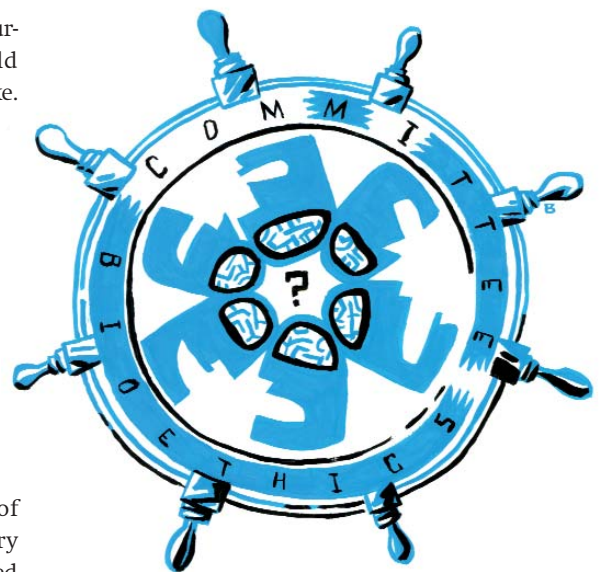


# As patients what do we know about bioethics committees?

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If we are sincere and demanding with ourselves and with others, ethics should always be present in every action we take. And what are ethics? Philosophically speaking, they are defined as the set of moral principles on which our behaviour is based. Moral principles (in other words values) change depending on the era and culture. If we attempt to focus on the problems raised by advances in the fields of biology, medicine and pharmaceuticals, along with the repercussion which these problems have for society, then we are talking more specifically about bioethics.

Bioethics committees were born out of necessity. Over the course of the 20th century a series of circumstances highlighted the need to set up committees of experts to study the changes and advances taking place in the field of medicine. For some years now the media (press, radio, TV...) have referred increasingly often to bioethics committees whenever they publish their studies on various current issues and those which could affect us now and in the future, such as: research with stem cells to discover new treatments; some considerations regarding abortion; the selection of embryos prior to implantation in order to select those which do not carry an illness, or to be in a position to allow a newborn child to cure a sick sibling, along with a number of studies as to the various ways of dealing with death. All those issues which, years ago, would



have been unthinkable have in some specific cases rocked public opinion (such as the instance of Eluana Englaro, the Italian girl in a coma many years ago, or the Spanish baby born following an embryo selection process who provided a cure for the illness threatening the life of her brother) give rise to discussion and debate within such committees of experts. Increasingly, through the high profile of such cases and the desire of the committees themselves to publish their findings, these debates enter the public realm.

It may, however, be the case that for the general public bioethics committees seem a little distant, since they are not direct con-

sultation bodies. The situation is different from that of patients (or their companions or relatives) requiring advice when receiving medical treatment at a healthcare institution, who can draw on the support of healthcare ethics committees. These are not mandatory bodies but have gradually been set up at practically all public and private hospitals. They are made up of a multi-disciplinary group of individuals called on to deal with the queries presented to them by both professionals at the centre and users, who have access to them via the channels indicated by the hospital itself, with the aim of improving the quality of care.

Health professionals are required to take decisions which have direct impacts on our health, our quality of life and our death. Their task is one of great responsibility. Such responsibility existed even before the advent of all our current technology and medical advances, but as there is now more technology at the service of medicine, there are more treatments and we have much more knowledge about the human condition, medical practice has undergone certain changes. It would not be right to view the advances in science and technology used to improve people's living conditions as a problem. Nonetheless, the application of such advances can at times lead to doubt.

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In principle, what patients want is to be cured and to feel well. In the event of minor complaints, the fear of suffering and death is not so strong, but healthcare institutions deal with people suffering major illnesses and in highly critical circumstances. On occasion, during the process of some illnesses, the individuals concerned (either the patients themselves or their relatives or companions) cannot always take the decisions. In such cases it can be particularly helpful to take into consideration the perspective of all those involved (who are also represented on the committee): the doctors, the nursing staff, users, specialists... The queries which are addressed normally centre on the most decisive points in our life: birth and death. That is why these committees have to deal with such issues as: when it can be established that a person has died; when a patient should not be revived; what type of action should be taken with newborn babies in a highly critical state or with serious disabilities, or when and how life-support machines should be disconnected. Let us focus on each of these cases.

Healthcare ethics committees are required to debate when an institution decides that a person has died. The question would seem to be clear-cut: when their heart has stopped beating. But can one attempt to revive a person who arrives at a hospital dead? Yes, one can try. One must, however, establish principles in accordance with how long ago the heart stopped beating and evaluate the potential after-effects of the episode.

Could we, as patients or companions, even consider during the process of an illness the possibility of not wishing to be revived in the event of an arrest? Could one question whether or not a person admitted to hospital should be revived? This would then depend on their state of health, their age, prognosis, the quality of life they could achieve... Each case must be examined on its merits.

As premature babies can now be treated in extremely well-equipped neonatal units, a number of medical procedures can be performed in order to allow the baby to live, but is



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it right to take all these medical actions if the baby is suffering from serious conditions which will dictate its entire life?

In the event that the continuity of life depends on being connected to certain life-support machines, many doubts likewise arise. How long can such support be maintained? And if the person involved does not wish to live under such conditions? And if the person involved cannot decide, and instead his or her relatives must do so?

These are some of the questions which healthcare ethics committees are required to analyse and deal with. In all cases their advice serves simply as a guide, and the individual raising the query will decide whether or not to follow their recommendations. In other words, the function of a healthcare ethics com-

mittee is not to decide for others, but to advise them. Such committees should not act as expert witnesses or pronounce on any complaints or claims brought against healthcare procedures. They are simply a tool for consultation, a forum for reflection.

Healthcare institutions must work to promote dialogue between users, professionals and experts. And they have a great deal of work to do in terms of informing society and encouraging the general public to reflect.