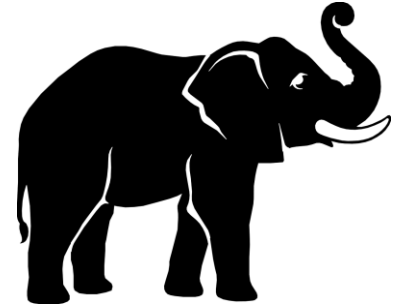
- A newly diagnosed PD patient and/or their caregiver should not adjust the medications without talking to their neurologist/PD specialist about some sort of adjustment strategy, formula, of whatever they can work out. After time, the patient and/or their caregiver will be more astute about medication adjustments.
- A Parkinson Support Group can provide a wealth of information to the patient and their caregivers. Attend meetings with family, caregiver, friends, neighbors, etc. They more they know the better they can support the patient.
- Visit PD websites and learn as much as you can. Become informed and aware.
- Don't forget that you have hired and are paying your doctor or medical provider. If you are not satisfied or don't have confidence – then by all means you are entitled to hire another doctor or medical provider. Warning – don't change doctors until you have a new doctor! A bird in the hand....

# Things CW and I Could Have Done Better On Our Elephant Journey



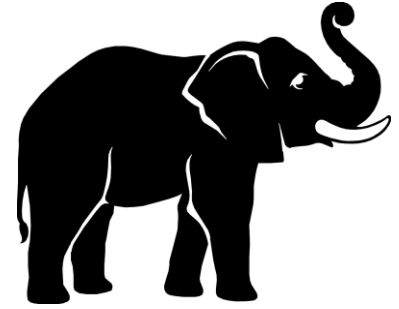
- **We should have kept all the “fluid” information we wrote down in a “single” notebook** – otherwise you may end up with too many little pages or scraps of paper to keep up with as you eat your Elephant
- **We should have followed-up on doctor’s appointments sooner** – should have called them instead of waiting for them to call us
- **We should have followed up on test results sooner** – should have called instead of waiting for them to call us
- **Don’t assume anything** – ask questions, ask questions....

# Last But Not Least



- **Only You are responsible for You** - You are the key to your own medical care
- **Communicate clearly and often** – Don't hesitate to ask questions, even if you have to ask them multiple times
- **Follow-up continuously** – Be persistent
- **Do your homework** – Become informed
- **A support system is important** – Friends, family, and a support group do matter and can help you.
- **Angels and Sometimes Luck** are always part of the picture

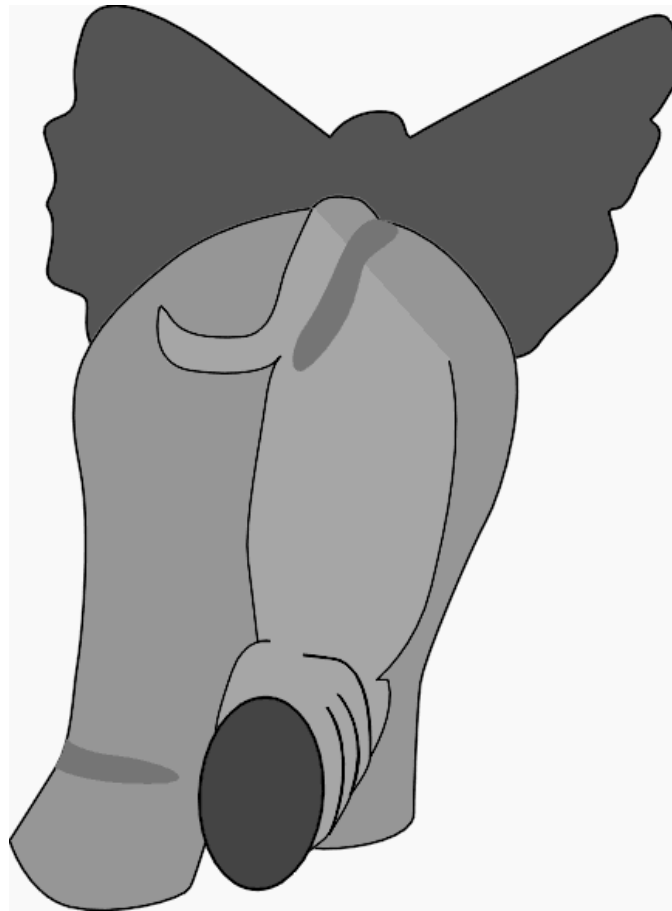
# You Are Unique



“Every PD patient is unique and everything about his or her disease is specific to him or her and ONLY to him or her. PD has only one time - NOW, the present. The previous hours do not forecast how you are going to feel. The only thing that is predictable about this disease is its unpredictably.”

~~Written by Rick Kramer and Margaret Tuchman~~





# THE END