

# YOUR CONNECTION

A Disability-Connections Newsletter

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## Top stories in this newsletter December 2019



Living Will vs Will To Live



Adapting Your Kitchen On A Budget



When Nonprofits Go Astray



Where To Turn In Time Of Crisis

## Living Will vs Will To Live

It is every person's right to control his or her own body including the right to choose medical care, medications and the right to determine how one will be treated if one is incapable of voicing an opinion. Of course, most people do not want to go on living as helpless victims of medical control after they lose the capacity to make decisions. This prospect fills us with dread and can be an unconscionable invasion of privacy. The "Living Will" appeared on the scene to calm that fear.

However, the primary danger of living wills lies in the fact that it is usually signed long before the person knows when he or she will be incapacitated or what the circumstances will be. Some people feel they would not want to live having to use a wheelchair or with a brain injury or loss of any of their five senses ect. But technology has progressed by enormous bounds to assist with any disability. At the time of signing the "Living Will" most people aren't even aware of how many ways technology can help them live more fully, therefore, not fully aware of their potential to a life of quality. "Living Wills" attempt to predict the future, so they are by nature broad and generalized.

### Why is it important to be specific?

You might be treated by someone who thinks you cannot be saved when you could. There is great danger that a vague description of what you do not want could be misunderstood or distorted so as to deny you treatment that you do want. There are those in the medical profession as well as the courts, not to mention the HMO's, that are so committed to the quality of life ethic that some may think patients with severe disabilities would prefer not to receive either life-saving measures or nutrition and hydration.

### What are the options?

There are a couple actually. One is a Durable Power of Attorney for Health Care. This is a document you can delegate to a trusted friend or a relative to become your agent for any health care decisions you are unable to make including medications as well as treatment procedures. It is much more specific than a Living Will and has areas where you can put in writing what you DO want. Another is Missouri's "Will to Live" document. This document starts from the principle that the presumption should be for life. However, it does provide a space for "Special Conditions" selected by you where you can state when to cease treatment and how. It will guarantee that you will receive the food and water you need should you become incapacitated, while allowing you to decide and state what you might consider "extraordinary care". Food and water are not medical treatment or machines but basic care necessities even if given by tubes, intravenously or other means. Medications should be given to alleviate pain not to shorten life.

### Is it the law?

Don't assume the "Living Will" or "Health Care Directive" or "Will to Live" documents are required by law and must be on file with a doctor or hospital before any procedure. While it is a good idea to do so, it is certainly not required by law. This misconception probably comes from the Patients Self-Determination Act, a bill that was passed in Congress in 1991. It says that facilities receiving federal Medicaid or Medicare funds (and that means almost all hospitals) must give adult patients, at the time of admission, written information on the "advance directives" that are legally available. In practice this federal requirement can make people think they must have an "advance directive". They may even feel pressured to sign a "living will" or "durable power of attorney" general form that could have the effect of stopping medical care and treatment – even medical care and treatment that could save their lives! Be ahead of the game and fill out your form of choice with the specific things you want or don't want before the need arises.

### Some Tips:

Be sure you understand the terms used in your health directive document. Make sure that your agent making those life and death decisions for you knows your intentions behind every choice. Introduce him or her to the advances of technology for people with disabilities so that they have a clear picture of what quality of life is possible. It is important that they have a broader knowledge of potential than the medical field generally exhibits. Marion Trimble

## 10 Things That Can Make Your Kitchen More User Friendly.

I love to cook! But I have difficulty keeping my balance because of neurological damage. It especially bothers me if I try to bend down to investigate cabinets or do too much walking back and forth in the kitchen. So, I adapted my kitchen area to accommodate my limitations. I wanted to share some ideas that have worked very well for me. These changes would actually work well for anyone.

**Add A Pantry** I bought my outdoor units from Walmart. They are intended for garage storage, but they work perfectly in my kitchen. I relocated my pots, pans, baking sheets, etc. so that I did not have to stoop to the lower dark cabinets and dig these items out. They are neutral in color, so they went with all my decor. I bought three because I have one for baking and cooking supplies another for my pots and pans and one for food storage. They were around \$77 each. I just bought one at a time.

**Add a small 4 drawer chest** I bought the same style and color in a four-drawer chest to house my big utensils, foil, zip lock bags, plastic storage containers and other attachments I don't use every day. Also found at Walmart for \$59. Although my kitchen has a good amount of floor space it only had two small drawers for utensils and the drawers would stick. This little chest has drawers that slide out very smoothly and the drawers are very deep.

- **Add a crate under your sink** I have a milk crate under my sink with all the cleaning supplies I use in the kitchen. I can easily slide it out to get what I want without getting on my hands and knees to find something in that dark space.
  - **Refrigerator organization** I organize my refrigerator so that breakfast things are together, leftovers are on their own shelf and heavy milk and juice containers are on the top shelf. This keeps me from stooping and pushing things around to find the butter hiding behind a big leftover dish that must be moved out first before I can find it.
- Utility cart** The utility cart can hold my heavy appliances like the KitchenAid mixer, the bread machine and food processor. Not only does it open counter space but keeps me from lifting items that are too heavy. All I have to do is roll it over to the outlets and I'm in business. I found this one at Lowe's.

- **An office chair** I use an inexpensive *armless* office chair and wheel around to gather ingredients for recipes. It works great for going from pantry to refrigerator to the working areas. It also works great for cleaning out those low refrigerator shelves and for cleaning the oven.
- **The garbage bowl** I learned this little trick from watching "30 Minute Meals" on the Food Network channel. Using a garbage bowl sounds trivial but believe me saving your time and energy walking back and forth to the garbage 20 times during meal prep is well worth the effort!
- **A good spice rack** I bought a spice rack that fits flush against the wall and sits on my counter. It saves reaching and looking for spices I use the most and it keeps things in order. There's nothing worse than trying to find a certain spice in a cupboard full of 50 or more that have fallen over or rolled to the back of a cabinet you can barely reach.

**And finally, the two things I could not live without** I could not function at all without my two sets of cheap kitchen scissors. I use them to open packages boxes snack bags you name it. They are my extra set of hands. The second thing is the simple wooden clothespin. I use these to fasten snack bags, bread, brown sugar bags and anything else that needs a closure. They are cheap and easy to use and not near as frustrating as those little twist ties. Marion Trimble



## When Non-Profits Go Astray



What is a non-profit exactly? A nonprofit organization (NPO, also known as a non-business entity) is an organization that uses its surplus revenues to further achieve its purpose or mission, rather than distributing its surplus income to the organization's directors as profit or dividends. They have a tax exempt status granted by the Internal Revenue Service after conditions are met such as purpose, limitations on spending and external safeguards.

The main purpose of a nonprofit is to serve the needs of the communities they have indicated in their application. They are not "agencies" or "businesses" they are private as opposed to governmental, self-governing, voluntary and of public benefit. In the United States there are three main economic sectors that serve the citizens "wants" and "needs". These are the government, the for-profits and the nonprofits. For-profits supply our "wants" based on supply and demand. These profits are based on delivering those products and services to the consumer for a price. These are the community's desires beyond their needs.

The non-profit is responsible for "needs" that the government does not have a direct responsibility to deliver. These needs and a goal to achieve them should be instilled in the mission statement. The problem that often raises its head is when the aggressive hunt for money wedges itself between the mission and the survival of the organization.

Nonprofits begin their noble causes no doubt with services and programs to fill those gaps of need but they must be ever diligent they do not get engulfed by their collaboration with the donor class to the extent it offers only token assistance to the people it serves causing it to smack against their mission. Once they demoralize that, you must ask why their doors remain open at all.

Not all nonprofits fall prey to the irresistible security money and power offer. However, those that do, make you wonder if the acquired wealth they accumulate is for the advancement of who they serve or who serves them. Marion Trimble

Nearly all men can stand adversity,  
but if you want to test a man's character,  
give him power. — Abraham Lincoln



## **IN TIME OF CRISIS**

Sometimes we find ourselves in situations where we may be homeless, in abusive relationship, or have no food.

If you find yourself on the verge of being homeless consider going to your local library. With the help of the librarian you can find resources to assist you in finding shelter, food, and legal aid.

If you need to talk to the police, please do! But be careful, the police and others you may communicate with may be mandated reporters. A mandated reporter shall report any suspicion in which a person or a child's welfare may be at risk in their opinion.

A place for people with disabilities to consider is ILRU.org. This site lists all of the Centers for Independent Living nationwide to help you to find one near you to assist in your specific situation. The Center near you has trained specialist who will know resources in your community.

Please share your suggestions by going online to our Facebook Page Disability-Connections. We are founded in an "each one teach one" philosophy that collectively has the power to change people's lives for the better through our experiences.

William Stork

