

## **EDF RESOLUTION ON ACTIVE TERMINATION OF LIFE OF INFANTS WITH IMPAIRMENTS AND THE RIGHT TO LIVE**

*Adopted by the EDF Annual General Assembly  
on 28 May 2006 in Rome*

### **1. BACKGROUND INFORMATION**

The issue of neonatal intensive care and active termination of life of infants with disabilities has been in the centre of discussion between paediatric experts and representatives of the disability movement for a long time. In 2001, the Ethics Working Group of the Confederation of European Specialists in Paediatrics (CESP) raised a number of questions regarding neonatal intensive care in their article on *Ethical dilemmas in neonatology: recommendations of the Ethics Working Group of the CESP* (published in *European J Pediatr* 2001; 160:364-368).

Subsequently, with this article, a protocol prepared in 2002 by paediatricians of Groningen in the Netherlands (so-called *Groningen Protocol*) in collaboration with the district attorney and presented in *New England Journal of Medicine* 2005; 352:959-962, contains general guidelines and specific requirements concerning active termination of life in infants with severe disabilities. The Groningen Protocol is based on the analysis of 22 cases of euthanasia in infants which have been reported to district attorneys' offices in the Netherlands in the 1990s and subsequently reviewed by the paediatricians from Groningen. All cases concerned infants with very severe forms of spina bifida, who were classified into three categories: first, infants with no chance of survival; second, infants with a very poor prognosis and dependent on intensive care; third, infants with a hopeless prognosis who experience what parents and medical experts call 'unbearable suffering', including the prospect of an extremely poor quality of life.

The criteria used by the Public Prosecutor to assess the cases were: the presence of hopeless and unbearable suffering and a very poor quality of life, parental consent, consultation with an independent physician and his or her agreement with the treating physician, and the carrying out the procedure in accordance with the accepted medical standard.

These arguments for having ended the lives of the 22 infants are now being contested by other paediatricians in the Netherlands who claim that spina bifida is not a reason for unbearable suffering, and that a lot of means are available to alleviate the pain of a suffering infant.

Although not a binding law, the Protocol serves as a set of accepted guidelines followed by the Dutch authorities during investigations of euthanasia in infants.

## 2. INTERNATIONAL HUMAN RIGHTS INSTRUMENTS

Several internationally adopted instruments protect the right to life of all individuals. They do not distinguish between individuals with and without disabilities. In particular, the *UN Convention on the Rights of the Child (1989)* recognizes every child's inherent right to life, and obliges States parties to ensure to the maximum extent possible the survival and development of the child, whereby no child is deprived of his or her right to access to facilities for the treatment of illness and rehabilitation of health (Articles 6 and 24 (1) of the Convention). The *Convention for the Protection of Human Rights and Fundamental Freedoms (1950)* too, unequivocally provides in Article 2 that "everyone's right to life shall be protected by law." This is also reflected in Article II-62 of the current draft of the *Constitution for Europe*. The Constitution's articles II-61 and II-63 respectively refer to the Human Dignity and to the Right to the Integrity of the Person.

In Article 10 of the *Convention on the Rights of Persons with Disabilities*, which will be adopted in December 2006 and is to be signed and ratified afterwards, "States parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others."

## 3. EDF VIEW

In its 2003 resolution *Prenatal Diagnosis and the Right to be Different*, the European Disability Forum sharply condemned active termination of life on the ground of disability. EDF is of the opinion that proposing parents to actively end the life of their infant with impairments puts considerable psychological pressure on them. Arguments of the poor quality of life of people with disabilities prevent parents from making an informed choice. Such arguments violate universally accepted principles, whereby in all actions concerning children, the best interests of the child should be a primary consideration (Article 3 of the *International Convention on the Rights of the Child*). Instead, parents of an infant with impairments should be provided with concrete experiences on disability.

This EDF resolution underlined the right to live of all infants with impairments and the right to access to all treatments which can improve their quality of life and prevent them from further impairment.

EDF affirms that quality of life cannot be predicted and depends on many factors which are equal for all children irrespective of their physical and intellectual condition. The presumption of bad quality of life of infants with impairments only takes into account the medical definition of disability, which locates the disability exclusively

within the individual. However, since its 2001 publication *International Classification of Functioning and Disability (ICF)*, the World Health Organization considers 'disability' to be an umbrella term combining the existing medical and social definitions. The latter clarifies that the impairment of a capacity does not in itself count as a disability, but becomes a disability if treated by the society in a manner that puts the person with impairment at a disadvantage. The argument of a poor quality of life contradicts this universally accepted vision.

#### **4. RESOLUTION**

The European Disability Forum meeting at its Annual General Assembly on 27/28 May 2006 in Rome has agreed on the following resolution and decided to transmit it to all relevant stakeholders at the national and the European level:

1. All infants with impairments have the right to live and to benefit from all treatments which can improve their quality of life or prevent further impairment. Active termination of life of infants with impairments should not be permitted on the basis of their expected quality of life;
2. A disability should never be an argument not to provide available life-saving and life-improving treatment;
3. Pain and suffering of the infant must not serve as justification for active termination of life. Instead, alleviation of that pain and suffering must be sought as the primary solution;
4. It should be acknowledged that differences enrich society and that all people can contribute to society provided that these differences are accepted and inclusive measures are taken onboard. The level of a society's civilization can be measured by the attitude towards those people who find themselves on the other side of the spectrum of what is regarded as the norm;
5. Societal assumptions about the quality of life of people with disabilities or social provision cost factors should not justify active termination of life on the ground of disability in violation of internationally accepted human rights principles. Instead, all possible measures must be taken to increase the quality of life of persons with disabilities through their participation in professional, social and cultural life of the society;
6. Organisations of disabled people must be full partners in debates on the moral and ethical dilemmas raised by decision making for infants with impairments;
7. Counselling for parents should be supportive, focusing on all aspects of life for a child with impairments. Parents should be informed about all recent scientific advances that have improved considerably the quality of life of people with impairments, and about legislative initiatives, including non-discrimination and

human rights legislation, which offer more legal protection to disabled people and their families. They should also receive information and access to care and support opportunities, which may help the optimal development of the child;

8. Any explicit or implicit bias, practice or procedure in counselling that devalues the worth of the life of people with impairments is a form of discrimination and is a violation of universal human rights principles, which may be open to legal challenge;
9. Every form of discrimination against disabled people should be outlawed including in any legislation on active termination of life of infants with impairments;
10. The term 'euthanasia' is not appropriate when it refers to an infant with impairments who is not likely to die and should therefore not be used as a synonym of 'active termination of life'.