

Tips for a new caregiver

- Take care of the caregiver — ask for help. Even if you are calm, compassionate and tough, care giving puts relentless stress on your body, mind and soul.
- No matter how difficult it is, talk with your loved one about end of life issues, wishes, preferences. Do this sooner, rather than waiting until it is too late in the progress of the disease.
- Do the documentation: update wills, advance directives, funeral preferences (have copies readily available)
- No matter how difficult it is, have meetings and discuss the situation with family members (include close friends where appropriate) so everyone is on the same page. We made this easier by dealing with end of life desires of patient and spouse (mother's and father's, in our case) at the same gatherings.
- In Georgia we have what I call a "short form advance directive", the POLST form (Physician Orders for Life Sustaining Treatment). It has three signature lines: Patient, Patient's Authorized Representative, and Physician. Fill it out, get it signed, stick it on the refrigerator, give it to the paramedics or take it to the hospital.
- It matters little what the clinical diagnostic acronym is (MSA, PSP, CBD, ?), most of the care providing will be the same activities.
- Consider brain donation for research purposes — get names, telephone numbers of donation coordinators, fill out forms, stay in touch with the institution. [Note from Robin to Bill: This is a primary activity of Brain Support Network. Learn about our process.]
- You have to become educated about the brain disorder(s) and teach health care providers about the rare condition your loved one is experiencing and the expected decline in their abilities function normally. One mention is not enough, you have to train them.