

Treatment of Children With Severe Congenital Malformations

Contact(s):

Heather L Monroe

The birth of a child with severe congenital abnormality such as a myelomeningocele presents both parents and physicians with difficult decisions which are made more difficult by the uncertainty of prognosis. Although it is unlikely that a consensus could always be achieved as to which children should be treated, agreement can be reached about some of the basic ethical principles related to decision-making.

The primary responsibility of the neurosurgeon according to the recently formulated Code of Ethics of the AANS is to "provide the best care for the patient that available resources and circumstances provide."

When confronted with a problem for which he/she is unfamiliar, the neurosurgeon is obligated to use consultants and other health care providers with recognized records of excellence as a source of information concerning current therapies and prognoses.

The neurosurgeon is specifically cautioned against using "quality of life" criteria in his or her determination of treat ability. He/she should render an opinion as to the feasibility of surgery and the prognosis, if known, for future cognitive and physical outcome. The patient's parents or other surrogate decision-maker should then attempt to arrive at a decision which would represent the child's best interest. Institutional committees may sometimes help in this decision-making process but must be considered to have only a consultative role.