

Ethical Code

endorsed by the EAGS
London/Soestdijk, 1996

Preface

The 'Ethical Code' is meant as a set of principles, drawn up by the European Alliance of Patient and Parent Organisations for Genetic Services and Innovation in Medicine (EAGS) in consultation with its members with the professional advice of Mrs. Jeantine Lunshof, ethicist.

The first draft was produced during a meeting in Soestdijk, the Netherlands, and discussed in the Annual General Meeting of EAGS in Berlin, 1995. The text was finally endorsed in the Annual General Meeting of EAGS in London, April 12, 1996.

Introduction

The European Alliance of patient and parent organisations for Genetic Services and innovation in medicine (EAGS) is a European umbrella organisation of patient organisations concerned with genetic and congenital disorders. It represents European umbrella groups for specific conditions and national umbrella bodies for the whole range of genetic conditions.

EAGS calls on behalf of families with genetic and congenital disorders for:

- equal access to full information,
- early diagnosis at accredited centres,
- the maintenance of confidentiality,
- the freedom of choice for all within the legal framework of each country.

In the light of recent rapid scientific advances, EAGS has recognised the need for a basic set of statements pertaining to the ethical issues created by our increased understanding of human genetics. EAGS endorses the standpoint recently agreed by the WHO:

"Genetics and biomedical technology open up vast avenues for research and can provide humankind with much needed therapeutic tools. But, where human life and dignity are at stake, technology cannot be left to govern ethics on an empirical basis." (WHO, Summary statement on ethical issues in medical genetics. Geneva, February 1995).

EAGS, therefore, expresses its basic tenets in the following statements.

Statements and guidelines

1. Medical genetics should serve the interests of the individuals who are affected or at risk from a genetic condition.
2. Needs-based access to information and facilities should be safeguarded.
3. Individuals should be free to decide for themselves whether or not to make use of the available information and facilities.
4. Genetic services are to facilitate diagnosis and provide options for and leading to informed decisions about preventative measures and/or treatment, and the consequent provision of appropriate needs-based services.
5. The continual improvement of the quality of life and of care and support of those affected by hereditary or congenital disorders is to be promoted, particularly by encouraging and supporting any necessary changes in legislation at national and at European level, to the benefit of patients with genetic disorders.
6. Persons with a disability or disease are entitled to unrestricted acceptance and solidarity from society.

Commentary

1. Genetic counselling should be undertaken by qualified personnel. It should be comprehensive in its scope. Preferably it should be available in clinical genetics centres or in affiliation with such centres.

Clinical genetics centres cannot be developed in every country immediately, but the demand for them derives its legitimisation from the complexity of medical genetics as such and from the need to create expertise to interpret or manage this complexity.

Genetic counselling should offer:

- information about and knowledge of the hereditary aspects of conditions or diseases
- referral and access to consultation with medical doctors, specialised in diagnosis and treatment of a given condition or disease.

Options should be offered:

- for consultation with qualified social workers, psychologists and other relevant professionals regarding the social and familial consequences of the disease,
- for the meeting with representatives of patient organisations, if the counsellee wishes so.

2. Information about genetic services should be made available to all who may benefit from it. Genetic facilities should be within reach, both geographically and financially, for all who wish to make use of them.

3. Knowing one's own and/or one's partner's genetic make-up creates options for action regarding genetic testing and reproductive choice. The decision concerning the preferred course of action to be taken in the light of this information rests solely with the individual or the couple, within national legal frameworks. There should be no third party coercion. This also applies to the option for prenatal diagnosis and the freedom to act upon the consequences.

Utilisation of genetic services must be voluntary. Any pressure to utilise all available technology for diagnosis or risk assessment should be avoided.

The principle of privacy protection and respecting a wish not to be informed may interfere with moral obligations towards relatives at risk.

Within the medical and institutional setting adequate measures for data protection should be safeguarded.

4. The general goal of genetic research is treatment of genetic conditions.
Genetic services are to be directed towards accurate diagnosis and treatment of genetic conditions and to provide information concerning appropriate care and other options, if no effective treatment is possible.
Genetic information can enable individuals to adopt strategies for reducing the risk of or preventing certain conditions, e.g. lifestyle changes, dietary measures or the avoidance of certain occupational hazards. This does not dismiss companies from their responsibilities for safer workplace and environmental conditions.

5. For disabled persons the limits to self-determination and the opportunities to live a fulfilled life are set by their living conditions and by the standard of care and support that is available. These depend largely upon the structure and organisation of national facilities for health and social care, and as such are amenable to being influenced by public pressure or other factors - unlike the pattern of the disabling condition.

Member organisations of EAGS regard the articulation of the needs of those affected by genetic disorders and to initiation of action that will bring services into being that will respond to these needs appropriately and effectively as a major task. This will involve action at national and at European level.

6. The existing and ongoing debate on priority setting in health care reveals the possible conflict of interests between the individual and society.
Discrimination against disabled persons should be excluded.
Persons with a disability or disease are under all circumstances entitled to full civil and human rights and to participate fully in all aspects of the society in which they live.