

Ethical and Legal Issues in Neurology: Chapter 18. Ethical issues in the care of the neurologically devastated infant (Handbook of Clinical Neurology)

Tracy K. Koogler

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The debate surrounding neurologically devastated newborns, whether due to severe prematurity or genetic malformations, has continued for over 40 years. Duff and Campbell (1973) first discussed allowing these children to die in the 1970s. In the 1980s, others fought to make sure these children with disabilities were afforded all the rights of other children. Recently, some commentators have advocated for withdrawal of therapies and even euthanasia in the Netherlands. Who is right? What are the ethical principles that should be followed? What decisions are appropriate for distraught parents to make? This chapter reviews international views, laws, and guidelines surrounding the therapies and limitations of care for these imperiled newborns. An ethical argument is presented for how to determine best interests for these special children utilizing the best interest standard. Parents and physicians need to use their individual expertise and values to work together to determine each individual child's best interests. Physicians may have to carry the burden for making final determinations to alleviate the guilt families may have in deciding to limit therapies.

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