



# Negotiating Hope and Acceptance

by Jon Caswell

Just as no two strokes are alike, no two stroke families are the same. How families handle strokes can range from complete denial to meticulous micromanagement of every medical, financial and emotional detail. And how families respond to long-term, possibly disabling illness can affect the survivor's outcome because it can affect how they see themselves.

"People cope best when they have a sense of control over their lives," says psychologist Barry J. Jacobs, Psy.D., author of *The Emotional Survival Guide for Caregivers*. Their ideas about this control often define how patients and family members react to a stroke. "Some individuals believe knowledge is power, a way to control their future health. These individuals scour the Internet, join chat rooms, compare opinions and uncover alternative remedies.

"Other people find knowledge disempowering," says Dr. Jacobs, who is the director of behavioral sciences for the Crozer-Keystone Family Medicine Residency Program in Springfield, Penn. "They feel stripped of control of the outcome when they receive definitive medical pronouncements. When they try to shield themselves from 'bad news' or simply reject it, we call it 'denial.'"

Minimization is another strategy often witnessed in people who don't think knowledge is power: "*I know I've had a stroke, but it's not that serious. These drugs, this rehab, that doctor will do the trick.*"

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# Information and Partnership

In a condition as serious as stroke, the flow of medical information plays a large role in the sense of control and well-being of both patients and family members. “Because of this, doctors are often treated like potential adversaries — either squeezed for information or kept at arm’s length to deflect what they say,” Dr. Jacobs says. “Doctors commonly complain that they are often treated as part of the health problem. In addition, different doctors feel differently about whether to share everything or just give the Cliff Notes version. Some have qualms about sharing information with relatives.”



Dr. Barry Jacobs

Though this has changed over the years, the ideal physician-patient relationship described in modern textbooks is defined as partnership. “This partnership can become strained if there are mismatches in communication styles or information-sharing preferences between patients and physicians,” says Dr. Jacobs. “For instance, a frightened patient and a close-to-the-vest physician may not mix well, nor would a mistrustful patient and a bold neurologist be a good

match.” When the personalities of specific family members are factored in — say, a relative who readily shares uninformed and unsolicited opinions — the partnership can become even more strained.

“When the partnership breaks down, the patient’s prognosis is often one of the main areas of disagreement,” says Dr. Jacobs. “The stakes are high because few things affect our sense of control more than our health and the illness that compromises it.” Healthcare professionals, with broader scientific knowledge and clinical experience, often take a more circumspect view of possible outcomes than patients and families. The doctors would call their perspective realistic, while a family might feel it was too pessimistic, not giving enough weight to intangible, metaphysical aspects of healing. Family members are more likely to view things in terms of will to live, the hand of God, and the healing power of family and prayer.

“It’s difficult to tell which attitudes reflect reasonable hope and which are sheer fantasy, well-intended but pie-in-the-sky wishfulness,” says Dr. Jacobs. “And this is important because hope is essential for keeping up a patient’s morale.

“Not only do professionals, patients and family members disagree on what to expect, among patients and their relatives there are often sharp disagreements about whose vision of the future should hold sway. For instance, if one family member seems overly pessimistic, the others may debate him vociferously. Or if someone is too optimistic, then others may make comments to bring him down to earth. As the illness drags on, the tension between hope and fantasy often increases and becomes a major stressor for everyone involved.”

It is common for patients and relatives to have different perspectives on the patient’s situation. Some survivors may accept their deficits as the price of moving on with their lives, while family members may judge such acceptance as resignation. Voicing that opinion may cause the patient to feel that he or she isn’t doing enough. How can stroke families navigate that passage between hope and wishful thinking, acceptance and resignation?

## The Power of Positive Thinking

“‘The power of positive thinking’ is a commonly held belief in our culture,” says Dr. Jacobs. “We talk about silver linings, the dark before the dawn. The entire American ethos of pushing into new frontiers is based on the idea that we have within us the determination to face all challenges and succeed.”

It turns out that there are benefits to that mindset, which social psychologists Shelley Taylor and Jonathon Brown call “positive illusions.” For two decades they researched the impact of positive attitudes and beliefs. “They concluded that when people believe in themselves and their capabilities for dealing with difficult events, regardless of their actual ability to handle them, they cope much better overall,” says Dr. Jacobs. “In other words, *overrating* yourself frequently helps. And the opposite is also true, if you regard yourself less positively and more ‘realistically,’ you may be less able to cope and more prone to depression.

“Dr. Brown theorized that if you believe you’re hot stuff, then you’re more likely to judge negative circumstances as challenging rather than crushing. If you believe you’ve got what it takes, you’ll take actions with confidence rather than remain passive in fear. If you confidently take action, you’ll feel greater control over adverse situations and have less emotional distress.”

The past 20 years have seen the rise of a “positive psychology” movement that has investigated the effect of these positive attitudes and beliefs on how people react to catastrophic events. One of the movement’s core findings is

that when people are raised to be optimistic — that is, they hold on to positive beliefs about the future even during difficult periods — they contend better with life’s disasters without becoming depressed. On the other hand, those who develop pessimistic outlooks and self-blame stumble into despair when the going gets tough.

Says Dr. Jacobs, “Applying the theories of positive illusions and positive psychology, we can surmise that believing that you’re going to get better has advantages over being consumed with anxiety about your fate.

Optimistic patients and families see complications as bumps in the road, not the end of the line. If you’re a caregiver, your faith that you’re fighting a winnable battle may be a balm to your fatigue and self-sacrifice.”

Life-altering illness is a tough circumstance in which to hold onto hope and optimism. While that attitude may shield you from demoralizing news or give you faith that the family will get through this, unmitigated optimism can also be a blindfold. Optimism is not a panacea, especially when it spills into denial. “No amount of hope can negate reality,” says Dr. Jacobs. “Refusing to accept the consequences of an illness is not a positive achievement. In fact, that strategy often does more harm than good in long-term psychological adjustment.”

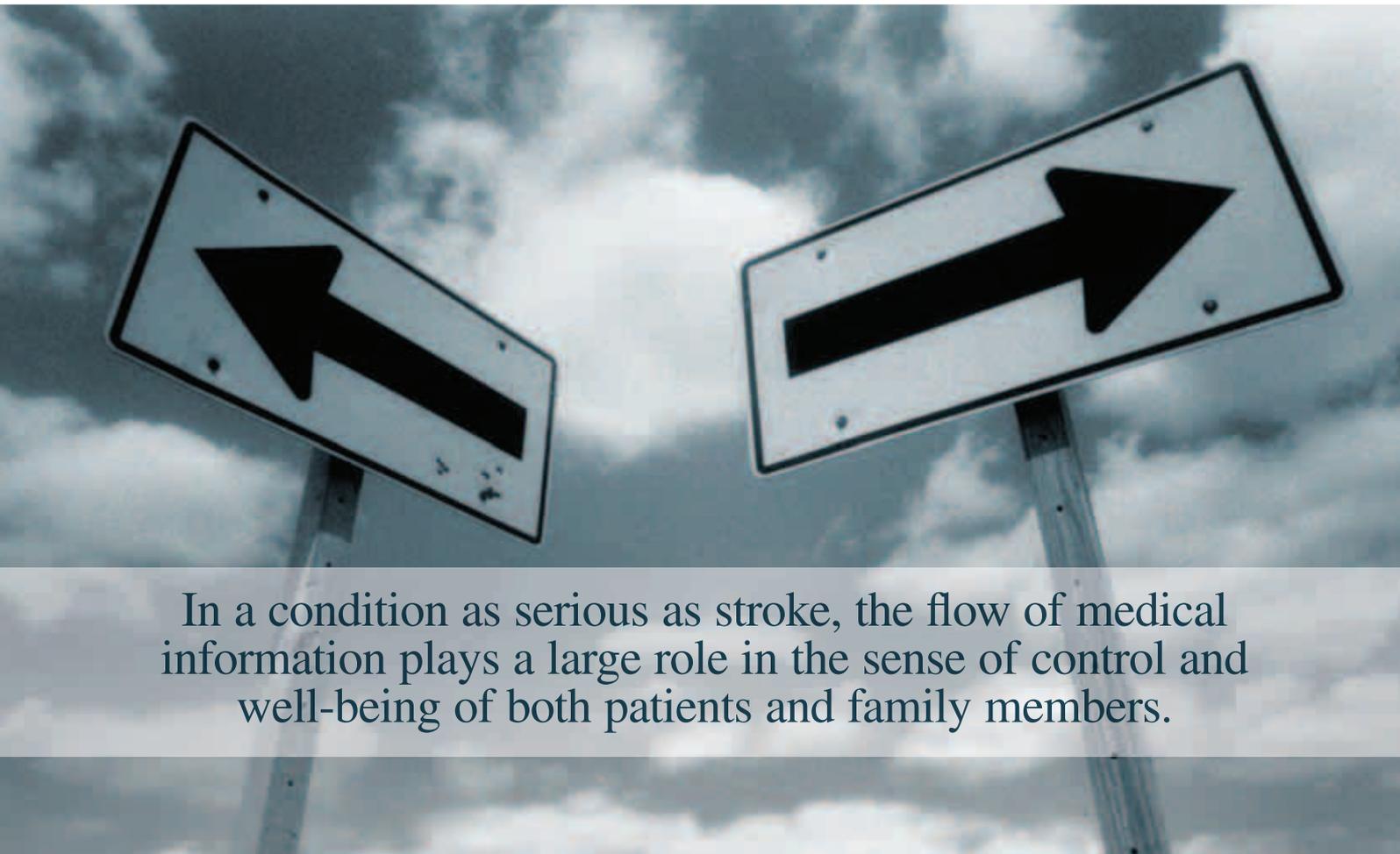
## Half-Full Is Better

How should stroke survivors and their families weigh hope and acceptance, fantasy and reality? In *The Emotional Survival Guide for Caregivers*, Dr. Jacobs uses the metaphor of the glass of water — is it half-full or half-empty? — to investigate this question. Perceiving the glass as three-quarters empty when it is actually half-full is a distortion of reality commonly associated with depression. “This belief will make an illness’s consequences feel more painful and increase suffering,” says Dr. Jacobs.

Perceiving the glass as three-quarters full when it is actually half-full is a distortion of reality often associated with a Pollyanna attitude. “This attitude substitutes naive belief for preparedness and makes any negative developments or outcomes more shocking and hard to adjust to. Both types of distortions should be guarded against.”

Still, distortions aside, is optimism helpful or should families and patients stick strictly to the clinical facts presented by the medical professionals? “On this question the research is clear: Half-full works better,” says Dr. Jacobs. “Even stretching reality slightly, say to two-thirds

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full, is okay. Reasonably optimistic patients and caregivers strive harder to find the best treatments, and they follow them with more rigor once they've found them. Hope carries them through rough patches. Staying positive allows them to try new solutions when the old ones stop producing results."

But staying positive shouldn't preclude feelings of worry, anger or sadness. "Squelching those feelings because they're too 'negative' can be damaging in itself. But those feelings shouldn't undermine a basic belief that things will work out in the end, that the illness will

- Endeavor to avoid the roller coaster of emotional reactions to every new development in your loved one's condition. When they have a good day in therapy, don't conclude the end's in sight. On the other hand, if today's prognosis is bad, don't count the survivor out.
- Take a longer, more dispassionate view. "Let time pass, events unfold and emotions settle," says Dr. Jacobs. "You'll be better positioned to assume a stance that's sensibly optimistic without being willfully foolish."

## Hope and acceptance — every survivor and every caregiver negotiates this passage in recovery of a life after stroke.

Hope and acceptance — every survivor and every caregiver negotiates this passage in recovery of a life after stroke. Perhaps, the goal is to gain peace of mind, but that rarely happens right away. Fear and stubbornness may play a big part in the negotiations. For reasons of her own, a caregiver may choose not to accept a prognosis and, thereby, ignores serious warning signs. Because he disagrees with a doctor's evaluation, a survivor may refuse to comply with a treatment regimen that will reduce his risk of another stroke. Denial of what's happening is not the same as peace of mind about what is to come.

"The families that I've seen cope the best with stroke over time," says Dr. Jacobs, "are those who view

be managed, and the family will endure. Patients and caregivers and professionals should all be united to fight the good fight. They should fight it believing they'll ultimately prevail. There's nothing fancy or innovative about this — most of us commonly refer to it as being cautiously optimistic, with an emphasis on the cautious."

Is it possible to find the balance called cautious optimism? In his book, Dr. Jacobs identifies three areas for caregivers to evaluate.

- Evaluate the medical situation as realistically as possible; be aware of *all* that you know about the stroke and the patient. Don't emphasize or discount either one.

the medical crisis as the beginning of the process of recovery and not just the end of life as they've known it. By pitching together, gathering information and nurturing realistic hope, these family members retain some sense of control in the midst of uncertainty. Sometimes, that's all it takes to help the patient feel supported and keep up his morale. Often, it what's necessary for the family as a whole to draw upon its innate courage and resilience. That makes a crucial difference to how caregivers and their ill loved ones fare emotionally, regardless of the eventual medical outcome." 

For more information on Dr. Jacob's book, *The Emotional Survival Guide for Caregivers*, turn to p. 42.

# One Family's Journey from Hope to Acceptance

Charlene Nassaney had a stroke at age 52, leaving her with right-side paralysis and global aphasia. Ten years later, despite the paralysis and aphasia, she has an active life filled with family, church and shopping. Today she is an accomplished seamstress, doll maker, gourmet cook and licensed hairstylist.

David, her husband of 31 years, has created a Web site chronicling her remarkable accomplishments: [www.charlenestrokesurvivor.com](http://www.charlenestrokesurvivor.com). We talked to him about how they got their lives back.

“We went through a three-year grieving process. In the beginning she had physical and speech therapy, and we hoped and felt that she would get better quickly. As the days ran into weeks, then months, now years, I'm glad no one told me that 10 years later we would still be affected by this. We probably would have quit.

“I am a counselor at our church in Santa Clarita, California, so going through the grieving process was on-the-job training for me. The first stage was **shock and denial**. She thought she was normal, and yet we couldn't understand her, which only made her angry. She thought there was something wrong with us.

“The second stage was **anger**, which she took out on everyone who loved her. It was not pretty. She truly hurt the ones she loved. I came very close to the end of my rope, but God kept giving me a daily dose of grace to tolerate another day until it got better.

“The third stage was **bargaining**. I suspected she was trying to bargain with God that if she did such and such a thing, He would heal her. But she finally came to a point that she realized God is sovereign, and He allowed the stroke to happen for a reason. Her faith was challenged. It is easy to have faith when all is well, but you really see how much faith you have when tragedy strikes.

“Fourth, **guilt**. She wondered if she caused the stroke by lifestyle and behavior, but none of the risk factors applied. The doctors never pinpointed a cause.



*The Nassaney family (David, standing, wearing dark jacket; Charlotte, seated, holding a grandchild)*

“The fifth stage was **depression**. Losing the quality of life you once had can cause you to wonder if life is really worth living anymore. Charlene wanted to die, but her faith led her to realize that if God wanted her dead, He would have taken her, so she must still have a purpose for being here.

“Sixth, **loneliness**. Loneliness is hard to overcome when you lose friends, your independence and the ability to communicate deeply. Her faith in God and hope in her future helped her break through.

“The seventh stage is **acceptance**, which came when the seeds of faith sprouted in her heart, and God allowed her to see the glass half-full, instead of half-empty. She took control of her life, redefined who she is, and re-established her self-worth.

“God has given us faith that she will speak again. We met a man who was like her for 10 years, then all of a sudden his brain ‘got it’ and he started speaking. He told Charlene, ‘Never give up!’ That renewed our hope. We will never stop believing there is hope.

“We believe in miracles. God has done so many for us already. Plus she has ministered to so many in her present condition, more than if she were normal. Our lives are in God's hands.”