

FEATURE

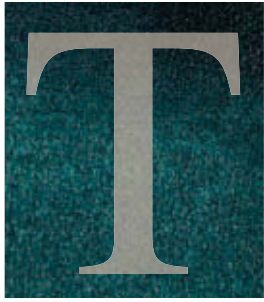
The background is a textured, abstract painting. At the top, a dark, stormy cloud hangs over a central figure. The figure is a person standing, rendered in dark, almost black tones with some highlights. The background is filled with vertical, textured brushstrokes in shades of blue, green, and brown, suggesting rain or a storm. The overall mood is somber and dramatic.

Living with Emotional  
**THUNDERSTORMS**

by Jon Caswell

STROKE MESSES WITH YOUR MIND, JUST ASK ANY SURVIVOR. AND THERE'S NO PREDICTING JUST WHAT KIND OF MESS IT WILL LEAVE.





The catalog of deficits caused by stroke is as wide ranging as the functions of the brain — from movement to speech to memory to emotions. Recently researchers have renamed an emotional deficit experienced by many survivors. Previously it had several names, “emotional lability,” “reflex crying (or laughing),” “emotional incontinence” or “pseudobulbar affect”; the new term is “involuntary emotional expression disorder” (IEED).

“IEED refers to a loss of control of affect or emotional expression such that a person more frequently, easily and intensely expresses emotion,” said Dr. Robert Hartke, a psychologist in the stroke program at the Rehabilitation Institute of Chicago, and also an assistant professor in the department of psychiatry and behavioral sciences at Feinberg School of Medicine at Northwestern University in Chicago.

“Most definitions of IEED state that the emotional expression is uncontrolled and without an apparent trigger. However, in my clinical practice, most people with the disorder have limited control, and the triggers are logical and identifiable. That doesn’t mean that the triggers are obvious to an observer or something the survivor would have been emotional about before their stroke.”

## UNDERSTANDING IEED

“To understand what the disorder is, one must first understand and be able to distinguish between ‘affect’ and ‘mood,’” said Dr. Mark Sandberg, director of psychology and community re-entry at St. Charles Hospital in Port Jefferson, N.Y. “Mood is an emotional state that lasts for prolonged periods of time; think of it as our emotional ‘climate.’ Affect is more of a moment-to-moment emotional expression — our emotional ‘weather.’ IEED is a disorder of affect. A person’s ability to regulate their outward emotional expression is damaged in IEED, and stroke is one of the common reasons why such damage occurs.”

IEED results from a malfunction in communication between the cortex, a more-evolved area of the brain that controls how we think about and label feelings, and the sub-cortical area, which is more primitive and controls how those feelings are actually expressed. “IEED is always associated with various neuropathologies,” said Dr. Sandberg. “It involves a loss of cerebral control involving emotional motor expression. It is not a psychological disorder like depression, although the person with IEED may also be depressed. It is a neurologically based disorder of affective expression.”

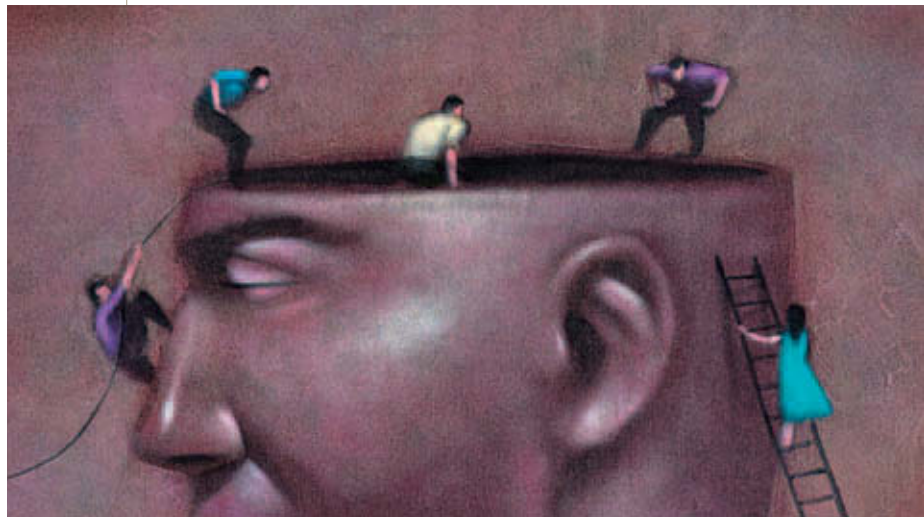
## WHAT IT FEELS LIKE

Peter Arnold, 66, of Chicago, can attest to the loss of control that comes with IEED. Before his stroke in 1991, he was a high-dollar commercial real estate attorney not prone to emotional displays. “Now I cry at the drop of a hat, and people have told me that that’s the result of the stroke,” he said.

Peter had two hemorrhagic strokes as a result of arteriovenous malformation. “Recently I was at a dance recital with a fellow stroke survivor, and I got very emotional. It was a friend’s recital, and I cried when we went in and I cried when we left. It’s not like I walk around the streets crying, I’m just more emotional than before.

“I didn’t realize it at first because I was living in ‘therapy world,’” he continued. “We stroke survivors go through a lot of readjustment to the outside world. Simple things, like crossing the street, can be very intimidating, especially here in Chicago. Those drivers are anxious to get going when the light turns, and because I’m handicapped, it might take me a little longer to get across, and the drivers would start honking and inching forward. I would stop in the street and start yelling at them. Even today I get angry at stupid things, like the way people drive, but mostly I control it.”

“The majority of stroke survivors can identify a thought or event that causes their tearfulness,” said Dr. Hartke. “Most frequent stimuli are associated with sentiment,



such as thoughts of family, loss and recovery associated with the stroke, kind gestures or expressions of sympathy, frustration over dependency, or even a sense of gratitude. Other people’s emotional expression can also precipitate it. I have seen this when working with survivors in group therapy. The idea of crying for no reason is perhaps fueled by the fact that the stimulus could be unusual or not obvious to the outside observer.”

There is not a consensus of opinion about how common IEED is after stroke. Research studies with larger samples estimate the prevalence at 11–34 percent. It appears *(continued)*



Off-label use of antidepressants has been somewhat successful in treating IEED. Anti-epileptic drugs may also be useful for stabilizing survivors' moods.

of uncontrollable expression are out of proportion to the underlying mood, and unlike depression, the features of which last over time, IEED symptoms come quickly and then leave. Most of the clinical features of depression are not features of IEED."

### TREATMENT

Given that the disorder carries so many names, it is not surprising that there is no agreed-upon treatment. Proper diagnosis is step one.

"It is important to keep in mind that IEED has to be taken in context," said Dr. Marilyn Kraus, a neuropsychiatrist and associate professor of psychiatry and neurology at the University of Illinois at Chicago's Center for Cognitive Medicine. "IEED is rarely an isolated entity. For example, it can occur with other types of mood and behavior problems or cognitive problems.

"First, a full assessment of the patient's neurobehavioral status is needed," she said. "It is necessary to know if there are cognitive deficits, or other mood or behavioral problems, so any treatment targets as many symptoms or deficits as possible and doesn't worsen other problems. For example, in a patient with IEED who also has attention problems, a goal would be to choose an agent that could help with the emotional dysregulation and either help improve attention or at least not worsen it. Conversely, a patient with insomnia or anxiety might benefit from an agent associated with sedation or that has a more calming effect."

Although a new drug is currently being evaluated, at this time there are no FDA-approved medications specifically for IEED; however, off-label treatment with antidepressants has had some success. Tricyclics and



Dr. Mark Sandberg



Dr. Robert Hartke

to be more prevalent in older patients and those who have had prior strokes or who experience stroke in certain parts of the brain, like the basal ganglia.

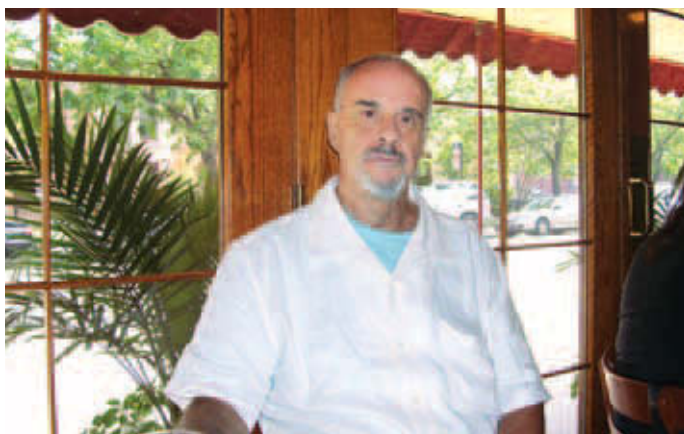
The disorder often brings consequences on an emotional, social and occupational level. "If a person has been emotionally reserved all of their life, onset of IEED after stroke can feel self-alienating and anxiety-provoking," said Dr. Hartke. "Stroke survivors I have worked with make comments about how it makes them feel unlike their usual selves, out of control and crazy. IEED can cause social embarrassment and disrupt or distort communication in ways that are puzzling and frustrating to a stroke survivor. It can also slow down therapy sessions while survivors regain their composure. In the more intense IEED sometimes seen in survivors of brainstem stroke who may have had a tracheotomy, it can be exhausting and put a person at risk for aspiration."

"The consequences of IEED can be disabling to social and occupational functioning, and can surely undermine a survivor's self-esteem and psychological well-being," said Dr. Sandberg. "Most of the time it creates a pattern of uncontrollable crying; less common is uncontrollable laughter. You can imagine the social consequences of such behavior, particularly when it occurs within a social exchange."

### IEED AND DEPRESSION

Although survivors with IEED may be depressed, IEED and depression are distinct disorders. IEED involves a disconnection between mood, which is the cognitive aspect of emotion, and affect, which is its physical expression. "Many patients with IEED also experience depressive symptoms," said Dr. Sandberg. "And depression can make the affective displays more prominent. However, the bouts





Peter Arnold

selective serotonin reuptake inhibitors such as Elavil, Zoloft and Prozac are the most frequently used, generally in doses lower than those prescribed for depression. Anti-epileptic drugs may also be useful for stabilizing survivors' moods.

"There are side effects possible with all the medications that can be used," said Dr. Kraus. "The thing to keep in mind is that an injured brain may be more sensitive to side effects, so practitioners should generally start with a low dose and go slowly with any increases."

Peter Arnold does not take medication for IEED, though he does take anti-seizure medication to control seizures that resulted from his strokes 15 years ago. He's learned how to overcome his bouts of uncontrolled emotion through self-observation. "The most distressing thing to me is being taken over by my emotions," he said. "Most people don't control themselves. Through Alcoholics Anonymous (AA) and training I've received to be a drug and alcohol counselor, I've gotten the tools I need to understand why I get so emotional."

"At first, I was more detached from the events; they just seemed to happen," he continued. "But then I started to feel the feelings, and that opened up a whole world of feelings that I didn't know I had. I was always an emotional person, but I didn't realize it. It took a long time for me to figure out who I was. It produced a lot of revelations."

## HOW TO RESPOND

Family and friends often feel uneasy when they observe an episode of crying or an angry outburst. "The best thing for them to do is be supportive," said Dr. Sandberg. "When the episode is over, help the survivor redirect their attention back to the previous conversation or activity and resume what had been their focus of attention. Family support is a critical factor in resuming a meaningful and satisfying life when faced with residual neurological features from a stroke."

"From a more psychological and behavioral standpoint, education of the stroke survivor and their family as to

"It took a lot of work, but I've learned to control my emotions much better," said Peter Arnold. "I feel that being more emotional has improved me in some ways. I feel more empathy for people now."

what IEED is all about can be extremely helpful," said Dr. Hartke. "There are simple behavioral strategies that can help, such as distracting the person from the stimulus, or having the stroke survivor use verbal clarification about how they are really feeling in order to regain control and clarify communication. In some instances, taking slow, deep breaths can help. None of these strategies has been systematically studied. I suggest them based on clinical anecdotal experience with patients."

The intensity of the emotional response may decrease over time, especially if it is associated with a single stroke or other neurological event. Research suggests that frequency and intensity diminish during the first year post-stroke.

"It is important for family and friends to realize that IEED is an emotional reaction with a definite physical cause," said Dr. Hartke. "I often describe it as a misfiring or disconnection in the brain that disables a filter or moderating mechanism so that emotional expression can just 'pop out,' like an emotional thunderstorm. Where in the past the survivor may have only experienced the cognitive portion of an emotion and 'kept it inside,' now he or she has much less control of the nonverbal expression of it."

"When family members realize this, it is easier for them not to focus on the expression — which can prolong it — but rather aid the survivor through distraction, which can help them move through the expression more quickly and with less embarrassment," said Dr. Hartke. "It is important for family members not to get embarrassed along with the survivor. Instead, they could ask for verbal clarification of how the survivor is really feeling: For example, asking, 'Are you really that sad right now, or is this just one of those moments because of your stroke?' This way the survivor can gain control by more clearly stating how he feels."

When survivor Peter Arnold starts to go off into an angry response in traffic, for instance, his wife Paulette steps in. "She tells me, 'stop it,' and I do. I just let people go around me now. I realize I can't control other people."

"It took a lot of work, but I've learned to control my emotions much better," Peter continued. "I feel that being more emotional has improved me in some ways. I feel more empathy for people now. I never really cared about other people before. I feel more compassion now." **SE**