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Strategies for PH Patients Transitioning to Long-Term Care

"With my mother, it was very tough. Everywhere we went – rehabs, nursing homes, assisted living – they weren't equipped to deal with six-to-eight liters of constant oxygen. Many times, she would run out during lunch or dinner because they would not fill her tanks," said Caleb Walden, pulmonary hypertension (PH) caregiver for his mother, Donna Harrison. Caleb dealt with a string of issues that many other PH patients and caregivers deal with — from low sodium diets to supplying medications — when transitioning PH patients into long-term care facilities. "Every new facility brought new challenges and staff to retrain," said Caleb.

When individuals with PH transition from their home or hospital setting to long-term medical care facilities, both the patient and caregiver can face unique and extremely complicated challenges. Simple, daily routines may not seem simple when dealing with long-term medical care facilities that are not equipped to handle all different types of medical conditions. The situation starts to become stressful and worrisome when you find yourself asking questions like:

- Who's supplying the medicine?
- Is the medication the correct dosage?
- Does the staff know how to administer treatments and protocols?

Some facilities don't admit PH patients because of the complicated or expensive medical therapy. As PH patients live longer, due to medical advancements and treatments, what does their journey look like?

"No one told us it would be easy, but I would have loved for someone to very harshly explain how difficult it is to navigate through this health care system with PH," said Caleb.

Along with assessing the type of long-term care setting for PH patients, each patient, caregiver and medical provider will approach the challenges from different perspectives as they assess expectations, challenges and next phases for all parties involved. Here are some of the steps toward making a decision on long-term care, depending on whether you are a patient, caregiver or medical provider.

Learn about the types of care facilities out there (see glossary at end of article):

- Assisted Living
- Nursing Homes
- Hospice
- Palliative
- Respite
- Long-term

Visit nia.nih.gov/health/what-long-term-care to get more information on what type of long-term care is available and what might work best for your situation.

"What will I do when I'm 65, and where do I go if I need assistance? How will I pay for it?"

- Doug, 16-year survivor

"What happens if I outlive my husband? What will happen to me?"

- Evette, 14-year survivor

"I got divorced, and my parents are now my caregivers in their 80s."

- Joanne, 21-year survivor

Patients

What to expect?

- You will be asked questions about your end of life plans.
- You'll encounter challenges and delays – things may not go as smoothly as you would hope.
- You will have to educate long-term care facilities about your medical needs.

What are the challenges?

- Costs and insurance.
- Specialty medications – the ability of long-term care facilities to administer treatment or cover costs.
- Uncertainty of staff who are not trained to administer complex medications.

Ways to navigate.

- Do research ahead of time – visit facilities, ask them questions, explore your insurance benefits and other insurance options or programs such as long-term care insurance.
- Communicate your expectations and needs to the facility.
- Help end the stigma around these topics by talking about them. Share this article with someone else. Share your experiences or thoughts about long-term care in a PHA Facebook group. Hold a support group meeting around this topic.
- Consider your own end-of-life preferences and communicate these thoughts to your loved ones or caregivers. Complete a living will document or advanced directive and assign a power of attorney (POA).
- Talk to your PH Care Team – ask these questions of your medical provider: Can you direct me to a hospital social worker who can work with me on this? Can you tell me about previous patients transitioning into long-term care or hospice? Do you have resources to help with end-of-life planning? Is there a palliative care service available?

Caregivers and Loved Ones

What to expect?

- You'll have difficult conversations.
- Be prepared to provide a lot of emotional support, perhaps running errands, helping with research about facilities.
- You may need help defining and understanding the options (which facilities provide which services, if long-term care insurance provides coverage and for what).

What are the challenges?

- Trust – trusting that your loved one will be cared for well, trusting that staff will provide the right/best care.
- There may be more questions than answers – delays, confusion, lack of clarity about the process by several different parties involved.
- Exploring options, discussing plans with loved ones and visiting care facilities is often time-consuming.

Ways to navigate.

- Be respectful of your loved one's decisions, even if they are not the same choices you would make.
- Talk with caregivers and patients – open a dialogue with others who've experienced it.

¹<https://www.nia.nih.gov/health/residential-facilities-assisted-living-and-nursing-homes> Last accessed July 2, 2019.

²<https://www.ahcancal.org/ncal/about/assistedliving/Pages/What-is-Assisted-Living.aspx> Last accessed July 2, 2019.

³<https://www.nia.nih.gov/health/what-long-term-care> Last accessed July 2, 2019.

⁴<https://www.nhpco.org/patients-and-caregivers/advance-care-planning/advance-directives/what-are-advance-directives/> Last accessed July 2, 2019.

⁵<https://www.mayoclinic.org/healthy-lifestyle/consumer-health/in-depth/living-wills/art-20046303> Last accessed July 2, 2019.

⁶<https://archrespite.org/> Last accessed July 2, 2019.

⁷<https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care#hospice> Last accessed July 2, 2019.

⁸<https://www.nhpco.org/patients-and-caregivers/about-palliative-care/> Last accessed July 2, 2019.

GLOSSARY

Nursing home: Nursing homes, or skilled nursing facilities, provide a wide range of health and personal care services. These services typically include nursing care, 24-hour supervision, three meals a day and assistance with everyday activities. Rehabilitation services, such as physical, occupational and speech therapy, are also available.¹

Assisted living: Assisted living is part of a continuum of long-term care services that provides a combination of housing, personal care services and health care designed to respond to individuals who need assistance with normal daily activities in a way that promotes maximum independence.²

Long-term care: Long-term care involves a variety of services designed to meet a person's health or personal care needs during a short or long period of time. These services help people live as independently and safely as possible when they can no longer perform everyday activities on their own.³

Power of attorney: A medical power of attorney (or health care proxy) allows you to appoint a person you trust as your health care agent (or surrogate decision maker), who is authorized to make medical decisions on your behalf. Before a medical power of attorney goes into effect, a person's physician must conclude that they are unable to make their own medical decisions.⁴

Medical Providers

What to expect?

- Lots of questions, confusion – expect to be challenged.
- You may have to take the lead in raising the issue, and indeed may have to re-introduce this topic multiple times until the patient and/or caregiver is comfortable discussing it.
- Be a champion of your patient's goals. Encourage your patients and their families to pursue options and knowledge about elder and end of life care.

What are the challenges?

- Patient/caregiver may push back against end-of-life planning.
- The patient's preference may not be realistic or attainable.
- Educating untrained or uncertain staff in the best interest of the patient's care.

Ways to navigate.

- Introduce a discussion about end-of-life care in a group setting, such as a support group meeting or staff/committee meeting in order to get people, and yourself, more comfortable with this topic.
- Maintain a list of facilities that have accepted PH patients; Find patients/caregivers who have successfully transitioned and are willing to talk to others.
- Encourage your patient/caregiver to be persistent, too.
- Advocate – get out there and talk to long-term care facilities, educate them to get on board, so when they are faced with a PH patient, they have some understanding.
- Provide care coordination support – set up introductory meetings, follow up on requests, provide contact information for concerns.

Living will and advance directive: Living wills and other advance directives are written, legal instructions regarding your preferences for medical care if you are unable to make decisions for yourself. Advance directives guide choices for doctors and caregivers if you're terminally ill, seriously injured, in a coma, in the late stages of dementia or near the end of life.⁵

Respite: Respite is planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult.⁶

Hospice: Hospice provides comprehensive comfort care as well as support for the family, but, in hospice, attempts to cure the person's illness are stopped. Hospice is provided for a person with a terminal illness

whose doctor believes he or she has six months or less to live if the illness runs its natural course.⁷

Palliative care: Sometimes referred to as “comfort care,” palliative care is a specialized approach to the treatment of patients with a serious or life-threatening illness. The goal of palliative care is to provide relief from the symptoms, pain and stress of serious illness. It is also designed to improve the quality of life of both the patient and the patient's family.⁸

PHA Resources:

- PHA support groups, telephone support groups and Facebook groups – connect with others and talk about these issues. [PHAssociation.org/Support](https://www.pulmonaryhypertension.org/Support)
- Insurance Guide – explore insurance options. [PHAssociation.org/Insurance](https://www.pulmonaryhypertension.org/Insurance)