



Parkinson's Foundation

Advanced PD and Palliative Care in the 21st Century

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November 27, 2018 1pm ET

Better Lives. Together.

Objectives

1. List the symptom burden for people with Parkinson disease (PWP)
2. What is palliative care and is it for me?
3. Advance Care Directives – and why you should have them



The North American Narrative

Individualistic

Strong, independent

Meritocracy –

“Just work harder if things aren't going well, if things don't go well, it's because you didn't work hard enough”



When you only have a hammer in
your toolbox, everything is a nail

Getting a Better Toolbox

Be informed

Bring a spouse/relative to visits

Write down questions

Write down the answers

Ask for clarification

Be “out there” – engaged, social, frank



Consider bringing Nonmotor Questionnaire to your visit - completed

- 1 Dribbling of saliva during the daytime.

- 2 Loss or change in your ability to taste or smell.

- 3 Difficulty swallowing food or drink or problems with choking.

- 4 Vomiting or feelings of sickness (nausea).

- 5 Constipation (less than three bowel movements a week) or having to strain to pass a stool.

- 6 Bowel (faecal) incontinence.

- 7 Feeling that your bowel emptying is incomplete after having been to the toilet.

- 8 A sense of urgency to pass urine makes you rush to the toilet.

- 9 Getting up regularly at night to pass urine.

- 10 Unexplained pains (not due to known conditions such as arthritis).

<https://www.parkinsons.org.uk/professionals/resources/non-motor-symptoms-questionnaire>



- 11 Unexplained change in weight (not due to change in diet).
- 12 Problems remembering things that have happened recently or forgetting to do things.
- 13 Loss of interest in what is happening around you or in doing things.
- 14 Seeing or hearing things that you know or are told are not there.
- 15 Difficulty concentrating or staying focused.
- 16 Feeling sad, 'low' or 'blue'.
- 17 Feeling anxious, frightened or panicky.
- 18 Feeling less interested in sex or more interested in sex.
- 19 Finding it difficult to have sex when you try.
- 20 Feeling light-headed, dizzy or weak standing from sitting or lying.
- 21 Falling.
- 22 Finding it difficult to stay awake during activities such as working, driving or eating.
- 23 Difficulty getting to sleep at night or staying asleep at night.
- 24 Intense, vivid or frightening dreams.
- 25 Talking or moving about in your sleep, as if you are 'acting out' a dream.
- 26 Unpleasant sensations in your legs at night or while resting, and a feeling that you need to move.
- 27 Swelling of the legs.
- 28 Excessive sweating.
- 29 Double vision.
- 30 Believing things are happening to you that other people say are not.



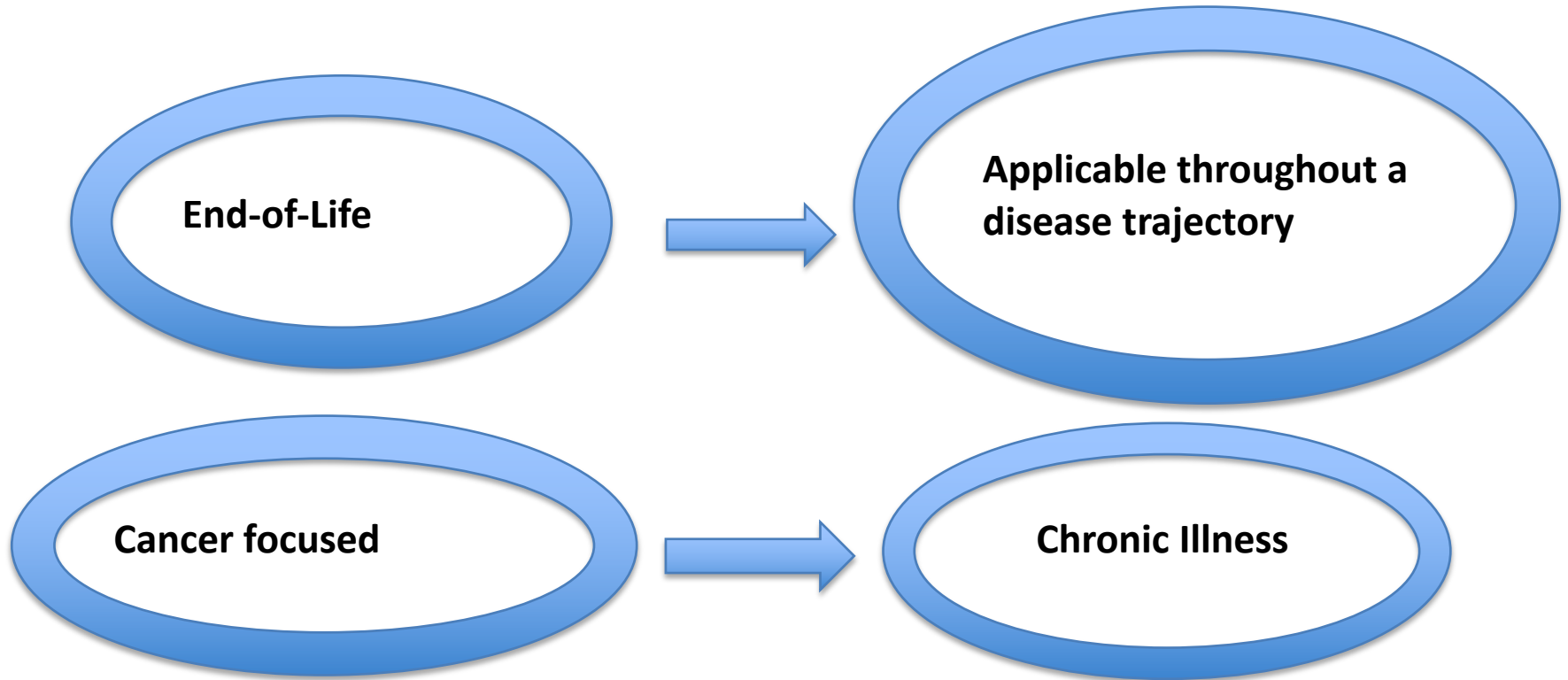


6 month life expectancy

What Can Palliative Care Provide?

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates psychological and spiritual aspects of pt care
- Offers support to help the family cope
- Uses a team approach to address needs
- Will enhance quality of life and may positively influence the course of illness
- Is applicable early in the course of illness**





Palliative Care for Parkinson and Related Disorders

Program began in 2007 at University of Toronto

Restarted in 2015 at University of Alberta

Follows the principles of palliative medicine

In collaboration with Palliative Care, Spiritual Care and
Neurology



No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
No Tiredness <i>(Tiredness = lack of energy)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
No Drowsiness <i>(Drowsiness = feeling sleepy)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
No Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Lack of Appetite
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
No Depression <i>(Depression = feeling sad)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
No Anxiety <i>(Anxiety = feeling nervous)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
Best Wellbeing <i>(Wellbeing = how you feel overall)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Wellbeing

No _____ Other Problem	0	1	2	3	4	5	6	7	8	9	10	Worst possible
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Edmonton Symptom Assessment System - rPD

No Stiffness 0 1 2 3 4 5 6 7 8 9 10 Worst Possible Stiffness

No Constipation 0 1 2 3 4 5 6 7 8 9 10 Worst Possible Constipation

No Swallowing Difficulties 0 1 2 3 4 5 6 7 8 9 10 Worst Possible Swallowing Difficulties

No Confusion 0 1 2 3 4 5 6 7 8 9 10 Worst Possible Confusion



Why so much paper?

If your doctor don't ask, your doctor doesn't know what's happening to you

It's hard for PWP and families to know what is related to PD and what isn't



1. Try levodopa particularly in Multiple System Atrophy, some Progressive Supranuclear Palsy, some with Corticobasal syndrome
2. Range of motion exercises if able
3. If not able, passive range of motion
4. Ask about botulinum toxin
5. Ask about pain medication



Active or Passive Range of Motion Exercises



Mild

ASA,
Acetaminophen,
NSAIDs

Moderate

Codeine,
Tramadol

Severe

Morphine,
Hydromorphone,
Methadone








Heat or cold

Use of Opioids in Neurodegenerative Illnesses

1. Most patients underuse their prescription
2. Drowsiness and thinking problems may limit dose and therefore pain control
3. Pain medication for chronic pain should be used routinely with breakthrough doses
4. Pain medication prior to exercise may improve ability to move



Bristol Stool Chart

Type 1		Separate hard lumps, like nuts (hard to pass)
Type 2		Sausage-shaped but lumpy
Type 3		Like a sausage but with cracks on its surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges (passed easily)
Type 6		Fluffy pieces with ragged edges, a mushy stool
Type 7		Watery, no solid pieces. Entirely Liquid

Signs of Constipation

Bloating

Stomach pain, Back pain

Hurts to poo

Poo like rocks

Hemorrhoids

Your pills don't work

Appetite is lost



Good Things About a Daily Poo

Pills work better – you can move better

Easy to poo – and it isn't a chore

Diet is probably better

Appetite improves

Reduce your cancer risk



Dietary Treatment

Drink enough water – 8 eight ounce glasses/day

Watery fruit

Raw veg (cucumbers, tomatoes (yes, I know it's a fruit))

Less meat, more beans

No white bread, rice or pasta

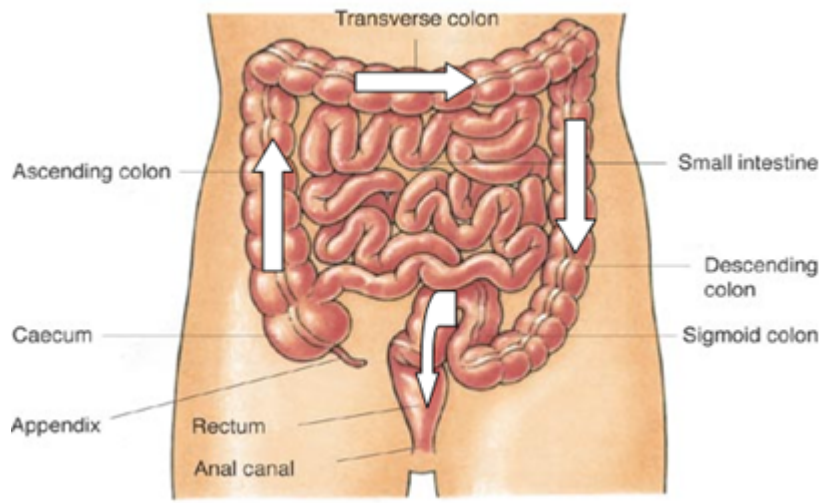
Whole grain bread, brown rice, whole grain pasta

Dried fruit: figs, dates



Constipation treatment

Exercise!
Abdominal massage



10-20 minutes/day

Medication Treatment for Constipation

PEG 3350, Laxaday, Miralax

NOT absorbed

NOT “addictive”

You can take up to 4 doses a day

Tasteless, odorless

Put in any drink or on top of food

Senokot to stimulate the bowels



Existential Distress

Why has this happened to me?

How can I go on?

How can I find meaning in life?



Existential Distress

Is different from depression

Stems from an event/s that shake one's faith in the logic of the world

“I am a good person, why do I have this @#!! Illness?”

“I've led a healthy life, why is this happening to me?”

“What's the point?”



Dealing with Existential Distress

Speak to a Spiritual Care practitioner

Speak to your pastor/priest/rabbi/Imam

Psychologist with experience in chronic illness

If your local palliative care team is open to neurologic patients, seek a referral



<http://www.gowish.org/gowish/gowish.html>





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Very Important

To have a doctor who knows me as a whole person

To be treated the way I want

To have my family prepared for my death

To have my financial affairs in order

To say goodbye to important people in my life

To be free from anxiety

To take care of unfinished business with family and friends

To have my family with me

To maintain my dignity

To be able to talk about what death means

Somewhat Important

To know how my body will change

To remember personal accomplishments

To have a nurse I feel comfortable with

To meet with clergy or a chaplain

To be mentally aware

To be free from pain

Not being a burden to my family

To have someone who will listen to me

Not being connected to machines

To have my funeral arrangements made

To be able to help others

To trust my doctor

Not dying alone

Not being short of breath

To feel that my life is complete

To prevent arguments by making sure my family knows what I want

To have an advocate who knows my values and priorities

To be kept clean

To keep my sense of humor

To be able to talk about what scares me



What people want

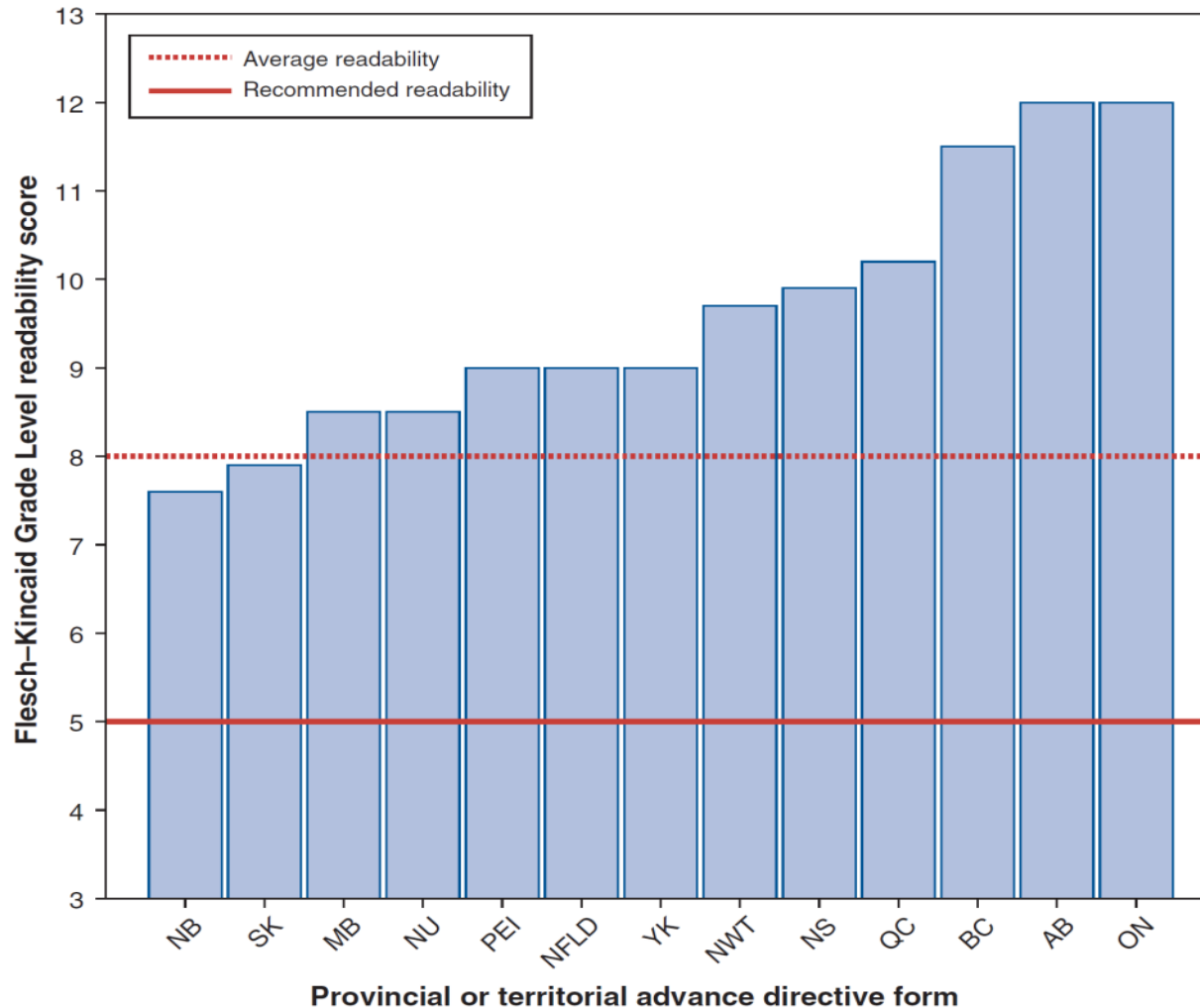
- 90% think its important to talk about their loved ones' and their own wishes for the end of life
- 60% don't want their family burdened by tough decisions for them
- 70% prefer to die at home
- 80% want to talk their doctor about end of life care
- 82% think its important to have their wishes in writing

What is

- Less than 30% have done so for themselves and their family
- 56% have not communicated their end of life wishes
- 70% die in hospital, nursing home or long term care facility
- 7% have discussed end of life with their doctor
- 23% have actually done it



Approved Forms Don't Make it Easy to do Advance Care Planning



Richard, Richard, Johnston, Miyasaki CMAJOpen 2018



ELSEVIER

Contents lists available at ScienceDirect

Parkinsonism and Related Disorders

journal homepage: www.elsevier.com/locate/parkreldis



Expert
Briefings
Parkinson's Foundation

Short communication

Decisional capacity for advanced care directives in Parkinson's disease with cognitive concerns[☆]

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20/50 had impaired decision making despite having
“normal” cognition

Capacity requires

Understanding and Appreciation

Reasoning

Expressing a choice



Advance Care Directives

Who should have them?

Everyone over the age of 18 or consent in your State

Forms: Five Wishes – it is a legal document in the State of Maryland (fivewishes.org)



Five Wishes

1. The person I want to make care decisions for me when I can't
2. The kind of medical treatment I want or don't want
3. How comfortable I want to be
4. How I want people to treat me
5. What I want my loves ones to know



Conclusions

1. Think of non-medication approaches first
2. Use medications as prescribed
3. Movement helps a lot of symptoms!
4. Thinking about your values can help cope with Existential Distress
5. Advance care plans should be completed by everyone







REGISTER NOW!

Parkinson.org/Summit



Caregiver Summit

Saturday, December 1, 2018

Cumbre Para Cuidadores

PRESENTING SPONSOR



Allied Team Training for Parkinson's Disease (ATTP®)



 Professional
Education
Parkinson's Foundation

MARCH 27-30, 2019
IOWA CITY, IOWA

Resources



National Helpline

Available at
1-800-4PD-INFO or
Helpline@Parkinson.org
Mon- Friday 9 am to 8 pm ET

Podcast: Substantial Matters

New episodes every other Tuesday featuring Parkinson's experts highlighting treatments, techniques and research.

Parkinson.org/Podcast



Fact Sheets and Publications

Get the resources and information you need to start living a better life with Parkinson's.

Aware in Care Kit

Includes tools and information for people with PD to share with hospital staff during a planned or emergency hospital stay.

Parkinson.org/Awareincare

