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**Encompassing compassion.**

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### Encompassing Compassion

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*Pediatric* neuroradiology requires a compassion that extends beyond the bounds of routine Radiology. Four examples illustrate how encompassing that compassion must be for the physician to participate meaningfully in the care of the child.

#### Family Involvement

The child is part of a family unit. Serious illness in a child stresses the unit severely, so care of that child is care of the entire family. Young themselves, the parents respond to their child's illness in strange, sometimes inappropriate ways.

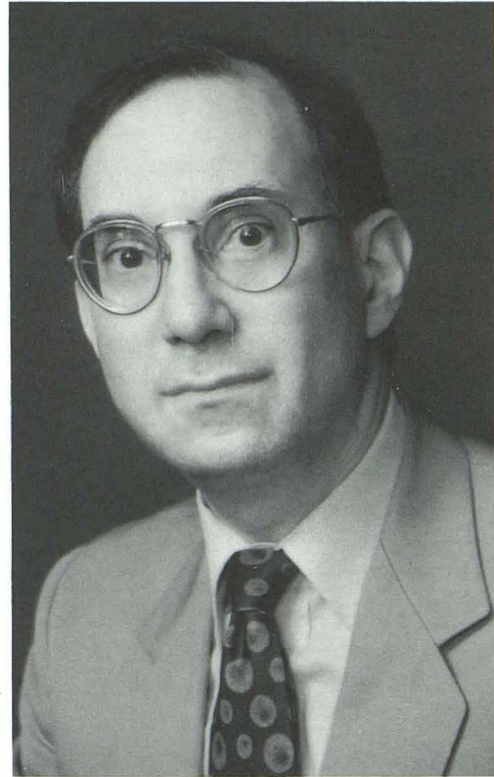
We have seen the two-income, double-Yuppie family intent on the good life simply reject their ill newborn, as if they had a contract with God for one normal child, and God defaulted. To help these infants, we ran a child placement service from the hospital.

Conversely, we have seen the good family with three children, literally selling their business, their home, and their car—bankrupting themselves and mortgaging the future of their normal children—to pour all their resources into the care of a newborn with no prognosis, a child who will never develop even a social smile.

Both families, and those in less extreme positions, must be helped to understand their child's disease, its prognosis, its treatment or management, and the best way to cope with the problem *as a family*. They must be helped to participate in the short-term care and then integrated into support groups of parents with similar children to maximize their ability to assist their child over the long haul.

#### Role Model

Some of the congenital malformations are frankly repulsive. *By example*, the physicians



caring for the child must give the parents the courage to face their kid. We must look without disgust. We must touch and treat with humanity and tenderness. As physicians, we may only have to look once distantly, with no personal involvement. The parents have to cuddle and kiss the child. They have to say to themselves, "This is myself and my future, flesh of my flesh and blood of my blood," and then take the infant home to show to their relatives and neighbors as their baby and their heir. *By example*, we can lead. As models, we can set their role and lend direction in an experience that lies outside the expectations of any young parent.

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## Relieving Guilt

The parents of a sick child are usually bewildered and guilt-ridden. They ask, "Why us?" "What did we do wrong?" "Where did we fail?", and "Why was this punishment visited on us?" They worry: Maybe they shouldn't have taken a drink, smoked a cigarette, gained so much weight, dieted so strictly, had intercourse so often. We can help to alleviate guilt. Where possible, it was my practice to take the parents into my office to show them color photographs of other children with the same malformation or disease. I would deliberately select a few examples of children who were less affected and many examples of others far more severely deformed. This proved to be worth doing. Simply by showing the parents that their child's condition is well known, even common; that it has a name; and that many other children have it in more severe form, you can relieve the parents of guilt for whatever they are worried they have done. You can make them see their child as one of a group of unfortunates, not as a sign of their failures, and you can have them leave the office feeling they don't have it so bad as the next guy. This manipulation of parental attitude helps the parents to accept their child and to integrate the child into their home and family.

The children too feel guilty. Each child has done something he was told not to do, lest he be punished. Suddenly he is ill. To the concrete mind of a child this is simply cause and effect. Like the parents, the child must be relieved of feelings of guilt for being sick and repeatedly assured that the illness is not a punishment for being bad. To the fullest extent possible for the age and maturity, the child must be helped to understand the origins and consequences of his illness.

## Excellence

Excellence is a mark of compassion, not elitism. It signifies the physician's acceptance of responsibility and successful preparation for the care of the patient. It is a quality apart from personality, for dour excellence may signal greater compassion than jovial mediocrity. The

Pediatric Neuroradiologist must learn the special technical and interpretive skills necessary to care for the sick child.

Children are hard to study successfully. They rarely hold still for an exam. They do not understand what you are doing, but are absolutely certain they want no part of it. When anxious, they will stall and have to go to the bathroom. When really frightened, they will scream and kick and bite. Compassion requires that the physician take the time to "kid" with the children, to gain their confidence, and to cajole them into going along with the study. Encompassing compassion requires, as well, the skill to do the job right the first time: one stick for a venopuncture, one exposure for a radiograph, so the study is *done when begun* to minimize the mounting anxiety and excruciating anticipation the child suffers from hesitant work.

*Pediatric Neuroradiology* addresses a highly specialized set of diseases in a restricted population. It is a bona fide subspecialty with a distinct body of knowledge that requires of its practitioners a working use of embryology and a firm grasp of the changing appearance of normal in each age group: premature through late adolescence. Pediatric Neuroradiology requires an understanding of the unique ways in which the pediatric central nervous system responds to disease and to therapy at each age. It requires ready facility with specialized equipment, special sedation protocols, and special drug regimens. For the Pediatric Neuroradiologist, encompassing compassion requires the long hours and the hard work necessary to gain an understanding of pediatric disease. It requires the excellence to perform and interpret the studies correctly, the confidence to commit the resources of the whole family to a course of action based on that interpretation, and the responsibility to accept for the child, and the family, the risks inherent in the studies and the chosen course.

Ultimately, encompassing compassion is the commitment to devote oneself to the discipline and to the child as if every patient were one's own child, whose happiness and continued health depended solely on your skill. The rewards for such devotion make the commitment a joy.