



CAREGIVING FOR PARKINSON'S

LIANNA MARIE – WWW.ALLABOUTPARKINSONS.COM



My Mom Val
(Lived 30 years
with Parkinson's,
including 8 with
dementia)

Mom's Journey

- ▶ Diagnosed in her late 40's (tremor in pinky finger)
- ▶ Was told by doc she "had the good kind" of PD
- ▶ Disease progressed slowly
- ▶ Learned by trial and error
- ▶ Wrote a book with Lianna (year 15)
- ▶ Diagnosed with PD dementia in her late 60's
- ▶ Lived 8 years in long-term care and passed away peacefully after short bout of pneumonia

Mom's Team For 30 Years Included

- ▶ Neurologists
- ▶ Ophthalmologist
- ▶ Physiotherapists
- ▶ Massage therapists
- ▶ Counselors
- ▶ Home care workers
- ▶ Paid caregivers
- ▶ Loving husband
- ▶ Family
- ▶ Palliative Care Physician*

THREE TAKEAWAYS



PLAN FOR PD



KNOW WHAT
MAKES THEM
GO!



MAKE LIFE
EASIER



PLAN FOR PD

CAREGIVING FOR PARKINSON'S

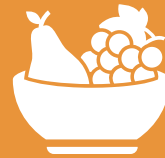


Parkinson's is a
snowflake
disease:
No two cases
are alike

PLAN WHAT YOU CAN



MEDICATIONS &
ON/OFF TIMES



NUTRITION &
EXERCISE



FUN THINGS (DO
WHAT YOU CAN,
WHEN YOU CAN!)

PLANNING FOR PARKINSON'S

“Parkinson's disease medications are as necessary for a Parkinson's patient as insulin is to diabetics.”

– Peter Schmidt, National Parkinson's Foundation

PLANNING PARKINSON'S MEDICATIONS

- ▶ Goal for drug therapy (levodopa) is to increase ON and decrease OFF times.
- ▶ **Know that it takes on average 20-30 minutes for Parkinson's drugs to kick in, but this varies from person to person and can be very unpredictable.** So can how long the ON time lasts. This can depend on everything from how long you've had the disease to what you've had to eat.
- ▶ Plan routines for meds and meals – know what foods your loved one can and can't eat to help the meds be absorbed and plan around that. E.g., high protein meals should be eaten at times when you're not taking levodopa as this amino acid competes for absorption with other proteins.
- ▶ Plan appointments and outings around ON/OFF times.

MEDS ON TIME, EVERY TIME!!

- ▶ One of, if not THE most important thing to remember as a Parkinson's care partner is that **timing** of their medications is **CRUCIAL**
- ▶ **A missed or delayed dose can quickly worsen non-motor and motor symptoms**
- ▶ A delay of even 5 minutes can cause a person to suddenly lose the ability to move, walk, and speak
- ▶ Conversely, doses too close together can result in too much meds in the system = dyskinesia
- ▶ Many hospitals organize medication administration around standardized times and allow meds to be given 30 minutes before or after these times. **But PD medications should be given on the patient's schedule, not the hospital's**

EXERCISE AND PARKINSON'S

“Exercise is an important part of healthy living for everyone, however, for people with Parkinson's disease exercise is not only healthy, but a vital component to maintaining balance, mobility and daily living activities, along with a potential neuroprotective effect.”

– Parkinson's Foundation

EXERCISES FOR PEOPLE WITH PD

- ▶ **ROCK STEADY BOXING** - www.rocksteadyboxing.org
- ▶ **PEDALING FOR PARKINSON'S** - www.pedalingforparkinsons.org
- ▶ **LSVT BIG** - www.lsvtglobal.com/LSVTBIG
- ▶ **YOGA** – www.yogaforpd.com
- ▶ **TAI CHI** – www.taoisttaichi.org/taoist-tai-chi-arts-and-parkinsons-disease
- ▶ **DANCING** - www.danceforparkinsons.org
- ▶ **MORE EXERCISES FOR PD** – Fighting Parkinson's E-book
(AllAboutParkinsons.com/shop)
- ▶ **CHECK WITH YOUR LOCAL PARKINSON'S FOUNDATION FOR EXERCISE CLASSES IN YOUR AREA**



Dancing!
(year 10
with PD)



Going for
a walk
(year 18
with PD)



Playing
piano
(year 25
with PD)



KNOW WHAT MAKES THEM GO!

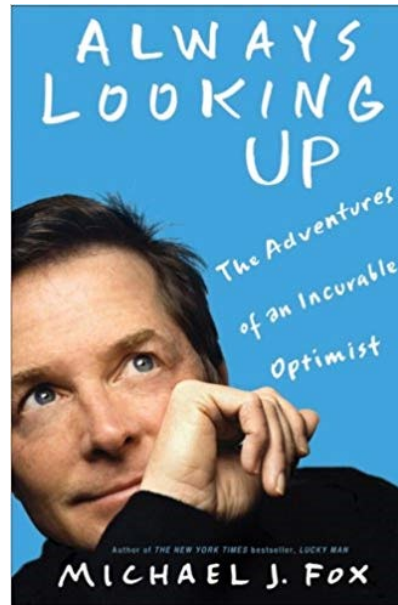
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KNOW WHAT MAKES THEM GO!

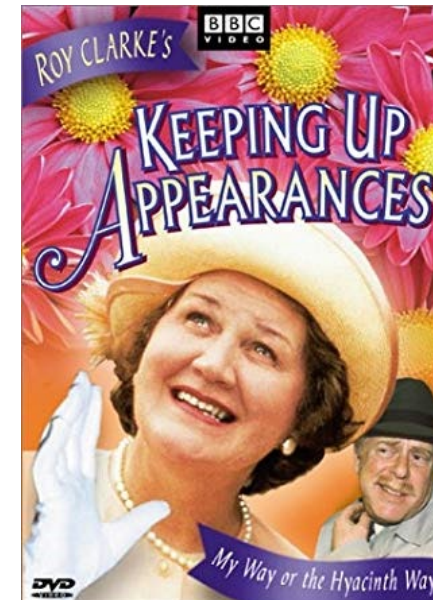
What helps them get moving?



What or who inspires them?



What makes them laugh?





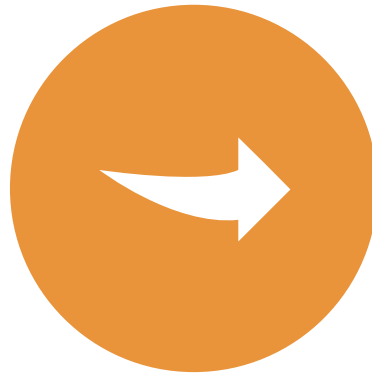
MUSIC IS
A MUST!!!



KNOW WHAT MAKES THEM NOT GO: FREEZING OF GAIT (FOG) TRIGGERS



NARROW
DOORWAYS



CHANGING
DIRECTIONS



CROWDED SPACES

WHAT TO DO ABOUT FREEZING

- ▶ COUNT STEPS AS THEY WALK – One, two, three... March, “left, right, left, right”
- ▶ PLAY FACE-PACED MUSIC WITH A BEAT – Use a smartphone or iPod
- ▶ SUGGEST THEY SING A SONG IN THEIR HEAD – Row, row, row your boat...
- ▶ SUGGEST WALKING SIDEWAYS - Especially through doorways
- ▶ SUGGEST WALKING IN A SKATING MOTION – Slide one foot at a time across the floor
- ▶ TRY USING THE LASERCANE – Bright red line acts as visual cue - www.ustep.com
- ▶ PLACE YOUR FOOT IN FRONT OF YOUR LOVED ONE - Or ask them to visualize something they need to step over
- ▶ BE PREPARED – Know that freezing can occur at any time



MAKE LIFE EASIER

CAREGIVING FOR PARKINSON'S

THE 3 'KNOWS'

1

KNOW PARKINSON'S – Learn the basics of the disease (including non-motor symptoms)

Parkinson's is a Mind Body Disorder

- ▶ Primary motor symptoms (T.R.A.P.): Tremor (resting), Rigidity (stiffness), Akinesia/Bradykinesia (slowness of movement), Postural Instability (loss of balance)
- ▶ Non-motor symptoms can be as debilitating (if not more) than motor symptoms



Examples of non-motor symptoms

- ▶ Depression, anxiety, irritability, apathy
- ▶ Cognitive Impairment (up to 40% have MCI at diagnosis and 80% have dementia 20 years after motor symptom onset)
- ▶ Sleep disorders (insomnia, excessive daytime sleepiness, vivid dreams, talking and moving during sleep, restless leg syndrome)
- ▶ Hallucinations & delusions
- ▶ Pain (many forms)
- ▶ Excessive sweating (without exercise)
- ▶ Constipation & feeling full after eating small amounts
- ▶ Urinary urgency, frequency & incontinence
- ▶ Orthostatic hypertension (drop in blood pressure when standing, light-headedness)
- ▶ Sexual problems
- ▶ Impulsive control disorders (binge eating, excessive shopping or gambling –usually result of medications)

THE 3 'KNOWS'

1

KNOW PARKINSON'S – Learn the basics of the disease (including non-motor symptoms)

2

KNOW YOURSELF – What you can & can't do

KNOW YOURSELF

Know

What are your strengths and weaknesses? Are you naturally a patient person? Or the opposite? **BE HONEST WITH YOURSELF.**

Make

Make time for yourself as a care partner. Keep your life in **balance** as much as you can.

Get

Get in tune with your creative side ("Turn your broken heart into art").

Find

Find a support group (check with moderator first to ensure it would be a good fit).

Ask

Don't feel bad about asking for HELP – you are HUMAN not SUPERWOMAN/SUPERMAN.

THE 3 'KNOWS'

1	KNOW PARKINSON'S (motor & non-motor symptoms)
2	KNOW YOURSELF (what you can & can't do)
3	KNOW YOUR LOVED ONE (ask questions!)

HOW DO YOU WANT TO LIVE?

- Important question to ask, whether you are a person with Parkinson's or a care partner
- What do you want to do?
- Who do you want to do it with?
- What do you want your legacy to be?



HOW DO YOU WANT TO LIVE?

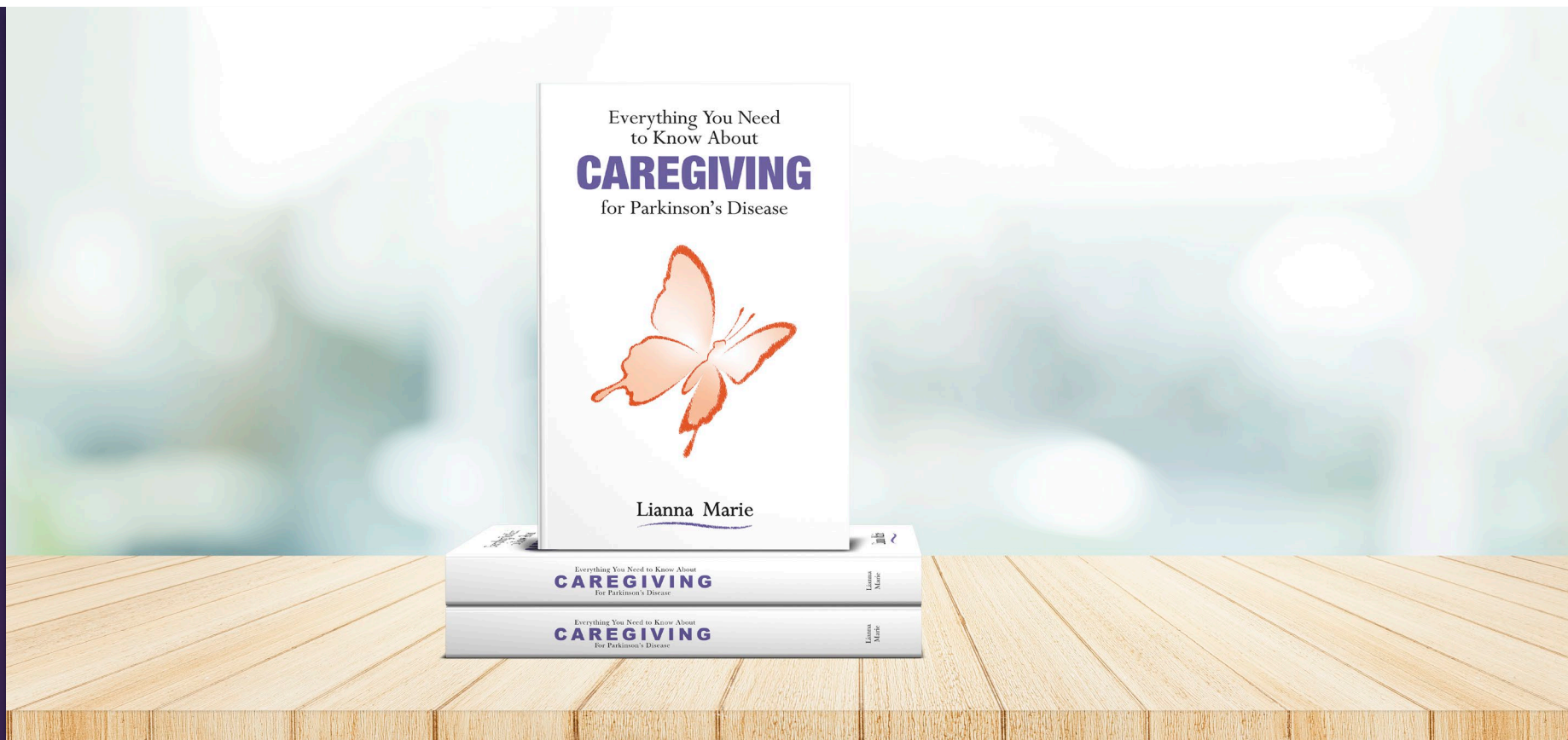
- Important question to ask, whether you are a person with Parkinson's or a care partner
- What do you want to do?
- Who do you want to do it with?
- What do you want your legacy to be?



HOW DO YOU WANT TO DIE?

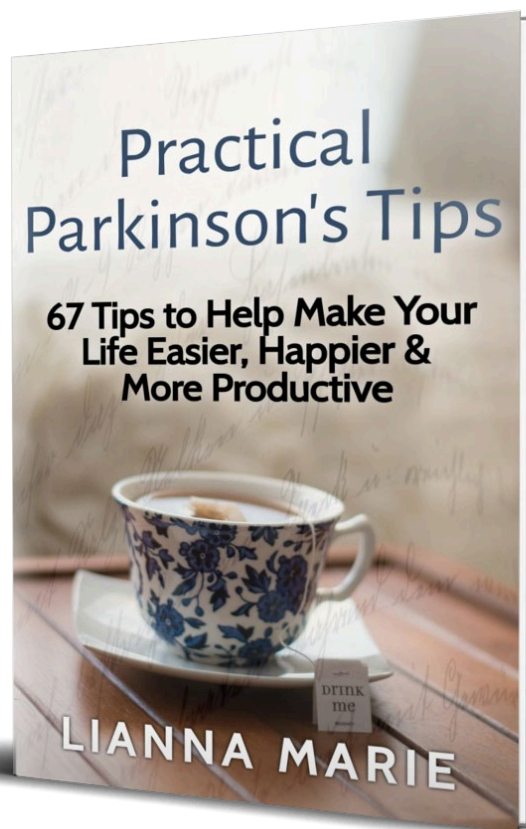
- Where will you be living? Who will you be with?
- Many are so focused on NOT dying that they cease to LIVE





WANT MORE INFO?

EVERYTHING YOU NEED TO KNOW ABOUT CAREGIVING FOR PARKINSON'S DISEASE



THANK YOU!

GO TO OUR WEBSITE AND
CLICK ON "TIPS" TO GET
YOUR FREE E-BOOK!