

Pr Régis AUBRY (F)

26/07/2012

English translation: Kathy WEBB-PEPLOE

**End of life :
ethical dilemmas where economics, medical progress
and the patients' rights meet**

My talk will be divided into two parts: first of all, I will lay out the facts about the limits to progress in the field of medicine, the developments in human rights as related to the sick and the budgetary constraints affecting our societies. Secondly, I will reflect on the ethical dilemmas engendered by the coming together of these various factors.

1. The facts concerning the limits to progress in the field of health-care, the development of the sick person's human rights and the budgetary constraints affecting our societies.

1.1 - Advances in modern medicine lie behind complex and singular situations, which we could never have imagined, and behind new forms of vulnerability (1)

If modern medicine allows us to slow down or altogether halt illnesses, which without it, would have very quickly led to death, it also engenders chronic disease and at the same time complexity and vulnerability.

By pushing back the frontier between life and death, medicine has led to clinical situations and ethical considerations never before thought of, propelling medical professionals into a veritable *no man's land*.

The complexity of the states brought about by medical advances is born of the growing gulf between life and what we have become accustomed to calling 'functional autonomy': a man can now live with an organ which has partially or totally failed because science and technology can often replace the failing organ's function.

A tetraplegic can live with a body which feels nothing and is immobile, not just because others don't abandon him, protect his body, feed him and palliate his loss of autonomy, but also because that person's consciousness and his environment enable him to find a purpose to his life.

A man can live nowadays with a chronic disease or an illness which has been rendered chronic, which is slowed down by his treatment, because he hopes to and actually does experience the purpose and the

pleasure of a life which is no doubt not what he had imagined but it is still a life. It's a question about a new appearance or 'face' for end of life, which can less and less be reduced to what one used to call the terminal phase. The end of life is getting longer. It is becoming a part of life, which we want to be able to invest in if we want it to have any meaning.

But how can one live well with an illness which may well be slowed down but which is a part of you, ever present and permanent ? How to live well with the possibility of having several chronic and/or acute illnesses, and sometimes several disabilities all mixed in together ? How to live well when awareness of your mortality is ever present and when the mere fact of existing gradually becomes suffering ? How to live well when the loss of autonomy affects all the parts of your body ? How to live gravely ill, as an invalid or simply frail, when the social norm is more about doing rather than being ? Similarly, what is the life of a person in a chronic vegetative state ? What is the life of a person with profound dementia or a severe physical or mental disability ? What is life like for a person on their own, outside any social or familial network, affected by an illness which is gaining ground and is unfortunately not going to end in cure ?

The technical and scientific advances in medicine lead to the type of questions which, by their nature, have no easy answers because they generate complex clinical scenarios and new forms of vulnerability; these so-called 'advances' only constitute progress if society is capable of bringing them into the open and constantly questioning them. In order to assign a role in society to the person who is 'not productive' in a difficult economic context, in an age when reasons to act too often trump the time to weigh ethical considerations, we need to be different. In other words, the right of each person to be recognised as one human amongst many, however frail they are and whatever the limits of their existence, needs to be one of society's principles.

1. 2 - The complexity and vulnerability brought about by medical progress are increased by the effects of change in our society as well as by the economic climate

- *Increase in solitude*

Man is more and more alone. As a corollary of changing family landscapes: we are seeing today a huge increase in solitude. In 40 years, the proportion of people living alone has more than doubled, going from 6.1% of the population in 1962 to 10.3% in 1990, to 12.6% in 1999 and it will be close to 14% in 2004¹.

Amongst older people, this proportion is significantly increasing: if a third of people older than 65 live alone at home, we know that 53% of women older than 80 live alone, in other words one in two.

- *The emergence of the patient's rights*

In past times it was a sign of respect for the patient to keep from them details of their illness, to avoid making them anxious. It was the doctor's role to relieve them of their anxieties. The 1950's were marked by huge advances in medicine such as the discovery of antibiotics. These advances have contributed to the fact that medicine now seems to be the bearer of all hope...unrealistic hopes no doubt which were disappointed in the 1980's when new illnesses such as AIDS emerged, showing that limits to life and to knowledge still exist and that medical science cannot abolish them. A few scandals later (contaminated blood, growth hormone.....) that confidence in medicine has mutated into an increasing suspicion about medical care with a capacity for the best as well as the worst.

¹ Jacques DUPÂQUIER. 'The prolongation of life expectancy and its multiple consequences.' Académie des Sciences morales et politiques, Session of Monday 8th January 2007. Available on : <http://www.asmp.fr>

Following community pressure, a willingness to reinforce the rights of the sick has emerged by including them in national and European legislation (The Oviedo Convention for the protection of human rights and the dignity of the human being ; the European Charter of the rights of patients). In France, two recent laws² have been passed establishing a major change in the relationship between the carer and the patient and in the relationship between the patient and the citizen. Nowadays, the ill person becomes an active participant in health, in their health; there is no longer any question of a paternalistic medicine where one could make decisions about what was best for another person... It's up to the person at the centre to know everything that affects them. It's up to the person concerned to decide whether they want to accept what is suggested to them as treatment for their illness.

Highly symbolically, the Convention of Oviedo signed in 1997 and ratified in France in 2012 states therefore that *'a medical intervention can only be carried out after the person concerned has given their free and informed consent.'*

- **Economic constraints**

The increase in life expectancy and the formidable technical and scientific advances in medicine have their own cost. Yet financial provision is limited, particularly in the context of an economic crisis.

2. Questions arising and the emerging debates within our societies

- **2.1 - The return of uniqueness and individuality in a context marked by the hegemony (supremacy) of 'normal' and the pre-eminence of science**

The complexity of scenarios brought about by modern medicine also bring into focus the uniqueness of these situations. Because they are individual, they do not fit neatly into the norms, into scientific rationality, and therefore into a medicine founded on facts (evidence-based medicine) since in each case no one can have experienced it before and therefore be expert (2).

How to approach an unthinkable situation? The response to such a question can no doubt be found in another question: how to respect mankind and what is more, help him when one is confronted by the uniqueness of his situation and by his own individuality ?

With classical rational medicine being found wanting, the risk is that we move from the 'hyper-rational' to the irrational. Subjectivity (made up of emotion, beliefs, masks, projections, fears etc.) must not prevent rigor nor erase common sense, even if it is inherent in every decision. Active listening to the words of the sick person, the interdisciplinary approach to a complex situation and team-working are all tools serving a working rationality aiming to find a centre ground between two extremes : on the one hand 'taking in hand' and on the other 'abandoning' the person. Both these extremes, in effect, negate the 'object of care' who is the person, certainly vulnerable and dependent on others, but often capable of understanding and giving their opinion, of making choices. At any rate, far more than is often thought...

- **2.2 - Towards a modern medical service of vulnerability and uncertainty**

- ***Uncertainty and responsibility : complex situations require us to work differently.***

Complex clinical scenarios bring us back to the particular dimension of Man who is suffering. We have already seen how the particularity (even uniqueness) of the situations we encounter distance the doctor from his usual landmarks, from 'Science'.

² Law n° 2002-303 of 4th March 2002 relating to the rights of patients and the quality of systems of care.
Law n° 2005-370 of 22nd April 2005 relating to the rights of patients and the end of life

Losing his usual scientific markers, the care-giver finds himself confronted by the question of limits – the limits of knowledge, the limits of life, his own limits and those of the sick person -. He has to confront uncertainty. Can one care if one has doubts ? Is not doubt part of care ? (3) Or, on the contrary, in an uncertain situation, can the doubt which overcomes the carer push him off balance and in the end stop him from doing his work of caring ? Not knowing is a difficult position to maintain when you are called on to be responsible, to make decisions, to 'make choices'.

But doubt may also be appreciated as an epistemological tool allowing review of certainties and uncertainties, verification of the justification (and therefore the point) of projects and treatments. So doubt is the opposite of certainty: it is a skill upon which rests the decision-making with regard to the choice of how to act. In other words, doubt mandates thinking before acting, it encourages reflexion on the justification for and point of this particular course of action. It invites debate about one's choices or one's convictions. It forces one to listen to others' convictions and to respect other tenuous arguments which might lead to other choices about the same subject.

The least bad choice is most often the one which takes the middle position, at the cross-roads of the different ways of looking at the ill person and at their situation (4). If it is probable that a decision taken in this manner is more respectful of the ill person and more suited to them, it is also certain that it will be more easily taken by the doctor and by the team caring for the patient in terms of bearing responsibility for it.

One condition *sine qua non* of embracing complexity and resisting the temptation of science and technology is to trust oneself and to work as a team.

When confronted by unique and complex situations where uncertainty plays a central role, all the people intervening on the health of the ill person have to know firstly that they don't know what is best for another and that science and technology are not solutions but tools.

Having faith in oneself means that one has a certain self-respect, that one has 'done the guided tour of one's self' in 'working on oneself'. It is not currently clear that study, and particularly study of medicine, encourages this.

To work in a team, respect has to be at the centre of the professional relationships. Even if working in a team imposes a certain hierarchy, needed to progress the systems of care and to build new services, this hierarchy must in no way be reduced to the dimension of 'authority'. In effect, each individual can and must, from their particular perspective, contribute to a reasoned approach to that complexity and that uniqueness that is the patient. That arbitrary and traditional hierarchy between doctors and other care-givers can get in the way of the collaborative discussion and the function of the team. It needs to be progressively eradicated to allow every member of the team to freely put forward their point of view, grounded in their profession, about the 'complex situation before them'. Inter-disciplinary working is characterised by interaction, mutual influence, culminating in an evolution and a reciprocal transformation of knowledge in a spirit of collaboration (5).

Doubt therefore acts as the motor of progress in that it facilitates inter-disciplinary working as a way of dealing with complexity. The doubt inherent in approaching complex and unique situations, thus applied, may be fruitful giving rise to creativity and invention. Doubt and uncertainty oblige professionals to permanently adapt their reasons for caring in order to reduce the gulf between prescriptive treatment and reality. 'Working is a process of discovery' (*Travailler, c'est trouver*), writes with some justification C. Dejours (6), underlying the necessity for professionals to put in place informal arrangements for resolving the problems posed by confrontation with everyday reality, to live with error (and therefore responsibility), to forge a mind that is critical of what is considered normal and critical of protocols, and definitively to seek to obtain recompense which is not confined to financial reward but which (also) resides in a symbolic acknowledgement (*gratitude, respect*): 'people want us to be aware of all of themselves that they have poured into their work – their intelligence, their intuition, and also their hard work and their suffering.'

- From uncertainty in medical treatment to maintaining hope for the sick.

Uncertainty can after all be the origin of a new approach in the relationship between the care-giver and the patient.

In a season and context where there is a tendency to always reduce the time taken and see action as the priority, we often confound speed and performance. Time is certainly a tool in performance because it is during this time that communication can take place, that a relationship can be forged marked by faith and confidence in the other.

The capacity to make relationships requires time, in that it signifies 'knowing how to make the link', but it also gives authenticity and in the end maintains hope.

It is in this respect that the link between uncertainty and hope exists. Contrary to the notion often propagated in medicine, the patient and particularly the doctor must not appear too sure of themselves. Living with uncertainty is normal if one works with humanity and therefore with otherness (individuality). Maintaining uncertainty is re-assuring: sometimes the patients' hope is mixed in with those cracks of doubt mentioned by the doctor. Yet, hope (*l'espoir*) is the motor of life; it has an existential dimension and it facilitates hopefulness (*l'esperance*) which has an eschatological dimension, relative to what surpasses life, to a form of transcendence. This is why, even right at the end of life, patients still hope...

- 2.3 - Rethinking the notion of performance as a measure of complexity, of individuality, of uncertainty.

Notions of performance and of profitability, having passed from the financial domain and from business to health organizations are now inching towards the main players involved in delivering healthcare. What does performance mean for a care-giver? What does it mean to be profitable if one is a care-giver? Does performance just mean being profitable, profitable at any cost?...

These questions can shock and surprise because they are not anchored in the caring tradition, but they are relevant, because aiming for the best, for an improvement in health is a qualitative process which is mediated by those giving care.

In order to be constituents of performance, the objectives of effectiveness, efficiency and sometimes even profitability need to be achieved by means that are socially acceptable and therefore justifiable ethically. In effect these questions, posed in an economic context which is very tightly constrained (institutions need to break even, for example), risk prioritising profitability in the financial sense (via imposing tariffs for activity for example) whereas other dimensions of care might be worth exploring (clinical, social profitability etc.). Thus tools exist to improve clinical performance. Inter-disciplinary working is one, as are morbidity and mortality meetings, but attaching tariffs to activity can also be used if we take the trouble to question their use and their limits. These tools of clinical performance are used to limit risk, improve the quality of health and minimise costs.

Can one talk about performance in a situation characterised by uncertainty?

These uncertain clinical situations are becoming more and more frequent in the domain of medicine and particularly at the end of life where the situations are complex, the people very vulnerable and where the people delivering health-care are constantly working close to their limits (limits of life, limits of knowledge, each individual's limits particularly each person engaged in the caring profession...).

There is a lot of room for subjectivity (perceptions, resentments, opinions, interpretations, good sense but also fears and hope mixed in) to deflect the carer from his usual rational and scientific reference points, forcing him to move outside himself, to take into account that huge subjectivity, but also to integrate the situation in the person's environment (giving its rightful place to the person's nearest and dearest, to their environment, to their choices, their culture, their beliefs and their convictions...)

A priori, tackling these situations in order to perform well cannot be profitable financially (although ? ...). In effect, performance seems in these situations to be linked to working in a multi professional team. This work allows us to coordinate the different players worried by the complex situation, to anticipate possible complications and the possible responses to these complications, by sharing experiences, cases they have seen, reducing the part played by subjectivity in those decisions and limiting eventual suffering at work, or personal suffering. In addition, by mandating reflection before action, the interdisciplinary or collegiate approach to complexity can limit those often maladapted and costly bio-medical responses which are a product of unreasonableness and of a form of therapeutic relentlessness.

The profitability of this approach to improving performance can certainly be measured indirectly by savings generated and suffering avoided, by the satisfaction of care-givers and that of the patients and their relatives...

- 2.4 - The high stakes when it comes to training health professionals and the need to think of new health professions.

Those delivering health-care are going to have to prepare themselves to face up to the new realities with which they are and will be confronted.

It will be necessary to re-consider the initial and continuing training of health professionals in order to confront the new challenges arising from the progress made in medicine in the 20th century. These challenges lie in those areas of competence which are little or not at all addressed by current medical training: the mechanics of ethical reflection, relationship and communication, working in a co-ordinated team (7).

Even the methods and stages of training will need to be completely rethought. It is absolutely essential that those who are going to work together to care for a person also train together. At the moment training is delivered in a 'tubular' or categorised fashion.

It is also necessary to integrate the current alternation between training and practice. Nowadays there is also not enough work analysing what happens in the different stages of training and education often fails to integrate the academic, the theoretical and the analysis of how care is delivered.

It is essential to think of delegating jobs as health professionals. In the field of chronic disease, does the role of education as therapy have to stay solely the domain of the medical professional? Shouldn't tomorrow's doctor devote himself to that clinical work involving complexity, vulnerability and uncertainty for which he will have been trained? Diagnosing and integrating the constituents of complexity will lie at the heart of what tomorrow's doctor does. To accompany, to educate will be a role shared by all health professionals who will have trained together.

New professions are going to see the light of day in order to deal with these new realities generated by the progress we have seen in medical science. In effect, the needs expressed by these new patients are going to require new competences in the field of co-ordination. It will probably be necessary to create professions which lie at the interface between what exists today in order to co-ordinate those different areas (health, medico-social), different needs (social, medical), different influences (personnel, professionals, systems...). In economically straitened times, following the prevailing theories about keeping care close to home, co-ordinators will be created in order to improve the quality of the health of people, allow deliverers of healthcare to work at the centre of their profession, and probably at the same time reduce or avoid an increase in costs.

- 2.5 - The importance for our society of becoming aware of this 'new era' which is end of life

In our illusion of a death that has been overcome, managed by modern medicine, we have gradually slid towards a form of denial of man's mortality during the 20th century. We didn't realise that medicine was

generating vulnerability and complexity. We never imagined this new face of end of life which is life with illnesses which cannot be cured.

The price of this lack of forethought has been doubled in terms of our growing realisation of the scale of the problem at the beginning of the 21st century. On the individual level, this translates into an increase in the anguish generated by death and the end of life and probably mirroring this, by an accentuation of questioning the purpose of living. On the political level, this translates into an awareness of the need for a democracy to take care of the most vulnerable, and the realisation that our systems are relatively badly adapted to social companionship and to organisation of systems for delivering healthcare.

And so, the ageing of our populations and questions of dependence have not always been given their correct importance. How will our societies accommodate the dependence, the loss of autonomy generated by the consequences of medical progress ? More and more people are going to live longer and longer with more and more diseases which are more and more severe. What sort of living space will these people live in ? What will be the premises adapted to loss of autonomy ? How do we respect the desire of these vulnerable people to choose where and how they live without accepting the usual, often institutional models which are proposed to us ? What point will there be to the life of people if illness and handicap are coupled with loss of autonomy and restriction in freedoms ?

- **2.6 - The necessity for the individual to take back responsibility for those aspects of his health which have been over-medicalised.**

By handing over the end of life to the medical profession, our societies have finished by confining it. They have left out those questions concerning areas of social and individual responsibility.

Two consequences are particularly visible in France: a tendency to over medicalise and over hospitalise people at the end of their lives; the main place of death is now the hospital (8).

Yet the end of life and death are not just about medicine and health. They are above all about the individual and the citizen. Hospitalisation and medicalisation are only part of the taking account and the taking in charge of this evolution of our modern society. It has to be said that between the traditional home and the hospital or the institution we lack alternatives to staying at home just as much as to admission to hospital.

We must give thought to how we accompany people at the end of life by taking a new look at the end of a life which is getting longer by very reason of advances in medicine.

- ***The need to acknowledge the role of next of kin***

Effectively, another question arises; what is the role of the next of kin when a patient lives a long time with a disability or dependency, or a serious illness? Accompanying a seriously ill person is made difficult for the next of kin in our modern societies. The availability of next of kin and their willingness to face up to existential questions are reduced by the coming together of several factors. In addition to that collective denial of our mortality which we have talked about before, recent profound alterations in 20th century society have contributed to a type of lottery when it comes to assisting relatives who are made vulnerable by illness or handicap. We can think of, in a non-exhaustive list, the developments in women working, the secularisation of our society, the disappearance of the traditional idea of the family, the over-importance placed on the value of work.

Faced with the reality which for a long time was unthinkable that life comprises a new phase - that of end of life, we must newly recognise the need for expertise and time for relatives to assist (lit. accompany) their nearest and dearest.

So, it seems we must help those next of kin who find themselves in the position of carer sometimes 'in spite of themselves'. Helping them deliver these acts of care, helping them to give themselves permission

not to, and helping them by finding their limits, the early signs of exhaustion... These are the new objectives of health professionals and those near to patients as well as their family and friends.

It is also necessary to acknowledge the right to respite, and to make possible places for respite care in order to allow these people to keep going until the end in their role or mission of caring. Remember that the French law number 2010-209 of the 2nd March 2010 aiming to create a daily care allowance for a person approaching end of life is probably the first political implementation of this realisation and acknowledgement. The reflection going on at the moment in political circles about respite centres is probably another aspect of this growing awareness of the problem.

- *The need to develop new forms of interdependence (joint liability)*

At the point where the awareness of the reality of these new forms of end of life, the emerging rights of patients and economic constraints meet, it seems absolutely essential that new forms of interdependence are developed in order to preserve our society's cohesiveness.

How to help the most vulnerable and the least fortunate amongst us? New forms of charity, and more broadly new forms of altruism will become necessary. New forms of collective sponsorship or business sponsorship will need to be thought of. Starting with school and children's education, we will need to foster that culture of cooperation which is so necessary. We also need to think of helping the vulnerable as our duty.

Mirroring this need, there is a risk: that of a new form of xenophobia.

Our society is confronted by the feeling that each person's future is going to be characterised by these complex questions, particularly because the subject is avoided by the media and in public debate. Each person has this anguished, confused feeling that profound changes will need to be made in order for our society to face up to this demographic reality (more and more people will live longer and longer with more and more serious illnesses). This anguish is coming up against a more and more utilitarian view of life in our capitalist society. The 'good life' is one which leads a man to be useful, to make, to produce and to earn. That utilitarian vision of life leads certain seriously ill people to feel and to express a feeling of being useless or undignified. It is less and less rare to hear the following phrase from the mouths of patients: *'What is the point of living since I'm no longer good for anything, I'm a burden for my relatives ?'* That utilitarian vision of life also leads certain healthy people to ask themselves whether there is any use prolonging the life of people when they are no longer productive and they are costing money.

- 2.7 - Progress and economic constraints – necessary choices

Three *a priori* irreconcilable expectations co-exist in our society: ever greater expectations of users of health services, a pressure by companies to adopt their innovations and an expectation by managers that health spending should be controlled.

Does our expectation regarding medical progress not derive from a form of denial of our mortality, of the relative transience of life ?

In the future, will we have the means to fulfil our ambitions, our knowledge and our capabilities ?

In a context of limited financial resources, 'do we have other choices rather than making choices ? Certain Anglo-Saxon countries are already limiting their permission for treatments where the cost is judged to be too great. An organization such as the National Institute for Health and Clinical Excellence (NICE) in Britain, for example, integrates medical and economic criteria as soon as a treatment receives permission to market it.

Should we not exert choice in the financing of progress ? Should we not ask the question whether it is appropriate to pursue or not pursue expensive treatments in patients who have advanced disease,

advanced in the sense of jeopardising quality and meaning of life, when the treatments are expensive and carry with them uncertain benefits and certain risks ?

In a democracy with limited finances, a vital choice can impose itself, even if it risks being unpopular, between financing technical and scientific feats of prowess and guaranteeing equality of access to healthcare for everyone. Since each clinical situation is unique and the decision to limit or to stop treatment has to be taken in the light of that uniqueness, such a decision cannot be the result of a general rule (the law): this type of decision can only be arrived at by an ethical approach where the question of the *purpose* of the medical intervention so applied is considered during the whole management process.

It would be better for our society to have the courage to ask itself these questions now; without it we will see emerge and develop a perversion of relationship, and doubly so: amongst the 'well', the risk of ostracising those who are certainly ill, but therefore are costly; amongst people who are ill or vulnerable because of a change in their health, a risk of feeling guilty, of feeling shame.

- **2.8 - The need for public debate**

There is unfortunately little if not no real public debate on these questions which are nevertheless essential for the future of our societies.

All the questions we have posed seem to be unknown. They seem to be obscured by the reliance on this one question; should the law permit assisted suicide or euthanasia? This focus on one question, the impassioned emotion associated with it by public opinion, the strident publicity given by the media to this confrontation of ideas is questionable. Perhaps it is an avatar of the denial of our society of man's mortality and a way to avoid questioning ourselves more deeply.

There is also a problem with one approach to questions about the end of life - biased opinion polls directed at well people being asked to imagine themselves at the very point in life they are most anguished about. And so, it could all be summarized in a binary approach: one must be for or against euthanasia and therein lie the answers to all other questions. In fact, those patients who are ill and their relatives lie somewhere between the arguments for and against. Between the arguments for and against there is a position where one no longer confuses one's personal convictions with certainty; each person can therefore experience the meaning of uncertainty: a mixture of contradictory desires, fears and envies, feelings of guilt and of legitimacy. There can be no certainty about the less bad response to hugely complex situations concerning greatly vulnerable patients. Who would dare to maintain that the law alone could resolve such unique situations? Without doubt, laws need to evolve and adapt to new expectations and new needs in our societies; without doubt we need to take into account the reality of unliveable lives which are the unforeseen consequence of medical advances.

But it would be dangerous for the law to precede debate, and by that I mean a real debate. It would be dangerous to obscure the reality and the complex ramifications of the questions which are being posed.

- **2.9 - Should the law be changed to allow assisted suicide and/or euthanasia ?**

All the same, considering the role of the law, it is clear that it is a priority and an obligation to not engage in or to stop treatments which are deemed not in the best interests of the sick person. Besides this is the spirit of current French law³.

This will probably avoid creating innumerable situations which are so complex and associated with so great a suffering that they lead to a desire for death.

³ Law n°2005-370 of the 22nd April 2005 relating to the rights of patients and to the end of life.

Of course, in a broader debate about the right of each person to choose their mode of death, the question of assisted suicide – maybe more so than that of euthanasia – poses itself in our societies.

These are not the only questions, far from it, but these are the questions which we will need to include in a carefully managed public debate, which will take time and which mandates that we abandon passions and caricatures.

In conclusion

I am certain that we need to take into account much more than we have previously, the reality of the change which is happening in our modern society as a result of the unforeseen consequences of medical progress and particular those technical and scientific developments in the field of medicine. This is giving rise much more than we could have imagined to clinical scenarios of great fragility, great vulnerability and of dependence. These questions are going to have a not negligible economic impact. More and more people will no longer be able to be 'active' in the sense that our capitalist societies mean and expect.

The global reduction in birth rate, the increase in life expectancy and even more than that the increase in life expectancy of the sick or handicapped is also going to rock the foundations of our social fabric and will need a profound debate about the future of our society, the necessity of developing new forms of interdependence and probably new forms of modern economy. Focussing the public debate on questions about the right to euthanasia or to assisted suicide, while probably necessary, is on the face of it a new aspect of our society's denial, faced with a reality which causes us anguish.

BIBLIOGRAPHY

- (1) AUBRY R. Plus la bio-médecine progresse, plus elle crée de l'incertitude. In : Brun D, coord, Actes du 13^{ème} colloque de la société médecine et psychanalyse : "Entre autorité et incertitude : moments critiques ". Paris. Editions Etudes freudiennes ; 2012. p-
- (2) GORDON C. S. SMITH. (2003) Parachute use to prevent death and major trauma related to gravitational challenge: systematic review of randomised controlled trials. BMJ 2003; 327
- (3) AUBRY R., coord., L'euthanasie et la mort désirée : questions pour la société et la pratique des soins palliatifs. Paris. SFAP Mutualité Française ;2005. p.38-80
- (4) Edgar MORIN, Introduction à la pensée complexe (1990). Paris. Editions Seuil, Points essais, 2007.
- (5) Jürgen HABERMAS. De l'Ethique de la discussion (1991). traduit de l'allemand par Mark Hunyadi. Paris. Editions Cerf, collection « Passages », 1992, 202 p (1re édition 1991).
- (6) Christophe DEJOURS (2003). L'évaluation du travail à l'épreuve du réel. Critique des fondements de l'évaluation. Paris, INRA Editions, 2003.
- (7) AUBRY R, MALLET D. Réflexions et propositions pour la formation médicale. Pédagogie médicale. 2008 ; 9 (2) : 94-102
- (8) Observatoire national de la fin de vie : fin de vie : état des lieux. Rapport au premier ministre et au parlement, 2012. Consultable sur : http://onfv.org/rapport_annuel.html