The View From Here

Illness has an evil twin -- isolation. Make friends with it

August 1, 1997 By Victoria A. Brownworth

My bedroom windows open onto my garden. The view is beautiful -- lush and green now in high summer; in winter, starkly white. Scents drift up with the season -- crisp, cold and spicy or redolent with roses and gardenia. Birds in the big evergreen and greengage plum trees serenade daybreak and nightfall. Raccoons, squirrels, possums, even bats add to the array. More country than city, the view comforts with both its constancy and its changeability.

Yet my garden, which in my healthier days served as a sanctuary from the gritty city, is now a kind of chador. Despite the loveliness, I sometimes feel trapped, anxious, desperate to escape into a world I can see but not get to. My isolation may be aesthetically more pleasing than most, but it's still a gilded cage: I'm not here by choice; illness is my prison. And I hate it.

Sick people who would never get well were once called shut-ins. Not always literally shut in, we are still frequently shut off. Sometimes what shuts us off is geography: An AIDS diagnosis can be very burdensome in rural areas or small towns where services may be few and a public declaration still stigmatizing. People in cities, on the other hand, can often take their pick of AIDS organizations and self-empowerment groups, but isolation -- illness' evil twin -- is a lurking predator. While disabilities physically confine only some to wheelchair or bed, all of us are vulnerable to the psychological effects of sickness: Depression; a sense of helplessness and hopelessness; a dangerously narrow vision of the future that magnifies the inevitability of suffering and death. Quarantined from the life we led when healthy, we may let these emotions quarantine us from the life that remains, and its diminished but definite promise.

I have spent the better part of the past year in bed. Unable to walk without aids or maneuver my wheelchair in the narrow second-floor hallway, I am homebound, shut in. I work, eat, read, watch television, talk on the phone and sleep -- in the bedroom. One room. All the time. I sometimes feel like a prisoner, unable even to pace my cell; frustration builds over the limitations induced by illness. My worst days are more like part of a life sentence than a life.

Becoming homebound at first shattered my daily routine. Some friends drifted away; my work suffered. Mornings disappeared into the newspaper; tuning into the midday news turned into afternoons of soap operas; evenings presented my only contact with another human being when my lover came home. I quickly discovered that the difference between solitude and isolation is that little matter of choice.

There were tricks I had to teach myself to keep isolation at bay. Beware how you spend your time: If you're no longer able to work (or if you work at home), stick to a regular routine. Keep the television off during the day -- it renders you passive and less able to interact with real people. Reading (or audio books if your vision is failing) stimulates more and makes for more-alluring conversation with friends.

Staying connected to the world beyond your bedroom windows is vital. Find ways to get out occasionally and have a buddy visit regularly. Get involved in support groups -- in person, on conference call or via the Internet. Some friends will disappear. Make new ones.

In truth, it's much easier to prevent isolation than to cure it. Keep watch for depression's warning signs: Solitude becomes loneliness. You stop returning calls, drop favorite activities. Have you talked to your doctor or therapist? It's up to you to ask for help.

But responsibility also falls on those close to you. Before isolation sets in, give them permission to be pushy. When they wonder, "Do you want a visitor?" they should already know not to take no for an answer. Make a point of preparing for hospital stays by setting up a telephone tree. A hospital irony is that you're surrounded by people but only rarely the ones you want to see.

Isolation can make us acutely aware of all we've lost to illness. Counter that peril with action. Think, feel, read, reflect, keep a journal, love. A friend with AIDS had always wanted to paint; when he could no longer work, rather than lament, he learned the fine art of watercolor. I don't do much frivolous socializing these days, but I've published five books in three years and taken up quilting. I'm too ill to garden, but not too isolated to sit by the window with the afternoon sun on my face and feel grateful. The world's near enough to touch, and life is still in my grasp.

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