Advanced PD and Palliative Care in the 21st Century

Janis M. Miyasaki, MD, MEd, FRCPC, FAAN
Director, Parkinson and Movement Disorders Program
University of Alberta

November 27, 2018 1pm ET
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.
Palliative Care ≠ Hospice Care

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 patient 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
Original Palliative Care/Hospice Movement

21st Century Palliative Care

End-of-Life

Applicable throughout a disease trajectory

Cancer focused

Chronic Illness

Original Palliative Care/Hospice Movement

21st Century Palliative Care
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
<table>
<thead>
<tr>
<th>Item</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Worst Possible</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Pain</td>
</tr>
<tr>
<td>No Tiredness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Tiredness</td>
</tr>
<tr>
<td><em>(Tiredness = lack of energy)</em></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No Drowsiness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Drowsiness</td>
</tr>
<tr>
<td><em>(Drowsiness = feeling sleepy)</em></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No Nausea</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Nausea</td>
</tr>
<tr>
<td>No Lack of Appetite</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Lack of Appetite</td>
</tr>
<tr>
<td>No Shortness of Breath</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Shortness of Breath</td>
</tr>
<tr>
<td>No Depression</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Depression</td>
</tr>
<tr>
<td><em>(Depression = feeling sad)</em></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No Anxiety</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Anxiety</td>
</tr>
<tr>
<td><em>(Anxiety = feeling nervous)</em></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Best Wellbeing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Wellbeing</td>
</tr>
<tr>
<td><em>(Wellbeing = how you feel overall)</em></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No Other Problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Other Problem</td>
</tr>
</tbody>
</table>
### Edmonton Symptom Assessment System - rPD

<table>
<thead>
<tr>
<th>Symptom</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Stiffness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Worst Possible Stiffness</td>
</tr>
<tr>
<td>No Constipation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Worst Possible Constipation</td>
</tr>
<tr>
<td>No Swallowing Difficulties</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Worst Possible Swallowing Difficulties</td>
</tr>
<tr>
<td>No Confusion</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Worst Possible Confusion</td>
</tr>
</tbody>
</table>
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
<table>
<thead>
<tr>
<th>Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type 1</td>
<td>Separate hard lumps, like nuts (hard to pass)</td>
</tr>
<tr>
<td>Type 2</td>
<td>Sausage-shaped but lumpy</td>
</tr>
<tr>
<td>Type 3</td>
<td>Like a sausage but with cracks on its surface</td>
</tr>
<tr>
<td>Type 4</td>
<td>Like a sausage or snake, smooth and soft</td>
</tr>
<tr>
<td>Type 5</td>
<td>Soft blobs with clear-cut edges (passed easily)</td>
</tr>
<tr>
<td>Type 6</td>
<td>Fluffy pieces with ragged edges, a mushy stool</td>
</tr>
<tr>
<td>Type 7</td>
<td>Watery, no solid pieces. Entirely Liquid</td>
</tr>
</tbody>
</table>
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 break, 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
Advanced Care Planning: Wishes and Reality

What people want

90% think it’s 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 it’s 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
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
ACADIA Pharmaceuticals
Allied Team Training for Parkinson’s Disease (ATTP®)

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