Resources – The Team You Bring With You

Sometimes the problem with accessing resources is not the unavailability of resources, but rather the reluctance to ask for help or identify the skills of readily available candidates.

Some barriers to accepting help include the patient or primary caregiver's belief that no one can do anything to help. The "whole" is too large to tackle.

Another reason someone may not want help is the fear of losing control. Most of us have spent years trying to gain control over our lives and asking for help can activate our deepest fears at a time when vulnerability is already an issue.

There are fears about losing privacy – both by having to share information, as well as personal privacy.

Given the legitimacy of all these feelings, there are still very good reasons to address these resistances, for the benefit of the PALS and for the primary caregiver and family. No one can do this alone. The medical side brings its team; you also have a team to access. To re-use a phrase that unfortunately became attached to a political agenda: It takes a village. People in your world want to help. They may need direction as to how, when and what.

Some roles your circle of care may already include: (with thanks to the book Share the Care):

The researcher: The researcher type is someone who likes gathering information. The person who tells you about the new restaurants or plans vacations down to the smallest detail. This is someone who can amass information about treatments, care, community resources, etc. He/she can put together information for the PALS to review as desired.

The experienced caregiver: Someone who has taken care of a loved one has information that can save steps with current needs. Access their experience that they will undoubtedly be willing to share.

Chief cook and bottle washer: Someone who can be available to run errands, cook a meal that's ready when you get home from a long clinic day, can pick up dry cleaning, etc. – someone who you don't necessarily call on for anything medical, but is an extra set of arms and legs.

The Special Skill person: an attorney friend who can help with legal questions, wills, POA; an insurance expert friend who understands fine print.

The Handyperson or Weekend Carpenter: Around the house chores.

The Doctor Visit Accompanier: the calm listener who can help prepare a list of questions with you and take notes at the visit.

The Driver: Someone who can take the kids or the PALS to appointments locally.

These are just some ideas to help you look at the circle of friends, acquaintances, colleagues, extended family members who you would gladly help - with an eye to helping them help you. Often people don't know what to offer - specific ideas allow people to pitch in and not overextend themselves and disappoint you. The combination of the professional team and the personal team you can amass can provide comprehensive support to the PALS and family.