

Work In Progress

Women with Chronic Illness: Overcoming Disconnection

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Work in Progress

Work in Progress is a publication series based on the work of the Jean Baker Miller Training Institute at the Wellesley Centers for Women. Work in Progress reflects the Institute's commitment to sharing information with others who are interested in fostering psychological well-being, preventing emotional problems, and providing appropriate services to persons who suffer from psychological distress. These publications also reflect the belief that it is important to exchange ideas while they are being developed. Many of the papers are intended to stimulate discussion and dialogue, while others are finished research reports.

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About the Authors

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Abstract

Within the framework of Relational/Cultural (R/C) Theory, five psychotherapists and educators offer new ideas about how women can live well with adult-onset chronic illness. After reviewing R/C Theory, the authors identify the processes of recognition, renegotiation, and regeneration, which they refer to as "The Three Rs." These processes provide a useful framework for understanding the development of women who must cope with chronic illness. The authors illustrate their points by sharing their personal stories.

Diversity is a major theme in the '90s. We believe that the spectrum of diversity should be broad enough to include people with chronic illness or disability. In 1994, with the encouragement and support of Jean Baker Miller and the Stone Center, a call was issued for group members who were interested in exploring how women's psychological growth continued through the experience of developing and learning to live with a chronic illness or disability.

Over time, a core group of five members has evolved: four of us are therapists and one is a cross-cultural trainer/educator. Each of us is living with a chronic illness. There is no widely accepted term for the particular segment of the population that we represent. For purposes of clarity, in this paper we define the group of people with adult onset chronic illness (AOCI) as those who have a non-congenital condition. The onset of illness occurs in adulthood when the individual has already established a sense of identity. We include those with cancer and AIDS within our umbrella definition because of the commonalties we have found. The term chronic illness, for the purpose of brevity, is intended to include adult onset disabilities as well.

We are white, educated, heterosexual, and middle class, with a wide range of economic circumstances. While we do not directly address economic issues, we are all aware that access to sufficient, reliable income and quality health care are crucial aspects of coming to terms with a chronic illness. We have tried to be mindful of the uniqueness of our experiences and circumstances and do not intend to speak for women of different backgrounds.

We write about women's experience, as that is ours (and much that is written is only about men, and usually doesn't value relationships). While we do not argue that this experience excludes any parallels with men, we focus on women's psychological

development and how it interacts with illness and disability.

Increasingly we speak about the personal meaning of the dramatic life-changing events imposed by the development of a chronic illness, and we have searched for the common threads in our experience. We have discovered that, for each of us, living successfully with a chronic illness has been a process of recognition of the changes and their implications, renegotiation of identity through relationships, and regeneration as we continue to grow and develop with the experience of illness. We think that our stories demonstrate the processes of **recognition**, **renegotiation**, and **regeneration**.

A Relational Approach

Relational/Cultural Theory provides a framework for understanding the ways in which we respond to, and continue to develop with, the experience of chronic illness. For women, relationships—the inner sense of connection with others—are the central feature of development. Connection is key to development, not separation/individuation, as has been postulated by traditional psychodynamic theories. Mutual interaction, in which both people participate and enlarge themselves, others, and their connections, is essential for enhancing growth (Miller, 1984; Surrey, 1985; Jordan, 1991).

It has become clear to us that the quality of our relationships is central to our ability to live successfully with illness. That quality can, in fact, facilitate or hinder our ability to cope. The denial of illness from a loved one can challenge one's own recognition of and adaptation to illness, while support and reciprocity can foster one's process of coming to terms with illness. Such connections come from a variety of sources—spouse, parent, child, friend, professional, or members of formal and informal support groups.

In considering the connection between relationships and the vicissitudes of chronic illness, we state emphatically that relationships, no matter how positive or plentiful, are not curative. Suggesting otherwise places an unfair burden of guilt and/or shame upon people who have chronic illnesses.

It is critical to understand that relationships that provide the most emotional healing are not one-sided, intended only to provide care for the one who is ill. The relationships are mutual, with care flowing in both directions. Judith Jordan states that “the relational perspective stresses ‘being-in-relation,’ an

interactional, ongoing ‘process of being’ rather than a static structure dedicated to increasing self-sufficient functioning” (Jordan, 1997, p. 29). We have come to realize that, although our physical health has changed, our capacity to “be-in-relation,” to care for, be empathetic to and connect with others, remains. Mutual relationships are key to living with chronic illness.

The Three R's

The diagnosis of AOCI is a profoundly life-altering event. The change in a woman's health and the resulting physical and emotional shifts are extremely upsetting. The qualities of health she once took for granted in her body—these can include function, mobility, strength, appearance, energy level, and/or healing ability—are not as they were. Since many illnesses can be debilitating and painful, as well as life-threatening, this can be a frightening and disheartening time in a woman's life. The process of moving forward and coping can seem impossible, for so much has been changed and lost. Life no longer presents itself in a way that is predictable and easily understood. Rather, it is more often unpredictable in nature.

Living well with chronic illness can be achieved. We have identified the concepts of **recognition**, **renegotiation**, and **regeneration** as key to a woman's adaptation to living with chronic illness. These processes are nonlinear. They are cyclical, recurring throughout a woman's lifetime. The wide breadth of these experiences can range from practical to existential.

Recognition is the conscious awareness of a serious change in health status. It is a process that is separate from, but related to, a diagnosis, in that one can be acutely aware of a shift in health long before medical confirmation. Each woman needs to move into understanding that this illness may profoundly change the way life will be—including the possibility of a shortened life span. Recognition takes many forms; it is a lifelong process that involves mourning losses and identifying changes that can occur daily.

The process of recognition addresses the existence of illness as well as its effect on women's relationships. The traumatic impact of the chronicity of illness may lead to disconnection. A woman may isolate herself out of fear and shame, while significant others may withdraw in response to their own reactions. Ideally, connection will be maintained and others can assist a woman with ownership of her illness by their willingness to both hear her experience

and reflect back their reality. Equilibrium can be restored with mutual empathy, reconnection, and open communication.

Renegotiation is the process of integrating the experience of illness into one's identity—"Who am I now?" A woman is *not* her illness; she is someone who has become ill or disabled. The integrative process involves new learning in all relationships. The recognition of a new health reality becomes a stepping stone for renegotiating one's own needs and one's response to the needs of others. As time goes on, and chronicity persists, the process of renegotiation continues. Moving toward connection and empathy in relationships can be a crucial and valuable piece of this work.

Regeneration is the process of creating meaning and connection in one's life. It may involve a different focus and/or approach in one's career and personal interests. Ongoing and mutual relationships will have changed and grown in ways that reflect the adaptations forced by the experience of illness.

For us, our work as psychotherapists and educators is an integral part of our regeneration process. The regenerative part is taking what we have learned and using it to help others to cope. Sharing our personal knowledge of AOCI can be an essential and healing tool. We can validate the experience of others as we give voice to the life-changing experience of chronic illness.

Our stories

Due to space limitations, we cannot tell our stories in their entirety. Instead, we will each focus on a particular aspect of our illness experience, highlighting it in relational terms, tracing the process of recognition, renegotiation, and regeneration.

Barbara

For the first fifteen years, I told no one about my illness. Members of my immediate family knew I had rheumatoid arthritis but I "passed" as a physically healthy person in the workplace, among friends, and even when separated and later divorced, with significant others. I looked very healthy, and because my illness was largely invisible, I had the option of choice. I could conceal or reveal my problems. There was never any doubt about which was preferable. I did not want anyone to know that I felt damaged, so I learned to hide the symptoms of my illness, to feign wholeness and wellness, to do everything I could to look just like everybody else.

So much energy went into that denial. And always, always there was the fear that I might be

discovered, that my private shame might become public knowledge. My secret had to be maintained at all costs, so I became highly skilled at camouflage. Was I limping noticeably? It was a blister from new shoes. Or my foot had gone to sleep. Or any one of a dozen other possibilities. I maintained a mental library of reasons, excuses, diversions. When anyone questioned my fabrications, I smiled brightly, confidently, and acted as if nothing was wrong. To my great relief, everyone always believed me.

The real problem, or so I thought in my denial, was having no way to prepare for every situation, for every eventuality. I had to be constantly alert, always ready to invent some new excuse. There were numerous incidents where my undisclosed health problems caused misunderstanding, but I preferred to be considered uncooperative than to be seen as not "normal." One disturbing event I remember quite clearly embodied many of the crucial issues of disclosure.

At the time I was working as a programmer analyst for a major computer manufacturer. The company was renowned for its somewhat sexist policies, but I was young, ambitious, and had two sons to feed. I could compete with the best of them. I worked very hard, stayed late, came in on the weekend with my youngest in tow. After only a year, I was promoted to an all-male group in executive reporting, the most admired and influential team in the company. It was also frightening to be so visible and to be unsure of my ability to handle the increased responsibilities.

Shortly after my promotion, management decided to restructure the physical layout of the department. I came in to work one morning to find my co-workers taking down partitions and moving furniture. My desk was scheduled to be moved to the opposite side of the building, and one of the younger men in the department saw me and hurried over to help.

This was the moment I had always dreaded. The desk was enormous and very heavy; moving such a load could cause permanent damage to my hands and wrists. But I had worked too hard to be considered one of the company's achievers to disclose the real reason for not helping. There was nothing in my bag of tricks to explain my refusal, so I just stood there, unable to speak, literally paralyzed with fear and indecision.

The young man waited several minutes and then began to berate me. It was clear to him that I was refusing to help because I thought only men should move heavy furniture. He denounced me as one of

those feminists who want new rights as long as they can retain old entitlements. He angrily concluded, "All of you disgust me." I was so frustrated at my inability to speak the truth to him that after the confrontation I felt really ill. Few times in my life have I experienced such rage or felt so impotent.

Two years after this event, I had my first hand surgery, and dissimulation was no longer possible. Looking back on all the years I deceived others, I think I also deceived myself. As long as I didn't admit to having serious health problems, I could pretend that everything was still the same, that nothing had changed. There was always the vain hope that the illness would vanish as suddenly as it had appeared, and I would once again be just like everyone else. That first surgery, the irrefutable physical proof that my health and life had changed forever, ended years of denial. The process of acceptance also began when my illness finally became visible.

Maureen

I developed Chronic Fatigue Syndrome at the age of 33. My daughter was eight and my son was two. We lived with my husband in a small house, a "handyman's special," in Cambridge, where I was born. Life was busy. There were two careers, two kids, perennial home repairs, and my mother, dying a slow death from emphysema.

Over a period of time, I came to recognize that something was very wrong with me. I was exhausted beyond my ability to describe; I had fevers, swollen glands, night sweats, irritable bowel symptoms, muscle and joint pain, and more. Yet they found "nothing" wrong for the first year and a half. I was told it was "all in my head," which I think is particularly embarrassing and frustrating for a therapist. When I was finally diagnosed, I was relieved that my illness had a name and that I was not crazy.

At first, I tried to do everything that I had been doing in my roles as mother, wife, and professional, with extremely poor results. Although it seemed impossible to let go of any of my "duties," that kind of renegotiation was precisely what I had to do. And I have had to learn to ask for help. This meant undoing the learning of generations of women on both sides of my family, which said, "Do your own work. Help others, but never ask for help."

I have discovered that my relationships are fuller and more genuine now that I am able to both give and receive care. The essence of what I have to offer others is not embodied by the ability to bake 60 dozen Christmas cookies (which I did one year before

becoming ill) or by the number of clients I see in a week. What I have to offer is my caring, my desire to connect, in whatever form that takes, with family, friends, clients, and colleagues. And that regeneration, the caring and desire to connect can only occur in relation to the caring and desire to connect with others. As I have moved toward more connection in my relationships, I have found that others are willing to join me in this connecting (without the enticement of cookies).

Dana

At age 25, I was an energetic young woman with close friends and an exciting job teaching high school history, so when I awoke one morning to a world that was spinning around me, I lay in bed, waiting for the ear infection to pass. Five days later, when a neurologist diagnosed me with multiple sclerosis, I burst into tears of shock and fear. This was the stuff of telethons and of other people. How could it happen to me? I stayed in the doctor's office for an hour, crying and asking questions. I kept thinking she must have a busy schedule, she should kick me out, but instead she patiently answered my torrent of questions. Would I die? Should I move to a different climate? Would the double vision return? What was the difference between multiple sclerosis and muscular dystrophy?

One week later I celebrated my 26th birthday with a party. I wanted and needed to gather my loved ones around me. I felt that with them I would find the connections that would help me get through my pain and fear.

It was during subsequent flare-ups over the next several years that my identity shifted and I began to recognize the reality of MS. I no longer had the energy that teaching high school demanded, and though I continued to teach, I was depressed and declined most social engagements. I have clear memories of lying on my bed, overwhelmed by fatigue, bouts of double vision, or impaired coordination. When I lost my balance, I had to use a walker. When my hands felt like boxing gloves, I could not tie my shoes. Sometimes, the frustration I felt with my now unfamiliar body made me scream out loud as I ranted against the cruelty and isolation of this illness. Yet, in this solitary state, fatigue gave me the time and space to contemplate God and Spirit. I knew that I was something more than my ability to walk or even to talk. It was connection with others that was vital, for without that, I would lose the essence of who I am. Relationships and their bonds created through intimacy and mutuality still brought joy and meaning into my life and helped me to know myself. I had

begun the process of renegotiating my identity—of valuing who I was intrinsically over what I did. I often return to this renegotiation as I think many with chronic illness do. There are times when, due to fatigue or physical incapacity, I cannot not perform daily chores or participate in activities outside my home. Maintaining the ability to accept and embrace myself nonetheless was and remains an essential task and a gift.

There were a few friends who withdrew from me during those early years because of their fear or my neediness or both, but others took their place. During one flare-up, a rare friend called me every day to ask how I was and then just listened while I told her. She didn't demand anything of me; she helped me to scream, to cry, or even to laugh. Over the phone, I talked with my brother in New York. He, usually so fearful of expressed pain, was able to share my fear, my frustration, and my tears. During one flare-up of intense vertigo, and punishing self-blame, I lay on my bed with my eyes closed, asking myself and my brother what I had done to bring on this episode. He reminded me that the illness was not my fault; it was probably all due to the position of the constellations in the sky. Sceptic that he is, his humor helped me to test my reality and to reconnect with some vital part of me. My relationships with others nurtured me.

Over the last ten years, my MS has been relatively stable. I have come to call it my MS for it is an illness that varies so from person to person, and I have developed a relationship with that illness: sometimes it is one of anger or fear, sometimes one of peace. Flare-ups occur less often than they once did and they are still scary. My eyes tire more easily now and fatigue comes more readily. I know one day I may have a flare-up that could cause a rapid downhill progression. People ask me how I live with that knowledge. I don't really know. It's just my life.

My husband and I met ten years ago. It is a relationship of deep connection. We now live in a co-housing community with 23 other families who know and care about one another. They may not hold the cure for my immune system gone awry, but when disability reasserts itself, they provide support and connection, that, whether ill or well, is my lifeblood. Community helps me to regenerate; its web of connection replenishes my life with meaning.

Kitty

I first experienced symptoms in 1975 but did not receive a diagnosis of multiple sclerosis until 1977—pre-MRI days. I remember experiencing great relief at having a name to apply to my experience. Much later

I understood what that diagnosis might mean.

Being a woman, relationships have always been important to me. With my first neurologist, I focused as much on my relationship with him as I did on my illness.

He acted like I was the first patient who asked him how *he* was and then listened to his answer. I will not, cannot, be in a relationship with someone without acknowledging they are a person who has a life of their own, no matter what I need from him or her.

My reaction to my bizarre symptoms was to isolate myself. I did not believe my "healthy" friends would relate to or want to be around me. I only allowed friends who were caretakers in my life—and believed they only allowed me in their lives because I was weak. Slowly, because of friends drawing me out, doing things with me, and inviting me to do things, I began to believe and feel I was important and I had an illness. Up until that time, I believed I was only my illness. Making this distinction was a significant developmental step.

Over the years I have had many "life lessons" from my experiences with this chronic illness. In 1984 I had a real blow when a man for whom I cared deeply told me he could not be in an intimate relationship with me because of my illness. I now know that was his issue and not mine, but at the time I was devastated and felt it just confirmed my initial fears—I was ill and no one would want to be with me. Once again, relationships were very important. Friends let me know that my issue was feeling unworthy and that his issue was not being able to deal with my illness. Through love, support, and being valued by others, I emerged strengthened with honest sadness and not with self-deprecation.

Again recognition, renegotiation, and regeneration were necessary. I had to recognize my illness and realize it scared some other people. I focus primarily on the now because if I think about the future and "what ifs," I will just scare myself when I can't possibly know what will happen. Renegotiation meant not hanging my well-being on one other person and feeling "unworthy" because of a rejection. Regeneration meant more than going on with my life, it meant loving me and my life and creating realities that could work for me. I took control where I could while living with a condition/disease that was out of my control. I had to know "me," my feelings, perceptions, and abilities. Knowing me meant I was more authentic in connection and others could respond to me authentically. Through mutual relationships I could be and know me.

Betsy

I was diagnosed with breast cancer in the fall of 1990, at age 48, three weeks after being married. In the midst of exhilarating happiness and a sense of moving forward, I experienced profound despair, terror, and a sense of doom. The progression of my life was shattered by these facts: I had breast cancer and I could die. Within days I was in surgery. Then the wait for pathology reports, then more surgery—a partial mastectomy. In a week I was being pressured to decide about more treatment choices, which sounded so invasive they took my breath away. My life was out of control.

Recognition of this new reality—a possible *fatal* illness—was very difficult. No one could tell me how I contracted this disease. I had no risk factors in my family or in my lifestyle, and no symptoms. This small cancer could not just be cut out, gone forever. I had to endure seven weeks of daily radiation. At this point, my soul, as well as my body, was scarred, and I was in a constant state of chaos and disbelief. The weeks of radiation treatment seemed endless not so much out of fear of the treatment, but because of what I saw—so many people, so terribly ill. I slowly began to recognize that my life, if I were fortunate enough to survive, would never be the same. I had to assimilate that truth, as painful and scary as it was to me. That process moved me from denial and chaos into reality. It enabled me to slow down and begin to focus on coping.

Renegotiation, for one diagnosed with a chronic and life-threatening illness, is an ongoing process. I had to learn to separate myself from cancer and the “what if” threat of spread or recurrence. I had to be able to live fully, to stay connected with people. Life was not all about breast cancer, and I was not just a breast, or Patient Number Whatever. Isolation was not renegotiation, it was denial, an obstacle to reclaiming my life. So I began to include my family and close friends in my pain instead of protecting them from it. I was learning that relationships were still open and mutual; I was the one who retreated, held back my feelings, afraid this disaster would deny me the intimacy I needed. Self-reliance was only one part of coping. Asking out loud for comfort was not a weakness, but a strength which led to renewal of intimate relationships. I renegotiated with my important people, and with myself, a different way of being in this new reality.

As radiation treatment progressed, I found renegotiation a more difficult process in the treatment setting. I approached the medical people in my usual

holistic way, sharing my feelings about how I felt along with the facts of my physical condition. I sensed a distance from these caretakers, and I actually envied them for their invulnerability. They put their focus on the cancer itself, that tumor, this treatment. But I, as a person, felt disconnected. There was little expression of empathy regarding my mental state; one radiologist I met with weekly told me I was “different from other women, who are grateful we are saving their lives.” This amazing comment was in response to my dismay at severe skin burns and anticipation of what two more weeks of radiation would add. The doctor would not validate *my* reality and could not extend herself with empathy. Her distancing from the cancer disconnected her from me and presented an obstacle to my healing.

Regeneration has slowly evolved for me as I have tried to make sense of this experience. In 1990, I thought my life was over. I thought the fear would never leave my mind, that I could not count on a future. As time passed I found ways to cope with the uncertainty, to live with cancer. I discovered healing places that nurture my soul and allow me to feel hope. The ocean, and all of nature, bestow their gifts on me daily. My husband and my two sons continue to laugh with me and love me. I am able to live in the moment, as a relief from fear, and also look ahead. My work as a therapist has focused on counseling people with breast cancer and other life-threatening illnesses. I have stood in places to tell my story and have led workshops to help others understand some of the ways to cope. I hope to continue to reach out to others in my work. I think my experience with breast cancer has deepened my capacity to connect and give back to my clients a healing place.

Discussion

The onset of chronic illness is a major event in a woman’s life. Women who are able to create and maintain connections, or mutually empathic relationships with others, are better able to continue to grow and develop as the changes imposed by chronic illness occur. Through our work and experiences, we have identified the processes of **recognition**, **renegotiation**, and **regeneration** as a useful framework for understanding how women live well with chronic illness. These processes are cyclical and fluid in nature. They often overlap and will each be revisited many times throughout our lives.

In the process of **recognition**, many women struggle to negate their health problems, as if a chronic illness could be eliminated by hard work and personal effort—the “pull yourself up by the bootstraps”

approach endemic in this culture. Each of us have experienced some degree of denial at various points in our illnesses. It is an expected piece of the recognition process. Denial can shield one from the full impact of a diagnosis, allowing time to recognize, in a more gradual way, the losses that illness entails. This period of “coming to terms” with an illness is a time to move toward deeper connection in existing relationships as well as to develop new relationships (with health care providers or members of support groups, for example). As these relationships become able to sustain us through the recognition of the extent of our losses, denial decreases.

As Barbara and Maureen’s stories demonstrate, it can take considerable time to recognize and overcome the societal pressure to appear and behave as if one were healthy. Barbara’s prolonged period of denial and her efforts to “pass” (Hillyer, 1993)¹ as a healthy person were challenged only when she required the first of many surgeries which made her condition visible. Until that point, she had clung to her established internal image of a healthy person. Her body had changed and what she was able to do had also changed, but she continued trying to live as if the alterations in her health were temporary and reversible.

For some, like Kitty, Dana, and Maureen, receiving a diagnosis gave a name and validity to the changes in the way their bodies felt. There was a sense of relief when a diagnosis confirmed that it was not “all in her head.” The bewildering and frightening symptoms were a part of something that could be labeled, though not satisfactorily explained or cured. Betsy’s experience of the diagnosis was different, in that it was sudden and shattering. Coming to terms with the diagnosis of cancer is made more difficult by the absence of prior symptoms and the brutal undeniability of the pathology report. Cancer is a life-threatening illness, and we see it as a chronic illness as well.

Jordan states that, “Our internal images, expectations, and organizations of experience change to accommodate newness in our surroundings, and we later change what we take in during the process of assimilating it. Ideally, growth occurs through mutual initiative and responsiveness in relationship, what we might call mutual accommodation and assimilation. Responsiveness to other individuals, as well as having an impact on them, leads to our own growth” (Jordan, 1997, p. 139). Though the onset of chronic illness cannot be seen as “newness in our surroundings,” it can be conceptualized as a newness in our physical experience, our internal images, and our relationships.

The processes of mutual accommodation and assimilation described by Jordan parallel the renegotiation piece of our model.

As we have struggled to recognize the impact of chronic illness in our lives, we have faced the reality that our lives are forever changed. Disconnection is a central part of chronic illness. All that we have known and come to depend on is no longer experienced in the same way. As our lives unfold, it can be as if we are in infancy again. We move through, relearning in a new way, what we thought we already knew. Connections with others—family, friends, colleagues, health care providers—have been the arena in which the recognition of these changes have taken place. Mutually growth-fostering connections allow us to recognize the newness and to continue to develop as changes continue to occur.

Renegotiation entails taking the information that we have recognized, that certain changes have occurred in our lives, and putting that knowledge into practice. As the term suggests, the process is relational in nature. For Maureen, there is an ongoing process of renegotiation with her children. She constantly strives to find a physically and emotionally comfortable balance between meeting her needs and meeting their needs. There are times of frustration and bitter disappointment when she is unable to participate in an important activity, and there are times of joy when the balance feels just right. Kitty has used a scooter to get around since she became unable to walk. She constantly renegotiates with her physical environment. Will the sites she enjoyed with friends when she was walking be accessible to her now? Consideration of Kitty’s mobility needs becomes a part of the renegotiation of her relationships with others.

Regeneration is really about connection. It is a process of “making meaning” of our altered lives. This occurs within the context of mutually empathic relationships. The writing that you are now reading represents a part of the authors’ regeneration. We have met together for several years to talk about the psychological development of women who experience chronic illness. Our discussions, our reading, and our writing have fostered ongoing growth in each of us. The sharing and writing of our stories—the pieces of our lives affected by illness—has put voice into our experience, deeply connecting us and creating among us a mutual trust, empathy, and caring. We speak openly about our situations, symptoms, and fears. We negotiate around our needs and feel no pressure to put up a brave front when we are not feeling well. As Arthur Frank expresses in *The Wounded Storyteller*,

there is “the need of ill people to tell their stories, in order to construct new maps and new perceptions of their relationship to the world” (1995). We, who have been challenged by illness, feel safe with each other. This safety allows us to take our stories to the world outside our group, hopefully encouraging others’ voices, empowering them with our modeling, connection, and regeneration. Many areas of life provide the opportunity for regeneration: family, friends, colleagues, neighborhoods, churches, support groups, relationships with health care providers, quilting groups—wherever one feels comfortable and encouraged to connect in a mutually empathic way. Dana finds this in her unique co-housing community, as her home life and neighborhood provide caring relationships in an atmosphere of mutuality. Finding a place of safety in which one can speak freely of one’s experience is essential. Part of regeneration can be a deepening awareness of the positive relationships in our lives. It can also provide an opportunity to recognize those relationships that do harm and take steps to heal, change, or end them. Regeneration offers us the chance to reaffirm the importance of the relational world and to foster meaning through connection.

Through all three processes, one can find the impetus for growth. Learning to face one’s fears, frustrations, and disappointments in relationship with the important people in one’s life is empowering for both parties. Giving voice to one’s experience with illness is courageous; courage can inspire growth and empower others to connect with their potential for courage as well. By sharing our stories with you, the reader, we hope to encourage your growth.

1 The concept of passing in society, of appearing to be a member of the dominant group, has long been used when examining racial issues. The term is applicable to those with invisible disabilities as well.

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