Meeting minutes from Chapel Hill PD Support Group 2/7/17

Discussion on hospice, with Shannon Pointer, RN, of Hospice of Alamance-Caswell

- People avoid hospice: learning about it, talking about
- Associated often associated with imminent death
    - "Certification of terminal illness," which is required by a physician for a hospice referral, states "6 months or less to live" because there has to be some type of timespan associated with this type of service… but the truth is that no one ever really knows
    - People can be on hospice for hours, days, months, or even years
- When thinking about hospice eligibility, you need to paint an overall picture of how someone is functioning/progressing
    - Not just the diagnosis but also complications
    - Parkinson's may be the secondary diagnosis (to cancer, heart failure, etc.)
- "The surprise question" is a good way for doctors and families to ask themselves if someone is appropriate for hospice = Would you be surprised in the person was alive in 6 months? If yes, hospice is typically appropriate
    - Other signs that someone may be hospice eligible: Has there been excessive weight loss? Has person been in and out of the hospital often? Increased symptoms/general decline recently? Are there re-occurring pressure sores, UTIs, falls, pneumonia?
- Anyone can make a referral (there is "no bill for a conversation"), meaning a family member can call. If you want to move forward with services, hospice will then call on the doctor for an official referral.
- Hospice is a "one day at a time business" because someone's status/experience is constantly changing and we can't make any assumptions or generalizations
- Ask yourself "What if I did have only 6 months?" It's time to plan, gather support, focus on quality of life
- Some physicians are reluctant to refer to hospice
    - They may not understand that death doesn't have to be imminent
    - May be afraid that the patient/family will think they've given up on them
    - -> You can break that ice
- Hospice does a lot more listening than talking
    - They want the "patient to be driving the bus"
    - They want to honor their unique wishes/beliefs
    - A person's wishes/mindset is not ready for hospice yet, even though they're technically eligible, hospice will respect that
- No aggressive treatment but does treat things such as pain, infections, wounds, anxiety, agitation, phenomena
- Physical/Occupational/Speech Therapy can be a part of hospice, when focused on safety/quality of life
- Hospice discharges a fair amount of people who have improved on hospice services
    - Patient assessed after initial 90 days, then every 60 days does a re-evaluation
    - Discharged if improving or sometimes of stabilized
- Designed to keep people at their home whether that is house, facility, or homeless shelter
- A hospice home (facility):
    - Used for:
        - Imminently dying (2 weeks or less)
            - Often those who are not wanting to die at home
        - Symptom management (pain, out of control so doesn't have to go to hospital;
        - Respite care up to 5 days (e.g., if a caregiver needs a break or travels)

    - Not all hospices have a hospice home/facility
    - If in facility for lower level of care (respite or stabilization) there is a cost associated with room & board, which is typically about $150/day but this varies by hospice and is often sliding scale (especially if non-profit)
- Myth: All hospice patients get morphine
- Hospice is not 24/7 care in the home
    - It coexists with other services in home
    - Nurse visit 2-4 times/week and a CNA for bathing, if needed, 1-5 times/week
    - BUT is available 24/7
- Other services from hospice, besides a nurse:
    - Social Work: counseling, resource connection
    - Chaplain (if you choose): Counsel around spirituality/religious beliefs
    - Bereavement counselor (if you choose): Up to 13 months after the death of the person
    - Volunteers (if you choose): Sit with the person
- Some hospices also offer:
    - Grief support groups
    - Caregiver support groups,
    - Dementia specialist
    - Assistance with advanced care planning
    - Music/Animal/Aroma Therapy
- You do not need to be Do Not Resuscitate (DNR) to be on hospice
- Medicare/Medicaid/VA pay 100%
    - This includes the care, meds, supplies (bed, diapers, oxygen)
- Hospices can be for-profit or non-profit
- Will typically work with patients if insurance doesn't cover hospice benefit (especially if non-profit)
- Grief support for 13 months after for family
    - Even if patient only on hospice for a few hours
- How to find a hospice?
    - Ask families you know and your neurologists who they have used and why
    - Search on NHPCO.org
- How do you choose a hospice?
    - Look for ACHD accreditation
    - Response time
    - Involvement in the community
    - How many volunteers do they have
    - Do they offer extra resources (e.g., support groups, educational events, dementia specialists)
    - -> Research it early & beforehand so you know what hospice you want
- Palliative care – a model of care that focuses on comfort and quality of life
    - Hospice is palliative care applied to end of life
    - Anyone can get just palliative care, even cancer patients seeking aggressive treatment
        - Often a consult service at the hospital
        - There are some free-standing in-home palliative care agencies; even some that are related to a hospice agency so that you could transition from one to the other if needed
- You have the ability to undo anything
- Don't have to stop seeing Parkinson’s doctor -> In fact, even if you don’t see them, hospice can/should consult with them
- You don’t have to stop Parkinson’s meds
    - Only do that if they are not necessary (i.e., not alleviating symptoms or causing worse symptoms)