

Framed by Dignity

Anne Ryden

THESE pages place the experiential and the rational in collision. They are an exploration of loss and grief: experienced then, now observed, though, even in observation, there is experience. Standing guard over this excursion is the idea of dignity. I will examine instances of dignity as it manifested itself in the diagnosis in July 1996, the birth on August 19, 1996, and the death on April 10, 1997, of my daughter, Ever. To attempt to narrate the experience is to attempt to make sense of it by laying and layering the segments of the experience to rest in different discourses, through different ideas. If I am at all dignified in doing this, it is not because the events are dignified in themselves, but because I am exploring them in relation to the concept of dignity. In representing these events, I am moving from the experiential to the rational, and to do so I have to make the events make sense. To represent something, to make it make sense, is to frame it in one way or another. In this piece, I encapsulate my experience within the confines of the various meanings of the word “dignity.” In doing this, I explore some of the dynamics and the determinants of dignity when it is linked to the privileging discourses, the inherent gendering of these discourses, and their preference for the mind rather than the body. Privileging one signifier entails suppressing another. Ultimately, if the meaning of the experiential is denied, the body is erased.

My response to loss has been to try my utmost to remain, or perhaps just to appear, rational, sane, and composed. In this, I have been

guided by the need to attain or retain some form of dignity. And I wonder, in a culture rooted in reason, might dignity be the arch-signifier of sanity? Dignity, it would seem, operates as an absent signified, as a validity tester of responses and behaviors. Dignity contains. Dignity controls. Whatever form of expression it may take, dignity itself is an absent presence referred to, related to, dependent upon. It is conferred, it is assumed, it is taken, and it is always there as an ordering principle.

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Reason is the first principle of all human acts; all other principles obey reason, though in different degrees.

Aquinas

At varying times in history, humankind's desire to know has sometimes been directed toward knowing the world and sometimes toward knowing the self. The former is known through the sciences, the latter through philosophy. In both areas of inquiry an hypothesis is posed, checked against agreed-upon facts, then accepted or rejected accordingly. The more metaphysical problems of being and of self are explored through a thesis (an incomplete truth) and antithesis (its contestation) that lead to a synthesis, a more complete truth, or at least the illusion of it. Most of the time we know that A is A because it is not B, a supposed fact and not really that different from a proven hypothesis or a tested synthesis. We have ordered our world, we have invented science, we make sense of everything that surrounds us and that is us, but the conflict between the experiential and the rational remains even when the rational may be merely the unquestioned, naturalized, and theoretical set of beliefs arrived at through arbitrary lines of investigation. Reason inhabits a landscape of binary oppositions. It follows a linear trajectory from cause to effect. Meaning is the totality of this logical pair. As reason is the foundation of Western thought, we have come to expect that any event may be explained rationally. There must be a cause. The cause must have an effect. The event must mean; it must make sense. If there is a problem in the realm of being, we turn to philosophy; if the problem is of the body, we turn to medical science. And we expect to find an answer. We cannot conceive of knowledge without meaning,

and to place that condition on knowledge may limit what we can ever know, and how much we can ever hope to understand.

As vehicles in service of truth and knowledge, both scientific and philosophical inquiries insert distance between the individual person and the subject of inquiry. Yet, my experience tells me that such distance is a luxury I cannot afford when my body becomes a site of contestation. In that event, something we may call foundational thought comes into being, and it is so inherent it makes no difference that we are not born with it. Reason disguised as instinct often comes to our aid in times of crisis.

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For the man who is truly good and
wise, we think, bears all the chances
of life becomingly and always makes
the best of circumstances....

Aristotle

The experience of unreason suffuses this essay, this story. Even when everything is completely normal, I find my pregnant body strangely alien: too close to nature, too out of control, proving that control is always only illusory. So I take recourse in science.

Ultrasonic scans let us invade the privacy of the unborn child. While these scans are most accurate in the latter part of the first trimester when the baby is still being formed, they can be used at a very late date in gestation to determine the age of the fetus with some accuracy. Ultrasonic scans sometimes reveal abnormalities. When this happens, concerns over miscalculations of due dates are immaterial. Instead, the parents-to-be get a crash course in the anatomy of the human heart. A baby can thrive in the womb with only the right half of the heart developed because the placenta acts as a life-support system. Such a baby is born looking healthy. Every baby's first breath is a signal to the heart to complete itself. It has to change from prenatal to postnatal blood flow. For this to happen, the *ductus arteriosus*, which up until birth has allowed the free flow of blood between the left and the right sides of the heart, must close. In babies with only half a heart, that ductus is their only link to life, but theirs, too, will close. It may take a couple of days, a week, and rarely, some months. Faced with this, how do you prepare yourself to relate to a baby who will be in the process of dying rather than growing from the moment it is born? How do you comprehend that a

condition so fatal can come into existence even before the pregnancy is confirmed? It is the “always already” in a physical form, embedded in your own body. And how can I put into words my wish to deny the pregnancy, the banal yet profound wish to turn back time? How do you make sense of the paradox that by giving birth, you are giving death? Through the body, unreason forces itself upon the mind.

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My heart is a muscle and it pumps blood....

Tex Perkins and Dan Rumour

Hypoplastic left heart syndrome (HLHS) occurs in about one in ten thousand babies, and it is fatal. That condition combined with a transposition of the main arteries, where the aorta rises out of the right side of the heart rather than the left, is even rarer. But HLHS combined with a transposition of the main arteries makes a life-giving operation possible. For the doctors and the hospital, such an operation means a potential medical celebrity. Huge prestige accrues to those who overcome the obstacles nature places between life and death. As arbiters between these two poles of existence, the medical profession arguably forms part of a new kind of nobility. Their status ensures their dignity. Among them there is still some haggling about rank. The entry of women into the profession only makes the ranking more complex. A female obstetrician had the opportunity to put her name to the diagnosis of the rare cardiac condition in the thirty-five-week old fetus I was carrying, because the male pediatric cardiologist, who should have performed the scan, was on leave. She pronounced the verdict in its most final form: hypoplastic left heart syndrome. She painted a very bleak picture. She even seemed to gain some perverse pleasure from it. She was proven partly wrong by the specialist in the field, the pediatric cardiologist, who put his name to the discovery of the even rarer condition of transposition of the arteries. His diagnosis made a life possible.

At this point, and in the specific setting of medicine, my role as mother-to-be vanished. And so, to an extent, did the individual doctor's. All was replaced with an institution that was only dealing with the mother to the extent that she was an obstacle to be overcome so they could get to the patient, the baby. Through the hospital hierarchy it filtered down to me that it was preferable for the baby to

be born early in the day, and early in the week so that all the specialist medical staff would be available. This message was unrelated to all other information I had received: that the baby would be born and remain healthy for a few days, that drugs could keep the ductus open until an operation could be performed, and that it is best for babies, and their mothers, if the birth happens when both are ready. Reasserting her position, the female obstetrician insisted on delivering the baby, although there was nothing to suggest the necessity of her presence. When the day of delivery arrived, however, it was the midwife and not the obstetrician who set the birth in motion. In induced labor, there is nothing very glamorous about rupturing membranes, but by enforcing all her own decisions regarding the birth, the obstetrician had already wielded her power, and did not need to be present in order to be powerful. A very clear hierarchy of medical nobility was operating. The obstetrician bowed down to the pediatric cardiologist. Although she was the hospital's specialist in difficult deliveries (mine was not one of them), he was the specialist in saving newborn hearts. And below the two of them, specializing in humanity and the delivery of babies *with* rather than *for* or even *in spite* of mothers, we find the midwife.

In this setting, dignity seems dependent on the privileging of discourses. Who speaks the greater truth? But perhaps even more so, who is further removed from the body? Whose knowledge is cleaner? The pediatric cardiologist had beautiful clean hands. The privileging of discourses may also have to do with how far one is removed from death. It might have to do with the very central function of the heart in maintaining human life, the complexity of something so seemingly simple. I do not know. The patient's discourse does not really come into the medical decision-making process except as an obstacle to be overcome. A privileged discourse silences other discourses. If rank is about the right to speak, silencing denies a subject dignity.

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The discipline of suffering, of *great* suffering—do you not know that it is *this* discipline alone which has created every elevation of mankind hitherto?

Nietzsche

In the hospital, dignity finds more than one expression. Where the various doctors and specialists gain and retain their dignity through their rank, the dignity of midwives is expressed through compassion. Midwives occupy a contested territory in the hospital hierarchy. They are most often women, and they have been delivering babies since forever. Their creed is to assist nature rather than to manage and control it, and perhaps even more importantly, their care begins at conception not at labor. With the invention of obstetrics, the pregnant body came to be seen as an unnatural state in need of medical assistance. It was no longer a natural part of human propagation, and midwives were relegated to a different role of assistance; they became the assistants of obstetrics. So whereas the midwife traditionally has been there for the triad of the mother, the baby, and the birth, the obstetrician's first allegiance is to the baby, not the mother. To both the pediatric cardiologist and the obstetrician, I was a presence they would do without if only they could. Over the last couple of decades, however, a new generation of midwives, defiant in the face of medical science, have (re)emerged. I was lucky enough to meet some of these remarkable women. Their defiance gave me the space to retain some dignity because they allowed me to simply be a mother having a baby, and one of them even tried to help me bring on labor naturally to help me retain some sense of control in the medical system. That same midwife assisted at the time of the birth; she thanked my partner and me for having let her help and commented on what an extraordinary couple we were. She said she wished she had known us before this time. It was as if we would be too exalted for her to know now because of the suffering she perceived to be ours. Great suffering commands respect, and in her eyes, ours ranked high above her own. Her choice of words and her demeanor conferred dignity upon us, or more precisely, upon the people she perceived us to be.

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But I must add that those qualities in the Duchess which might have remained somewhat hidden, Fortune, as if admiring such rare virtues, chose to reveal itself through many adversities and hard blows, in order to demonstrate that in the tender soul of a woman, and accompanied by singular beauty, there may also dwell prudence and a courageous spirit and all of those virtues very rarely found in the staunchest of men.

Castiglione

Comportment. Dignity in the representational. The discipline of self-control. The midwife was the first of many to comment on how well we handled that whole period in our lives. After Ever died, there were even comments on the beauty of our grief. I suspect the praise had to do with the discomfort we spared those who made such comments. Around the same time I recall hearing about a girl who touched her collar every time she saw an ambulance, the gesture a wish that the ambulance not be for her family. I thought, How selfish of her; she sent the ambulance to my door instead. But in that sense of being spared lies the beauty, I think, that other people saw in our grief. For a while, death is in someone else's possession. With possession comes responsibility. Ever's death was our loss, to be handled with care. Dignity was my unarticulated way of testing and managing my actions and responses.

The loss came in two installments. First, there was the loss of the promise of a healthy baby when congenital heart disease was first diagnosed. Then there was the loss of the child. I reasoned and rationalized. I thought it was lucky that it was me, and not my partner, who had to come to terms with the physical paradox of an extremely active baby in the womb who would not live once born. Lucky, because I would never have understood the physicality of it, the reality of it, without being the body in the middle of all of this. And without understanding, I could not have been supportive. I said absurd things: how lucky it was that it had happened to us because a primary concern was that our older daughter was not scarred by it, and not everybody would have the resources to ensure that. (How do you know if you have scarred a child?) And, while Ever was living, I

would talk about the privilege of no fear. I already knew what the worst would be, so I felt free to enjoy every day.

This last absurdity led to another rationalization: it could have been worse. Because I knew Ever could die any day, I was always prepared. Every night I would take stock and see that I had no regrets, that there was nothing I would have done differently. I was preparing myself for a guiltless loss. These kinds of considerations meant that I always appeared one step ahead of catastrophe. They also meant I had no place to collapse. In all of this, I have held on to some kind of sanity through reason, by making even the senseless make sense.

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Faith is of the things that are seen
not, and hope of the things that are
possessed not.

Aquinas

“I have said a special prayer for you and Ever and I know your little girl is alive now with God in heaven and you will all be together again one day. You must look at it as all that little Ever did was fall asleep in the arms of Jesus and she’ll be smiling down on you now.” (This is from a letter of condolence I received in April 1997.) Oh, for that certainty. The letter writer later visited, one hand holding a Bible fringed on three sides with yellow flags marking suitable passages and a pot of stew in the other. The part of him that brought the Bible became the focal point of my anger. So presumptuous. So naïve. So very selfish. In retrospect, I know there was dignity in his presence, not the least because he let me keep the stew when I refused the Bible. I have always felt guilty about the way I did that.

On Thursday, the tenth of April, 1997, Ever did not seem to wake up properly in the morning. She was very tired. When I put her in her cot for a sleep, she protested in a manner I had never seen before. I picked her up and carried her around. My partner phoned the hospital. I think Ever stopped breathing. I know we tried to resuscitate her. An ambulance came. At the hospital after final, madcap attempts at resuscitation were made, we were given medical “consolation”: even if she could have been saved, she would have suffered severe brain damage from lack of oxygen. The partial postmortem we authorized, as much for the sake of medical science

as for ourselves, yielded nothing. There was no explanation why the heart did not form properly. There was no explanation why she died when she did.

In our culture, old age has become the only acceptable cause of death, and the discipline of medicine, our saviour when life is in danger, happily occupies the too-high pedestal we have offered it. It is thus a shock to find out how little doctors know, how basic and crude their operational procedures are, how unglamorous. They do not have high-tech heart transplants to offer needy babies with congenital heart disease. All they can do is to stitch a piece of rubber tubing (very good quality, of course) between the heart and the aorta. The cardiologist, not the surgeon, calls it a plumbing job. For me, before, during, and after these events, medical science has remained the unquestioned and largely presumed saviour of life. Contrary to my expectations, medical science had very little to offer. Ever. Despite the disappointment of this shortcoming, of this frustration of hope, I still see medicine as saviour, even though this is contradicted by my experience of its limitations and futility. This is a contradiction so large that I cannot allow myself to begin to comprehend it. But the experience of medicine's shortcomings needs to be placed somewhere. If it can't be placed, it can't be made to make sense, and without sense there is no sanity. Without sanity there is no dignity.

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