Heart Sisters

For women living with heart disease

The loss of 'self' in chronic illness is what really hurts

AUGUST 2, 2015JUNE 9, 2016 ~ CAROLYN THOMAS

by Carolyn Thomas (https://myheartsisters.org/yes-it-s-all-about-me/) ♥ *@HeartSisters (https://twitter.com/HeartSisters)*

People living with chronic illness already know that the triple whammy of ongoing physical symptoms, psychological distress and the discomfort of medical procedures can cause us to suffer. But when California sociologist **Dr. Kathy Charmaz** studied chronic illness, she identified an element of suffering that is often dismissed by health care providers.*(1)*

As she explained in research published in the journal *Sociology of Health & Illness*, **a narrow medicalized view of suffering** that's defined as physical symptoms only ignores or minimizes the broader significance of suffering in a way that may resonate with you if you too live with a chronic illness like heart disease:

> *"A fundamental form of that suffering is the* ***loss of self in chronically ill persons*** *who observe their former self-images crumbling away without the simultaneous development of equally valued new ones.*
>
> *"The experiences and meanings upon which these ill persons had built former positive self-images are no longer available to them."*

I don't know about you, my heart sisters, but I felt profoundly moved when I first read those words about *"the loss of self"*. Dr. Charmaz captured in her study's conclusion precisely what I've been feeling and trying to write about for seven years! She's also the author of the book *Good Days, Bad Days: The Self and Chronic Illness in Time (http://www.amazon.com/Good-Days-Bad-Chronic-Illness/dp/0813519675)*.

This loss of self she describes can start early – sometimes even before a diagnosis is made – and continues to grow insidiously from there.

For example:

- **Pre-diagnosis:** Physicians can discredit our own definitions of self when we're seeking help for early troubling symptoms (e.g. when we try to convince a dismissive doctor: *"I know my body, and something is just not right!")* Dr. Charmaz warns that physicians sometimes treat undiagnosed persons *"as neurotics whose symptoms are either nonexistent or psychosomatic in origin, leaving the patients feeling unsupported or guilty of having brought their discomfort upon themselves." See also: Heart Attack Misdiagnosis in Women (https://myheartsisters.org/2009/05/28/heart-attack-misdiagnosis-women/)*

- **Beginning of illness:** *"Generally, ill persons report that although family and friends readily demonstrate their interest, attentiveness and assistance when illness begins, as time goes by such involvement tends to dwindle to only few members of the immediate family."*

- **Worry about burdening others:** Although some married women in the study reported that their husbands were *"exceedingly helpful, supportive and protective"*, several married women expressed fear of greater impairment since their husbands *"did not like sick people". See also: Women Heart Attack Survivors Know Their Place (https://myheartsisters.org/2009/09/13/women-heart-attack-survivors-know-their-place/)*

- **Unpredictability:** The nature of living with a chronic illness means sometimes we just can't predict when we might have a *'good day'* or a *'bad day'* – or even intermittent *'bad spells'* during any given day. *"Due to their unpredictable conditions, these patients suffer disruptions of their lives and selves that go far beyond physical discomfort. Such disruptions may include the necessity of quitting work, limiting social engagements, or avoiding activity."*

- **Limitation of life:** When people are forced into limiting normal activities to protect their health, adds Dr. Charmaz, they may do so at great costs to one's self-image. *"Most importantly, living a restricted life can foster an all-consuming retreat into illness."*

- **Work:** Some chronically ill people feel well enough to continue working, while others are no longer able to work – but coping with either decision can affect our sense of self, as Dr. Charmaz explains: *"When fortunate enough to work, ill persons frequently feel they have to restrict all other activities in order to manage the demands of their jobs. But when forced to leave work, they may be reduced to living marginally, leaving their prior social worlds entirely." See also: How Working – And Not Working – Affects Heart Disease (https://myheartsisters.org/2012/07/30/working-and-heart-disease/)*

- **All-consuming focus:** Serious illness can flood identity. The seriously ill person may have essentially lost the ability to minimize his or her physical condition, explains Dr. Charmaz. *"Their illnesses become the focus of their lives as treatment regimens, living with constant discomfort, medical appointments, and the problematics of mundane activities structure and fill their days." See also: How Ruminating Hurts Your Heart (https://myheartsisters.org/2011/06/02/ruminating-hurts-your-heart/)*

The world is set up for the healthy and able, she adds – a fact the ill and disabled usually do not question.

She believes that this reality may help to explain why the patients she studied (living with a range of chronic illnesses including cardiovascular disease, diabetes, cancer, multiple sclerosis or lupus) so often judge themselves by yardsticks more appropriately applied to the healthy and able.

One of the most useful parts of this study is the expansion of the word *"suffering"* to include a loss of self. As Dr. Charmaz defines it:

> *"The language of suffering these debilitated people spoke was a language of loss. They seldom talked of gaining a heightened consciousness of the world, revelations about self or insights into human nature from their experiences. Instead in their suffering, they experienced the heightened self-concern described above."*

But wait . . .

Lest you interrupt at about this point to mention ________ *(insert name of any celebrity patient who has "battled" a devastating health crisis and emerged a happier, stronger, far more heroic version of their former selves)*, Dr. Charmaz is careful to point out the key differences. On one hand, you have those who are still living with the debilitating daily reality of chronic illness. These are not the same at all as those who at one time in the past may have had an episode of serious illness – **but then got better**:

> *"For (the latter group), such periods of serious illness became the foundation for re-evaluation and change of self.*
>
> *"These individuals spoke of earlier crises as periods of time when they were free from the ordinary bonds of routine existence. That freedom heightened their consciousness of who they were and who they wished to become.*
>
> *"For these people, illness became **a tool of self-discovery** and a fundamental source of later self-development.*
>
> *"But those who were currently seriously debilitated and still in the throes of multiple health crises, were much less positive about their experience of illness."*

All is not necessarily bleak, however, for all those living with chronic illness. For example, I was particularly struck by this observation about the power of choice from Dr. Charmaz:

> *"As long as an individual feels that he or she exercises **choice in valued activities** and some freedom of action to pursue these choices, everyday life does not seem so restrictive, suffering is reduced, and self-images are maintained."*

This really helps to explain why I love doing my women's heart health presentations (https://myheartsisters.org/yes-it-s-all-about-me/about-my-presentations/) so much. These have been described as *"part cardiology bootcamp – and part stand-up comedy!"* Since my own heart attack, I've spoken to thousands of women about the important subject of women's heart health. Yet each talk takes a heavy personal toll, sucking every shred of energy I can muster. I'm utterly drained by the time I step off the stage, and more importantly need at least one full day afterwards just to recover) but I love every single minute while I'm up there, so to me it's worth the price – for now, or as long as I'm able.

It would certainly be easier and less painful for me to avoid this exhaustion by not booking any talks in the first place – but for that time when I'm able to be onstage, as Dr. Charmaz would say, I get to retain glimpses of my old pre-diagnosis self. I can feel even briefly like a smart and competent and *"normal"* person once again. This means a lot to me given that so much of life with ongoing and debilitating cardiac issues no longer feels *"normal"* at all.

Or as Dr. Charmaz would define it, although much of my former self-image has crumbled away, I'm now trying to manage this *"simultaneous development of an equally valued new one."*

Q: How have you tried to maintain your pre-diagnosis self-image?

(1) Kathy Charmaz. Loss of self: a fundamental form of suffering in the chronically ill. Sociology of Health & Illness. 28 JUN 2008. DOI: 10.1111/1467-9566.ep10491512
Thanks to Irish health activist Marie Ennis-O'Connor (who blogs at Journeying Beyond Breast Cancer (http://journeyingbeyondbreastcancer.com/)) for pointing me to the Charmaz study.
See also:

- *The new country called heart disease (https://myheartsisters.org/2010/10/09/new-country/)*

- *Living with heart disease – and your whole family (https://myheartsisters.org/2015/04/12/heart-disease-in-the-family/)*
- *When grief morphs into depression (https://myheartsisters.org/2010/10/29/dr-aletta-five-tips-depression/)*
- *Hypervigilance: waiting for that second heart attack (https://myheartsisters.org/2014/06/22/hypervigilance/)*
- *Living with the “burden of treatment” (https://myheartsisters.org/2013/02/16/living-with-the-burden-of-treatment/)*
- *How to be a “good” patient (https://myheartsisters.org/2011/08/09/how-to-be-a-good-patient/)*

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CHRONIC ILLNESS DR. KATHY CHARMAZ LOSS OF SELF SELF-IMAGE UNPREDICTABILITY

Published by Carolyn Thomas

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34 thoughts on “The loss of ‘self’ in chronic illness is what really hurts”

1. Pingback: A Heart For Chelle
2. Pingback: Overcoming Fibromyalgia
3. Pingback: Health as a Human Right
4. **Lilian**
   SAYS:
   AUGUST 5, 2015 AT 8:51 AM
   This is really interesting. As someone with congenital heart disease I haven’t experienced the ‘before’ and ‘after’ of chronic illness – it’s just always been there. But I think I’ve still experienced loss of self – the me that could have been.

   I’ve spent time wondering what it’s like to be ‘normal’, and even, to some extent, grieving for that person, and for the things I wanted to be/do that I couldn’t/can’t do. I’m feeling the losses more as I get older, particularly since our daughter was born – like Charlotte, I find I’m having to decide what to do and what to sacrifice in order to use my energy levels efficiently and I worry about being judged by people if I (e.g.) take the bus instead of walking up the hill!

   Thanks for posting this and for the rest of your blog – it’s fascinating and helpful.

   Reply
   1. **Carolyn Thomas**
      SAYS:
      AUGUST 5, 2015 AT 2:20 PM
      Thanks Lilian for introducing a reality that’s often overlooked. Much of what’s been written focuses on non-patients who suddenly become patients, and not on those like you who haven’t experienced that ‘before’ and ‘after’ shock. Your “taking the bus up the hill” comment reminds

me of how tricky having an invisible diagnosis can be – yet as the old saying goes: "what you think of me is none of my business!" Speaking of before and after, I really enjoyed your **blog post/photos** on your kitchen shelves makeover – very inspiring!!! Readers, take a look at Lilian's kitchen photos…

Reply

1. **Lilian**
   SAYS:
   AUGUST 8, 2015 AT 9:11 AM
   Thank you! Glad you liked the shelves makeover.

   I do find it difficult to not care what people think of me.

   Reply

5. **Nancy's Point**
SAYS:
AUGUST 4, 2015 AT 10:36 AM
Hi Carolyn,
This is such a spot-on post. The loss of self is very real and I don't think this sense of loss necessarily ends when treatment stops or after a certain amount of time has passed. I am still trying to reclaim my 'old self' in so many ways and at the same time move forward by accepting who, what and where I am now. There is so much collateral damage that goes along with breast cancer treatment. I am still trying to put the pieces back together and I work daily at not comparing the old me with the new me. There are days when I still feel as if I fell through a trap door.

Thanks for the great post.

Reply

1. **Carolyn Thomas**
   SAYS:
   AUGUST 5, 2015 AT 2:29 PM
   Hello Nancy! Wow, you have hit the nail right on the head with your unique observation about what happens when treatment ends. It's not like you can flip a switch and suddenly all those traumatic fears and worry and trauma instantly disappear. I've heard many breast cancer patients say that even passing that magical five-year survival milestone doesn't mean the effect of those losses instantly evaporates.

   Reply

6. **Charlotte**
SAYS:
AUGUST 3, 2015 AT 11:39 AM
This really struck home for me. I've lived my entire adult life with chronic disease — I experienced kidney failure when I was 21 years old and it took 2 transplants & 5 years to stabilize. I was in mostly good health for quite a few years — had kids and *"did it all"* (the mom-thing, job, volunteering, etc.) but the *"health issues"* always seemed to be some sort of looming presence in our life — knowing that someday the kidney can fail and my health is a fragile thing.

The last five years have brought on several new autoimmune diseases, and now it seems that heart disease is also a new companion in my life.

The article touches on some very real points about chronic illness that I can relate to:

1–*"the language of loss"* — it seems that every day or week there's one more thing that I can't do that I could do before. It's so hard to hear myself use that language, much less admit to the losses that are adding up.

2–how your family & friends are *"all in"* at the beginnings of an illness, but their interest wanes as time goes by. I learned that lesson a long time ago, and it holds so true. In fact, I make sure that when there is an illness, a surgery or a death, I bring a meal or send a note much later — after the rush of support from everyone else. Sadly, it's as time goes by that many of us really feel the need to talk and process what's happening and changing — and that's when everyone expects us to be getting on with our **new normal**.

3–having to make choices about what activities are my priorities — for me I've been focused on keeping my job (which I've worked so hard to achieve and keep!) and participating in my teenager's lives.

What's not mentioned in the article, but that I feel often is **the sense of being judged by others**–I know I'm doing my personal best all the time, and my family knows that and I remind myself of that constantly. However, it's still hard to be out around my co-workers and other moms who are able to manage jobs, kids' schedules, housework, laundry, cooking, shopping, exercise and still chaperone for the band trips when I feel victorious if I was able to get to a band concert one night after work, but only if we ordered pizza for dinner.

Chronic illness really can help you learn about how strong you really are… I really know how to dig deep to find the will to keep going and I've learned how to prioritize what means the most to me. But, there is no doubt that it brings a lot of loss, pain and hardship — the *"suffering"* that perhaps the world hasn't quite recognized yet.

Reply

1. **Carolyn Thomas**

SAYS:

AUGUST 3, 2015 AT 12:43 PM

Beautifully said, Charlotte. You are like the expert poster child for managing chronic illness ON TOP OF everything else you must handle in life, at work, in the family, etc. I'm so glad you added the *"being judged"* issue. As Dr. Charmaz writes in her study, people living with chronic illness tend to *"judge themselves by yardsticks more appropriately applied to the healthy and able"* – and many times we assume (rightly or wrongly) that others must be judging us as harshly as we judge ourselves. Thanks so much for adding your comments here.

Reply

7. **MioMyo**

SAYS:

AUGUST 2, 2015 AT 5:25 PM

Well, honestly I was never a highly socialized person, and there is not much change in this with my sickness. Through all my life it was extremely difficult for me to be in public places & speak with big audiences. Oh, I did that successfully if necessary, but inside I felt exhausted. So, the people who can easily speak in public are like heroes for me. You are a hero, Carolyn! ❤

But some strange things happened to me after I got a chronic disease. For example, I felt sort of curiosity towards surrounding people: they do not feel what I experience, how then could they try to understand/support me? It was always hard for me to receive compassion from other people. And my illness makes this worse, unfortunately. Luckily, I can close the doors, turn off the phone and start to paint. This helps, so far..

Reply

1. **Carolyn Thomas**

   SAYS:
   AUGUST 3, 2015 AT 6:06 AM
   Thanks for this observation. You're right of course that others don't feel what you experience (nobody can feel exactly what anybody else is experiencing, right?) I'm curious if this is also true in reverse, when others need **your** compassion. Do you still try to support/understand them even if you cannot feel what another person experiences?

   Reply

   1. **MioMyo**

      SAYS:
      AUGUST 3, 2015 AT 10:00 AM
      Thank you so much for asking Carolyn..

      Strangely, but first my effort when somebody suffers/needs help/just needs a word or advice — is to satisfy their needs immediately. I feel this as "necessary to do now" so much, that I cannot even calm down until I go there and do it. All my neighbors know this my "feature", as I provide them with free vegetables from my garden, listen about their issues/problems/thoughts, discuss their kids, relatives, spouses, water their lawns etc. I love to do something for somebody. But unfortunately I do not feel I deserve the same attitude to me in reverse. I have no idea why…

      Reply

      1. **MioMyo**

         SAYS:
         AUGUST 3, 2015 AT 10:15 AM
         People love to ask me for help, and I am great with that. But it is almost physical pain for me to ask/get help from others. I start to feel almost guilty, lazy, worthless… When I was at the hospital, my friends provided my family with food and I felt AWFUL (though, I had to feel grateful). I refused to let my friends visit me in the hospital, and probably offended them by this.

         Of course, when you are sick, it is not so bad to ask others for help — for example, my garden needs much work which cannot be provided now by myself only. But, listen, I am not able to ask for help even of my older son, who is 18 and can finish all the garden works within one day… What is wrong with me.

         Reply

         1. **Carolyn Thomas**

            SAYS:
            AUGUST 3, 2015 AT 12:52 PM
            I can relate to what you're saying! I wonder if this is some kind of Slavic trait that we share: I come from a long line of fiercely independent, crazy-hard-working women who would never say NO to anybody in need (except to themselves!) It was only after my heart attack that I learned that when friends and family told me they really wanted to do something to help me out, **THEY MEANT IT**! And whenever I refused their offers of help, it was like an insult to their good-hearted generosity! I had to learn to answer in this way: *"Well, I could really use some help with ____"* – and every single time, my friends and family jumped on the opportunity to pitch in. They wanted to be helpful – otherwise they would never have offered, right?

And they all knew I would do the same for them. We have to treasure each offer of human kindness – there are many who never get such offers from others around them.

And as for your 18-year old son, you're doing him (and his future wife) a big favour by expecting that his role as a family member is OF COURSE to pitch in with tasks like gardening (ideally without even needing to be asked!) It's good training for becoming a good man.

Reply

8. **Jennifer**

SAYS:
AUGUST 2, 2015 AT 4:26 PM

This post was very moving to me, as were the replies. My loss of financial independence, career, colleagues, plans and dreams was as personal as my diagnosis was. I found it lonely, not to mention discouraging to repeatedly lower my expectations for my day, my week, my future. My coping mechanisms included joking about everything and indulging my love of reading. Fortunately my husband has a good sense of humour – we both imagined a different life when we married.

Reply

1. **Carolyn Thomas**

SAYS:
AUGUST 3, 2015 AT 5:58 AM

Thanks for sharing your perspective here, Jennifer. *"Repeatedly lowering expectations"* is indeed discouraging – on the other hand, it can also be a realistic coping mechanism, a reminder to not fight *'what is, is'*. And joking is yet another very useful tool!

Reply

2. **Charlotte**

SAYS:
AUGUST 3, 2015 AT 11:53 AM

Jennifer,

I may be reading too much into your post, but it sounds like you are fairly young and were just getting started with life when you were diagnosed. It that is true, then I am truly sorry for your loss(es). Like you, I was diagnosed with a chronic illness as a young woman–and it left me unable to start my career at that time, newly married, unable to start a family, and we had just moved so my husband could start his career. When you say you found yourself lonely, I can relate. Lonely and afraid is the overwhelming memory I have of that period in my life. And how discouraging and sad it was to have to continually readjust our expectations for life – we certainly had imagined our life turning out differently too!

I don't know where you are in this process, but I believe that just from what you've posted, you have the right mindset to get through to the other side of this! You recognize that you need coping mechanisms and you are using them! It sounds like your husband is supportive – and that can't be discounted! Your new life will probably be quite different from what you expected – but there's a really good chance that your new normal might be even better.

Reply

1. **Jennifer**

SAYS:
AUGUST 3, 2015 AT 3:30 PM

Charlotte & Carolyn, I wish I had known you years ago. I was indeed very lonely at the beginning of this journey, but not as young as you might think, when I had to stop working.

In the spring of my last year of high school I got “mono” (infectious mononucleosis) so I missed finishing school with my class. This exhausting disease kept recurring over the next few years so I kept dropping out of post-secondary school.

I married at 21 & I had 4 children, the youngest a baby, when the marriage ended 13 years later, 2000 miles away from family & old friends. For ten years I was a single mother, until age 44, now with the diagnoses of asthma, chronic fatigue syndrome & fibromyalgia. Planning for my independent future, I had used up all my savings to go to school. The year after getting a university degree in nursing, I was working “relief”, i.e. totally unpredictable, 12-hour day & night shifts, when I married for the second time in 1996.

In 1998 I was forced to stop working due to heart failure.

My colleagues had not become friends, because I didn’t share a schedule with anyone. My classmates during my 4 years of school had been years younger than me and not mothers, so they had gone their separate ways. The few people I knew all worked, so were home when my husband was home. Besides, it took all my energy to be “up” emotionally (& physically when possible) when he was available. I felt very isolated.

Throughout my adult life I’ve had more fatigue and less stamina than anyone else I’ve known. During this marriage I’ve had open heart surgery twice and been a hospital patient several times: once when my husband was having heart surgery himself and once for almost a month – admitted a couple of days after we moved to a condo apartment (because I could no longer manage the stairs in our town house).

If we didn’t laugh every day I don’t think I could survive. We laugh and tell our stories as funny anecdotes, sharing more laughter. My far-flung grown children give phone support. Each of my 2 daughters has dropped everything to fly in to help, with their brothers supporting them. I’m lucky to have a loving family & really, to be here all.

Reply

1. **Carolyn Thomas**

   SAYS:
   AUGUST 3, 2015 AT 4:44 PM
   Well, my dear Jennifer, when we look up the word “survivor” in the dictionary, I expect to see your photo there… I know that when others read your story here (although I know this is only a tiny fraction of what the harsh reality of living it was actually like), those people also living with multiple chronic illness diagnoses will relate to what you went through in a way that those living with the luxury of “healthy privilege” simply cannot imagine. Thanks so much and keep on laughing…

   Reply

9. **Curious to the Max**

SAYS:
AUGUST 2, 2015 AT 2:46 PM
Another thought provoking post, Carolyn. As I’ve struggled with losing both my *“mojo”* and *“self”*, I’ve come to the realization (for me) that the loss of my identity started from birth but it took a medical “crisis” to slap me in the body and make me realize that.

It's almost impossible not to define my identity by what I can do/not do. Hey! I was applauded for taking my first baby step, my first poo in the toilet!!!! My Baha'i faith is the only thing that keeps me anchored in the belief that I am, we are, spiritual beings rather than human-doings.

HOWEVER, belief and "Identity" are still a slippery slope for me as I long for something literal, physical and temporal to bolster my human image. My struggle is wanting to identify with *Being* but measuring myself with *Doing*. Not sure I'll ever be be able to stop struggling as long as I'm human but the awareness has been a positive paradigm shift for me.

Reply

1. **Carolyn Thomas**

   SAYS:

   AUGUST 3, 2015 AT 5:53 AM

   "My struggle is wanting to identify with Being but measuring myself with Doing." Brilliant summary, Judy-Judith! Trouble is, of course, that it's effortless to focus on *"being"* while we're still *"doing"* pretty well whatever we want to do. I thought of this yesterday while out for a walk with my son and daughter-in-law. At one point, I observed: *"I don't think it's possible for me to be moving any slower without just stopping!"* I simply could not seem to move my feet more than in a painfully slow shuffle. I was both fascinated and horrified by this observation! Yes, I was *"being"* with two of my favourite people on a lovely sunny afternoon, but I continue to be surprised by each new decline in *"doing"*.

   Reply

10. **Julaine**

SAYS:

AUGUST 2, 2015 AT 11:30 AM

Thank you for this wonderful article! After my heart diagnoses, I lost my *"creative mojo."* I am an artist, and it's been a year after my open-heart surgery, but something is still not right. Not giving up, I'm trying to be a patient patient, sure that my artistic expression is still there inside…

Reply

1. **Carolyn Thomas**

   SAYS:

   AUGUST 2, 2015 AT 1:42 PM

   You've *lost your mojo!* What a perfect way to put it, Julaine. But keep alive that conviction that your artistic expression IS still there somewhere inside, just struggling to figure out how that's going to look from now on. Don't force it… it will slowly reveal itself….

   After my heart attack, when I started doing public presentations based on what I'd learned during my **WomenHeart Science & Leadership training** at Mayo Clinic, my longtime public relations friends teased me: *"This is what happens when a PR person has a heart attack: they just keep on writing and speaking and looking stuff up – because that's all they know!"*

   It's very different than before – or is it? Best of luck to you in tracking down that mojo….

   Reply

11. **Marie Ennis O'Connor**

SAYS:

AUGUST 2, 2015 AT 7:26 AM

Reblogged this on Journeying Beyond Breast Cancer and commented:
I am a huge admirer of Carolyn's writing and work. She has long been a beacon of light in the blogosphere for me. Here is her latest blog post on the loss of self in chronic illness. I feel sure you will identify with this.

Reply

1. **Carolyn Thomas**
   SAYS:
   AUGUST 2, 2015 AT 10:38 AM
   Thanks for reposting this… 🙂 ♥

   Reply

12. **Marie Ennis-O'Connor**
    SAYS:
    AUGUST 2, 2015 AT 7:25 AM
    I'd been looking forward to reading this, Carolyn. I was so struck by this study when I read it, and I could identify readily with it.

    I believe that this loss of self is a huge driver for patient blogging, involvement in online community, etc. It's a way of finding our voice again, of learning to live in a new identity. It's a way of taking the elements of our lives that have been shattered by illness and disease and weaving them back together again.

    When I give presentations on this topic, I often quote from Arthur Frank's seminal work on the wounded storyteller: *"Seriously ill people are wounded not just in body but in voice."*

    Thanks for giving voice to the patient experience with this wonderful post.

    Reply

    1. **Carolyn Thomas**
       SAYS:
       AUGUST 2, 2015 AT 8:15 AM
       Thank YOU Marie for being the one who initially let me know about the Charmaz study. Like you, I instantly identified with it. It's comparable to "**sense-making**", another concept that's common to so many of us: trying to make sense out of something that makes no sense at all.

       I love the image of weaving those shattered elements of our previous lives back together again. It's like knitters I know who describe ripping apart a wool sweater to remake it into something new. We really miss that lovely old sweater that took so long for us to make, but we hope that the new scarf and mitts we're able to create will keep us warm, too. 😉

       Reply

13. **The Accidental Amazon**
    SAYS:
    AUGUST 2, 2015 AT 6:54 AM
    So many people experience this with so many illnesses.

    The loss of self can be huge with metastatic cancer, for instance. There is so much collateral damage from any cancer treatment, that many of us whose scans and tests remain negative after initial treatment never get back to who we used to be.

    The fact that this loss of self frequently also has financial consequences — because of the impact on being able to work, which can diminish greatly, as it has for you, or being forced to live on disability income — makes it even harder. Illnesses that cause chronic pain are also so hard to deal with, and healthcare still offers so few effective options to control pain, never mind eliminating it.

    This loss of self is like a protracted identity crisis. I feel like I'm still working through it, still trying to figure out what I can do and what I can't in the wake of collateral damage from cancer treatment. It's very hard to stop comparing oneself to one's former *'normal'* self, but I know that the less I focus on that comparison, the more I move toward acceptance. A continual challenge.

Thanks for this, Carolyn. Great post.
Kathi

Reply

1. **Carolyn Thomas**

   SAYS:
   AUGUST 2, 2015 AT 8:06 AM
   Such good points, Kathi. I too was struck when reading the Charmaz study of how this loss of self can be a consequence of so many different serious diagnoses. And as you so correctly say, a *"protracted identity crisis"* in so many ways.

   Reply

14. **Judy Kendle**

SAYS:
AUGUST 2, 2015 AT 5:54 AM
Still struggling with this one, Carolyn. And suspect I always will. "Lost" my volunteer job at a local art gallery after my heart attack, the result I suspect of fears about my health and/or my age – I wasn't actually told not to come back, but I got the message.

Also find my husband's hyper vigilance, bless him, endearing sometimes, but annoying at other times. I am still able to do the laundry, for example! And count out my own pills. Even found myself inexplicably angry at my daughter on her recent visit – felt patronised by the tone in her voice and her attitude towards me. Seemed to me, she now viewed me as yet another responsibility, on a par with her four-year-old daughter. Perhaps I'm super sensitive, but found myself angrily responding – *"Listen, I'm still the same take-charge, competent individual I always was, simply one who's had a heart attack. Do not speak to me in that tone of voice and/or discount what I have to say."*

She – and I – apologised and the visit then went off without another hitch, thank goodness. I do still have an active social life and have undertaken personal family history projects to fill in the gap left by the volunteer activity. Plus daily exercise now takes up a significant chunk of time. But clearly, I have lost self-confidence – and the confidence of others, it would seem, at times. Grrr!

Reply

1. **Carolyn Thomas**

   SAYS:
   AUGUST 2, 2015 AT 6:17 AM
   Hi Judy – you bring up such an important point that the Charmaz study touches on, too: that when others view us as *"sickly"*, it can really shake our sense of self-image. I had to laugh at your response to your daughter (not that it's funny, but only because I recognized my own gut reaction to being treated *"differently"*). I eventually realized that I'd harboured longstanding preconceived judgements about *"sickly"* people (had never been one myself) so at the time, I felt quite defensive about ever identifying (or being identified) as one of *"them"*….

   Reply

15. **Jen Thorson**

SAYS:
AUGUST 2, 2015 AT 5:42 AM
Exactly. The loss of my self as a healthy marathon mom who might have more kids or run a marathon at 60 was the hardest part of all that has happened to me.

And the new selves I gained paradoxically the best part of all that has happened to me.

Reply

1. **Carolyn Thomas**
   SAYS:
   AUGUST 2, 2015 AT 6:09 AM
   Thanks so much for adding that perspective, Jen. I think you’re right – being able to somehow focus on a potential “new self” post-cardiac event seems to be the key.

   Reply