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Responding to Loss: A Practical Framework

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Today I'm talking about loss related to disability, and grief related to that loss. This topic is unusual for me, since I generally focus on the positive — on what we have, rather than on what we've lost. And I think a positive focus is central to coping with, rather than succumbing to, the disability and life with disability. So before getting into loss, let me start with a positive focus.

In an odd way, polio supported this hopeful focus. Initially it took us down to our weakest point. But then, remember how in those first weeks and months after having polio, we were always getting better? Especially in the first six months, but even two years later some of us were getting neural return, which meant increased functioning.

The loss was there, obviously. But it wasn't the focus of our rehabilitation efforts. We focused on what we were getting back, on what we could do.

Today there's strong evidence that a positive attitude contributes to health and longevity. Humor and an optimistic outlook have especially been identified and studied as contributing to health. Not only are psychological factors influential in maintaining health, but, in fact, the powerful healer in many medical studies appears to be faith in the cure, sometimes called the placebo effect.

So, a positive focus is healthy and contributes to adjustment. But there is a reality of loss to disability. And some of us are facing new loss right now. Therefore to focus only on the positive, and to ignore the loss and its pain, cuts us off from being in touch with ourselves.

Looking back to 1955, I remember that my main struggle was in getting out of the iron lung and onto the chest respirator and rocking bed. This process took five months, and by the time it was accomplished, I was pretty well reconciled to my paralysis — it was by then a fact. I don't remember ever really grieving my loss.

How many of us really grieved our loss? For some the loss was temporary though initially frightening, yet recovery seemed complete so the fear was put aside.

Others were too young to know the implications of their loss. Many used defense mechanisms and coped. But how many of us went through the tasks of grieving and effectively grieved our loss?

Now many of us are facing new loss. If we didn't deal with our earlier loss, if we didn't "grieve" it, we might find our current situation complicated by unresolved feelings from the past. For example, the anxiety related to our early paralysis, later reduced by returning function, may recur as we face decreasing function. And we are facing significant loss through aging and through post-polio sequelae.

I've used the word "grieving" several times. What do I mean by this? Grieving is the process of adapting to loss. If grieving is incomplete, then further psychological growth and development can be impaired. Some theorists describe grief as a series of stages or phases that we go through when facing loss. Elizabeth Kubler-Ross, in her work with death, is probably the most familiar, with her stages of denial, anger, bargaining, depression, and acceptance. Some disagree with this approach. They question whether these stages are correct, whether all people experience any or all of them, and whether they are experienced in the same fixed sequence.

I'd like to focus on a practical approach to dealing with or grieving a loss which is based on tasks that we can work on, rather than stages which we simply go through. It is based on a model developed by William Worden, a Harvard psychologist, that he recommends for grief counselors and therapists to use with their clients who have experienced loss. Worden deals mostly with loss through death, but his approach also fits losses of all kinds, including loss through disability.

With Worden, we work through these tasks in our own style and at our own pace. No one size fits all. And we can take responsibility for ourselves.

Worden's four tasks are these: 1. Accept the reality of the loss. 2. Work through to the pain of grief. 3. Adjust to an environment in which that which was

lost is missing. 4. Emotionally relocate that which was lost and move on with life. Let's take these one by one.

First, accept the reality of the loss. Some losses are clear and unambiguous, such as death, job loss, amputation, or a severed spinal cord. But their reality may still be hard to accept. Defense mechanisms such as denial operate to shield us from being overwhelmed by the full impact of the loss. We simply cannot believe. We cannot accept that the loss is irreversible; we think it is temporary.

Coming to the acceptance of the loss takes time, since it means not only an intellectual acceptance but also an emotional one.

When the loss is less defined and ambiguous, then acceptance becomes even harder. This is the case with polio; originally we did not know what our final loss would be because we kept regaining function. With post-polio sequelae, the loss is gradual. Dealing with loss is even more difficult when it raises latent anxiety.

So we have to work at facing and accepting the reality of the loss — to face the facts! Perhaps the best way to do this is to talk about the loss, to put it into words. Talking about any loss makes it real.

The second task is to work through to the pain of grief. Identify and express the feelings related to the loss. Be in touch with yourself and what you are feeling — sadness, relief, whatever. The hardest feelings to work through are anger, guilt, anxiety, and helplessness. The common way to avoid this task is not to feel. Bury the feelings. But as someone once said, when you bury feelings, you bury them alive. And they will find some other ways of expressing themselves.

Anger can turn inward and cause depression or lowered self-esteem. Feelings ignored can contribute to substance abuse, stomach problems, skin irritations, or acting out behavior. Some writers are describing what they term a "chronic sadness" seen in some people with disabilities. It doesn't qualify as a depression, or even as dysthymia, but seems to be a sadness which underlies much of their behavior. This could be one outcome of not finishing work on task two.

Jacqueline Kennedy Onassis was a tremendous example on how to hold a nation together during a time of loss and grief. But with her stoicism, she was not a very good example of how to grieve in terms of experiencing and expressing feelings. We tend to compare our insides with other people's outsides; we don't know what they are feeling inside.

The important thing is to identify and be in touch with your feelings and to find your individual way to express them. Some people find keeping a journal helpful, to

write out their thoughts and feelings. Others use music or art. But do identify them, and do express them.

Once identified and expressed, your feelings must relate to some meaning. Sadness must be accompanied by an awareness of what was lost; anger needs to be properly and effectively targeted; guilt needs to be evaluated and resolved; and anxiety needs to be identified and managed.

The third task is to adjust to an environment in which that which was lost is missing; learn to live with what you have left after disability, and without that which you've lost. This task is familiar since it is the major focus of many rehabilitation programs.

Losses through disability include not only the physical and functional losses, but also the social losses of changed status, minority group membership, possible job loss, and possible self-esteem changes. If you have struggled through life to maintain an able-bodied group identification and suddenly find yourself needing crutches or a wheelchair, you are dealing with a loss greater than simple loss of function.

In rehabilitation, this means learning new ways of doing things, or accepting help where help is needed. It may mean using a wheelchair some of the time, or a ventilator to sleep. It may also mean changes in priorities and self concept, and less independence. These are things we have been hearing about for years: Conserve and preserve. But they are also part of the grief work, and things we can do and can work on. We can all probably list things that we need to work on. It may mean seeing a counselor or joining a peer support group to work through some of the changes we find ourselves resisting.

The fourth task is to emotionally relocate that which you have lost, and move on. Find a special emotional place for the way you were, and then reinvest in life, get on with living, the way you are. This is the key to successful completion of grief work.

Do what you can do, now. Do not get quagmired in the way things were; value that, but move on to what is possible. Find new relationships and activities that you enjoy and that are fulfilling; find new ways of doing what you previously enjoyed.

Now remember, these tasks were identified to be used by counselors in grief work. But their focus is on practical tasks that each of us can do. There are people who are stuck in their grief work, and they may need to see a counselor to work through their blocks. But either way, working through these tasks on your own or seeking help, I see as taking self responsibility.

Although a positive focus is helpful in adjusting to disability and increasing loss, we need to be in touch with ourselves and our feelings, recognizing the negative feelings as well. We need to work through our feelings, and deal realistically with our situation: to grieve our



Disability as a Life Course: Implications of Early Experiences for Later Coping

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"We had the experience but missed the meaning" wrote the poet T.S. Eliot, (1952), an observation that is indeed true of many people who became disabled from polio in their youth: they have never evaluated the events that happened to them and their reactions to those events.

In youth, polio survivors adapted to their disabilities, and their coping strategies served them reasonably well until they encountered a crisis in post-polio syndrome. Psychologists define a crisis as an event that threatens a person's way of life and from which there is no escape. Because the usual methods of coping are ineffective, crises cause considerable distress and tend to trigger emotions experienced in earlier crises. We often respond to our present problems with feelings and behaviors that relate more to the past than to the reality of the present (Miller, 1992).

Two important assets in coping with post-polio syndrome are a strong sense of self-worth and supportive social relationships. Although early experiences with polio often damaged our self-esteem and trust of other people, these feelings remain as a largely unrecognized legacy. Only by understanding the meaning of past experiences can we begin to free ourselves from their often malignant long-term effects.

I will briefly outline typical experiences with polio and then go on to describe the effects of these experiences in the lives of 176 people with post-polio syndrome who I have studied for five years.

For most survivors, the initial experience with polio involved long separations from their families and suffering from paralysis, pain, and frightening procedures while being cared for by distant and sometimes abusive staff. Asper (1993) has described how such emotional abandonment in youth shapes the adult personality. She

loss and to move on. If we live in denial, or cut off a large part of our experience from ourselves, leaving it unresolved, we will live emotionally shortchanged.

I will end with a quote from Virgil: "Here's Death, twitching my ear: 'Live,' says he, 'for I'm coming.' So, live! ... in all dimensions of your being. □

Worden, J.W. (1991). *Grief counseling and grief therapy: A handbook for the mental health practitioner*. New York: Springer.

found that as adults such people typically exhibit the following behavior:

- ◆ Fail to acknowledge the degree of their early abandonment and suffering;
- ◆ Fear later abandonment;
- ◆ Are out of touch with their feelings;
- ◆ Display false self-sufficiency;
- ◆ Demand impossible standards from themselves;
- ◆ Feel excessive shame;
- ◆ Respond to others' needs but have little idea of what is good for themselves;
- ◆ Are unable to ask for or to accept help because they fear repetition of their early experiences;
- ◆ Lack compassion for themselves.

Our second negative experience with polio occurred when we returned home from rehabilitation. Polio survivors were the first major group of people with disabilities to be integrated into western society (Trieschmann, 1987). Negative attitudes toward people with disabilities were far more prevalent in those early days than today (ICD, 1986). Some of us probably experienced these primarily as exclusions that echoed earlier abandonment, e.g., the parties we were not asked to, the friends who dropped away, the physical barriers that excluded or exhausted us, the devaluing assumptions that "normal" people made about us. Others experienced overt rejection, e.g., teasing and aggression from other children and occasionally from even their own families. Phillips (1990) claims that Americans regard people with disabilities as damaged goods. As members of society, we tended to adopt its standards and to agree that we did indeed fall short.

Of course, we did not acknowledge these painful and uncomfortable feelings very often, but they spurred us on to become super-achievers. Our mental equation seemed to be that if we were better than average in everything we did, we would cancel out the deficiency of our disability. For some of us, the nicest compliment we could receive was, "I never think of you as disabled."

Leaving rehabilitation meant, too, that most of us lost contact with other polio survivors; thus, we had no one in our social group who had had experiences similar to our own and with whom we could discuss and evaluate the past. Also, as Zola (1982) pointed out, there is a strong social taboo against talking about one's disability.