Dementia

Preplanning, expert care and human compassion help manage the trauma

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The memories bring a pained grimace to the face of Aldo Gomez. He remembers when Ken, his ex-lover, was in the hospital, seriously debilitated with kidney and gall bladder failure -- and AIDS dementia. Ken would periodically thrash about in bed, fending off imagined attackers. But those battles couldn't have been worse than fighting with hospital staff who disbelieved his complaints about no one answering his 3 a.m. buzz seeking relief for a parched throat. A condescending nod was apparently more easily given than a glass of water.

Then there was what happened to Bryan, another PWA Gomez cared for. Living in a Houston hospice, this 36-year-old was often mistaken for someone 30 years his junior. At his worst, he would babble incoherently. So hospice workers treated him like an idiot -- and he knew it. At one point when he was lucid, Bryan asked for a book to read; a nurse gave him *Green Eggs and Ham* by Dr. Seuss. Later Bryan pulled Gomez over and said, "Get me something else and keep that person away from me."

It's no secret that the prospect of losing one's ability to think, joke, explain -- in short, to lead a normal life -- is terrifying, particularly to HIV positive people. "The possibility of losing brain function is always in the front of one's mind," says Richard Wagner, director of Paradigm, a San Francisco service organization for people who consider themselves terminally ill. "I always ask the people I advise, 'What is the worst-case scenario?' Very rarely if ever will they say, 'Death'; usually it's, 'The loss of my capacity to be human.' That's what they fear most. And perhaps rightfully so."

Add to this the unfortunate labels "demented," "mentally ill" and "dangerous" and you've already branded the person a member of the inhuman race. "You find yourself saying, 'It's worse than a child,'" says Wagner. "This person you knew and loved no longer has a personhood." In her new book, *Positively Well*, Denver nutrition educator Lark Lands, PhD., stresses the need to use the more inclusive term "HIV-associated cognitive and motor complex" (CMC), because it covers the range of symptoms encountered in central nervous system dysfunction. "The term 'dementia,'" she writes, "engenders fear in many and can be socially stigmatizing. This has kept many people from admitting that they have any symptoms of cognitive dysfunction for fear of being called 'demented.'"

By whatever label, the cognitive and functioning problems faced by PWAs can evoke fear and loathing in those around them. But continuing to respect the person's humanity is key. And before

CMC ever strikes, there are many preparatory steps caregivers can take to manage its personal consequences later on. Meanwhile, treatment options do exist. But the key is proper diagnosis, to make sure you know exactly which condition you're dealing with.

HIV-associated cognitive and motor complex, unlike neurological opportunistic infections such as toxoplasmosis, cryptococcal meningitis or progressive multifocal leukoencephalopathy (PML), describes a global attack on the central nervous system. Dr. Richard Price, chief of neurosurgery services at San Francisco General Hospital, uses toxoplasmosis to illustrate this. "Toxo does get to the brain via systemic infection," Price says. "It may be in the muscle, for example, but that's usually not significant. It tends to show up as a clinical disease in the brain, causing lesions the size of a marble in one or several parts of the brain."

CMC, on the other hand, doesn't show up on magnetic resonance imaging (MRI) as areas of infection. In complex ways not fully understood, the neurons themselves are injured and caused to behave abnormally. The result is a motor slowing of the entire body -- walking, arm movements and speech patterns. In addition, the person has difficulty with concentration and memory and may be depressed or agitated.

But the day-to-day emotional stresses of living with HIV can be enough to make anyone depressed, agitated or less than perfect in performing routine tasks. So it's safe to say that someone experiencing these problems should not jump to conclusions about his or her state of mind. Dr. Mark Leary, deputy chief of psychiatry at San Francisco General Hospital, notes, "A few medications -- AZT and dapsone being two -- can cause some of the same symptoms. Pain-killing drugs in particular can mimic dementia. Also, several neurological infections look like dementia and are treatable."

One of those is neurosyphilis. Many HIV positive people are coinfected with the bacteria -- called a spirochete -- that causes syphilis, according to Dr. Edward Hook, professor of medicine at the University of Alabama, who has studied the two diseases for 15 years. Early in the course of syphilis, Hook says, spirochetes invade the central nervous system and can later cause neurosyphilis, a "dementia-like syndrome" hard to distinguish from HIV-related CMC. A panel convened in 1994 by the Physicians Association for AIDS Care (PAAC) found a "recent upsurge of neurosyphilis cases...in persons coinfected with HIV."

So Hook emphasizes the importance of thorough syphilis testing, including a spinal tap if the blood test is positive. "HIV dementia is a diagnosis of exclusion, so we want to exclude anything we can treat and neurosyphilis is eminently treatable." He adds, "Too often, we've been surprised to find syphilis in individuals who felt they had no reason to worry about it."

Thus, for those with cognitive problems, a carefully differentiated diagnosis is key. (See Crazy? Not at All .) Apparently this is a lesson even primary care physicians need to learn. "There is so much misdiagnosis when it comes to neurological dysfunction, it's become the norm," says Sally Cooper, executive director of the PWA Health Group in New York City. "There's a sloppiness and lack of understanding of how complex it is. And with primary care physicians, there is much less belief in

the individual [patient] to the point where they are suspicious of what the individual is experiencing." Cooper's advice is to keep friends close by who will be honest about any changes they notice. "And get to a neurologist," says Cooper. "You know you're not who you were, and that's part of the horror."

he message on his machine is upbeat: "Sorry I haven't got back to you sooner, but I've been busy with everyone dying around here." Paradigm's Wagner, a jovial and refreshingly honest man (some might deem him flippant), talks casually about dying as if, well, as if this isn't America, where the subject is encrusted with so much denial. But it's his business: He helps people who self-identify as terminal make preparations for their eventual passing. When asked about dementia, however, his *allegro non troppo* falters. He's been a caregiver to a person with CMC more than once, and the experiences have left their scars.

"Caregiving at the final stages of people's lives is hard under the best of circumstances," says Wagner, "but there are little rewards when people who are lucid can say 'thank you' and recognize you as the significant person that you are in their life, and perhaps give you blessings before they leave. For demented persons, that is not available. There are no thank yous, no recognition of either what the caregiver is providing or even who he or she is. That is so fundamentally hurtful to the caregiver, particularly if it's a partner. I find that a lot of those people have a really difficult time with their grieving process because their partner or friend was unable to help them through it."

Paradigm's approach is predicated on preparing the terminally ill person for whatever may occur in the near or distant future, not unlike sex education or family planning. Wagner views the living will and the dying will as equally essential -- key tools to have in place for peace of mind. This may seem fundamental, but most people feel that adding mortality to their vocabulary means giving up. They have trouble understanding that for both the caregiver and the PWA, these proactive steps can bring a profound sense of control to an inherently unstable situation. Wagner tells his clients, "We know there's going to be one casualty. There doesn't have to be two."

When Ken developed CMC, Aldo Gomez's hands were tied by not having made these preparations. Ken was experiencing episodes of agitation and fogginess. Sometimes he would demand an ice cream sundae from the Dairy Queen an hour's drive away. Or he'd refuse to take his pills, thinking he already had. The episodes became more frequent and longer lasting. When they ended, he wouldn't remember what had happened and the best he could do was offer an apology.

During one of these episodes, Ken was brought to the hospital vomiting green bile, and Gomez had no authority to make medical decisions for him. "We never drew up a medical power of attorney," Gomez says, "so we had to get the mother's permission for everything, and she had no idea what was going on. She even tried to have me kicked out of the hospital a couple of times."

Gomez took care of Ken for a year and a half before he passed away, a burden that sometimes became almost more than he could bear. Having to care for someone entirely dependent on him -- compounded by the inadequacy of local support services -- was something he never imagined

would require so much legwork. “If I had to do it again, I would demand to discuss with the person how they would want things taken care of,” says Gomez. “Then I would yell until I got what I wanted from the system.”

A checklist materializes on Richard Wagner’s PC -- some 30-odd tasks and papers to complete as part of putting a PWA’s affairs in order. It includes a declaration of executor (someone you wish to make decisions for you), funeral wishes, managing bank accounts, provisions for pets and final letters to friends and family, to name a few. They are best kept accessible, Wagner warns, not locked away in a safe deposit box. It also helps if the people closest to you have copies of all the paperwork.

Most important, these papers should be drawn up while one is in relatively good health, since a PWA can progress from full cognition to severe mental incapacity in just a few weeks. “Everyone, regardless of whether she or he is HIV-infected, should have a will that is carefully drawn so that it’s not later subject to challenge,” says Mark Elovitz, a lawyer with the American Civil Liberties Union’s AIDS Project. “It is crucial for setting down exactly what you want to happen in a variety of circumstances.”

Equally important is honestly communicating the expectations, needs and limitations of caregiver and care-receiver alike. Wagner advises the person who is sick to clearly state likes and dislikes. Likewise, he urges the caregiver to learn how to say, “I can honor that, but I can’t be present,” instead of making decisions against the will of the person he or she is caring for. Says Wagner, “Inevitably, even the people who love us the most will try to cut our legs off, not because they want to hurt us, but because they think that is the best way to be present for people who are sick. We incapacitate people long before they are incapacitated themselves.” So, as indelicate as it may sound, decisions about who will change diapers, clean bedpans, keep house, cook meals and answer phones are best made in advance.

Certainly not everyone with HIV disease will develop CMC. Some studies estimate that at least 20 percent of people with AIDS will develop some degree of CMC, but the general consensus is that the condition is less prevalent now than earlier in the epidemic. “It’s paradoxical,” says Richard Price of San Francisco General. “You would think that prolonged survival would mean more cases of dementia. The easiest explanation is the wide use of antiretrovirals such as AZT.” Price goes on to explain that devastating cases are rarer and, when present, more often in late-stage AIDS than in the past. “Now we’re seeing a number of patients who have mild symptoms, such as a little trouble concentrating. But a mild case does not necessarily mean they are going to develop major dementia.”

Nutrition educator Lark Lands agrees. Her effusive personality -- her terms of endearment, even the subtitle of her book, *A practical guide to nutrition, drugs, and therapeutic agents, energy therapies, psychoimmunity, and hope!* -- carries over into her optimism for the future of AIDS treatments. “I have seen a great many people with memory loss and other early signs of CMC who reversed it amazingly,” says Lands. “If people reduce their viral load and take tumor necrosis factor (TNF) inhibitors such as thalidomide and pentoxifylline, vitamin supplements and

antioxidants, maybe we'll find more effective ways to achieve full restoration of cognitive function."

Lands's holistic approach to CMC treatment encompasses all known, preventable mechanisms of neuron injury and death. The first is a theory of primary infection of the nerve cells by HIV itself. Researchers, however, discovered that often a person can be severely affected by CMC and have very little HIV in the neural tissue. They also found that quantity of dead nerve cells does not correlate with degree of dysfunction.

So scientists began looking for mechanisms that cause neural injury through indirect processes triggered by the presence of HIV. These can be either products of immune system cells such as TNF, which occur naturally but can, in high concentrations, damage the tissue, or compounds produced by the virus itself. This is where CMC research is now focusing -- developing drugs to inhibit the unabated production of these compounds, in addition to reducing the exposure of the central nervous system to HIV via existing antiretroviral drugs.

Other factors also seem to contribute to the likelihood that an HIV positive person will develop CMC. Dr. Harry Hollander, director of the Infectious Disease Specialties Clinic at the University of California at San Francisco, explains that nutritional deficiencies (particularly of vitamin B12), drug and alcohol abuse and possibly age may play a role. Young and old brains seem most susceptible to CMC, explaining its high incidence in children. For older people, the cause may have to do with simultaneous Alzheimer's disease. "If somebody has a history of drug abuse, is relatively old and nutritionally deficient," says Hollander, "I would estimate his chance of developing CMC at three to four times higher than somebody with none of those risk factors."

Nutrient deficiencies are often overlooked as a contributing cause of cognition problems, not to mention wasting and increased susceptibility to opportunistic infections. "Neurologists have long known that chronic infection in someone with vitamin deficiencies -- which most people living with HIV are known to have -- is strongly associated with neurological problems," writes Lands. "Although most of the dysfunction related to vitamin deficiencies can be reversed in early deficiency stages, there is definitely a time window after which it may no longer be possible to reverse the damage." Lands cites vitamins B1 (thiamine), B3 (niacin), B12 and folic acid as necessary for normal cognition that are often deficient in people with HIV.

Providing care to a person with CMC may not be an intuitive process. "The most important thing," Price says, "is that no matter what they look like when their functions have slowed, you should continue to treat them like you would otherwise -- that is, with kindness and patience." He explains that a person experiencing CMC should not be treated like a child. "You just have to make sure that things are getting through and be patient. Treat them as an adult and give them a chance to reason through and understand things." And because he or she is having trouble concentrating, it helps to structure things. Post a large calendar with the date and log daily medications on a big board. They may have lost their usual sparkle or spontaneity, but are often still quite capable of reasoning. "You may just have to help them out," Price emphasizes.

For Aldo Gomez, the hardest part of caring for Ken wasn’t the vomiting or incontinence. It was the agitated behavior and false accusations, like the one about Gomez keeping his friends away from him. But Gomez knew Ken wasn’t lucid: His eyes would glaze over and get that sleepy look. Every so often, though, there were those gratifying moments when, at the height of Gomez’s frustration, Ken would see through the fog and help out.

The reality is that HIV-related cognitive problems are painful for all concerned. By keeping their own humanity intact, caregivers can protect the humanity of those they’re trying to help. And by getting medical tests and available treatments at the earliest sign of symptoms, and making all possible plans for future decision-making, both PWAs and their caregivers can ease the journey -- if it comes -- into dementia.
