

**19th International Meeting of the
World Federation of Neurology Research Group
on Huntington's disease**

**14th International Meeting of the International
Huntington Association**

Panum Institute, Copenhagen

Opening speech sunday 26 August 2001

by the chairman of the Danish Council of Ethics

Erling Tiedemann

Good morning, Ladies and Gentlemen,

My name is Erling Tiedemann; I am Chairman of the Danish Council of Ethics – and very happy that the organizers of your meeting have invited me to be involved in welcoming all participants to Denmark and, on this occasion, to introduce you to the Council of Ethics.

With the raft of complex ethical dilemmas linked with hereditary disease and genetic testing, the Council of Ethics will inevitably have to deal with issues similar to those that you will be concerned with as researchers, scientists and care-givers, or as representatives of patients and parents associations.

It is therefore of great value for us on the Council to have, as an eminent and particularly respected member, Doctor *Sven Asger Soerensen*, who is also involved in organizing your meeting.

The Council of Ethics in Denmark was created in law in 1987. The Danish Act on the Council of Ethics was passed by a large majority of the Danish Parliament (the so called *Folketing*), and the Council commenced its work in January 1988.

The decision to set up a council of ethics was finalized at the request of a committee under the Danish Minister of the Interior. It published the report "The Price of Progress" in 1984. The task of this committee was to examine the ethical problems concerning genetic engineering, in vitro fertilization, artificial insemination and fetal examination. The committee was set up in the light of the rapid development in the field of reproductive technology. Another explanatory element might also be that the subject was being intensely debated in the media.

The purpose of setting up the committee was to lay the groundwork for a political resolution on the question of whether medical research in the fields of reproductive technology and genetic engineering needed formal regulation.

The committee suggested that a central ethical council for the health service should be created - and created *by law*.

The purpose of the Act, and therefore of the Danish Council of Ethics, is to ensure that the Danish Parliament, the health authorities and the general public are continuously given advice and information on ethical problems arising from developments in the health service and the field of biomedicine.

The Act also mandates that a parliamentary committee on the Council of Ethics shall be set up.

The purpose of this regulation is to safeguard the closest of relations between the Danish Parliament and the Council of Ethics. The parliamentary committee has a certain influence on the composition of the Council of Ethics, as the Act empowers the committee to appoint half the members of the Council. Furthermore, the parliamentary committee follows the work of the Council in terms of joint meetings and can also ask the Council to treat certain topics falling within its terms of reference.

The Council consists of 17 members in all. The Chairman is appointed by the Minister of Health from among the nine members designated by the parliamentary committee.

The remaining eight members are designated by the Minister of Health, partly on the recommendations of the National Board of Health and the Danish Medical Research Council.

In practice, every effort is made to constitute the Council from as broad-based a section of professionals and lay persons as possible.

Thus, on the present Council, there are: four doctors, two legal experts, one former college principal, two social counsellors, one trade-union consultant, one master of

science in political science, one midwife, one chief nursing officer (CNO), one Master of Arts (MA), one ethnologist, one doctor of science (DSc) and one former county mayor - that's me ...

The broad make-up of the Council says something about the distinctive way that we in Denmark have chosen to organize an assembly whose purpose is to inform politicians and the general public about ethical problems.

The ethical issues of life and death constantly being thrust upon us by developments in medical science and biology are precisely characterized by their continued inability to be resolved by factual expert knowledge alone. They are issues on which a stance is taken based on values and attitudes adopted after being properly and rationally informed.

This is something the Council achieves, in part, by sourcing expert knowledge from outside. It is therefore important to stress two things about the Council of Ethics in Denmark:

Firstly, the Council can be said to make its statements not only by virtue of the expert knowledge it commands in certain defined areas, but also to take up its position on a universal and common basis.

Secondly, the Council not only presents majority decisions in its reports, but also lends visibility to the attitudes and arguments of both the majority and the minority - and sometimes even more minorities ...!

The Council of Ethics, then, is not a body that tells politicians the right thing to do on the basis of some special, privileged, prior knowledge or some received wisdom.

On the contrary, it is a democratic assembly that discusses the relevant topics on an objective and well-informed basis, after which it is obliged to present its points of view and recommendations to the health authorities and the parliament.

The Council has two important tasks, both of which are defined in the Danish Act on the Council of Ethics.

Firstly, the Council is engaged in drafting reports, statements and recommendations on issues and problems that will ultimately be brought for a decision before the Danish Parliament or the health authorities.

The Council of Ethics has established itself as an important consultation partner in Danish politics, and the parliament and Ministry of Health have been known to delay taking a stance on a particular matter until the Council has produced its statement.

Secondly, it is an important task for the Council to promote the *debate* on ethical problems in the health sector among Danish society. Members of the Council of Ethics often give talks and lectures, and present their views on the Council's work in the media. Incidentally, it should be mentioned that there is often great media attention surrounding the reports published by the Council of Ethics.

The *consultative* function can therefore be said to have the positive side-effect of generating great media publicity and involvement among the population at large concerning such ethical dilemmas.

But the Council itself also arranges conferences, publishes debate outlines and essay collections, and in some cases has produced public information videos.

Finally, our homepage deserves a mention as a particularly important "window onto the world". Our statistics show that it is predominantly secondary schools and institutes of higher education that make use of the homepage, where among other things it is possible to read many of the publications the Council has published.

This gives us some idea that we have a firm grip on the young generation. This is very important for us, after all, as young people are the ones who will be making decisions on many of the new technologies whose outline we can only make out faintly at present.

So the Council of Ethics has treated a wide spectrum of topics in relation to health service operations such as: gene technology, conditions for the demented, assisted reproduction, late abortions, use of coercion in psychiatry, fetal diagnostics, euthanasia, extremely premature babies – and most recently, of course, reproductive and so-called therapeutic cloning.

Of special interest to those present here, in particular, will probably be the Council's report on genetic testing of healthy subjects, dealing with all the tricky questions on the right to know and the right not to know, and touching upon its significance for the labour market and the insurance world.

The Council's debating activities take place at many different levels and in many different contexts. The broad debate on different ethical problems often serves as a chance to leave individual cases for a while and look at things in a slightly broader perspective.

A special project is the creation of an Ethical Forum for Young People, which did initially meet for a single day and adopted its own statement on reproductive cloning.

I should also like to mention that, within various international contexts, the Council of Ethics participates in processes intended to help put proper international controls in place in the biomedical field.

Last year, for instance, the Council submitted its consultative comments to the Council of Europe on a draft supplementary protocol on fetuses, to be inserted into the Convention on Human Rights and Biomedicine. In its consultative comments the Danish Council criticizes certain articles, while expressing satisfaction regarding certain others. Some of them can even serve to enhance the Danish legislation on assisted reproduction.

The Council is critical about some *overly* liberal formulations on research done on fertilized ova, while conversely it considers that the precise definitions of "human embryo" and "fetus" in the draft should be included in the Danish legislation — an excellent example, then, of fine international interaction.



In dealing with all these topics, the Danish Council of Ethics shares its fate with ethical councils in other countries — and with anyone making a serious attempt to adopt both a rational and an existential approach to such questions.

We are faced with a multitude of dilemmas – and according to one of my dictionaries a dilemma means "a forced choice between two alternatives, both of which are unfavourable".

It is as if the ethical values we advocate are at loggerheads with one another. Regard for benefiting life seems to be at odds with regard for preserving life, - and so on and so forth.

In an open and pluralistic culture where values are no longer necessarily collective, we are also faced with the difficulty of producing tenable arguments – and one of the tasks of ethics, as you will know, is to provide justification for our moral choices and positions.

The debate in society – and sometimes even in specialist circles – is indeed often borne on dubious lines of argument.

I am sure that those of you present here will be familiar with standard arguments and ready-made responses, even from their home countries. Such standard arguments often go along the following lines - as for example:

"After all, we are already doing such and such – what would be to stop us now doing this or that?"—an argument we know from experience can very well be linked with a denial of the existence of ethical slippery slopes ...

Or another example: "It won't be quite as bad carrying out therapeutic cloning aimed at treating disease as it will be performing reproductive cloning that will result in the birth of a human clone!" That is possible; we need to discuss it. But one thing does not necessarily become ethically acceptable just because something else is worse.

And, as a final example of very common standard arguments: "They're doing it anyway, abroad!" Perhaps the most hard-hitting ethical argument of our time: "They're doing it anyway, abroad!"

I know full well that many issues about right and wrong, ethical or unethical, cannot be answered once and for all, and that much depends on situations and circumstances.

Often, ethical deliberation has to consist of weighing up opposing values. And there is often an ethical price to be paid for achieving an ethical benefit.

At the same time, however, it is important to adhere to the knowledge that there *are* also ethical absolutes that cannot be cancelled out by situations and circumstances.

Rape and genocide are always unethical. Slavery likewise –and there is no use arguing by saying that slavery may well be unethical, but as long as people confine themselves to keeping only a couple of slaves, then it is acceptable ...

No, it never is!

Not infrequently, it happens that ethics is made out to be a kill-joy or a spoil-sport – in other words, ethics is equated with a great deal of more or less superfluous concerns that are being discussed by ageing people, in particular, sitting up in their ivory towers – completely oblivious to the problems that, say, severely ill people may be having ...

So when a new form of treatment comes along, those people with the ethics immediately come rushing in with hand-wringing arguments and start talking about slippery slopes and other evils.

Yet no picture of ethics could be further from the truth.

In reality, ethics is only an expression of mankind's millennium-long attempts to take a realistic stance on the concept of *the good life* – but that is to say the good life understood in a broader context and in the longer term.

It is not about the kind of good life that can be achieved on the back of a night of partying, perhaps, but would trigger such a hangover the next morning that the good life would ultimately be experienced as a fleeting phenomenon.

The point at issue is to perceive ethics as the great emancipator.

We need to get away from always thinking of ethics as belonging within a frame of reference of moralizing, condemnation, stigmatization and prohibition.

Much rather, ethics should be thought of as belonging within a frame of reference of realism, sustainability, ecology and anchorage in the sound, the healthy and the authentic – indeed, precisely in *the good life*: that which endures, that which is good and useful – tomorrow as well – and for people other than oneself.



I should like to conclude by thanking the assembly – not only for the invitation to be involved in placing ethics on the meeting's overall agenda, but also for the significant work being carried out by those present in the form of researchers, care-givers or people providing care for families and patients with a severe hereditary disorder.

May your series of meetings on important topics and the panel of weighty speakers provide yet another contribution to the investigations into this disorder.

And may you yourselves after the meeting travel home with an impression that perhaps *something*, but certainly not everything, *is rotten in the State of Denmark*

Thank you for your attention.