Notes on “The End is Dear” with Pat Myatt, Penn Medicine at Home (formerly Neighborhood Hospice)

Pat Myatt is the Support Services Coordinator at Penn Medicine at Home (formerly Neighborhood Hospice) and has been doing this work for 20 years. Neighborhood Hospice originally started in Wayne in 1912 with neighborhood ladies who wanted to make sure people got good care. In 2007 they rented space for the inpatient hospice unit across from Chester County Hospital.

Discussion of “Walking the Hundred-Mile Road” (handout) - There are a lot of myths and fears about hospice. It used to mean the person had a week to live, all treatments were done, they had cancer and nothing could be done. Now there are more treatments and people live longer even with pancreatic cancer.

We don’t plan ahead for death like we do for life. We do think about retirement. Having a good death is as important as having a good life. Most people just want to not wake up some day but that is only 10% of people.

How do you talk to someone about hospice? She asked who had an experience with it. One shared that the hospital suggested it and they signed up, but family didn’t like it and they went to look for another hospice which they liked better. Hospital discharged her to home with hospice. She lived 2 weeks.

Pat says that hospice is not appropriate for everyone including this 108 year-old who told her doctor she wanted to live as long as she could. Her daughters needed help in the home for her, but she didn’t want hospice because she wanted to live. And she had nothing in writing (it was 20 years ago). So hospice didn’t happen, but she had home care and her daughters got some private care and ultimately she came back to hospital and had declined a lot and couldn’t make decisions, and then went home again, but on hospice and died 2 weeks later. On the other hand a 25 year old asked for hospice. You honor a person’s wishes.

2 kinds of people - 1. People who plan and communicate and learn from others’ experiences. 2. People who do not, like the 108 year old. Need seeds planted. It’s good to have thoughts and wishes written down.

Everything starts with the doctor (who has to write the order for hospice care), but you have to tell the doctors what you want because they may not bring it up. They want to keep us alive, make us better – their definition of being successful. Our definition of being successful might be different. Doctors are different in their use of hospice. Pay attention to how you feel about your doctor.

People may have short term goals like “live through the holidays” and then they die in January.

It is hard in the medical community to stop something (treatment) once it has started. Ethics committee gets involved. It can be hard for people to accept that someone might choose not to have or to stop treatment or eat when they could. Hospice can be helpful here.

Hospice can also have graduates. People stabilize.

Hospice Services: doctor orders it and it can take place in nursing homes, at home, assisted living facilities, and stand-alone inpatient facilities.

It started in England with Dame Cicely Saunders in 1948 who saw people living in pain in hospital, and introduced a bit of morphine at bedside to help people have a comfortable death.

Services include an ala carte menu of services. Process involves the doctor writing an order for hospice. Hospice (nurse, social worker) comes out and meets with patient AND family. It is hard to be the family member who wants to feel the patient is comfortable etc. There is a nurse coordinator (who can arrange for physical therapy, medication, communicates with doc). Hospice team is available 24/7. The doctor may recommend hospice when s/he realizes that patient is coming to hospital more often, has tried all the antibiotics or treatments.

Hospice is very family centered - they work with family members who choose to be involved, even if distant. Hospice is very individualized; you don’t have to be home bound, your needs may vary week to week, versus home care where you are supposed to be home bound.

Hospice is paid for by Medicare, and all insurances. Mostly at 100%. It is a Federal program.

Volunteers (mostly found at non-profit hospices) are involved with pet therapy, listening, just being present, maybe making birthday cakes etc.

Home care aides – are an extra pair of hands, extra baths, extra changes of clothes,

Personal care would involve things that regular aide can’t get to. Extra advocate.

Inpatient care is for those who have no family to care for them or no housing or care needs that are too great for the family. There are 3 inpatient units in the Philadelphia area including the one across from Chester County Hospital

What happens the last 2 days? People come to the inpatient unit when constant care needed. Hospice starting in final days is crisis intervention. It is better when it starts earlier so hospice can get to know the family and help them deal with feelings, regrets, right some wrongs, see what comfort looks like. There is more time to develop trust, bring them along to make things more comfortable for patient. Inpatient unit can be neutral place for family with conflicts... Families come away grateful. Hospice can help families understand what to expect.

When Death is Near, A Caregivers Guide – booklet available from Penn Medicine at Home. People are more afraid of what will happen as they are dying; they don’t want to be alone. One of goals is to have someone with the person at the time of death. Then family can feel comfortable that patient was not in pain and not alone. Families can know when to come versus when not to come. There are signs: everyone has different process. Talking with someone else could involve you sharing your own process.

When someone goes home from the hospital; hospice can arrange all equipment (bed, oxygen, etc), staffing, medications, anything for comfort, chaplains, (staff bring sense of peace). Doesn’t cover giving meds at night. They will do death pronouncements and will go out at night if person is dying.

Inpatient unit: quiet, private rooms (13 at Pat’s), patients come who have medication issues, have lots of care needs and are stressing family out. This hospice has even cared for people from prison, younger folks, family wants to remember dad playing baseball, not dying on the couch. Can provide respite for 5 nights. People can relax. The only equipment is oxygen. Social workers and chaplains can help families work through things, what would mom want? It is focused on what the patient wants, not what the doctor wants or nurse, even if staff might wish for a different answer. At this hospice (Pat’s) staff is very in tune with each other. Family can be family, not a caregiver again in the inpatient unit.

One activity shared of making a fingerprint tree when family had a dying member - family members sign under the roots and all get a copy.

Volunteers: Could be embroidering at the death bed; people vary as to what interaction they want. Some bring in food. It is not meant to be long term, there are not a lot of activities. Focus is on end of life care. But families can cook and hang out. Volunteers bake birthday cakes, deliver suppers (restaurants donate food).

Hospice team has bereavement team and will follow families if they want for up to 15 months after the person dies. They run bereavement groups in a number of locations. They run support groups, make home visits, see people who come in, recommend private therapists, send cards. Groups are closed groups, 10 weeks long, free and could be anywhere. 250 people show up monthly at a diner who have been part of a group over the years!

Quakers should use all the services! They should not count on only meeting support and feeling that a chaplain not appropriate. No such thing as too much support. Keep an open spirit!

Myths: People need to get a little more knowledge, seeds need to be planted about the benefits of hospice. Any good hospice would want to start the process with no commitment. They’ll go to homes and talk about hospice, or people can have a tour of inpatient unit. It may be a red flag if any group won’t allow you to do that.

Myths have been: You have to be in your final week, it’s only for cancer. If I go on hospice, I’m going to die sooner. However, it can be for any disease. Average length of service is 35 days, but it is intended for last 6 months of life (you aren’t kicked off, however). Every 2 months they are recertified. Patients can be on for a year, or more, on and off.

Ethical issue of how to tell people they are on hospice when the family doesn’t want the patient to know. Know that the patient will find out! Good communication is needed; sometimes hospice is not appropriate. It can be hard to decide when to get off the “treatment train”.

Near the end: Remember that CPR can break ribs; hospice takes all the aggressive treatments off the table. Hospice will keep someone comfortable. Pain meds, manage secretions, difficulty breathing,

Diversity - some cultures are hesitant to accept care from the medical community, because of things that have happened. But there is more acceptance. Some people need to keep medical issues in the family but things are changing. Diversity of staff is a challenge since they can only offer jobs to people who apply, but they are working to increase diversity. They are working on getting more people who speak Spanish.

They will come out and speak to groups. Chester County, Delaware and two others. It can be hard to decide when to get off the “treatment train”. <https://www.medicare.gov/hospicecompare/>

is a website to look at. Pat doesn’t recommend a for profit hospice. Non-profits have great volunteers. Look for inpatient unit in case you end up needing it. Crozier, Phoenixville, Philadelphia and Chester County have inpatient units.

Notes by Lynne Piersol