

# MY BRAIN HAS A HOLE IN IT

Lessons Shared from One Family's Response to the Unthinkable



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Gordon and Jill have generously offered their experience, strength and hope. Like most of us, they were not prepared for the circumstances in which they found themselves. By considering the following, you can help your family and loved ones navigate the unexpected more smoothly, and focus energy on the healing process.



## 3 A.M. LIST

As Gordon puts it, here is some information for the “what happens at 3 a.m. list”. Copies of the following documents, plus any other paperwork relevant to your circumstances, should all be kept together in a secure location:

- Will
- Power of Attorney
- Durable Power of Attorney for Health Care and general Power of Attorney for any business decision
- POLST (Physician Orders for Life-Sustaining Treatment)
- Passwords and banking information
- Passwords to computer, cell phone, home accounting system
- Payment information for mortgage, utilities, credit cards, any other debt obligation
- Email accounts, names and passwords
- Health insurance policy, information, contact information
- Birth Certificate
- Marriage/Divorce Certificates
- Hospital preference
- Medication list with prescription numbers, pharmacy (ies)
- Physician(s) contact information
- License/Passport/other photo ID
- Investments, retirement accounts, life insurance, disability insurance, accountant with contact information

Decide now with whom to share the list. Make sure they know where to find the information when needed. If you keep relevant documents in a safe deposit box, does your family member or loved one know where the key is? Are they included on the signature card at the bank?

# LET'S GET PRACTICAL

The mundane, everyday obligations get put on the back burner when a crisis arises. However, those obligations don't just disappear, and the longer they don't get done, the more stress there is at home. Rather than asking if there is anything you can do, suggest specific ways you can ease their burden. Here are a few practical ways to truly help:

- Set up a communication device for friends and family to keep up with what is going on. Coming home from the hospital every day and having to retell the day's events 20 times on the phone is exhausting. Consider [caringbridge.org](http://caringbridge.org) where the caregiver can type a message and friends and family can send messages back.
- Are there children still at home? Offer to talk to the principal at their school to alert them to the crisis. If the child is going to miss some days of school, establish a method of communication for homework, etc. Are your kids on teams together? Offer to take them to practices and games. Crises are hard on kids – maybe offer a play date to give kids and parents a break.
- Is this a long term crisis? Disability insurance often takes months to commence payments while medical bills come immediately. Consider setting up a bank account and spread the word that donations are welcome.
- Establish a yard work schedule. If the grass is growing, it still needs mowing. If you and/or a group of people are able to provide this service, let the caregiver know that you will handle the yard for # weeks/months.
- Establish a housecleaning schedule. Even if you can volunteer to vacuum or clean the bathrooms on certain days, that is a huge help. Offer to run errands if needed.
- Establish a meal schedule. Popping over randomly with this or that to eat is disruptive and generally wasteful. At one point, I had almost 3 dozen brownies in my refrigerator but no milk or bread. Be the point person in establishing a meal schedule so the caregiver can plan for food. Are meals what he/she needs? Create a meal delivery plan with delivery times. We kept a cooler by our door and people put the food in the cooler between 5 and 6 p.m. Do donors want the containers back? Then they should put their names on them. Are groceries or toiletries what he/she needs instead? Establish a list and a delivery plan.
- Do you have some “handyman” skills? Depending on the nature of the crisis, there may need to be some alterations at the house, such as installing grab bars, moving furniture, etc.
- Do you have a list of all your families medications? Make a medical card to keep in your wallet (and each family member). It should include all current medications, dosage and frequency, emergency contacts, medical allergies, and physician information. For examples, look online for “medical wallet card.”



Scan showing the “hole” in Gordon Viggiano’s brain.

As with anything, to be truly helpful during a crisis, you should do what you say you are going to do with no surprises. Random acts of kindness are lovely, but in the middle of a life changing event, help that is reliable and practical is essential. Knowing that the day-to-day details are covered allows the caregiver to focus on the major issues at hand.



## WHAT CAN I DO?

What can I do to help my friends and loved ones when a crisis happens?

As a friend or relative of someone going through a health crisis, you want to be as caring and helpful as possible.

Some things to consider:

- Be aware that lack of sleep, fatigue, sleep disturbance, trouble concentrating, appetite disturbance, forgetting, headaches can all be natural responses to stress and grieving, both for the caregiver and the person with the illness.
- Know that personality changes may occur during this time.
- Give your loved one the added benefit of space to be who they are, at that moment.
- You don't have to know the “right” thing to say. Most of us don't. Being actively present and listening can be the greatest gift.

Take your lead from the person. If it seems helpful for them to talk about their experience, allow them to do so. If it isn't useful or they seem to want to avoid it, allow that too.