



Struthers Parkinson's Center

Enhancing Quality of Life Through Early Palliative Care

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LEWY BODY DEMENTIA COMMUNITY

1



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Hospital and Surgical Safety in LBD

- Even a conscientious and caring culture can create uncertainty and danger
- Preparation and expectation setting
- Careful evaluation of options are important



2



Hospital and Surgical Safety in LBD

1. Manage expectations and expect turbulence
 - Even "minor" surgeries or admissions can have unexpected twists and turns
 - Acute confusional episodes/"delirium"
 - Expect extra time for recovery
 - Prepare for possibility of aspects of incomplete recovery



3



Antipsychotic medications

- Should be absolutely avoided if at all possible!
- Particularly Haldol which is often given in ER and hospital settings
- This can dangerous for people with LBD
- LBD ID bands
- "Dr. Jones, I just want to be sure you're aware my loved one has been diagnosed with Lewy body disease and we would like to avoid any medications like Haldol."



4



Other medications to approach with caution

- "Anti-cholinergics" - e.g. Benadryl – often given for poor sleep or agitation
- Benzodiazepines like Valium or Ativan
- Dopaminergic medication timing



5



Possible Points of Advocacy for a hospitalized loved one

- Avoiding medications
 - Psychiatry consultation
- Parkinsonian medications on time
- More time and/or re-evaluation(s)
 - Fluctuations impact assessments
- Palliative care consult in the correct setting



6



"So doctor, should I still get my knee replaced?"

- Many surgeries and hospitalizations are critical
- Many are cosmetic or truly elective
- Many are in between
- No one size fits all, but the extra risk of complications changes the math



7



Palliative Care in LBD

8



Key Messages



Palliative care is an additional layer of support that aims to be person- and family-centered



Palliative care tries to address spiritual, social, psychologic as well as physical pain



Lewy body dementia presents unique palliative care needs



Palliative care is not hospice

9



What is palliative care?

- Palliative care is an approach to the care of persons living with serious illnesses that focuses on improving quality of life and reducing suffering through a whole person approach.

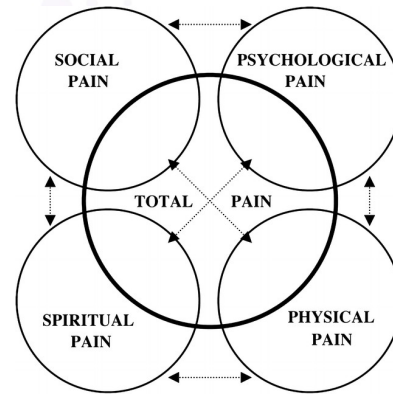


10



What is palliative care?

- Interdisciplinary approach to care: MD, RN, SW, chaplains, therapists
- Recognizing and treating physical, emotional, and existential/spiritual pain
- Worries and anxieties about having a serious illness like LBD, discuss and think about symptoms, sometimes talking about the future

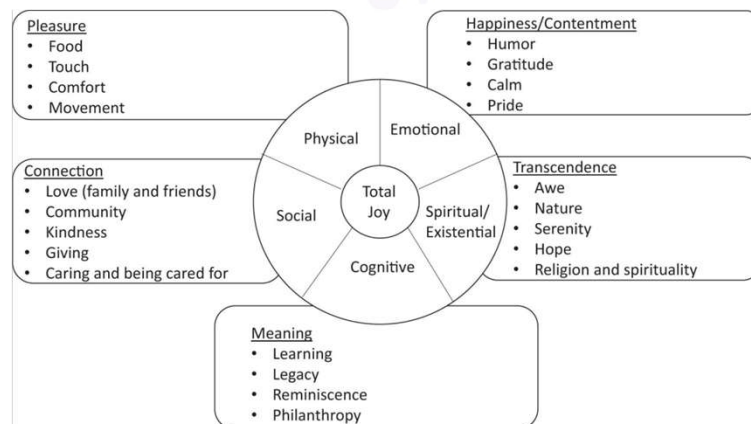


11



What is palliative care?

- Total Joy as an inversion of total pain



12



Spiritual distress LBD

- “I was always a do-er” or “He was always a do-er”
 - “I’m not the person I was before”
 - “I love doing [...] and now I can’t anymore”
 - “I don’t know who I am now that I can’t [...]”
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13



Spiritual distress



Often this is difficult for medical systems to process



Depression? Is this a ‘medical’ illness?



Please doctor don’t make me take another pill



Is this even something to “fix”? Something to talk to your doctor about?

14



For patients and families:

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Your well meaning but stressed and uncomfortable provider may want to prescribe a medicine in response to your spiritual pain

"My main goal was just to bring it up, I don't think I need to take another medication for this"

"Prozac is a good idea – let's keep it in our back pocket for now"

"Do you know if you have access to a chaplain?"

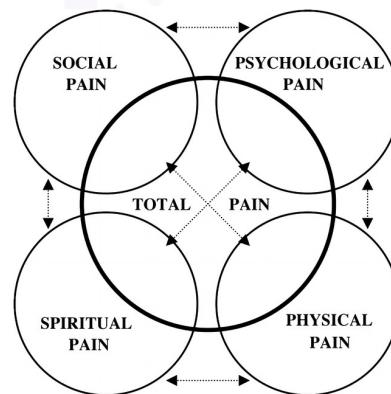
15



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Social Distress

- "I used to care for everyone and now I need them to care for me."
- "I'm not much help to my wife anymore."
- "It's too hard to get out anymore."
- "I'm with them all the time and can't get a moment to myself."



16

16



Social pain



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- There may or may not been medical/medication approaches to these concerns
- Limited and poor programmatic support through the medical system -- e.g. can get very expensive medicines but not care partners
- Consider social worker for resources
- Consider counseling for support and/or therapy

17



Social Changes

- Ambiguous loss
- Care partner support and assessment
- Family support
- Changing roles in a relationship
- Loss of autonomy
- Economic strain
- Communication difficulties
- Social isolation



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18



Psychologic pain

“What does the future hold?”

“Will I be okay?
Will my family?”

Anxiety,
depression,
psychiatric
symptoms

19



Treatment may be *information* presented in empathic but direct way



May also be pharmacologic treatments



May also emphasize support/non-medical approaches

20



Physical Pain/Symptoms

- Pain often undertreated
- Sleep disturbances common and complex
- *Trade offs* become key feature of treatment and decision-making in complex
- Lewy body dementia presents a few specific treatment challenges that become more important over time

21



Psychiatric symptoms in LBD

Psychiatric symptoms are disruptive of routines and equilibriums at home.

Trade off between motor and psychiatric symptoms

In difficult to treat symptoms, face a trade off with things like sedation or risk of serious infection.

- How people view these type of symptoms and trade off varies greatly and reflects very important differences in religious and cultural beliefs



22

22



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Values guiding discussion and treatment

- *Are there things you particularly worry about? Are there things you're hoping for?*
 - *What have you heard from other doctors about what's going on with your LBD?*
 - *How do you see what's going on?*
 - *Can you imagine a time when you might have to face a tradeoff between safety and independence?*
-

23



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Advocacy ideas:

- Start with what's most important:
 - "I want to be sure you know that being at home is most important and we are willing to take on some risk to do that."
 - "The most important thing for us to make sure that we do not risk a fall or an unexpected illness."
 - What do you think would make that most likely to happen?
 - "I recently went to a talk on palliative care. Do you think that could help in this situation?"
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24



Does palliative care work for Lewy body disease?

- Yes!
 - Improved patient and care partner quality of life
 - Improved some PD-specific symptoms
 - Nothing in medicine is a panacea
 - Importance of relationship – with providers, staff, nurses, institution, and across time

Research

JAMA Neurology | Original Investigation

Comparison of Integrated Outpatient Palliative Care With Standard Care in Patients With Parkinson Disease and Related Disorders A Randomized Clinical Trial

Benzi M. Kluger, MD, Janis Miyasaki, MD, Maya Katz, MD, Nicholas Galifianakis, MD, Kirk Hall, MBA, Steven Pantilat, MD, Ryan Khan, MD, Carli Friedman, LCSW, Wendy Carrik, BSN, Yukio Goto, MD, Judith Long, MS, Diane Fairclough, DPH, Stefan Silau, PhD, Jean S. Kutner, MD

IMPORTANCE Parkinson disease and related disorders (PDRD) have consequences for quality of life (QoL) and are the 14th leading cause of death in the United States. Despite growing interest in palliative care (PC) for persons with PDRD, few studies are available supporting its effectiveness.

OBJECTIVE To determine if outpatient PC is associated with improvements in patient-centered outcomes compared with standard care among patients with PDRD and their caregivers.

Editorial

Supplemental content

25



Early Palliative Care and LBD

- Talking about the future
 - Conversation vs paperwork
 - POLST, POA, “that form we filled out with the attorney,” surrogate
 - Family members and patients may want different information
 - “They don’t tell me anything!”



26



Early Palliative Care and LBD

- Talking about the future sometimes includes talking specifically about issues regarding the end of life
- This is always first up to the patient – not a standard part of every visit
- This is not always a driving concern of patients or families



27



Questions about the future

- What stage am I in?
- What should I be looking out for?
- How long can I stay in my house?
- What is hospice and when is it appropriate?
- How can I be sure that what I want will be respected?
 - Who makes decisions and what those decisions are based on?
- Sometimes talking about time, sometimes not

28



The road may not always feel clear

- Loss of purpose or identity is common
- It may not be easy to find it again
- May not be the biomedical system that helps find it again



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29



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Palliative care is not hospice

- Hospice is a federal program typically through Medicare that completely changes a patient's relationship with healthcare
- You get meds, RN, MD, medical equipment, and therapists, SW, and chaplain but give up things too



30



What does an appointment look like?

- Mostly, like any other appointments you've had
- *Values and what is important for you to discuss*
- Medication
- Forms
- Referrals



31



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32