

Home Alone

Many people think of “independence” not in terms of how well they can dress themselves, transfer into bed, or drive, but in terms of their ability to live alone in their own home. Many of these people use hired helpers or assistants who come into the home, do what needs to be done, and then leave. Such helpers, rather than spelling dependence, are in fact a tool for the individual’s independence.

Is this “life on the edge?” Many would say so. And it’s true: many disabled people who live on their own are playing “beat the odds,” hoping that nothing happens while they’re alone. This brochure describes some of the issues people “living on the edge” might consider to lessen that “edginess” – to decrease the risks they face and to increase their own peace of mind.

Communicating

Most of the strategies that make a difference fall into two broad categories: those that increase your ability to communicate with the outside world – quickly, easily, and at all times – and those that lessen the chances of the unforeseen happening.

The Basics...

Whether you’re trapped alone on top of a mountain, in a blizzard with nothing but a cell phone, or alone in your home with a sophisticated call system, communication – more than anything else – is the key to both safety and survival. The bottom line: you need to be able to call for help from any place in your home, and in any situation. The best way to do this?

Call Systems...

Carry a “communicator” on your body at all times. Many people keep a cell phone clipped to their belts. (Note: On your chair, in your backpack, or on your lap will not be close enough if you happen to fall out of your chair!) If you can’t find a cell phone that can be adapted so you can dial or at least activate a pre-set emergency number yourself, consider a subscription call system. Some people use a service that provides them with a simple receiver they wear around their neck. If they push the button, the service is notified automatically. The service then calls them back on the phone to check on them. If the wearer doesn’t answer the phone, help is sent to the home. Some of these services will even call you if you fail to check in by a pre-arranged time each day. If you don’t answer, they’ll assume something has happened and send help.

There are many possible variations in the technology available in these systems. Some are quite sophisticated. For example, an emergency notification system might be established that places a sensor in a key place – your refrigerator door or under a carpet, for example. Then, if that refrigerator door doesn’t get opened or that carpet doesn’t get rolled over by the appointed time, help is again automatically notified.

For information on basic services like these in your area, start by checking out “Medical Alarms & Monitoring” in your yellow pages or “Personal Emergency Response Systems” on the Internet. For the more creative, sophisticated solutions, you might try calling an occupational therapist at your local

SCI rehabilitation center, a discharge planner at a local general hospital, a rehabilitation engineer, or again try the Internet.

Foreseeing the “Unforeseen:”

There are several things unique to spinal cord injury for which you need to have an emergency plan in place:

Leg Bags...

If you're planning on being alone for extended periods, you need to be able to empty your urinary collection device. If you can't, start looking at adaptations. Electronic switches, either touch or sip and puff, are available so that all you need to do is puff into a tube to open the valve that drains your leg bag. If you can't get into a bathroom or get your leg bag to the toilet, consider something like a kitty-litter box, on the floor. You can then wheel over it and drain your bag. Or, just use a larger sized bag during the day.

Autonomic Dysreflexia...

Are you prone to autonomic dysreflexia? Do you have a plan for dealing with it if you're alone? First, have a system so you can get yourself to sitting – loops on your bed, an electric bed, etc. Regardless of what's causing the dysreflexia, sitting up should cause your blood pressure to drop at least a little while you wait for help. What if that doesn't work? Check your urinary drainage system for a full leg bag, kinking, or other tube related problems.

What if your symptoms still keep getting worse and worse? If you know for a fact that your bladder or stoma will drain – or even just leak – when there is no catheter in, you may be desperate enough to try removing your catheter entirely. Yes, you'll get wet and you may need to go to the ER to reinsert it, but this is an emergency! If you have a plastic syringe, and if you have the strength and know how to use it, deflate the balloon that keeps the catheter in your bladder. The tube should then slide out. Otherwise, if you're able to use a scissors, cut the catheter tubing a few inches after it leaves your body (but before the first connector). The balloon will deflate, and you should be able to simply pull the catheter out.

What if none of this lessens your symptoms? Maybe your problems aren't coming from your bladder. Check your skin to see if there's pressure, pinching, or poking somewhere that you can't feel. Check your bowels. Can you do digital stimulation, just to see if there's a blockage that you might relieve?

Falling out of your chair...

Don't take chances – always wear a safety belt when you are alone. Make sure your helper has positioned the wheelchair's rear anti-tippers before he or she leaves you. And, make sure that a phone or call device is attached to your person – not to the chair.

Victimization...

You can't be too safe these days. How do you manage the fine line between safety and security? Do you leave your door unlocked, in case help should need to get to you quickly? Do you even answer the door if the bell rings and you're home alone? These are things you'll need to think about and decide for yourself, but here are some suggestions:

- Teach visitors to call first before they come, so you can know when to expect them.
- Give trusted helpers and assistants their own key. Then, they can let themselves in when they arrive, and lock you in when they leave – if that's your choice.
- Lower the peep hole on your door to a level where you can use it.
- Keep areas around your house, particularly the entrances, well lit.
- For a more "extreme" solution, install an intercom system to "screen" visitors before you let them in; you might even install electronic locks, like many apartment buildings have, so you can "buzz" visitors in.
- Finally, use your helpers as a safety net. Ask them to call you at certain times throughout the day. Put their phone numbers on your phone's speed dialer. If you want to be extra safe, buy your helper a pager service (under \$10/month), and set up a few simple "codes" so they know you're calling them, even if you aren't able to type in an entire number.

Anticipate and Practice

This has been just a taste of some of the possible issues to consider. The key is anticipating. Unpleasant as it may seem, try to come up with various worst scenarios. Think things through; talk your issues and ideas over with family members, friends, or helpers, and make a plan for what you might do. Cover all the contingencies, get organized, line up any equipment you might need in an emergency, and, where it's practical, practice. Good luck!

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