

# Palliative Care: Care for the Caregiver

To say Barbara O'Connell is a busy woman is an understatement.

She runs her own real estate firm just outside New York City. She's on the board of a non-profit organization and she has a son in graduate school upstate, whom she visits regularly. And all of that is secondary to her top priority: her role as caregiver for her husband, Tom, who's been living with Prostate Cancer for 12 years.

*"The part that my wife plays, is so incredible. She's my cook, she's my caregiver, she watches over my pain."*

*"His symptoms changed drastically in the past year and a half to two years. Total lack of energy requires much more sleep during the day; waking up every hour to two hours at night - which is very disruptive to both of us; increased and, debilitating pain."*

Those changes led Tom and Barbara to additional medical treatment, for people living with serious illness, called Palliative Care. It focuses on relieving the pain, symptoms, and stress of a severe condition and its treatment. Palliative Care is for the patient and his or her family, including the caregiver.

*"They anticipate what's coming. You don't know what's out there, so you, you're kind of fumbling along."*

The role of a caregiver like Barbara can run the gamut: from handling routine tasks, to managing medical care, to just 'being there' - to listen.

*"Caregivers tell us that they feel ups and downs; a lot of times, their emotions parallel the person who is sick."*

Caregiving can involve a range of emotions, including anxiety - over whether you are doing things "right"; guilt - that you're not doing "enough"; sadness - about the suffering your loved one is going through; grief - over the loss of the way things "used to be"; resentment - over being thrust into the role of caregiver even anger, directed at the person who is ill.

*"What I think is very important to remember, is that this range of intense emotions is perfectly normal. You're going through a - big adjustment, a big life adjustment; and you're watching somebody who you care about that may be suffering and dealing with illness."*

Recognizing and dealing with the feelings that arise from caregiving is important. So is taking care of your own needs. The failure to do so can lead to a host of problems, including lack of sleep; poor diet; being too sedentary; more frequent illnesses; social isolation; and substance abuse. To help manage the stress of caregiving: take some time each day, for yourself: try yoga, meditation, or even just a short walk; if you work, talk to your human resources department: they may be able to help you balance work with your caregiving responsibilities; and ask for help from a professional caregiver, family member, or friend, who can step in and allow you time off when you need it.

*"There is no shame in accepting help; and I think it's even important to say what form of help would benefit you, so that you get the help that you need."*

Barbara receives help from a close group of friends - who make sure she gets out.

# Palliative Care: Care for the Caregiver

*“Once I walk out that door, that’s my break. And, it’s two or three or four hours of being refreshed.”*

For Barbara, having the support of her friends - and knowing the Palliative Care Team is just as devoted to her as to Tom - makes the challenges of caregiving feel more manageable.

*“It’s an emotional type of impact on me, that I feel like, ‘Ok, I can - get up and do this again today - do what I have to do - go to work, take care of him, go to the doctor, go to the drugstore, shop again. That’s what that allows me to do.”*