

How Social Workers Can Help You in Your PH Journey

“I don’t need a social worker.”

Have you ever said that? If so, you aren’t alone. Social workers are an important but often underutilized part of the multidisciplinary care team. Personal experience tells me that this is likely due to confusion and misconceptions about the role of medical social workers. Anyone who’s watched televised medical dramas would no doubt believe that social workers are only called in to deal with troubled families and serve little purpose in the hospital outside child protection.

But the truth of the matter is that social workers wear many hats: supporter, educator, advocate, cheerleader and guide — to name just a few. The services they provide are often intangible. Social workers may not cure PH, but they focus on the patient and family, identify areas of need, and work to restore balance. Where most medical professions are disease-focused, social workers approach each patient with a broad lens, evaluating all the factors that influence the patient’s well-being, beyond their diagnosis.

So, what can a social worker do for you?

Support: Social work is, first and foremost, a helping profession. By nature of their training, social workers are well-equipped to provide emotional support when you need it — at the time of initial PH diagnosis, during hospitalizations or clinic visits, or when facing other life stressors. Crisis intervention and adjustment to illness are critical aspects of their work. They recognize that sometimes simply listening is what is needed most. Don’t be afraid to use your social worker for support. They are neutral, nonjudgmental and, trust me, nothing you say will shock them! Living with PH brings unique challenges. Your social worker can be a wonderful resource for support and encouragement as you learn more about PH and incorporate your diagnosis into your life.

Educate: Sometimes dealing with the healthcare system or community resources is like visiting another country complete with unfamiliar languages and foreign customs. Especially at the time of initial PH diagnosis, social workers play a central role in helping patients navigate unfamiliar systems, manage medical needs, and find balance. From identifying who’s who on the medical team to learning how to organize your personal medical record, social workers have information that can help you get the most out of your medical care while also ensuring that you have a life outside of your diagnosis. Not sure

what your insurance will cover? Unclear if PH qualifies you for state or federal resources? Worried about what accommodations you might need in school or for travel? Your social worker can answer your questions and give you the knowledge you need to move forward.

Advocate: Doctors, nurses, and other medical professionals are focused on your care, but like everyone, they can have strong opinions. Patients need a voice in their care. Social workers can help you express your wants and needs constructively, allowing you to be better heard by your PH team. Because of their understanding of your physical, social and psychological conditions, social workers also play a critical role in helping the medical team understand how to interact with you most effectively.

Connect: Living with PH can be isolating and overwhelming at times. It may feel as though no one really understands what you are experiencing or that you lack the resources to meet your needs. However, social workers are an excellent source for connecting you with other PH patients or caregivers and alternative supportive resources. Because of their work within the hospital system and the wider community, they are familiar with other individuals, support networks and community resources, such as PHA’s support communities, that may be helpful for you. A thriving support and educational community exists for PH patients and families — you just have to know where to look! Social workers can assess what your needs are and then make appropriate connections to those missing resources.

Empower: A patient or caregiver’s capacity to cope can be significantly diminished when confronted with a diagnosis of PH, a change in baseline function, or other life stressor. Social workers, through education, support and advocacy, provide a bridge for individuals back to stability and control. By helping you identify your own strengths and supports, they work with you to regain control of your life and improve your ability to cope.

Social workers can be your best ally in living (and thriving) with pulmonary hypertension. If your PH program doesn’t include a social worker, contact the social work department at your primary hospital and ask about resources. Better yet, request that your PH program add a social worker to the team and everyone will benefit! ♦

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