

Secondary Disabilities: The Vicious Circle

Ria Voss and Dan Voss

With Contributions from Lori Gillen, Suzanne Lowing, Helen Marty, and Mike Murray

This progression round-table discussion explores the role of secondary disabilities that can magnify the effects of primary disabilities, triggering a downward spiral that leads to greater impairment, depression, and even total surrender—a classic vicious circle. The objective is to share personal experiences and look for ways to break the vicious circle early—before the secondary disability compounds the effects of the primary disability. The strategy to combat this insidious syndrome is three-fold: (1) optimal medical treatment of the primary disability to minimize its effects, (2) maximum technological accommodations to compensate for the remaining deficit after medical options have been exhausted, and (3) psychological intervention to interrupt and reverse the secondary disability pattern before it creates the downward spiral—in essence, “blasting a hole” in the vicious circle.

Have you imagined what it might be like to be sitting at a networking luncheon table at an STC conference and be totally unable to hear the person next to you, let alone the people across the table, due to the ambient noise?

Most of us adjust to this situation by raising our voices and focusing more intently in order to be able to conduct conversation over the noise. But for those with a hearing impairment, the situation can become impossible.

We knew we had something important here.

Now let's suppose you are the person with a hearing disability who missed the benefit of the networking luncheon. It is now a week after the conference, you are back at work, and you have been assigned to moderate a table at an in-service training session sponsored by your department.

The noise level is actually not nearly as bad as it was at the recent conference, but the memory of the lost networking luncheon experience is fresh.

You look across the table at the people you are supposed to be hosting. Two cross-table conversations are adding to the background noise in the room.

Suddenly, your stomach constricts as if you had swallowed a whole ice cube. What if you can't hear the people at your table? How are you possibly supposed to fulfill your responsibilities as a table

moderator if you can't even hear the people you are supposed to be leading?

Somebody asks you a question. You have no idea what the person said. Your palms start to sweat.

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YOU CAN'T HEAR THEM!

Or do you just THINK you can't hear them? Welcome the world of secondary disabilities.

Co-author Lori Gillen has been down this road many times. Can the fear of not being able to hear actually cause one to be unable to hear? You bet it can.

Discussing this pattern with Lori as we planned for this year's AccessAbility SIG progressions in Baltimore, her co-authors recognized that our colleague was on to a critical factor that dwells right on the fault line between aggressive accommodation of disabilities and abject resignation to their debilitating effects. We knew we had something important here.

We banded the question back and forth amongst the SIG's Steering Team, and a number of our colleagues stepped up to disclose personal situations that paralleled Lori's experiences with a secondary disability. It became clear that the pattern was not limited to hearing disabilities.

FIBROMYALGIA AND COGNITIVE PROCESSING

First to speak up was Suzanne Lowing, a charter member of the Special Needs Committee that evolved into the AccessAbility SIG. Suzanne has fibromyalgia, lupus, and peripheral neuropathy—a nasty combination that generates a wide range of debilitating neuromuscular and organic symptoms.

Besides the capricious pain of fibromyalgia, the near-constant pain of the peripheral neuropathy, and the episodic systemic dysfunctions that characterize lupus, one of the most debilitating aspects of the disabling medical conditions has been a progressive cognitive deficit associated with lupus.

“I just can't process like I used to,” Suzanne reported. “It makes me very hesitant to speak up, for fear that I will look dumb.”

A number of her colleagues hastened to object, pointing out the many occasions when Suzanne has made cogent and lucid contributions to the SIG's initiatives.

"If that's cognitive dysfunction, I'll take a double dose," one of her colleagues declared.

Still, Suzanne pressed to make the connection.

"In the world of work, I was experiencing increasing difficulty having to listen, process, and respond at the pace expected. I couldn't think clearly and quickly at meetings. My brain would 'shut down,' and then I couldn't respond."

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"As a result of my disabilities, I was transferred to a position where I had to work more on my own, lessening the need to interact but imposing the need to perform on very tight deadlines," she went on. "I was at a complete loss after making numerous attempts to perform."

"I have made many attempts over the years of my illnesses to join in and try to live up to expectations, only to fail often and sometimes in very embarrassing ways."

It was hard for the rest of us to accept that the same person who had just provided such a cogent analysis of her own situation could be considered to possess a deficit in processing.

Now we ask you—does that sound like a cognitively impaired person to you?

Of course not. Do you *hear* that, Lori? Of course not—which is the whole problem.

PAIN, MOBILITY, AND FEAR OF COMMITMENT

Next to jump in was Helen Marty, who faces debilitating pain and significant mobility restriction from severe joint problems and other physical limitations.

"Where the secondary disability comes into play for me is in restricting my ability and my willingness to commit to projects," she explained. "You have seen this even in our own SIG operations."

"The problem is that when I am feeling reasonably good, I am confident that I can take on a project, so I commit to it," she explained. "Then I get halfway

through it, I hit a solid wall of pain, and I am unable to maintain the project schedule. I fail."

Several of us hurried to challenge her assessment, pointing out all the successes she has achieved in our organization.

"No, face it—sometimes I fail. And the effect of that failure is not to want to try again. I am much more hesitant to take on the next project. That, in turn, makes me feel useless, so I fall into a pattern of retreat. It's a vicious circle."

It sure is.

ATTENTION DEFICIT DISORDER (ADD) AND FOCUSING CHALLENGES

It was time for Mike Murray, the talented, ebullient, and huge-hearted editor of our online newsletter *Achieve!*, to jump into the fray.

"My diagnosed disability is Attention Deficit Disorder, or ADD," Mike explained. "This condition is a classic candidate for secondary disability, because there is such a thin line between being unwilling to focus and *unable* to focus."

Mike gave the example of when he was umpiring second base at a Little League game and had the misfortune to lapse into a classic ADD "zone-out" at precisely the time when a runner was sliding into second in a very close tag play.

"I came to the horrifying realization that even though the play had taken place right under my nose, I had absolutely no clue what had just happened," Mike confessed. "I had to admit that I had flat missed it and ask the home plate umpire, who was 90 feet away, to make the call. That was definitely one of my more embarrassing moments."

Coauthor Dan Voss believes Mike may have refereed some of his daughter's soccer games.

Nah ... just kiddin', buddy!

But seriously, how does this pertain to the secondary disability syndrome we were exploring?

We manage to our own expectations.

"That's easy," Mike said. "My expectation that my attention might lapse can easily become a copout for not focusing adequately. In other words, if I give in to the fear of ADD causing me to miss something, I

might cause that to happen myself when I might have been able to follow everything that was going on.” “We manage to our own expectations,” he concluded.

Speaking of managing to expectations, Lori Gillen reports that over the years her hearing disability has led to a secondary disability—a learned attention impairment.

“Being unable to hear, or having difficulty hearing, has caused me to tend to be less attentive,” she explained. “This, in turn, has limited the effectiveness of assistive technology for me, because even though technology might enable me to *physically* hear better, I still wouldn’t be able to process the information from the speaker because of my learned attention impairment.”

“To combat this pattern, I have to make a strong conscious effort to maintain my attention even when my hearing loss limits what I can process,” she continued. “If I *don’t* make that effort, frustrating though it may be, I run the risk of not processing information even when I CAN hear it.”

Once again, the vicious circle.

DEFINING AND SOLVING THE PROBLEM

With four candid and insightful case histories from within our own SIG family, we soon realized that almost any disability could be compounded by a secondary disability in a manner analogous to those we had just explored.

For example, a person with a mobility restriction might truly not be able to access a garden café in an elegant hotel because of an inherent design flaw in the building—or he/she might have been so discouraged by previous dead-ends as to give up and not even try, when in fact, there was a reasonably accessible path by which to access the destination.

Or a person with a visual disability might have had so many negative experiences with low ambient light or glare that he/she skips a meeting in a room that was perfectly well lighted to accommodate the disability.

OK, then—problem defined.

But if there is one thing that characterizes our AccessAbility SIG, it is a deep and abiding conviction that no problem is insurmountable—that problems are there to be solved.

So we set about to chart a course to solve this one—that is, to blast a hole in the vicious circle of secondary disabilities.

Co-author Ria Voss came into the forefront at this point in the equation. As a licensed clinical psychologist, she brought expertise in the third phase of our formula to interrupt and defeat secondary disability patterns—psychological intervention.

PSYCHOLOGICAL INTERVENTION

This paper will not address the first two steps. We begin on the assumption that these two actions have already been taken; that is, optimum medical treatment has been administered and state-of-the-art technological accommodations have been applied.

The resulting deficit represents the true effect of the primary disability—reality. The difference between that and the exaggerated effects of the disability defines the extent of the secondary disability.

So how can psychological intervention arrest and possibly even reverse that vicious circle?

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We begin by defining the difference between “secondary gain” and a legitimate secondary effect of the primary disability.

Secondary gain refers to a person’s tendency to blame everything on his/her disability. If others’ expectations are lower, then the risk of failure is less. Secondary gain creates a comfort zone that insulates the person from the anxiety associated with taking risks, but it can also imprison the person in a self-fulfilling prophesy.

Secondary gain can be internal or external. In the case of an internal secondary gain, consider a person with a hearing disability, who assumes he/she is not going to be able to hear. This person may avoid being in a position where this situation is likely to occur—thereby creating a comfortable box of isolationism that can become an insidious trap.

In the case of external secondary gain, if the rest of the world accepts your disability and does not challenge you to perform to your full capability, you may, indeed, get a “free ride.” But the ride isn’t really free at all; it’s quite costly. The price is your independence and your self-respect. And that’s not really a “gain” at all; it’s a loss.

RECOGNIZING AND CONTROLLING OUR FEELINGS

So how can that pattern be prevented? There are several courses of psychological intervention. One is

a technique known as Rational Emotive Therapy, or RET. In a nutshell, RET operates on the assumption that while we are not responsible for our gut feelings, we *are* responsible for controlling them once we recognize them.

As Martin Luther once said, “We are not responsible for the birds flying over our head. We are, however, responsible for not allowing them to make a nest in our hair.”

Take, for example, a belief that is founded on a false premise: e.g., “People who can’t hear are not as worthy human beings as people who can.”

If you believe you are deficient, you will BE deficient. If you believe you are whole, you will BECOME whole.

Once this false premise is understood, the person with the hearing disability can actively reprogram the silent “self-talk” that governs our day-to-day thought processes—in essence, the blueprint for our very existence.

So when the stomach-churning anxiety kicks in—“Oh, my God! I might not be able to hear them!”—the RET prescription runs along these lines:

“That’s right. I might not be able to hear them, because I have a hearing disability. But since that does not make me any less worthy as a person, I will simply ask the person I can’t hear to repeat what he or she said. End of problem.”

It isn’t quite that simple, obviously—psychological patterns can be deeply entrenched, and reprogramming can be an exhausting process. But it IS do-able, and the payoffs are enormous.

You can only be emancipated from your primary disability to the extent possible via medical science and technological accommodation. But you can be totally liberated from your secondary disability via your own conscious intellectual effort.

If you believe you are deficient, you will BE deficient. If you believe you are whole, you will BECOME whole.

IDENTIFYING AND NEUTRALIZING FEARS

Another psychological intervention technique to block the effects of secondary disabilities is situational analysis and behavioral adjustment.

Sticking with the hearing disability for a moment, the behavioral approach would call for the therapist to help the person with the disability explore all his/her

fears and separate them into two categories: legitimate (rational) and imaginary (irrational). Obviously, this therapy dovetails very well with RET, one of whose basic tenets is to identify false premises and refute them.

Let’s return to the hearing case, starting with the irrational fears. (*Note that Lori isn’t actually in the philosophical place that the following exchange implies, but it illustrates the concept of irrational vs rational fears.*)

“So, Lori, what might happen if you can’t hear?”

“People might think I’m stupid because I cannot follow what is going on?”

“Well, ARE you stupid?”

Embarrassed silence.

“I’m serious. ARE you stupid?”

Embarrassment turns to anger. “Of course I’m not stupid!”

“Exactly. And if you openly acknowledged that you had missed something due to your hearing impairment, how many people do you believe would think you were stupid?”

Silence.

“And in the remote possibility that somebody actually did call you stupid because you could not hear them, how much value would you place on their opinion?”

“Actually, I would think they were pretty stupid.”

Exactly. Once identified, irrational fears fade rapidly. Now let’s turn to legitimate fears. How do therapists deal with those? Through reality counseling.

REALITY COUNSELING

“Suppose you actually cannot hear somebody? Then what?”

Silence.

“Analyze your options.”

“Well, I could sit there like I was stupid or I could ask them to repeat themselves.”

“We’ve discussed where the first path leads you. What do you suppose would happen if you took the second??”

“It would be really embarrassing. I would get really nervous. It would be horrible.”

“Why would it be horrible?”

“Because I might have to ask the person to repeat him or herself several times, and after all that trouble, I STILL might wind up not understanding what the person said. That’s really a much greater fear than a fear of looking stupid. I just don’t want to put people through all that, to burden and frustrate them—and for nothing.”

“Well, that is a much more legitimate fear than looking stupid, but it still rests on two premises that need to be examined.”

“And those are?”

“Well first, how do you know the people you are asking to repeat themselves are ‘burdened and frustrated,’ as you put it?”

“I don’t want to put people through all that, to burden and frustrate them—and for nothing.”

“Is your right to hear ‘nothing’?”

“Well, it must be a real nuisance to have to keep repeating yourself and then the other person still can’t understand what you said.”

“And you *know* how other people feel, right? You can get right inside their heads, read their brain waves, and know for a fact just how much you are inconveniencing them.”

“OK, OK ... I get your point. What’s the second premise?”

“It’s the part you said about the efforts of others to communicate you being ‘all for nothing.’ Is your right to hear ‘nothing’?”

“I guess maybe I never thought of it as a ‘right.’”

“Well, maybe you should start thinking of it that way.”

Of course, Lori has already reached that place—which is why she is one of the shakers and movers behind the AccessAbility SIG.

But you get the idea. The key to behavioral therapy is to identify which fears are real and which are imaginary, learn to ignore (disempower) the imaginary ones, and then analyze and learn to cope with the outcomes of the ones that are real.

Clinical experience shows that this path of intervention through behavioral management

intervention can work pretty well with secondary disabilities—although individual results obviously vary with the individual. One useful technique is for people who are trying to manage their fears and minimize the effect—shattering the vicious circle of secondary disabilities—is for them to maintain a diary of their progress, recording instances and noting results.

BUT WHAT ABOUT PAIN?

But what about sheer unadulterated *pain*? How can RET and this behavioral management deal with *that* reality?

Remember that the first step is medical intervention—do everything possible to eliminate or to limit the pain at the source. The next step is pharmacological—limit the pain with prescription medication. There is a difficult tradeoff involved here—level of pain vs. level of awareness.

Co-author Ria Voss speaks not just as a psychologist here, but from personal experience. Her fibromyalgia and rheumatoid arthritis cause a constant, chronic low-level pain which, at unpredictable intervals, explodes into acute episodes where the pain can be totally debilitating.

“I am very familiar with this trade,” Ria explained. “In fact, in my role as a geriatric psychologist and social worker with Hospice, I frequently had to counsel terminal patients and their family members concerning the balance between pain management and cognitive awareness.”

What does she recommend?

“Personally, I have always tried to restrict the use of pain control medication,” she said. “However, experience has taught me that there are times when this is the best route. Pain is a major stressor, and if it goes uninterrupted it can trigger exactly the kind of secondary effect we have been discussing.”

You mean it can actually hurt more?

“I’m not sure exactly how you measure that, but if you measure it in terms of the debilitating effect, the answer is a definite Yes.”

STRESS MANAGEMENT AND RELAXATION

Other than medication, what else can be done to manage pain?

“Stress management techniques and relaxation therapy are two excellent courses of treatment,” Ria explained. “They work well in the treatment of pain

from physiological problems as well as in mitigating anxiety and psychological disabilities.”

“What about the situation Helen describes, where pain causes her not to be able to complete projects and sometimes sends her into depression?”

“Here, the best answer is probably a combination. Begin by acknowledging the reality that pain may, indeed interfere, and then find projects that are either short-term or easy to hand off to somebody else if a pain attack occurs—thereby maximizing the chances of success and minimizing the risk of failure.”

The worst form of limitation is to be unrealistic. That just sets you up for failure.

You mean to LIMIT yourself?

“No, I mean to be *realistic*. The reality is that if you have a disability, there are probably certain things you simply cannot do. The worst form of limitation is to be unrealistic. That just sets you up for failures that are much more limiting than the relatively minor adjustments that can be made to accommodate the legitimate deficits associated with your disability.”

In other words, if you have mobility restrictions, you should not aspire to a career as an NFL wide receiver—any more than you should try out for the NBA if you are 5-foot-2. But neither should you accept the fact that you cannot access a garden café at a fancy hotel.

Mike chimed in. “You mean that with ADD I probably shouldn’t apply for a job as an air traffic controller at O’Hare International Airport?”

Chuckles all around.

You got it, big guy. But don’t mothball your umpire’s uniform. You can always alert the plate umpire to back you up. And what’s the worse case: you blow an occasional call?

There could still be a bright future for you as a soccer referee. 😊

WORKING WITH YOUR LIMITATIONS

Seriously, though, when all is said and done, the best way to prevent secondary disabilities from magnifying primary disabilities is to confront your limitations realistically, honestly, and courageously.

Lori summed it up when she said, “It is very important for people with disabilities to confront their limitations realistically. It’s important not to pretend that they aren’t there—which is what many of us have done over the years.”

“It’s important for us to ‘partner’ with our disabilities, to make peace with our ‘inner demons,’ to make them work with us instead of against us, and to accept them rather than reject them.”

“That’s the first step—acceptance.”

It calls to mind the classic serenity prayer.

“God grant me the patience to accept the things I cannot change, the courage to change those I can, and the wisdom to know the difference.”

Amen.

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Ria Voss has 25 years’ experience in clinical psychology and medical social work. She holds a dual masters in the two disciplines from Rutgers University. She is currently unemployed due to the effects of fibromyalgia and rheumatoid arthritis. Her most recent specialty was geriatric psychological and social work. She worked for Memorial Hospice Care in Volusia County, helping terminal patients and their families accept the situation and make maximum benefit of the time remaining to them. Her clinical technique is eclectic—representing a blend of behavioral therapy, RET, stress management, image therapy, and psychodynamics (role-playing).

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Dan Voss has 25 years’ experience in aerospace at LMMFC-O, and he has also taught high school and college. He is a Fellow in the Society for Technical Communication and is a member of STC’s Orlando Chapter, where he has managed the Education Committee for the past 11 years. He has received the Chapter’s Distinguished Service Award. He managed STC’s Special Needs SIG (now the AccessAbility SIG) and remains actively involved in its initiatives. Voss has also served on STC’s Professionalism, Ethics, Certification, and Strategic Planning committees. Voss has presented at 14 international and 9 regional STC conferences. With Lori Allen, he co-authored *Ethics in Technical Communication: Shades of Gray* (Wiley, 1997). He is the only non-engineer ever to earn LMMFC-O’s Author-of-the-Year award. He has also published numerous articles in professional journals and other publications.