

A CHRONICLE: DAX'S CASE AS IT HAPPENED

Keith Burton

... The story of Don Cowart is remarkable in some ways but commonplace in others. A man's wish to die is rather extraordinary in and of itself; but the pattern of events that shapes such a wish often is woven of the fabric of life's everyday occurrences. Such is the case with Cowart.

Ray and Ada Cowart moved their family from the Rio Grande Valley to the small East Texas town of Henderson in the sixties. Ray prospered over the years as a rancher and real estate agent. Ada became a teacher in the Henderson school district. Their three children—Don, Jim, and Beth—were no different from other kids reared in a close-knit community. In fact, they were ordinary people living ordinary lives.

"Donny Boy," as he came to be called by his father, was popular in school and excelled in athletics. He was captain of his high school football team and performed in rodeos. He liked to take risks, a trait that often dismayed his mother. It was risk taking that would later lure him to skydiving, surfing, and other sports of chance.

Don Cowart left Henderson in 1966 to attend the University of Texas at Austin. He had planned to return home at his graduation three years later to join his father in business; however, when notified of his military draft selection, Cowart instead elected to join the U.S. Air Force. He became a pilot and served in Vietnam. He married a high school sweetheart in 1972, but they divorced eight months later. In May 1973 he was discharged from active duty and returned to Henderson, where he began working with his father in real estate.

July 23, 1973, seemed no different to Cowart from any other Wednesday. It was hot and sultry as the afternoon sun slipped low along the pine trees in the countryside near Henderson. Ray and Don had driven out to a ranch to look over some property being offered for sale by the owner. They parked their car on a bridge over a dry creek and took off by foot. They talked and laughed together as

they surveyed points of interest on the land. Their business completed, the Cowarts then returned to their car to go home for dinner.

The accident happened with no warning. The Cowart men had returned to their car but had not been able to start the engine. Ray had lifted the hood and removed the air cleaner from the engine. He primed the carburetor by hand and instructed Don to try the ignition. Several tries failed. It seemed to Don that the battery was near exhaustion. A final attempt proved fateful, however, as a blue flame shot from the carburetor and ignited a terrible explosion and fire.

Ray Cowart was hurled into heavy underbrush by the force of the explosion. The blast rocked the car and shattered window glass over Don's body. Around them, the fireball spread quickly, consuming pine trees and the scrub vegetation in the area. Don reacted quickly. He climbed from the burning car and began running toward the woods. But he was forced to stop by a fear that he would become entangled in the underbrush and slowly burn to death.

Don wheeled about and decided to chance the dirt road on which they had driven in. He ran through three walls of fire, emerged into a clearing, then fell to the ground and rolled his body to extinguish the flames. He got back to his feet and resumed running in search of help for his father.

It all seemed dreamlike. Don noticed his vision was blurred as though swimming under water. His eyes had been badly burned. Now the pain was coming in waves, and he knew it was real. He kept running.

Loud voices filtered through the woods. Don collapsed at the roadside as help arrived. He heard the footsteps of a man and then the exclamation, "Oh, my God!" when a farmer found him. Don sent the man after his father and lay wondering how badly he was burned. When the man returned, Don asked him to bring a gun—a gun he would use to kill himself. The farmer refused.

In shock, Don assumed he and his father had caused the explosion by igniting gasoline from the car's engine. Later he would learn that the explosion actually had been caused by a leaking propane gas transmission line in the area where they had parked. It was a freak event.

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Editors' note: Some text has been cut. Students who want to read the article in its entirety should consult the original.

A pocket of propane gas had formed in the dry creek bed. When the carburetor flamed up, it had ignited the gas.

Rescuers took the Cowart men to a hospital in nearby Kilgore. There, a decision was made to transport them by ambulance to a special burn unit at Dallas's Parkland Hospital. Ray Cowart died en route to Dallas. Don Cowart remembers incredible pain, his begging for pain medication, and the paramedic's refusal to administer drugs prior to their arrival in Dallas. By this time, Ada Cowart, too, was on her way to Dallas. She had returned home first to pack several changes of clothes. The radio had said the men were badly hurt. She didn't expect to return to Henderson any time soon.

Even as the ambulance sped the 140 miles from Kilgore to Dallas, Don Cowart's treatment regimen had begun. By telephone, Dr. Charles Baxter, head of Parkland's burn unit, had directed fluid therapies to help in preventing shock to vital organs. On examination in Dallas, Baxter found Cowart had severe burns over 65 percent of his body. His face suffered third-degree burns and both eyes were severely damaged. His ears and hands were also deeply burned. Fluid therapies continued and were aided by several other measures: the insertion of an intertracheal tube to control the airway, catheters placed in every body opening, treatment with antibiotics, cleansing the wounds with antibacterial drugs, and tetanus prophylaxis. Heavy doses of narcotics were given for the pain.

In the early days of Don's 232-day hospitalization at Parkland, doctors could not predict whether he would survive. It was touch and go for many weeks. Ada Cowart felt helpless; she could do little more than sit in the waiting area outside the intensive care unit with relatives of other burn victims, where she prayed and hoped for the best. Doctors permitted only short visits with her son. Don had given his mother power of attorney in the Parkland emergency room, and she in turn deferred to the medical professionals on treatment decisions.

For Cowart, there were countless whirlpool tankings in solutions to cleanse his wounds, procedures to remove dead tissue, grafts to protect living tissue, the amputation of badly charred fingers from both hands and the removal of his right eye. The damaged left eye was sewn shut. And there was terrible pain.

Through it all, Don had remained constant in his view that he did not want to live. His demands to die had started with the farmer at the accident site. They had continued at the Kilgore hospital, in the ambulance, and now at Parkland. He didn't want treatment that would extend his misery and he made this known to his mother and

family, Dr. Charles Baxter, a nurse named Leslie Kerr, longtime friend Art Rousseau, attorney Rex Houston, and many others.

Baxter remained undaunted by Don's pleas to stop treatment, dismissing them at first as the typical response of burn victims to the pain of their wounds and treatment. In time, however, he openly discussed Cowart's wish to die with Don, his mother, and his lawyer, considering all the medical and legal ramifications. Failing to get Ada Cowart's and Rex Houston's consent to the withdrawal of treatment, Baxter continued to deliver it.

For her part, Ada Cowart understood her son's pain and anguish. She was haunted, nonetheless, by these thoughts: What if treatment were ceased and Don changed his mind in a near-death state? Would it be too late? Furthermore, her religious beliefs simply made mercy killing or suicide deplorable options. These religious constraints were reinforced by her fear that her son had not yet made his "peace with God."

Rex Houston also had mixed feelings about Don's wishes. On the one hand, he sympathized with Cowart's condition—being unable to so much as take medication to end his life without the assistance of others. On the other hand, it was Houston's duty to reach a favorable resolution of a lawsuit filed against the pipeline owners for Ray Cowart's death and for Don Cowart's disability. With regard to the latter, he needed a living plaintiff to achieve the best damage award for the Cowart family. Moreover, Houston believed that such an award would provide the financial means necessary for Don Cowart's ultimate rehabilitation. He therefore encouraged Cowart to see the legal proceedings through.

In February 1974, the lawsuit was settled out of court—one day prior to trial. Almost immediately, Don's demands to die quickened. There had been talk before with Art Rousseau of getting a gun. Don had asked Leslie Kerr if she would help him by injecting an overdose of medication. Now Cowart even talked with Houston about helping him get to a window of his sixth-floor hospital room, where presumably he would leap to his death. All listened but none agreed to help.

On March 12, 1974, Don was discharged from Parkland. He, his family, and his doctors agreed that his condition had improved sufficiently to warrant his transfer to the Texas Institute for Research and Rehabilitation in Houston. Nine months removed from his medical residency, Dr. Robert Meier of TIRR found Cowart to be a passive recipient of medical care, although the philosophy of treatment in this rehabilitation center encouraged

patient involvement in treatment decisions. Previously Don had no say in his care; now he would be offered choices in his own treatment.

All seemed to go well during the first three weeks of his stay, until Cowart realized the pain he had endured might continue indefinitely, thanks to a careless comment by a resident plastic surgeon that his treatment would be years in completion. Faced with that prospect, Cowart refused treatment for his open burn areas and stopped taking food and water. In a matter of days, Cowart's medical condition deteriorated rapidly. Finding his patient in serious condition, Dr. Meier was deeply perplexed about what to do next. He believed it his duty to help Cowart achieve the highest measure of rehabilitation, but he was not inclined to force upon the patient care he did not wish to receive. Faced with this dilemma, he called for a meeting with Ada Cowart and Rex Houston to discuss with Don the future course of his treatment.

Ada Cowart was outraged by Don's condition. She had been discouraged from staying with her son at TIRR, and in her absence his burns had worsened. He was again near death, due to his refusal of whirlpool tankings and dressing changes. It was agreed in the meeting that Cowart would be transferred to the burn unit of John Sealy Hospital of the University of Texas Medical Branch in Galveston, where his injuries could again be treated by burn specialists.

On April 15, 1974, Don was admitted to the Galveston hospital, in chronic distress from infected wounds, poor nutrition, and severe depression. His right elbow and right wrist were locked tight. The stubs of his fingers on both hands were encased in grotesque skin "mittens." There was practically no skin on his legs. His right eye socket and closed left eye oozed infection. And excruciating pain remained his constant nemesis.

Active wound care was initiated immediately and further skin grafts were advised by Dr. Duane Larson to heal the open wounds on Cowart's chest, legs, and arms. But Cowart bitterly protested the daily tankings and refused to consent to surgery. One night he even crawled out of bed, hoping to throw himself through the window to his death, but he was discovered on the floor and returned to bed.

Frustrated by Cowart's behavior, Dr. Larson consulted Dr. Robert White of psychiatric services for an evaluation of Don's mental competency. White remembers being puzzled by Cowart: Was he a man who tolerated discomfort poorly or perhaps was profoundly depressed? Or was this an extraordinary man who had undergone such an

incredible ordeal that he was frustrated beyond normal limits? White concluded, and a colleague confirmed, that Cowart was certainly not mentally incompetent. In fact, he was so impressed with the clarity of Cowart's expressed wish to die that he asked permission to do a videotape interview for classroom use in presenting the medical, ethical, and legal problems surrounding such cases. That filmed interview, which White entitled *Please Let Me Die*, eventually became a classic on patient rights in the field of medical ethics.

Having been declared mentally competent, Cowart still found it difficult to gain control over his treatment. He and his mother argued constantly over treatment procedures. Rex Houston helped get changes in his wound care but turned a deaf ear to Cowart's plea to go home to die from his wounds or to take his own life. In desperation, Cowart turned to other family members for assistance in securing legal representation, but without success. Finally, with White's help, Cowart reached an attorney who had represented Jehovah's Witnesses attempting to refuse medical treatment, but he was not optimistic that a lawsuit would free him from the hospital.

Rebuffed on every hand, Cowart reluctantly became more cooperative. White secured changes in Don's pain medication before and after the daily tankings, making treatments more bearable. Psychotherapy and medication helped improve his overall outlook by relieving his depression and improving his sleep. Encouraged that he might still regain sight in his left eye, Don more or less accepted his daily wound care and even agreed to surgical skin grafts early in June 1974. By July 15, his physical condition had improved enough to allow him to transfer out of the burn unit of the John Sealy Hospital to the psychiatric unit of the Jennie Sealy Hospital in the University of Texas Medical Branch under White's direct care while his wounds continued to heal.

Amid these changes there were still periodic conflicts between Cowart and those around him over his confinement in the hospital. There were reiterated demands to die and protests against treatment. A particularly explosive encounter between Cowart and Larson occurred on the day preceding his second and last major surgical procedure in the Galveston hospital. Cowart had agreed to undergo surgery to free up his hands, but the night before he changed his mind. The next morning, Larson angrily confronted Cowart with the challenge that, if he really wanted to die, he would agree to the surgery that would enable him to leave the hospital and go home where he could take his own life if he wished. Anxious to do exactly

that, Cowart consented to the surgery, which was performed on July 31.

Don Cowart's stormy stay at Galveston finally ended on September 19, 1974. He had been hospitalized for a total of fourteen months, but at last he was going home. His prognosis upon dismissal was listed simply as "guarded."

Cowart was glad to be back in Henderson. The little things counted the most—sleeping in his own bed, listening to music, visiting with friends. But it was different for him than before the accident. He was totally blind, his left eye having failed to recover. His hands and arms remained useless. He was badly scarred. A dropped foot now required that someone assist him in walking. Some of his burn sites still were not healed.

Everything he did required the help of others. Someone had to feed him, bathe him, and help with personal functions. The days seemed endless. He tried to find peace in sleep, but even this dark release was impossible without drugs. While he couldn't see himself, Don knew his appearance drew whispers and stares in restaurants.

He had his tapes, talking books, television, and CB radio. He could use his sense of hearing, though not as well as before due to the explosion and burns. And he could think. For a while, he could see in his mind's eye the memories of earlier times. Then the memories started to fade.

Ada Cowart had lost much, but she never lost her religious faith. There had been times when even she had admitted that maybe it would have been best if Don had died with her husband. She reconciled her doubt with the thought that no mother can give up the life of a son. Ada never gave up hope that Don could find new faith in God.

Homecoming brought peace for a time. As Don's early excitement for returning home gave way to deep depression and despair, however, conflict returned to their lives. They argued about how he could occupy himself, how he dressed, his personal habits, and his future. Frustration led to a veiled suicide attempt, Don stealing away from the house during the night to try throwing himself in the path of trucks hauling clay to a brick plant. The police found him and brought him home quietly.

For the next five years, Cowart lived in a shadow world of painful rehabilitation, chronic boredom, and failed relationships. His difficulties were not for want of trying. With Rex Houston's encouragement and assistance he tried pursuing a law degree. Fortunately, his legal settlement with the pipeline company provided the financial means for the nursing care and tutorial assistance which would be required because of his massive handicaps.

Cowart tested out his abilities as a blind student in two undergraduate courses at the University of Texas in Austin during the fall of 1975. He spent the spring at home in Henderson preparing for the tests that were required for admission to law school. In the summer of 1976, he enrolled for a part-time course load in Baylor University's School of Law.

Don handled his studies at Baylor in fine fashion despite his handicaps, but the strain was tremendous. He was forced to live with other people, his independence was limited, and his sleep problems persisted. When a special relationship with a woman ended abruptly in the spring of 1977, his life caved in. He tried to commit suicide by taking an overdose of pain and sleep medications, but he was discovered in time to have his stomach pumped at the hospital emergency room. He had trouble picking up his studies again, so he dropped out before the spring quarter was completed.

Cowart returned home defeated and discouraged, living with his mother for the next half year. He resumed his studies at Baylor in the spring of 1978, only to drop out again before he had completed the third quarter in the fall of 1979. He again retreated to his mother's home, filled with doubts that he would ever be able to pass the bar. By the spring of 1980, he was ready for another try at schooling, this time in a graduate program in building construction of Texas A&M University. Once again, the old patterns of sleepless nights and boring days got the best of him and he made a half hearted effort at slashing his wrists with a razor blade.

Looking back, Cowart saw his futile efforts to take his own life as a bitter human comedy. The doctors in Galveston had encouraged him to accept treatment that would free him of hospitalization and permit him to end his life, if that was his wish. But he found it difficult to find a way of killing himself without bringing further misery on himself—brain damage or further hospitalization. Ironically, he realized that he was no more successful in ending his life than in making his life work.

As a last resort, Cowart contacted White for help and was voluntarily readmitted under White's care to the Jennie Sealy Hospital on April 12, 1980. During his month-long stay, he met with White for psychotherapy treatments daily. Even more important, his sleep problems were finally resolved by weaning him away from the heavy sleep medications that he had taken for years. Cowart describes that experience as being like "coming out of a fog." For the first time since his harrowing burn treatment ordeal, his sleep became normal and his depression lifted.

It was during this stay that I met Don Cowart and we began early discussions of a film that would eventually come to be known as Dax's Case. I still call him Don because that is how I know him, but he legally changed his name to Dax in the summer of 1982. Some commentators on the film speculate that this change of name reflects some personal metamorphosis that Cowart went through during his lengthy rehabilitation period. But Cowart offers a simpler explanation. As a blind man with impaired hearing, he often found himself responding to comments addressed to others bearing the name of Don. I accepted his reasons for changing his name but asked him not to think the poorer of me for persisting in calling him Don.

It would be easy to believe that Dax's Case, more than five years in the making, served as a crucible for Don Cowart's rehabilitation. During this time, new hope and independence came into his life. He started a mail-order

specialty foods business in Henderson using his creative powers. He moved into his own house. He became an articulate spokesperson for "the right to die" under auspices of Concern for Dying. And he married a former high school classmate in February 1983.

There is always another chapter, however. Even now, Don's life continues to shift. His first venture in business did not succeed financially. His second marriage ended unhappily. Amid failure has also come achievement. He returned to law school at Texas Tech University in Lubbock, where he completed his law degree in May and passed the bar in the summer of 1986. He set up a small law practice in Henderson and has recently taken in his first partner. He continues to represent his views on patient rights at educational symposiums and public forums. In time, he hopes to become a specialist in personal injury cases.

COMMENTARY

Robert B. White

Donald's wish seemed in great measure logical and rational; as my psychiatric duties brought me to know him well, I could not escape the thought that if I were in his position I would feel as he did. I asked two other psychiatric colleagues to see the patient, and they came to the same conclusion. *Should his demand to die be respected?* I found myself in sympathy with his wish to put an end to his pathetic plight. On the other hand, the burden on his mother would be unthinkable if he left the hospital, and none of us who were responsible for his care could bring ourselves to say, "You're discharged; go home and die."

Another question occurred to me as I watched this blind, maimed, and totally helpless man defy and baffle everyone: could his adamant stand be the only way available for him to regain his independence after such a prolonged period of helplessness and total dependence?

Consequently, I decided to assist him in the one area where he did want help—obtaining legal assistance. He obviously had the right to legal recourse, and I told him I would help him obtain it. I also told him that I and the other doctors involved could not accede immediately to his demand to leave; we could not participate in his suicide. Furthermore, he was, I said, in no condition to leave unless his mother took him home, and that was an unfair burden to place on her. I urged him to have the surgery; then, when he was able to be up and about, he could take his own life if he wished without forcing others to arrange his death.

But Donald remained adamant, and the patient, his attorney, and I had several conferences. Finally, the attorney reluctantly agreed to represent the patient in court. The patient and I agreed that if the court ruled that he had the right to refuse further treatment, the life-sustaining daily trips to the Hubbard tank and all his other life-sustaining treatment would be stopped. If he wished, he could remain in the hospital in order to be kept as free of pain as possible until he died.

Had Donald been burned a few years ago, before our increasingly exquisite medical and surgical technology became available, none of the moral, humanitarian, medical, or legal questions his case raised would have had time to occur; he would simply have died. But Donald lived, and never lost his courage or tenacity. He has imposed upon us the responsibility to explore the questions he has asked. On one occasion Donald put the matter very bluntly: "What gives a physician the right to keep alive a patient who wants to die?"

As we increase our ability to sustain life in a wrecked body we must find ways to assess the wishes of the person in that body as accurately as we assess the viability of his organs. We can no longer blindly hold to our instinctive tendency to regard death as an adversary to be defeated at any price. Nor must we accept immediately and at face value a patient's demand to be allowed to die. That demand may often be his only way to assert his will in the face of our unyielding determination to defeat death. The problem is relatively simple when brain death has occurred or when a patient refuses surgery for cancer. But what of the patient who

has entered willingly on a prolonged and difficult course of treatment, and then, at the point at which he will obviously survive if the treatment is continued, decides that he does not want further treatment because he cannot tolerate the kind of future life that his injuries or illness will impose upon him?

The outcome of Donald's case does not resolve these questions but it should add to the depth of our reflections. Having won his point, having asserted his will, having thus found a way to counteract his months of total helplessness, Donald suddenly agreed to continue the treatment and to have the surgery on his hands. He remained in the hospital for five more months until medically ready to return home. In the six months since he left, Donald has regained a considerable measure of self-sufficiency. Although still blind, he will soon have surgery on his eye, and it is hoped some degree of useful vision will be restored. He feeds himself, can walk as far as half a mile, and has become an enthusiastic operator of a citizen's band radio. When I told him of my wish to publish this case report, he agreed, and stated that he had been thinking of writing a paper about his remarkable experiences.

COMMENTARY

H. Tristram Engelhardt, Jr.

This case raises a fundamental moral issue: how can one treat another person as free while still looking out for his best interests (even over his objections)? The issue is one of the bounds and legitimacy of paternalism. Paternalistic interventions are fairly commonplace in society: motorcyclists are required to wear helmets, no one may sell himself into slavery,

etc. In such cases society chooses to intervene to maintain the moral agency of individuals so that their agency will not be terminated in death or in slavery. Society chooses in the purported best interest (i.e., to preserve the condition of self-determination itself—freedom) of the would-be reckless motorcyclist or slave. Or, in the paradigmatic case of paternalism, the choice by parents for their children is justifiable in that at a future time as adults, the children will say that their parents chose in their best interests (as opposed to the parents simply using their children for their own interests). That is, the paternalism involved in surrogate consent can be justified if the individual himself cannot choose, and one chooses in that individual's best interests

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Author's note: This article explores the sparse secular morality that can bind moral strangers, not the thick morality that should guide all persons in their choices regarding dying and death. The first is not adequate for a good death.

so that if that person were (or is in the future) able to choose, he or she would (will) agree with the choice that has been made in his or her behalf.

Thus, one can justify treating a burned patient when first admitted even if that person protested: one might argue that the individual was not able to choose freely because of the pain and serious impact of the circumstances, and that by treating initially one gave the individual a reasonable chance to choose freely in the future. One would interpret the patient to be temporarily incompetent and have someone decide in his behalf. But once that initial time has passed, and once the patient is reasonably able to choose, should one respect a patient's request to refuse lifesaving therapy even if one has good reason to believe that later the patient might change his or her mind? This is the problem that this case presents.

Yet, what are the alternatives which are morally open: (1) to compel treatment, (2) at once to cease treatment, or (3) to convince the patient to persist, but if the patient does not agree, then to stop therapy. Simply to compel treatment is not to acknowledge the patient as a free agent (i.e., to vitiate the concept of *consent* itself), and simply to stop therapy at once may abandon the patient to the exigencies of unjustified despair. The third alternative recognizes the two values to be preserved in this situation: the freedom of the patient and the physician's commitment to preserve the life of persons.

But in the end, individuals, when able, must be allowed to decide their own destiny, even that of death. When the patient decides that the future quality of life open to him is not worth the investment of pain and suffering to attain that future quality of life, that is a decision proper to the patient. Such is the case *even if* one had good reasons to believe that once the patient attained that future state he would be content to live; one would have unjustifiably forced an invest-

ment of pain that was not agreed to. Of course, there are no easy answers. Physicians should not abandon patients when momentary pain overwhelms them; physicians should seek to gain consent for therapy. But when the patient who is able to give free consent does not, the moral issue is over. A society that will allow persons to climb dangerous mountains or do dare-devil stunts with cars has no consistent grounds for paternalistic intervention here. Further, unlike the case of the motorcyclist or the would-be slave, in this case one would force unchosen pain and suffering on another in the name of their best interests, but in circumstances where their best interests are far from clear. That is, even if such paternalistic intervention may be justifiable in some cases (an issue which is different from the paternalism of surrogate decision-making, and which I will not contest at this point), it is dubious here, for the patient's choice is not a capricious risking on the basis of free action, but a deliberate choice to avoid considerable hardship. Further, it is a uniquely intimate choice concerning the quality of life: the amount of pain which is worth suffering for a goal. Moreover, it is, unlike the would-be slave's choice, a choice which affirms freedom on a substantial point—the quality of one's life.

In short, one must be willing, as a price for recognizing the freedom of others, to live with the consequences of that freedom: some persons will make choices that they would regret were they to live longer. But humans are not only free beings, but temporal beings, and the freedom that is actual is that of the present. Competent adults should be allowed to make tragic decisions, if nowhere else, at least concerning what quality of life justifies the pain and suffering of continued living. It is not medicine's responsibility to prevent tragedies by denying freedom, for that would be the greater tragedy.