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The Ethical Issues of Ageing

What is the point of concentrating the elderly all together in "residential homes"? What incentives for society to become more inclusive of its elderly population?

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I /Foreword on facts, issues and the context of a CCNE Opinion on this subject.

CCNE's Report N° 59 on "ageing" dated 25 May 1998 made findings and recommendations which, today, are still fully as topical as they were at the time. At this point, while still subscribing to this earlier report, CCNE wished to revisit the ethical issues raised by how our society copes with its own ageing.

Renewed consideration of this subject by CCNE seems to be necessary a little over two years since the vote on Law n° 2015-1776 of 28 December 2015 on society's capacity for adjustment in the context of a significantly ageing population.
Although the adoption of this law, in combination with Law n° 2016-41dated 26 January 2016 on the modernisation of our public health system, is undoubtedly beneficial[1], it would seem that the ethical substructure of a policy to cope with ageing has not been sufficiently subscribed to. To satisfy ethical principles of respect for the most vulnerable, it seems that substantial proposals must be made to complement measures already being set up.

It would appear that, although they were foreseeable, the consequences of longevity have not as yet been recognised for what they are, i.e. one of the major challenges facing our society in coming decades. The following points made in CCNE's previous report are still valid:

- As chronological age and expression of the biological evidence of ageing do not develop in parallel, we are observing an increase of disability-free life expectancy (DFLE). In France, DFLE is progressing at a faster pace than longevity, in particular for men.
- The consequences on these elderly people who are still free of disability are isolation and solitude brought about by the shattering of traditional family units in which the elders could still play a useful and active role. It is also regrettable that city planners failed to provide the elderly with arrangements for continuing to live near their children, albeit in conditions which allow for, as they should, the needs of different generations.
- The onset of physical and/or psychological dependency has two fundamental consequences. Firstly, considerable expense which plunges a significant number of those involved into becoming economically dependent on their families or on the community; and secondly, as they lose their autonomy and therefore their freedom of decision regarding the organisation of their daily life, they may become dependent on decisions made for them by others, which are frequently arbitrary even though they may stem from benevolent intentions.

In its conclusions and recommendations, CCNE's Report N° 59 noted:

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[1] No one can deny the importance of measures being implemented within the framework of the 28 December 2015 law on society's adjustment to ageing.
Nor can anyone deny the importance and impact of certain measures included in the law on the modernisation of our public health system (in particular the future creation of territorial healthcare professional communities, the "health-territory" agreement to combat medical desertification, the creation of territorial platforms to support healthcare professionals in the coordination and management of complex cases, the project to reactivate the shared medical case file, the creation of territorial hospital groupings *(groupements hospitaliers de territoire – GHT).*

"Ethical guidelines based on the three following areas:

> *- First of all, seek to reduce the inequalities of ageing which lead to inequity: social devaluation which accompanies legitimate access to retirement; negative images generated by ageing; ignoring the positive economic role for the family and society played by senior citizens; danger of inequality because of growing demographic imbalance between age groups.*
>
> *- Then, implement the ethical demands of prevention and management - in terms of public health - of dependency due to ageing. To do that, excessive compartmentalisation (due to the 1975 law) between health care and social care must be eliminated, and a reinforcement of the proximity approach to care.*
>
> *- Finally, develop actively education and research in geriatric medicine, in clinical terms, the social sciences, and fundamental research.*

It is possible to believe in a longer life span and still retain an optimistic view of the health of our oldest citizens. As regards the community, the issue will be played out in a race between biological youthfulness and demographic ageing, which leads CCNE to suggest that a geriatric programme for action should be implemented as a matter of priority with a view to solving the difficulties arising out of the multiplicity and intricacy of regulations, authorities and structures concerned."

In Opinion N° 121, "*The End of Life, Personal Autonomy, the Will to Die",* CCNE emphasised that *"what the community and the authorities should be fighting against are circumstances of clearly recognised indignity: lack of systematic access to palliative care, isolation of certain people at the end of their lives, poor living conditions and defective support for the sick and the disabled so that it becomes impossible for them to end their lives in their own home. The ultimate in indignity would be to consider that people have lost their dignity, have become unworthy, because they are sick, different, alone, inactive, costly..."*

This is why CCNE wished to initiate this reflection on the ethical issues of ageing. As a first step, the Committee considered one specific set of problems:

What is the object of concentrating the elderly all together in special homes, which become, often against their will, the place where they will live until they die?

Should benevolent principles and the wish, sometimes bordering on single-mindedness, to ensure the safety of elderly people, be allowed to take precedence over the wishes of those concerned when in fact, more often than not, they make it clear that they wish to avoid institutionalisation and its contingencies? Should the elderly be forced to live exclusively where they have no wish to be, and to make matters worse, at their great expense? Is keeping them at home, often the preferred choice of the elderly, technically feasible — account taken of possible exposure to risks (for example because of unsuitable accommodation) — and is it desirable in view of the frequent situations of solitude and isolation in which they are left and which specialist institutions are unable to alleviate in most cases? These queries have a bearing on fundamental principles. Principles related to the recognition and implementation of individual rights and liberties of the aged, particularly as

regards the systematic securing of informed consent, freedom of choice and participation as well as the right to protection and security.

The reasons for choosing this focus are that these problems are the subject of much debate and cannot be given unequivocal answers. But they are also a multi-facetted prism through which are observed a number of underlying issues such as the true place of old people in our society, the material and financial limitations attached to caring for senior citizens in their own homes, the medicalisation of age and ageing, issues with a bearing on the end of life[2], whether our medical and social healthcare system is adequately structured and regulated to cope with this reality…

It is certainly true that, due to social progress and formidable medical advances, the older generation is generally in good health, content and independent for a good part of the time following the end of the "active" period of their lives. Disability-free life expectancy (DFLE) is still increasing regularly for pensioners. But in parallel and in correlation with this progress, often a little later in life, after a pleasant DFLE space of time, more and more people are living longer and longer while coping with an ever-increasing burden of assorted acute and chronic diseases, frailties, disabilities and pain.

Now that today's society has consigned old age and end of life to the care of the medical world, they have in fact confined people because of their age and its contingencies, to "living environments" that are often places of violence or even abuse. Our society has excluded these matters from the sphere of social and individual responsibility.

There are two consequences, aggravated since the time when CCNE's Report N° 50 was adopted, which are particularly significant in France:

- A tendency to over-medicalise and over-hospitalise people as they reach the end of their lives —nowadays, most people die in a hospital[3];
- A very pronounced tendency to institutionalise the most frail among the elderly[4], with the enforcement of constraints — more or less psychologically justifiable — that make end of life even more unendurable.

But in fact old age and death are not the sole prerogative of medicine and public health. They concern above all the individual (the elderly people themselves but also those who are close to them and who nursed them and loved them) and the citizen. Medicalisation and its corollaries — hospitalisation and institutionalisation — are only one part of the management and attention given to these developments in today's societies.

Preliminary work on this Opinion, the main results of which are to be found in an annex to this document, shows that in fact the developments of our society make it difficult, both in

[2] *La fin de vie des personnes âgées*. (End of life of the elderly). Rapport 2013 de l'Observatoire National de la Fin de Vie, Paris, La Documentation Française, 2014.

[3] *Observatoire national de la fin de vie : fin de vie : état des lieux.* (End of life. Status report). Report to the Prime Minister and to Parliament, 2012. See: http://onfv.org/rapport_annuel.html

[4] *Observatoire national de la fin de vie. « Vivre la fin de vie chez soi ».* (End of life in one's own home). 2012 Report by the Observatoire National de la Fin de Vie, Paris. See : http://onfv.org/rapport_annuel.html

La fin de vie des personnes âgées. (End of life of the elderly). 2013 Report by the Observatoire National de la Fin de Vie, Paris. See: http://onfv.org/rapport_annuel.html

practical and in financial terms, to achieve truly appropriate care at home for frail and vulnerable elderly people (Annex 2.1).

These findings highlight the degree of mental and social distress such people are reduced to when they have lost their independence and autonomy. They feel that they are a burden on their nearest and dearest and even on society as a whole and harbour feelings of guilt to the extent that they experience a loss of dignity and even of legitimacy (Annex 2.2).

The situation is exacerbated by a form of segregation because of age, loss of independence and autonomy (Annex 2.3), and a tendency to negate any residual autonomy (Annex 2.5).

Moreover, the medicalisation of age and ageing very probably makes some people even more fragile and vulnerable and precipitates the onset of physical and mental dependency (Annex 2.4).

Further exploration of this situation leads to confirming the theory that there is a kind of collective denial of society's ageing and of our own ageing, a denial of what will be our own fate as we grow old, or even of our finitude. It reveals a latent form of ill-treatment of dependent old people, apparent in policies concerning them, but more generally socially and sometimes within families. This form of not entirely conscious mistreatment may potentially lead to exclusion of the elderly, particularly when issues need to be resolved concerning their state of dependency, loss of autonomy, physical vulnerability and the medical repercussions of these situations (such as losing automatic reflexes resulting in accidental falls, or else loss of balance and consciousness because of spontaneous or iatrogenic low blood pressure, etc.). And yet, given the way our social and healthcare systems are currently organised, respect for the most vulnerable no longer seems to be a priority. Obviously, although caring for the elderly in their own homes cannot be an intangible absolute, currently it is made more difficult or even impossible for several reasons:

- The existing situation will persist as long as helping so-called "natural" carers is not seen as a priority.
- The quality of professional assistance for home care is often defective because these professions are not sufficiently appreciated in social terms, are not well paid and professional helpers are neither properly supported nor adequately trained (Annex 2.8). Professional caregivers are too pressed for time and their turnover is too rapid as far as the person in need of care is concerned for whom this multiplicity of carers is intrusive. Any time-consuming relational care, which is so essential, is denied and excluded from the count of somatic and emotional care provision.
- The compartmentalisation of our public health system persists and worsens despite the simplification principles presiding over the creation of the *Agences régionales de santé* (ARS – regional health agencies). This has an adverse effect on the provision of solicitous support for the health and life of those in need and also on equality of access to it.

Alternatives to institutionalisation (not so long ago this was called "placement") are too few and far between. The rights of vulnerable people are not upheld as they should and could be (Annex 2.10). As a consequence, there is an increase, paradoxical but politically desirable, in the "*number of beds for residents*" in EHPADs, where professionals do the best they can with their sometimes inexistent resources. The number of depressed people in EHPADs is an

indicator of how much suffering and solitude they contain; similarly, the number of elderly people committing suicide, particularly concurrently with decisions to put them into institutions, should be a cause for alarm (Annex 2.2).

Overmedicalisation at the end of life should be a reason to reconsider when it contributes more to keeping people alive but in physical and mental pain (comparable to therapeutic obstinacy) than to a result that makes sense for the person concerned and for loved ones.

As a conclusion to this preliminary survey, our finding is of a somewhat disgraceful situation generating, as in a mirror reflection, feelings of personal indignity and increasing fearfulness of growing old in today's society. Undeniably, the fundamental rights and freedoms owed to everyone are under assault. Government must devote greater attention to the vulnerability brought on by advanced age and loss of autonomy. Henceforth, our society has an obligation to become more inclusive of its senior citizens, in particular those who are resident in institutions, where more than ever before, maintaining social interaction is of vital consequence.

II. Opinion

First of all, there is a need for our society to become aware of this “new age of man”, the end of life, and of this epidemiological reality of vulnerability, solitude and isolation.
Blinded by the illusion that all life's hazards are controllable by modern day medicine, during the 20th century we gradually evolved towards a form of denial of human finitude. These unspoken thoughts have two consequences on our awareness in this early part of the twenty-first century. On an individual basis, there is increased anxiety concerning the finiteness of life and our fate, which is to grow old and die and also, probably, as in a mirror reflection, an increase of misgivings about the meaning of life. In political terms, the consequences should be to feel that there is an imperious obligation for a democratic country to take care of the most vulnerable of its citizens and to realise that we are not competently organised as regards social and medical care arrangements.
Today, despite a number of positive development in the last twenty years, the organisation, the regulation and the funding provided for our medical and social systems and above all our public health system, are contributing to a reduction in the material facilities made available for “senior citizens” whose numbers are increasing apace both quantitatively and proportionately and whose needs are the greatest.
But in fact, the ageing of the population and the increasing vulnerability of some ailing people have not always been estimated at their real level.

How will this society keep up with this increased incidence of dependency and loss of autonomy generated by the consequences of increased longevity allied to clinical progress in the treatment of disease and the advent of “personalised medicine”? How can those who are in need of it be housed in accommodation suitable for diminished autonomy? How will we go about respecting the wishes of these vulnerable people regarding where and how they are living without necessarily accepting the normative — and frequently institutional — models that are on offer for them or even forced upon them?

What resources will be available to us (leaving aside personal compensation for loss of autonomy for the elderly and disability compensation for the disabled) to care at an appropriate cost for those whose autonomy and independence are compromised?

How worthwhile would life be for people if ageing, sickness and disability go hand in hand with loss of autonomy, reduced freedom and resources?

How, in parallel, can we avoid attaching excessive value to the intangible principle of autonomy to the detriment of the ethics of compassion, insofar as the demand and striving for autonomy cannot serve as an alibi for insufficient intergenerational solidarity, or even its absence?

The circumstances of these protracted periods of age and end of life of the elderly or of vulnerable people in general, due to the positive effects of a healthy lifestyle and of medical progress, both preventive and curative, should give us reason to reflect at several levels. In some cases survival and life prolonged with the help of new medical achievements may not be a recipe for “happy lives”.
It is unacceptable that vulnerability forces people to end their lives in circumstances and places where they can find neither the dignity nor the respect to which they are entitled.

Apart from the question of elderly people's rights, the issue actually facing us is the meaning of ageing in our society and the circumstances of the end of life of those who are no longer autonomous and have become physically dependent.

Beyond the limited issue of the fate of the aged, the more general problem of caring for new forms of frailty and vulnerability is one that our society must grapple with. This new reality that we have attempted to describe more fully here and in the annexes to this document must incite us to consider new forms of solidarity.
Failing this, we may also arrive at a selfish withdrawal on the part of the active and healthy section of the population and a collective denial of reality and of our social responsibility. Or even worse, it could trigger a new utilitarian norm, or a new form of xenophobia, reducing the value of life to a utilitarian dimension, that is the capacity to be productive and profitable; any deviation from this norm could then lead to ignoring those who are dependent and ceasing to care for the life of those who have become "unproductive" dependents, a burden on the community, or even go as far as to extinguish life.
It is also clear that the view that our society has of people that age or disease have rendered vulnerable has a significant effect on these people's mindset and in some cases may generate a feeling of unworthiness on their part[5]. How can we change this attitude? How can we reverse the trend we have described which views ageing as a problem? These questions have been the subject for discussion in countless commissions considering issues of "good" ageing, intergenerational solidarity, dependency (CESE, 2011). Society views the elderly who are losing their autonomy as a disaster in the making, so that old people are marginalised, devaluated and isolated. We could and we should see ageing and the conditions in which old people are made to live in a different light. Most of them, when they were active, devoted their strength and their skills to working for the community. Their readiness to assist and their wealth of experience should be accepted more systematically and with more respect.

We need to do more than make speeches and we should give another meaning to the expression "silver economy", in other words reach beyond the concepts of "products" and "markets" attached to this wording so that we rethink and reintroduce humanism, failing which no progress is possible.

Older people are a wealth of being… They are testimony of the aptitude of each of us to age and they make us think about the meaning of life in general and of our own lives in particular. People who are old today are those who have made us what we are and they are also, in a way, our living memory.

The major concern of this Opinion is therefore a question of policy. CCNE is proposing several concrete approaches to reinforce awareness of a reality, (the ageing of the population) and respect for the elderly.

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[5] Gérard-François Dumont, demographer, geographer, economist, heard by CCNE on 28 June, provides information aiding an understanding of societal attitudes. He reported that in the last sixty years there has been a paradigmatic modification in the attitude towards the elderly. When society only included a few old people they were regarded as being "wise, to be looked-up to and respected". In the same time period antenatal, neonatal and infant mortality was high and parents invested less feeling for very young children. Progress in public health and medical advances have led to an unprecedented increase in life expectancy and a reduction of perinatal mortality. Old people are less, or even no longer, considered to be wise and today's society invests far more emotionally in children and more generally, in the young.

1. **How can we contribute to changing attitudes and to modifying the way mature people are perceived?**

- *Perceiving people of advanced age as fully-entitled citizens with enforceable rights*
  Returning to fundamentals consists in reflecting and working systematically, day after day, on ensuring that old people in care homes, by virtue of their intrinsic quality as citizens, effectively enjoy their individual rights and liberties. They hold rights: professionals and family carers are duty bound to help elderly people to exercise these rights directly, or indirectly through legal representatives.

- *Modifying verbal standards*
  Verbal norms are revealing as a modification of our perception and as a form of discrimination or exclusion, although people using them do not realise that this is what they are doing[6]. Certain very frequently used wordings need to be recast, such as "*elderly person*" which is very imprecise anyway and can also be discriminatory.

  Similarly, the full name for EHPADs (*Etablissements d'Hébergement pour Personnes Agées Dépendantes* – Residential long-term nursing homes for dependent elderly people) should be replaced by language that does not have the pejorative connotations of the French words "HEBERGEMENT" (suggesting temporary housing for refugees or survivors of a disaster) and "DEPENDENT".

  The expression "neuroDEGENERATIVE disorder" carries the concept of exclusion and defective judgment. Finally, the word "institutionalisation" can be vexatious.

  The word "dementia" is also condemnatory; it is too close in everyday speech to the concept of madness and therefore contributes to the perpetuation of stereotypes. And yet, current research on cerebral plasticity provides evidence that Alzheimer's disease does not prevent people from reacting to emotional experience so that there is a possibility that care and attention could help to improve communication and quality of life.

- *The role of children's education (by parents and at school) in their relationship to older people and their early sensitisation to the concept of solidarity.*
  It would seem essential to teach the relativity of life, to make it known that ageing is a natural process, inherent to life. It also seems important to teach in school, even very young children, solidarity with those who are particularly vulnerable. In this way, a culture supportive of others, of altruism, consubstantial with life in a community, could see the light of day, thus facilitating the processes of intergenerational assistance. It

[6] Heard from Madame Catherine Ollivet – President of the *Collectif inter associatif sur la santé (CISS) Île-de-France, of France Alzheimer 93* and of the Advisory Board of the *Espace de réflexion éthique Île-de-France*, member of the *Espace national de réflexion éthique sur les maladies neurodégénératives*

would be interesting to perceive the impact of such an educational project; it probably stretches beyond the sole issue of solidarity and could be the point of departure for improving the "*quality of living together*".

Academic counselling units should try to enhance the prestige of professions providing personal assistance, by underlining their importance for society, the excellence of qualifications and qualities required of those practising them, as well as attractive and ongoing career prospects.

- *Enlist the support of the media to develop a positive view of "extreme old age".* The media have the potential as a formidable tool to raise awareness of the need for a paradigm shift. But it appears to us that, so far, the media's role has been closer to deformation or disinformation than to information. The reality of fragile people is sidestepped by the media since, be it on television or in print, and throughout society, youth and good health are overrated. Old age is only shown as an exceptional performance ("see how old she is and yet she is still around and lively") regardless of the person's actual physical and mental status. Vulnerability, the demeaning aspects of dependency and solitude are frequently experienced and yet they are rarely revealed to the general public, so that they are eluded and discredited. We can but hope that today's media (including the so-called social networks) will want to seize on this fundamental issue and give prominence to what we could expect society to do for people whose physical and memory abilities have been impaired by age so that, much against their wishes, they have become dependent on others, family carergivers or institutions.

- *Work on organising cultural activities inclusive of elderly dependent people, not just as an audience but also as participants*
  The study of the way in which the image of the elderly has evolved (Annex 3-3) shows the importance of cultural determinism in our perception of old age. These findings are of course a call on the educational system, but also on our culture. Apart from creative work to encourage a change of outlook focusing on age[7], the *"Culture et Santé"* schemes pave the way for cultural activities in hospital settings as part of agreements between regional cultural affairs (DRAC) departments and regional health agencies (ARS). There is a real need for systematic inclusion of EHPADs in these undertakings so that care homes for the elderly, like all the other health related institutions, can also benefit from cultural projects as diverse as artist-in-residence programmes, intramural exhibitions and workshops. There is a dual need in such settings for the running of intergenerational workshops: education *via* a meeting of generations (thus modifying young people's representation by replacing fantasy with physical, perceptive and interactive realities); and making the older generations aware of their particular and legitimate place within society. In a society which no longer has geographic unity as a model for the family, nor necessarily emotional unity, such intergenerational initiatives are an opportunity for the making of fortunate relationships[8].

[7] See for example Pina Bausch's show *Kontakhof pour dames et messieurs de plus de 65 ans,* or *N'attrape pas froid ma grand-mère* produced by the company *La Vaste Entreprise* (https://www.lavasteentreprise.org/LVE_Slide-Napf.html)

[8] Experiments conducted by la *Scène Nationale de la Filature* in Mulhouse showed that youngsters from secondary schools continued for several months after the workshops were held to go and visit elderly people from the *Doyenné de la Filature.* In similar experiments, primary and secondary schoolchildren became friends

2. How to cope with the modern clinical appraisal of vulnerability and uncertainty? Moving towards an epistemological refoundation of the public health system, of medicine and the training of healthcare providers and social workers

The following thoughts and proposals are somewhat external to the object of this Opinion which focuses on the concentration of the elderly all together in so-called residential homes. However, they concern a reality which, to our minds, is not sufficiently present in the considerations of public health. The ageing of our society is a change of paradigm: the elderly's confrontation with vulnerability is an increasingly resonant reality. This change of paradigm has a bearing on the very concept of health. It implies a reorganisation of our public health system. And it must therefore involve a reform of the training given to those who will be the healthcare providers working in this new environment.

- *Reverting to singularity and alterity in a standardised universe*

  The complexity of the situations generated by modern medicine is a consequence of the singularity of these situations. Because they are singular, they fall outside the norm, the social average and scientific rationality. Nor do they, therefore, fit in with evidence-based medicine since in such circumstances there is no such thing as expertise.

  This reality is unfortunate in a context typified by the hegemony of norms and the pre-eminence of science. How can we approach this unthought of situation?

  Since traditional medical rationality fails us, there is a risk of stumbling from hyperrationality into irrationality. Subjectivity (made up of emotions, beliefs, representations, projections, fears, etc.) may well be inherent to decision but must not be allowed to block out rigour or obliterate common sense. Listening with attention to what sick or elderly people have to say, an interdisciplinary approach to complexity and good team work are the keys to operational rationality so that a happy medium can be struck between two excessive positions: "management" and "abandonment" of the person concerned. These two extremes are a denial of the person as "an object of care" who of course may well be vulnerable and dependent on others, but who is often capable of understanding and expressing an opinion or of choosing between various possibilities… Or at least, a lot more frequently than they are given credit for…

- *Learn to work together as a team to enhance decision-making in complex situations marked by uncertainty*

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with people suffering from Alzheimer's disease, accompanied them in their wanderings, showed great willingness to care and interact in conditions where dialogue was sometimes very baffling. They also became acquainted with death in workshops ongoing throughout the school year when one of the participants died. This is all instructive response for young people's existential demand for truth on transmission, solitude and finitude. Is it not mainly the fears of active adults that lead to keeping children away from the presence of vulnerable people?

Because healthcare providers are often confronted with limits (the limits of knowledge, of life, of sense) they lose sight of their usual cues and must battle with uncertainty. They therefore need to learn to doubt and to manage this doubt which is inherent to their occupation. Not knowing is an uncomfortable position to be in when you are supposed to take responsible decisions and to choose between different courses. But doubt can also be seen as an epistemological tool for disputing certainties and uncertainties, for checking on the validity (and therefore of the sense) of healthcaring actions and projects. Doubt is a competence which ensures the need for debate before deciding on action. It calls for a demonstration of the soundness of a choice or of a conviction. It represents an obligation to hear out other convictions and to respect other arguments which may, for the same subject, lead to different decisions. The least harmful decision is often one which is midway between extremes, where the various viewpoints on the patient's situation intersect. While very probably a decision arrived at in this way is more likely to be respectful of the patient and be fit for purpose, it is certainly also true that it will be easier for the physician and the other health carers to assume responsibility for it.

A *sine qua non* condition for taking on complexity and resisting the temptation of relying entirely on technology and science is self-confidence and working as a team. When they are confronted with singular and complex situations where uncertainty reigns, all the health carers of a patient must first of all acknowledge that they do not know what is best for someone else and that science and technology are instruments, not solutions.

To be self-confident means a certain degree of self-esteem. It also means that you have achieved a clear view of yourself as someone who is essentially characterised by limitations. It is not absolutely certain at this point in time that higher education — medical studies in particular — are an encouragement to this end.

To work as a team, respect must be central to professional relationships. Although working as a team implies some degree of hierarchy necessary to make advances in healthcare projects and to construct departmental projects, hierarchy cannot be allowed to be limited to the single dimension of "authority". Each and every member of the team must, from wherever he or she stands, contribute to a rational approach of the patient's complexity and singularity. The arbitrary and traditional hierarchy among physicians and other healthcare workers may be an impediment to a discursive approach and working as a team. Such methods must gradually give way to a situation where each member of the team, speaking as a qualified professional, can freely express an individual vision of the "complex subject". The distinguishing features of interdisciplinarity are interaction and mutual influence, so that the final result is a reciprocal exchange and evolution of knowledge in a spirit of cooperation[9].

In this way doubt becomes an instrument for progress because it facilitates interdisciplinarity which is itself a method for dealing with complexity. The hesitancy inherent to coping with complex and singular situations can then become a fecund source of creativity and inventiveness. Doubt and uncertainty force the professions to constantly adapt their healthcare logic, thus reducing the gap between prescription and reality.

[9] Jürgen Habermas. *De l'Éthique de la discussion* (1991). Translated from German by Mark Hunyadi, Paris, Cerf, collection « Passages », 1992, 202 p. (1st edition 1991)

Rethink the concept of performance in the presence of complexity, singularity and uncertainty

The concepts of performance and profitability, after fading away from finance and business are now edging towards the health sector. As we have seen, at a time and in a context where emphasis is always placed on saving time and glorifying action, there is often the misapprehension that speed and performance are one and the same.

Uncertainty can be the origin of performance as a new approach to the relationship between health carer and patient. Time and even more important, availability — meaning that someone may have the time but not be readily available — are certainly instruments for performance. Using these instruments to communicate in rhythm with what each party is ready to say or to hear is how a trustful relationship can be built up with an elderly or ailing person. It is a fact that a climate of trust between the one who is cared for and the one who gives care is a factor furthering autonomy for both of them and for limiting anxiety.

What does it mean to be a high-performer for a health carer? When is a health carer profitable? Is being a high-performer the same as being profitable? Or does it mean efficiency regardless of cost? Such questions may seem shocking or startling since they are not rooted in the healthcare tradition, but they are pertinent because aiming for the optimisation and improvement of healthcare is a quest for quality which necessarily involves health carers.

In order to be constitutive of performance, efficiency and effectiveness and sometimes even profitability goals must be achieved by means that are socially acceptable and therefore justifiable in ethical terms. Such questions, put forward in a very restrictive economic context, may present the risk of designating financial profitability although other dimensions deserve to be explored (clinical and social returns, for example).

There are indeed instruments for improving clinical performance. They are used to control risk, improve the quality of health and optimise costs. Systems for reporting adverse events are one example. Interdisciplinary action is another, as are also mortality and morbidity reviews as is also the T2A pricing per activity system — the financial system used for short stays in hospitals — if only one takes the trouble of calling into question its use and its limitations. Sadly, the concept of "activity" in the T2A system is limited in scope and regarded as being no more than a technical procedure. How can interdisciplinary reflection as well as a decision not to act be appreciated at their true value when T2A at this point does not recognise that thinking things over before acting and deciding not to act, despite the fact that action is feasible, are probably the most complex actions of medical activity. Similarly, communicating with a patient in pain to listen, inform, help to get better, is not recognised for its true worth. Ultimately, there are no instruments with which to appreciate and improve a caring relationship.

Furthermore, in complex cases, it would seem that performance is related to an interdisciplinary approach[10] thanks to which the work of the various actors concerned can be coordinated, possible complications and possible remedies for them can be anticipated, experience and abilities can be pooled, the subjective component of decisions can be minimised and possible work-related or personal stresses can be limited. The profitability of such a high-performing approach could certainly be measured indirectly by savings on expenses, suffering and pain avoided as well as by the contentment of actors, patients and love ones.

- *Train health carers differently and invent new job descriptions in the health and social sectors*

  There will be a need to reflect on the initial and continued training of health carers and social workers in order to face up to the new challenges arising out of medical progress in the 20th century. These challenges require qualifications that current training courses for physicians do not address or only addresses marginally: the construction of ethical reflection, inter-personal relations and communications, interdisciplinary and coordinated working methods[11].

  Teaching methods need to be thoroughly reviewed. There is an absolute need for those who will be working together to cure and to care for their fellow human beings, to be trained together. But at this time, training is "tubiform", categorial, mono-professional.

  There is a need to integrate work-linked training but at this point, not enough work is being done on how internships work out in practice and there is often no integration between the theoretical academic approach and an analysis of practices.

  There is also a need to think in terms of transferring tasks from healthcare professionals to social workers. Should the monitoring of chronic conditions and therapeutic rehabilitation remain the purview of physicians *stricto sensu*? Shouldn't tomorrow's physician focus on that for which he will have been trained, i.e. clinical complexity, vulnerability and uncertainty? Diagnosing and orchestrating complexity will be at the core of the role of tomorrow's physician. Caring and educating will be a role shared out between all the healthcare and social care professionals who will have been trained together on such matters.

  New professions will be born to cope with these new realities generated by medical advances. The needs of these new kinds of patients and new kinds of elderly people will require coordinating skills. It will probably be necessary to create new professions, situated at the interface of those existing today so as to coordinate the various contexts (sanitary, medico-social, social), the various places where care is provided (hospitals, homes) or where people reside (at home or in an institution), the various needs (social, medical), the various players (people, professionals, structures, etc). In economically constrained times, with a mind to the logic of territorial proximity, there will be a need for new coordinators and case managers so as to improve people's quality of health, reduce the public health system's entropy, allow health carers to return to the essential core of their mission. By the same token it will probably be possible to reduce costs or at least avoid cost increases. On this point, managers for establishments and services must be

[10] Edgar Morin, *Introduction à la pensée complexe* (1990), Paris, Seuil, Points essais, 2007

[11] Aubry R, Mallet D. *Réflexions et propositions pour la formation médicale.* Pédagogie médicale 2008 ; 9 (2) : 94-102.

made aware of changes in the way treatment and care need to be provided for new dimensions to old people's lives. They must also learn to implement a policy for maintaining social contacts for those in residential care, through non-compartmentalised transversal cooperation between all the healthcare and social participants.

3 Towards new forms of solidarity to care for the most fragile and vulnerable in our society

- *Create a fifth section in our social security system?*

  The 1945 decrees created four sections of social security:
  - ✓ insurance against the risk of disease (sickness insurance covering also maternity insurance,
  - ✓ insurance against the effects of accidents at work and occupational diseases,
  - ✓ contribution to family resources depending on the number of children (child benefits)
  - ✓ payment of an old-age pension,

  These four sections of "social security" in light of their competence and resources, do not now, and will not in the future, be able to respond to the physical needs of age-related dependency. Nor will they be able to meet the costs of the various forms of accommodation or of preventing disablement and loss of autonomy connected to chronic or acute morbidity. In order to set up an ambitious public policy to cope with dependency (see the Conseil d'Analyse Economique's note by de Bozio et al. on alternative policies[12]), the authorities should create new social contributions to be paid by all taxpayers but with a progressive component so as to guarantee that dependency would be financed for everyone, regardless of people's capacity to pay and so as to avoid any increase of income inequality. These contributions should not be borne by salary-earning employees and their employers alone so as to guarantee financial equity regardless of age. These new contributions, to cover a fifth section of social security, should be calculated according to the wealth of taxpayers. Their object would be to cope with the demographic challenge of ageing and that of the social assistance implications of dependency, disablement and infirmities brought on by extreme old age in the context of the current demographic evolution.

  Currently, social assistance, accommodation and keeping people in their own homes are paid for by funds belonging to territorial communities who are straining to keep up with the transfer of responsibility and financial burdens, not always compensated for by central government as a result of decentralisation laws. The same community funds are also expected to contribute to the financing of medical and social establishments to house people whose meagre pensions are insufficient to pay for their stay in public EHPADs or private non-profit establishments participating in the public service as a result of agreements with social security.

  Administrative, regulatory and above all financial compartmentalisation between regional health agencies (ARS) — *via* the fixed allowance for healthcare paid to establishments from funds allocated to the *caisse nationale de solidarité pour l'autonomie* (CNSA) National solidarity fund for autonomy) — territorial communities, municipalities, territorial "*departements*" through their various social aid services and establishments (public and private non-profit EHPADs housing residents supported by social services, for

[12] Bozio A., Gramain A., Martin C. with the contribution of Masson A., "*Quelles politiques publiques de la dépendance"*, *Les notes du Conseil d'analyse économique*, n°35, October 2016.

which the single variable for budgetary adjustment is now the total payroll of healthcare professionals), can *in fine* work out to the disadvantage of the elderly.

In the circumstances, it would appear legitimate to consider providing for dependency by the creation of a "fifth social security section" insuring against the material consequences of loss of physical independence and mental autonomy. The "fifth section" concept is also consistent, *inter alia,* with the notion of the universality of healthcare management, with the difference between social assistance linked to the beneficiary's personal circumstances for which community solidarity acts as a substitute that may decide to recover its expenditure, and social security based on indemnity as the counterpart of a contribution[13].

As far back as 2007, the CNSA listed the limitations of the present system[14]: the inadequacy of the APA (*Allocation personnalisée d'autonomie* – personal autonomy allowance) as compensation for the remainder ("*reste à charge*") that patients or families have to pay out of their own pockets, the disparities between territorial departments and the complexity of regulations leading to breakdowns in access to social rights and the exhaustion of family health carers. The CNSA proposed that a distinction should be made between the issue of the consistence of the universal right to help for personal autonomy (a personal and multidisciplinary evaluation of needs based on a reference list of properties and services so as to define the various components of the personal compensation benefits) and the possible options for the financing of that right.

The CNSA was thereby emphasising the need for triple clarification concerning firstly the portion paid out of public finance and the individual or collective contingency schemes, secondly the taking into account of the beneficiary's resources in order to decide on access to financing or decide on the level of coverage by this financing and thirdly, the portion of such financing to be provided by national solidarity and the territorial budget.

The "fifth section (*5ème risque*)" plan seems to have been dropped in 2012 because of the cost. In 2008, a Senatorial information commission evaluated the burden on public funds that would be needed to cover the loss of autonomy of the elderly population at approximately 19 billion Euros, i.e. the equivalent of one point of gross domestic product (progress report by the joint information mission on the financial management of dependency and the creation of a fifth section dated 8 July 2008. But was this the only reason?

The existence of a fifth branch in the social security system does not appear straightforward in the current legal context… It would certainly be complex to set up but not an impossibility, as provided for by Article L. 111-2 of the Social Security Code: "*Later decrees could extend the scope of social security to… risks or benefits not included in existing regulations"* [15].

It should be noted finally that a number of commentators consider that policies on disablement and dependency are bound to converge sooner or later, although they are still planned separately, since they are seeking to achieve a common target: respond to the consequences of loss of autonomy. Criteria for dependency and autonomy should be

[13] Rémi Pellet, Arnaud Skzryerbak, *Leçons de droit social et de droit de la santé,* Sirey, 2008, pp.566-591

[14] 2007. Report by the *Caisse nationale de solidarité pour l'autonomie. Construire un nouveau champ de protection sociale.*

[15] Denis Piveteau, *Prendre en charge la perte d'autonomie ou : à quand le « cinquième risque » ? Thèmes et commentaires, quelle(s) protection(s) sociale(s) demain ?*Dalloz, pp. 79-9A

identical (without reference to age, in particular), be they those concerning disabled or those concerning elderly dependent persons, with the aim of creating a risk of dependency for which financing should also be planned[16].

On the issue of the "remainder" borne by families and the implementation of the maintenance obligation expressing family solidarity and setting a limit on public financing, this needs serious in-depth reflection because it is currently financed on a territorial basis and the various French administrative entities implement different policies so that the principle of equality of treatment is flouted.

The exemption by law of grandchildren and great grandchildren could be one option so as to harmonise current judicial practices as regards the implementation of the maintenance obligation. Similarly, the extent of accommodation costs involving the maintenance obligation could be redefined to cover only basic costs, i.e. board and lodging. Finally, limits could be set on the application of the maintenance obligation depending on the duration of its application and the degree of dependency of the elderly person.

- *Recognising the role of family "caregivers" and creating provisions for their full entitlement to respite*
  It would seem essential to recognise the role of families now that an ever-growing number of disabled or dependent people are living at home for long periods of time so that the assistance of their relatives is necessary in the form of presence and active help, or sometimes financial help. In our modern world, caring for an elderly or seriously sick person is no easy task for family members. Their availability and their ability to cope with the needs of their loved one are dwindling because of the combination of several factors. In addition to the collective denial of finitude mentioned above, profound and recent modifications in 20th century society have contributed to a form of disconnection as regards the care of people who have become vulnerable because of age, disease or infirmity. A non-exhaustive list could include the fact that more women are in employment, that society is increasingly secular, that the traditional image of family has disappeared in the wake of new family reconstructions and that values granted to work and money are overrated. More than ever, there is a need to recognise that caring for loved ones requires competence and time. Family caregivers are sometimes therefore rather unwilling. Helping them to be healthcare providers or on the contrary to free them from a feeling that they must do so whether to wish to or not; helping them by identifying their limits and the first signs of oncoming exhaustion... These are new tasks that members of the medical professions involved in the care of the dependent elderly will now need to master.

  A recent scientific publication[17] shows that, on average, elderly men spend 2.4 years and elderly women spend 3 years needing intensive care. These figures have considerable implications for the families who are supplying most of unpaid care for the elderly.

  As regards the very old, there is also a need to think about preventing the onset of exhaustion syndrome for family caregivers, particularly young grandmothers aged about 65-75, torn apart by the wish, or perhaps the duty, of looking after their grandchildren and

[16] Jean-Michel Belorgey, *Vous avez dit dépendance ?*Regards n°23, 2003, p. 14)
[17] Kingston A, Wohland P, Wittenberg R, et al. Is late-life dependency increasing or not? A comparison of the Cognitive Function and Ageing Studies (CFAS). Lancet. 2017;6736(17).

the need to be available to take care of very old parents. This is a real challenge for any caregiver looking after someone who is no longer physically, mentally and socially autonomous[18].

It will also be necessary to recognise a right to respite and therefore to provide for the creation of respite time and respite facilities so that caregivers can stay the course for their care providing mission. It should be noted that although there is no political awareness as such of this need, a number of local experiments on the subject of respite are in the process of seeing the light of day or coalescing in France[19].

Our entire public health system centres around the person concerned and devotes very little attention to the duo care giver/care receiver[20]. The healthcare paradigm should now evolve to include close relations, since the aid provided by caregivers is the *sine qua non* condition for keeping dependent people in their own homes. It is certainly true that "institutionalisation" and "placement" — wording that needs revising — may be in fact a physical and mental relief for relatives. But when institutionalisation becomes inevitable and is experienced as an imposition, as is often currently the case, it frequently induces feelings of guilt and confusion in carers. In fact, institutionalisation is now happening increasingly late in life. The average time spent by a seriously ill or disabled person at home before going into an institution is currently two and a half years. Structures for post-acute and long-term care, or even some medico-social structures are evolving, and will probably evolve further, towards care and intensive care for highly dependent patients. Staying at home is only conceivable if the premises are suitable as housing without adverse side effects for those concerned.

For all of the above reasons, a plan must be drawn up for the support and respite owed to caregivers so as to render possible and bearable the continuing tendency to abandon institutionalisation in favour of staying at home. Such a plan should aim to reverse the compartmentalisation of sectors and to reconsider the model for people's life and health experience. It should include the existence of halfway houses in a non-medical environment instead of in a hospital environment. This should take the form of respite in a variety of offers (respite housing, respite holidays, and a scheme involving professional help, called "baluchonnage" in Canada or "relayage" in France[21], and combined accommodation for carers and cared for, etc.). It should make a contribution to the institution of a universal right to respite by, for example, organising thirty days of respite in one or several instalments every year for all carers, to be paid for by the community. It should facilitate the training of healthcare professionals for these tasks and encourage the

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[18] Novella JL,Morrone I, Jochum C, Jovenin N, Blanchard F *« Prévenir le syndrome d'épuisement de l'aidant du sujet âgé dépendant pour un meilleur maintien à domicile »,* (Prevention of exhaustion syndrome in caregivers of elderly dependent persons so as to improve conditions for keeping them at home). *La Revue de Gériatrie,* 2001; 26, 2: 135-150

[19] On this subject, see http://www.france-repit.fr/ where the strength of this essential commitment to citizen action and solidarity can be measured.

[20] Audition of Monsieur Henri de Rohan Chabot, General delegate, France Répit. 17 May 2017

[21] A recent parliamentary report, by M.P. Joëlle Huillier. "*Du baluchonnage québécois au relayage en France: une solution innovante de répit. 2016"* – (Baluchonnage (Quebec) and relayage (France) – an innovative solution for the problem of respite) broaches this issue and should be studied. "Baluchonnage" is a system in which a professional helps out a familycare giver who is looking after someone who needs 24/7 attention at home, by taking over for several consecutive days.

pursuit of research on the subject. Perhaps a new profession, "*adviser for the support of carers*" should be created. All these new measures could logically be underwritten by the avoidance of indirect costs and by a form of insurance, this issue being the same as the inclusion of the coverage of such new expenditure by the "*fifth section*", as mentioned above.

- *Broadening solidarity by changes in social legislation*
  Although tangible changes are being processed in this connection, it would be good to develop an extension of labour legislation to include the possibility of a family member taking care of a sick or disabled person. There already are, it is true, special arrangements in social legislation designed to cover assistance for dependent people[22]. Several examples can be quoted: special compassionate leave or time-off entitlements that can be used to stop work temporarily to attend to members of the family in need. This is the case for the special leave given to family caregiver employees referred to in article L. 3142-16 of the labour legislation when a loved one (listed in the text of law) is severely disabled or suffers a serious loss of autonomy. There is also leave for family solidarity in favour of caring for a dying relative (article L. 3142-6). In this latter case, the employee is granted a daily allowance disbursed by the sickness insurance system following applications to the national central office for the allocation of allowances. With the agreement of their employers, employees may ask for this leave on a part time basis or in fractions. More recently, the 13 February 2018 law reinforced previous legislation on this subject with a system for the donation of unused days' leave to caregivers assisting loved ones losing autonomy or suffering disablement. It is worth noting, however, that these measures are for the benefit of employees and do not therefore concern people who are not employed.

  So how could legislation be improved and foster such solidarity? It should not continue to be restricted to family members alone, failing which we could be eternally harking back to the 19th century Napoleonic Code of law. The legislation must involve the whole country and its republican social system. *"Solidarity has effortlessly eclipsed fraternity in the list of the Republic's founding principles"*. Solidarity has become "the single general principle to which the Law refers social security today: *the principle of national solidarity*". It is a fact that the legal emergence of non-professional labour leads to demand for "*forms of legal recognition that are not directly monetary, but instead conducive to the granting of social rights*" [23]. Nor, for that matter, does anyone dispute the fact that these activities are socially useful and may furthermore generate savings in social expenditures.

  One approach that would be worth exploring could be the upgrading of the *compte personnel d'activité* (CPA – personal activity account). The CPA was created by the 8 August 2016 law on working conditions, modernisation of the social dialogue and the

[22] Law n° 2010-209 dated 2 March 2010 for the creation of a daily allowance for the care of a person at the end of life.
Decree n° 2016-1554 dated 18 November 2016 on special leave for a care giver in application of law n° 2015-1776 of 28 December 2015 in connection with society's adjustment to ageing and article 9 of law n° 2016-1088 dated 8 August 2016, on modernising the social dialogue and the safeguarding of careers.
Law n° 2018-84 dated 13 February 2018 creating a system for the donation of untaken days' leave to care givers assisting people who are losing their autonomy or disabled.
[23] Alain Supiot, *Les mésaventures de la solidarité civile*, (the misadventures of civil solidarity) Droit social 1999, p.64

protection of professional careers. The concept had been debated for quite some time, but its implementation in this instance was innovative: [24] attach rights and personal protection to individuals instead of to their employment or professional status. This was designed to take on board the fact that careers are increasingly discontinuous and, in particular, that during certain periods of time people may, for various reasons (unemployment being obviously the main reason) be outside the working orbit. Among the motives for setting up a CPA system there is also the wish to facilitate recognition of socially useful employment. The CPA system is based on three major principles: equality of accounting applicable to all workers, regardless of status, the portability of rights and the fungibility of rights so as to promote each worker's liberty and autonomy in the definition of his or her career. New categories of rights could be used to enrich the account, particularly rights in favour of the most vulnerable or those least favoured by the prospect of employment, but also by attaching more value to citizen commitments. Here again, the unavoidable issue of funding arises: by national solidarity, by employers directly or by a sharing system, or by the person concerned directly? The *France Stratégie* report puts forward a possible scenario: "...a personal activity account constructed around the concept of time periods, with a more coherent breakdown of the different time sequences throughout a lifetime, or even the recognition of non-market activities and fungibility of rights extended to compensation in time creating solvency for socially validated activities" [25]. Such are some of the potential purposes that could be made of the CPA system. Why should periods of time devoted by family and volunteer caregivers to helping dependent loved ones not be recognised? The time and effort spent in caring for someone could be recorded in the CPAs. Family solidarity could also be recognised, as is the case for citizen engagement, by the creation of a new account to be integrated in the CPA to accumulate rights to training time facilitating a return to paid employment. It is true that this would be a complicated system to set up and that this new entitlement will be difficult to organise technically and funding it will be even more difficult, but proposals could be submitted for interprofessional discussion on "the systems that could be integrated into the personal activity account" [26] as envisaged in the 2016 Law.

- *A focus on elderly people in severely precarious circumstances*

  People living in precarious circumstances have a much shorter life expectancy (between 54 and 60 years) than the rest of the population, but they also have dependency problems in their late years. With rare exceptions, for lack of financial resources, they do not have access to EHPADs. When they do, they frequently run into problems with adapting to life in a community because they previously lived very much in isolation. People living in precarious situations also face precariousness when they stay in their home with the help of friends or relatives to look after them and who therefore are not free to seek employment elsewhere. Such situations give rise to problems: 1) home care is costly for families; 2) health carers are aghast at the precarious lifestyle and tend to focus excessively on the precarious circumstances rather than on the person concerned; 3) such

[24] V. Alain Supiot (dir.), *Au-delà de l'emploi, transformations du travail et devenir du droit du travail en Europe, Rapport pour la Commission des Communautés européennes*, (Beyond employment: changes in work and the future of labour law in Europe) , Flammarion, 1999

[25] Selma Mahfouz*, Le compte personnel d'activité, de l'utopie au concret,* (The personal activity account, from utopia to concrete application.) France Stratégie, 2015; Droit social 2016, pp.789-791

[26] Isabelle Vacarie, *L'essor des comptes personnels, marqueur d'une recomposition du droit du travail,* (The development of personal accounts, markers for rethinking labour legislation) Droit ouvrier 2017, pp. 174-186

findings militate in favour of providing specialised training on precariousness issues for health carers as well as financial support.

- *Encouraging new types of volunteer work*
  There is a need to devise new forms of volunteer work so that the solidarity between those who are healthy and those who are sick or disabled and their loved ones can be put to good use. As regards palliative care on the one hand[27] and assistance to the elderly on the other[28], there is a readiness to volunteer. There is a need to imagine new types of voluntary care activities so that the real-life circumstances of frail and vulnerable people can be better understood. One possibility of developing a natural inclination to solidarity would probably be to educated primary school children on the role of voluntary work in the social structure.

  In this connection, it would be helpful to think up ways of relaxing existing regulations governing EHPADs so as to facilitate the presence of volunteer workers.

Better protection for vulnerable people via the appointment of an interdepartmental delegate for the protection of adults.
This was suggested in a recent report by the *Cour des Comptes*[29] (French Court of Auditors) pointing out emphatically that public policy on the protection of vulnerable people is neither embodied nor directed although there is abundant provision in law on this issue. It has now become essential to gather together a broad spectrum of collective and dispersed reflection into a project for a redefinition of social protection. In this way, it should be possible to respond to the challenges of ageing and, in particular, to the duty of respect for the rights of people whose vulnerability has been greatly increased by the failings of their decision-making capacity. The interdepartmental delegate for the protection of vulnerable adults would be tasked with reviewing — with a mind to transversality — issues concerning the vulnerability of elderly and/or disabled people, be they or be they not within the scope of legal protection[30].

[27] In this respect, Law n° 99-477 dated 9 June 1999 guaranteeing access to palliative care recognises and regulates volunteer work in end of life caring.
[28] Law n° 2015-1776 dated 28 December 2015 on adapting society to ageing provides for (Title I – anticipation of autonomy loss – Chapter III: Combatting isolation – Article 8 -) funding by the CNSA for training and assisting volunteers who are making a contribution to maintaining social cohesion.
[29] *Cour des Comptes*. *La protection juridique des majeurs. Une réforme ambitieuse, une mise en œuvre défaillante.* (Legal protection for adults. Ambitious reform and defective implementation. Communication to the *Commission des finances, de l'économie générale et du contrôle budgétaire de l'Assemblée nationale.* September 2016.
[30] Report « *Droit et éthique de la protection des personnes*», (Personal protection: law and ethics) *Commission nationale pour la bientraitance et les droits des personnes âgées et des personnes handicapées,* Anne Caron-Deglise, Karine Lefeuvre, Julien Kounowski, Benoit Eyraud, 4 mars 2015. by the national Sub-Committee for the fair treatment of the elderly and the disabled, and their rights). 4 March 2015.

4. **For a reinforcement of policies to care for the elderly**

Arnaud Montebourg and Michèle Delaunay, in the preface to their report to the *Commissariat général à la stratégie et à la prospective,* in December 2013[31], stated: *"The Silver Economy can lead to the creation of 300,000*[32] *new jobs in the home care sector by 2020. Our primary and vocational educational system should be able to steer young people and employees attending retraining sessions in the direction of promising sectors and professions included in the Silver Economy. There is an essential need for reflection on the attractiveness of this branch of activity".*
In a society struggling with employment and with a large number of people — young people particularly — unemployed, it seems likely that new forms of solidarity would be appreciated as meaningful and not just because of their job-creating potential.

Developing a culture of prevention the better to anticipate the "fourth age".
Old age is now divided into several periods of time: initially, the age of retirement (60 to 75 years), during which people are generally active, in good health, autonomous, capable of helping their families and are working with associations and/or engaged in professional activities. This group of people, who are only slightly dependent if at all, fill an essential role in the development of a preventive culture in preparation for the 4th phase of age. They are well able to organise new homes for themselves in order to move into housing that will be more compatible with possible future dependency; they can get in touch with associations with a view to developing better social, economic and cultural integration for the older age groups and, more importantly, help to develop ethics of hospitality for the elderly in the eyes of the public of whatever age.
In the second phase of age (75-80 years) the risk of isolation grows and ill health, directly linked to age, looms ahead.
In the third phase, after the age of 80, dependency and multiple health-related problems are more generally encountered and the problematic relocation in an EHPAD becomes a major issue. This is the time when remodelling the home, organising home care, establishing connections with caregivers, all become essential at a time when the elderly are becoming more vulnerable and less able to claim their rights and state their preferences. Anticipation of this time of life is therefore important the better to respect people's wellbeing and consent.

- *Developing intergenerational projects to fight against isolation, exclusion and exclusive concentrations of elderly people.*
  Intergenerational projects could be a welcome reaction to the "concentration/exclusion" of elderly people in dedicated establishments. It would seem essential to develop intergenerational experiments involving healthy and sick or disabled people, the young and the old, the gainfully employed and the unemployed or retired, etc. It would perhaps be an opportunity for nurturing essential solidarity and mutually instructive relationships in which people who have become economically "inactive" because of their advancing age could contribute the benefit of many years of experience and a rich array of

[31] Claire Bernard, Sanaa Hallal and Jean-Paul Nicolaï. *La Silver Économie, une opportunité de croissance pour la France. Rapports et documents.* (The Silver Economy, an opportunity for growth in France. Commissariat général à la stratégie et à la prospective. December 2013
[32] Which would represent a wage bill of about 8 billion Euros, but also a significant economic stimulant. This would be half the expenditure considered by the Senate's 2008 report mentioned above.

professional skills. Such projects should be integrated fully within the community so as to maintain presence of the elderly within society and facilitate access to the giving and receiving of services. It is easy to imagine how such novel projects could in fact become an exchange of mutually beneficial services between participants as well as factors for dissipating isolation and solitude for old people living either alone or even housed in an institution. Such projects could be the subject of experimentation and combined research with respect to structure and function and would, for example, make it possible to measure or estimate the link between autonomy and architecture, how forward planning can contribute to improve the image of elderly people in our society in the eyes of younger generations, provide fresh meaning to some lives, "social or socio-anthropological" benefits and contribute to reducing the impact of certain pathologies such as late-life depression.

- Reflecting on solidarity with the assistance of the digital revolution, home automation and robotics

Digital technology provides unprecedented opportunities for assisting the aged. It is up to us to make it into an instrument for autonomy and freedom, solidarity, a possibility for focusing on a humane attention to the human, a way of avoiding isolation and exclusion. If it is well thought-out, this shift to digital could contribute to the creation of new forms of solidarity. This is particularly well argued in the 2016 law on adjustment to ageing[33]since it militates in favour of using digital technology to keep people in their own homes and for the creation of new forms of housing such as autonomous residential projects meeting certain mandatory specifications for digital assistance technology. With the help of digital technology self-determination can be extended, such as making independent decisions to do something without assistance which otherwise would have to be decided and done by someone else, or simply doing something pleasurable with the beneficial effects known to exist on the quality of an ageing person's life. These digital tools can also improve the quality of life by overcoming disablement thanks to digital assistance in day-to-day activities: seeing, hearing, communicating, bathing, getting dressed, moving, going to bed and getting up, preparing meals and eating, shopping for food, leisure activities, keeping up with current events, taking part in social activity. Downloading suitable applications on computers, tablets and smart phones or acquiring specific equipment, ranging from robotic devices to specially designed home and prosthetic appliances can help to achieve these goals.

Altogether, digital technology helps to keep people in their own homes to the greatest extent possible without danger or loss of dignity. We are referring here in particular to the installation of appropriate sensors in the home for monitoring physical parameters such as a fall or lost consciousness, or activities such as the flow of hot water, the microwave oven or the television set to check on whether they have been used and if so, at what time and for how long.

These extremely positive points must not be allowed to obscure the need for vigilance and the possibility of risk. Firstly, as regards costs: purchase price, maintenance, upkeep. Ageing (and more generally disablement) has become a marketing "niche" with suppliers

[33] https://www.pour-les-personnes-agees.gouv.fr/actualites/la-loi-relative-ladaptation-de-la-societe-au-vieillissement

inventing a profusion of products at unreasonable prices to exploit vulnerability or emotional responses. Who wouldn't want "the best" for their parents? The digital inexperience of those ordering the equipment (families often) and the lack of legislation on digital assistance items which are not governed by rules for medical devices, must be taken into consideration. Other important points are dependence on suppliers, problems with interconnecting equipment and data (formats), whether equipment is supported by multi-platforms or require the purchase of a specific machine. Furthermore, at best data confidentiality is often ignored, or at worst, exploited. Connected objects (sensors mainly) supply a considerable quantity of confidential data (images, voice, movement, activities). This must be protected and remain under the control[34] of the people directly concerned, or failing that, under the control of their care givers. In conclusion, the responsibility and the ethics of scientists and engineers, and of those financing research must be subject to question: are scientific and/or technological innovations always a factor for progress and of real benefit for the people concerned?

At this point in time and in this context, the Silver Economy market is emerging with difficulty in spite of optimistic prospects[35]. Technology can help to alleviate in part the diminishing number of carers, who are often regarded as intrusive, and thus provide a more regular and pertinent monitoring service. Thanks to these tools, carers and healthcare professionals can gain remote access to data on state of health, nutrition, mobility, hygiene, etc. Some of the medical follow-up can be done without the elderly person having to travel to a hospital or see a doctor. This technical development is a remarkable tool but is a means to an end, not the end itself. Ensuring that the elderly themselves, carers and healthcare providers understand how best to use it is one of the challenges of the coming decade. In this time period, there will certainly be some major improvements to these tools and services and to their capacity for adaptation, interaction and attentiveness.

In conclusion, let us note that we are living in a time of major change and that the use currently made of digital technology is not necessarily a template for their use in future. The better grasp of these technologies by people currently in active employment or currently in their "third age" will help them with their planning for later years and will ensure that they are better able to make use of the digital tools of the future for their comfort and services. The same is true for carers and healthcare professionals.

- *Creating new jobs and rehabilitating proximity service providers*
  It is easy to imagine the massive potential for employment that could be offered by home domestic services, providing that those practising these professions — who are particularly exposed to emotional stress and "burnout" — are trained and assisted throughout their careers and that their valuable work is appreciated at its true worth with,

[34] We are referring here to control, not to ownership.

[35] "*With the production of home automation and assistance devices, the Silver Economy will also generate industrial and technical job opportunities (sales, installation, maintenance). There will be a substantial impact on a number of sectors: the tourist and leisure industries, construction and housing sectors with home adaptations, and, more generally everything coming under the name of "e-autonomy" (active or passive remote assistance, geo-assistance, remote medical assistance, lighting strip systems, etc.*)". Claire Bernard, Sanaa Hallal and Jean-Paul Nicolaï. *La Silver Économie, une opportunité de croissance pour la France.* (The Silver Economy, an opportunity for Growth in France). Reports and documents. Commissariat général à la stratégie et à la prospective. December 2013

inter alia, financial compensation in the form of a salary and regard for the onerous nature of the care they have to provide for the very fragile people they attend to.

In 2000, European governments made a commitment *via* the Lisbon Strategy, for the reinforcement of the competitiveness of their economy through innovation, research and qualification of the workforce, in particular as regards sectors exposed to international competition. According to the economist Nicolas Bouzou[36], Founder and Director of the consulting firm Asterès, *"... protected sectors of the global economy, such as those engaged in services to individuals which support the proximity market, should not be neglected. An increase in government allocations to this sector leads to increased salaries and job creations, all of which represents a factor for growth in the European Union at a time of economic recession…*".
A recent parliamentary report[37] made some interesting proposals as regards home care services (services d'aide à domicile/(SAADs). Among the points for improvement, it mentions funding the coordination of multi-purpose services for home care and assistance by regional health agencies (ARS). To quote this report, the *"central point" is the detrimental dichotomy between public funding for SAADs and the solvency of users within the personal autonomy allowance scheme (allocation personnelle d'autonomie – APA).* It also mentions "*the possibility of dropping the hourly rate and preferring a fixed rate for user participation".*

Currently, carers employed by EHPADs are swamped with work and often not sufficiently trained to cope with the moral support the residents are in need of. There is a desperate lack of equipment that could ease their burden (for instance ergonomic devices). SAAD employees (generally the SAADs are associations, but some of them are commercial enterprises) are mostly ill-trained, rated low on the prestige scale and generally underpaid although they are confronted on a daily basis with highly complex situations and have to face up to the vulnerability, loss of autonomy, solitude, isolation and reactive depression of the people they are supposed to "care for"; these professionals need to decode and "take on board" after a fashion the anguish of people who may be refusing to communicate or are aggressive. Such professional exposure to risk and misunderstanding by the community they work for must be recognised and there is a need to rethink the training procedures to include vocational training throughout a carer's career.

The concept of work performance in both EHPADs and in the patient's home, which sometimes leads to thinking of the employee wage bill as a variable in the composition of the budgetary adjustment of the institutions concerned or of the SAAD management organisms, should be reviewed. The performance of these assistance providers, whose contribution is akin to a public health contribution, should be enhanced by means of personalised counselling and support.

Finally, there is a need to build on emerging professional qualifications or professions such as case managers. Such employees are already engaged in activities but they need to be considerably reinforced. These are the "actions for the integration of assistance and care to preserve autonomy ("*méthodes d'action pour l'intégration des services d'aide et*

[36] *Les services à la personne en Europe*. (Personal services in Europe) Les cahiers de la santé. Hors-série (Think Tank européen Pour la Solidarité)
[37] *Mission relative à la tarification et aux perspectives d'évolution des Saad.* (Mission on a pricing framework and potential for development of SAADs). Rapport by Georges Labazée, M.P.. 2016

de soins dans le champ de l'autonomie" - MAIA) that include the need to assist in the health needs of the elderly by the use of three instruments:

- coordination so as to decompartmentalise the various sectors and construct a project to which all the actors involved can subscribe : decision makers, financial backers, assistance and care managers;
- an integrated advice system capable of providing, wherever in the country the information is asked for, a consistent and pertinent response to user needs, providing guidance to appropriate resources by integration of all the information desks deployed throughout French territory;
- a case management system for elderly people in complex circumstances (long term intensive follow-up including during hospital stays) to be implemented by case managers, in direct contact with the person concerned, with the doctor, with professionals health carers participating in home care. The case manager of complex situations would be the person to whom other players would refer and he or she would thereby be helping to improve the management of such situations throughout the country by identifying possible system shortcomings.

An important achievement would to work towards a consolidation of all the services for keeping the elderly in their own homes: SAAD, SSIAD, HAD (hospital nursing care at home), temporary residential care, residential services, EHPADs and daycare centres could be functionally coordinated in a territorial proximity-based framework. Having all these services grouped together or even merged would be a great help and simplification of the "one-stop desk" or single "basket of services" variety. If this were so arranged, elderly people suffering loss of independence and autonomy would be able to stay on familiar ground and keep the same health carers when they move, for example, from an SSIAD to HAD, or even moving from home to an "external EHPAD".

- *Adapting elderly people's dwellings*

Adapting people's homes, with the advice of an ergotherapist, in such a way they can stay there as they advance in age is one of the future's major challenges[38]. Now that the population is ageing, there is an essential need for land developers planning new places of residence to integrate the concept of a progressive loss of independence and/or of autonomy into their building plans and to adapt access to structures to suit people with disabilities.

The quality of life of the elderly depends just as essentially on their environment as it does on the provision of medical and paramedical care services. It is astonishing that decision makers do not calculate that the cost of adapting the environment is far less than the cost of providing healthcare and medical treatment. Adapting the home must be a happy medium between complete disfigurement and leaving things as they are, that is totally unsuitable for people with diminished independence. The approach must therefore be adapting the environment to the person and not the other way round, in a spirit of "risk assumed and accepted". An essential challenge is to arrange the home so that a person can move around in it, even though movement may entail a possibility of, for instance, falling. With an excess of assistance, people could end up being forced to a standstill.

[38] Hearing of Monsieur Jérôme Bataille, architect and town planner, 13 April 2017

Some interdisciplinary research involving both health and architecture[39] has shown that elderly people who have been suitably informed and who are keen to adapt their homes are perfectly capable of choosing among various options in order to arrive at a dwelling that is comfortable, safe, reassuring and yet not without charm.

- *In a single territorial area, encourage and diversify alternatives to EHPADs*
  Intergenerational habitats
  This form of cohabitation was originally designed to promote solidarity between various age groups. Intergenerational co-residence[40] can be related to precarious circumstances, such as an adult child supported and housed by an elderly parent, or an elderly parent living with children, where the two generations are providing mutual support.

  Self-managed housing
  Starting around 2000, in particular since the media coverage of the "*Maison des Babayagas",* the self-managed housing for the elderly theme is becoming popular in academic circles, among players in the field and the public at large. But the creation of this type of habitat is fraught with difficulties, the main one being the practical implementation of founding utopias. Constraints to make "living together" possible reside in coordination between autonomy and solidarity and would seem to be determined by the variety of life experiences of those who seek to set them up[41].

  Intermediary housing.
  Intermediary housing for the elderly offers an environment and services appropriate for problems connected to ageing but the accommodation itself is private and independent. Developers strive to preserve the feeling of being in one's own home to which elderly people are much attached[42].

  Living in such autonomous housing (*résidence-autonomie*, formerly *foyer-logement*) is often limited to a period of time between the previous domicile which had become inadequate or ill-suited and moving into an EHPAD.

  The change in legal status of the former *foyer-logement* to form the new *résidence-autonomie,* in the context of the law for changes in society to integrate ageing, means that residents can now continue to live there, despite a loss of autonomy. But when these residences take in "dependent" people, will they still be as attractive to the more autonomous elderly?

- *Considering EHPADS outside EHPADs and EHPADs tomorrow*
  To reduce the ghettoization of EHPADs, it might be worthwhile to think about developing the concept of EHPADs "outside" EHPADs. In new buildings for instance, by the same token as there are standards for a certain quota of social housing, there could also

[39] Després C et al., *Le logement et les soins dans le grand âge : briser les silos»,* Gérontologie et société 2017 ; 1 (39) : 107-124
[40] Jim Ogg et al., « La corésidence familiale entre générations adultes : un soutien réciproque », Retraite et société 2015/1 (N° 70), p. 105-125
[41] Cécile Rosenfelder, Vieillir dans un habitat autogéré : la question du « vivre ensemble » *Gérontologie et société* 2017/1 (vol. 39), p. 155-167
[42] Gérard A. Enjeux et stratégies de l'appropriation des espaces collectifs. *Gérontologie et société* 2017 ; 1 (39) :143-154).

usefully be one or two levels reserved for an EHPAD — for which a better name could be: residence with medical care and assistance for elderly people losing independence and/or autonomy" — where people needing these services in the building could be moved. It should be noted however that currently the point of financial equilibrium for an EHPAD is 80 residents and that regulatory construction standards for residential institutions will not be an encouragement for this kind of initiative. In contrast, creating in new buildings apartments where people who are already dependent would be housed and would get the follow-up care they need from a nearby EHPAD with its own health and medico-social resources, should probably prove to be possible without difficulty.

Existing EHPADs still have a role to play... But there is a real need for ethical action to bypass standards, prohibitions and laws that constrain and forbid, that prevent the exercise of the wishes and remaining capacities of people. Making it possible to cook, to garden; developing mutual aid between residents when one of them is experiencing an aggravation of dependency or autonomy loss... would be a way of making this ultimate stage of life more appealing.

Finally, it would be preferable for tomorrow's EHPADs to rehabilitate older constructions in city centres or in areas likely to become central or lively in the future. Tomorrow's EHPAD should be integrated in a single territorial system grouping together in proximity all of the services required for elderly people to be able to stay in their own homes, under a single territorial management.

V/ In conclusion

The institutionalisation of dependent elderly people, their concentration all together in residential establishments, excluding them from the rest of society, is probably the result of a collective denial of what old age, end of life and death can mean. It is not respectful of these people when it is the result of compulsion, which is often the case. Even when such compulsory institutionalisation is claimed to be with benevolent intentions and with the aim of ensuring the safety of vulnerable people, compulsion in itself, the frequent lack of any alternative to institutionalisation with, in addition, the obligation for those concerned to pay themselves for something they do not want, seems to be contrary to the ethics of respect for individuals.

The reality of change unfolding in our modern societies following on progress in healthcare and in particular technical and scientific medical advances, means that our fellow citizens must, collectively, become aware of the situation. The general ageing of our population generates situations of extreme fragility, extreme vulnerability and dependency. This finding has, and will have in the future, a significant economic impact on the need for new expenditure in the name of solidarity, but also as regards new employment and the development of a social and caring local economy. More and more people are and will be considered as "inactive" in the meaning understood and expected by our mercantile societies. Nevertheless, they have and will have in future a considerable positive economic impact, as described by the term "Silver Economy", although paradoxically many of them are perceived as generating an expense for the community.

In a democracy living under the constraint of its national debt and the chronic deficit of its social insurance systems, a crucial choice may become inevitable, even though it may be an unpopular one, between financing technical and scientific triumphs and guaranteeing equality of access to everyone, extended to include physical, mental and social well-being.

Our society would be well advised to face up courageously to these difficult issues without further delay; otherwise we could very soon be facing the emergence and development of a two-way perversion of relations: for the "healthy", the risk of ostracising people who, admittedly, are ill but who are correlatively a drain on resources; for those who are sick or vulnerable because of deteriorating health, the risk of feeling guilty or unworthy.

Starting with children at school, it would be good to introduce this necessary culture of solidarity. Considering assistance to those who are vulnerable as a form of democratic duty is a necessity. Our national educational system could aim to begin at a very early age teaching children to gain a better understanding of altruism and solidarity. Another educational goal could be to pass on to the next generation the concept that respect for older people is an imperative, that human life is not eternal, that growing old is everyone's fate and that there is a need to innovate in all forms of solidarity.

Developing dynamics and intergenerational organisation to integrate ageing into life would be to everyone's advantage.

To help people stay in their own homes, moving onwards with home automation and robotics and to reinforce the usefulness of these technologies, it would be essential and urgent to considerably upgrade training programmes and improve the financial attractiveness of professional home assistance. It would also be necessary to think up new forms of citizen solidarity. We need new forms of volunteer work, but more generally new forms of altruism. Associative and corporate sponsorship should be massively encouraged, valued and assisted by the State.

Our public health system needs to adapt to the reality of an ageing population, and to new forms of care required for people affected by a multiplicity of pathologies. Caring, with respect, for people who have become vulnerable as a result of old age and disease, helping them to retain their autonomy, should be caring activities appreciated at their true value. Tomorrow's hospitals — and EHPADs — must "break free" of their own walls so that care can be brought to people who need it rather than forcing them to come and fetch it as is the case today. For this to happen, there must be much more networking and coordination. A policy respectful of vulnerable people, with the means to protect them and the will to consider them as an asset rather than as a burden, would honour the notion of democracy.

IV/Annexes

Annex 1: Définition(s) of ageing

Generalities

All living creatures age, higher mammals in particular.
Ageing corresponds to the totality of the biological processes modifying the structure, the functions of organs and the connections between the different organs. It also contributes to modifications of the organism in its entirety.
The process begins with adulthood[43].
Human ageing, for men and women, because of human awareness of finitude, is evidenced in a particular fashion; humans age through the appearance of an array of more or less predominant physical and mental phenomena.

Everyone knows, or thinks they know, what an old person is, and yet nothing can be more difficult to define.
Ageing, as experienced by the person concerned, or as observed by someone else, is the result of the functional deterioration of peripheral organs (arthritis, wrinkles, breathlessness, etc.) but it is also the consequence of damage to the central and peripheral nervous system on four fronts:

- cognitive (a narrowing of the field of consciousness, forgetfulness, loss of memory of what a person is doing, an intellectual slowing down...),
- emotional (depression due to boredom; anxiety as time is perceived to be dwindling...),
- motor (slow and clumsy movement, instability and loss of balance causing falls),
- autonomic (sudden drop in arterial blood pressure when a person stands up, often leading to feeling a loss of balance, a form of vertigo sometimes followed by a fall, sphincter disorders, incontinence, constipation, urine leakage...).

The life of a person growing old is dominated by contradictions: "*I have too much time on my hands because I am isolated and lonely so I no longer feel like reading or even thinking, I am very bored and yet I am anxious because the time left for me to live is dwindling away. I want to see my family but I am afraid they will get tired of me or that I am becoming a burden to them. There are more things I would want but I don't dare ask for...*".
"Other" people's perception of someone who has aged plays a very prominent role: for family carers if could be "someone who was once loved becoming a burden", or less violent, someone who is now spoken to with polite condescension. A kind of stigmatisation of old age is built up along with such perceptions.

Ageing is not a kind of disability: disability stays constant while ageing is the result of a loss of ability, constantly evolving for the worse, but in successive stages.

Conversely, ageing is not always perceived as a decline because elderly people have acquired "experience and culture" that their younger contemporaries have not yet amassed. Such older

[43] Rose M. R. (1991). Evolutionary Biology of Aging. New York: Oxford University Press

people often set up "compensation" systems as though to slow down oncoming infirmities (sometimes appearing ridiculous when they are exaggerated).

1) Human ageing is "differential"

Ageing is not expressed in the same way and does not have the same negative consequences depending on:

- socio-economic classification: in which the differences are the most striking to the detriment of the lower occupations;
- where people live;
- people's personality, vitality, charisma, optimistic outlook (some "young" people are "old", some "old ones" are... "old" and there even "old" people who are "young");
- people's age (there is a major difference between someone who has recently retired and someone who is 85 or 100 and has been "inactive" for a long time);
- background, environment, behaviour, etc.

As an example, life expectancy at 35 is 42.6 years for a workman in contrast with 49 years for an executive; it is 40.7 for a person without a degree and 48.2 years for people with university degrees[44].

Functional organ deterioration is different depending on tissues (a heavily lined and wrinkled person may look "old", but has retained "a lively intellect and the capacity to plan for the future", while another person with a smooth skin, "looks young" but is already mired down in the trials and tribulations of extreme old age). Deterioration is also differentiated by the cellular variations of each organ. This is particularly visible for the central nervous system for which age-related deterioration may make people look older or younger, due to modifications in body language or facial expression.
Within the countless neuronal circuits in the brain, some age prematurely and others do not.
Human ageing is never homogeneous nor is it global.
It is always more or less partial (instability when walking, lack of motor coordination with inappropriate movements, unexpected loss of balance, some unusual oversights, loss of hearing acuity causing lack of attention in company, etc.)
Or it can even be isolated (for example, the premature ageing — deemed to be non-pathological — of a neuronal circuit in the hippocampus may bring about an isolated memory lapse, for instance.
An instance of functional deterioration beyond a certain level, albeit unrelated to age, can look like ageing.
Limited deterioration of several functions may induce ageing and look like ageing because of the accumulation of symptoms (slightly deteriorated eyesight, slightly arthritic knees, occasional loss of balance, a little inattention, etc.).

2) Ageing is more like slowing down than like losing abilities

Globally, whatever form it takes, ageing is expressed by slowing: after the acceleration typical of youth and adult stabilisation, psychomotor skills tend to slow down. Their tempo is slower than for those who are "active". With the onset of dependency, this difference is of major importance.

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[44] Hearing of Mr Alain Parant – Futuribles International - 30 March 2017

In psychological and cognitive terms, there is an observable increase in reaction time, impaired memory (loss of memory of proper names), attention deficits, growing difficulty in adapting to changes in lifestyle or home environment.
Several recent studies suggest that executive functions are among the first cognitive functions to be affected negatively by normal ageing[45].
This slowing down is frequently accentuated by concomitant deterioration of sensory functions: many older people do not hear, perceive and see as well as they used to, although they do not always notice or care to admit it. This is a factor favouring social isolation if these deficiencies are not compensated by appropriate devices.
A consequence of this "normal" slowing down is a discrepancy in pace between old and young; this mismatch becomes obvious when elderly people are confronted with the obligations for rapidity and performance of "modern day life".
As a result, there is a lack of behavioural congruence between people of different generations who no longer operate in the same timeframe.

3) Concepts of frailty and vulnerability

Chronic diseases and increasingly frequent health problems appearing as and when people age make some of the elderly particularly frail and vulnerable[46].

Frailty is a well-defined geriatric clinical syndrome[47]: it is connected to the fact that ageing reduces the body's potential to adapt in the event of sickness or stress due to a drop in the body's reserve capacities — capacities which an elderly person "depletes" when coping with effort, stress, trauma and disease. The aged body's reduced efficiency when responding and contending with such situations is characteristic of the vulnerability under discussion.
As examples, "normal" ageing renders people more vulnerable because they do not see so clearly (presbyopia), hear so precisely (presbycusis) which limits their capacity to listen, be attentive and therefore steer their way within a community and follow a general conversation.
An ageing heart makes for difficulty in adapting to physical exercise which soon turns into an effort with relative cardiac insufficiency as a consequence.
An ageing liver and kidneys have a deleterious effect on the metabolism and the elimination of molecules ingested or otherwise administered for medication. And yet, elderly people often have prescriptions for a large number of medications[48].

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[45] Bherer L, Belleville S, Hudon C. Le déclin des fonctions exécutives au cours du vieillissement normal, dans la maladie d'Alzheimer et dans la démence frontotemporale. Psychol NeuroPsychiatr Vieillissement 2004; vol. 2, n° 3 : 181-9
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[46] Santoni G, Marengoni A, Calderón-Larrañaga A, Angleman S, Rizzuto D, Welmer A-K, et al. Defining Health Trajectories in Older Adults With Five Clinical Indicators. J Gerontol A Biol Sci Med Sci. 2016;0: glw204. doi:10.1093/gerona/glw204
[47] Trivalle C « Le syndrome de fragilité en gériatrie »,*Med Hyg,* 2000 ; 58 : 2312-17.
[48] Lechevallier-Michel, N., Gautier-Bertrand, M., Alpérovitch, and all. 3C Study Group. (2005). Frequency and risk factors of potentially inappropriate medication use in a community-dwelling elderly population: results from the 3C Study. *European journal of clinical pharmacology*, *60*(11), 813-819.
Le Cossec C. La polymédication au regard de différents indicateurs de sa mesure : impact sur la prévalence , les classes thérapeutiques concernées et les facteurs associés . Les rapports de l 'IRDES 2015. 562

The concept of vulnerability is in some ways akin to the concept of disability as defined in the 11 February 2005[49] law which states, in article 114: *"In the meaning of this law, a disability is constituted by any limitation of activity or restriction in participating in community life by a person by reason of substantial, sustained or permanent deterioration of one or several physical, sensory, mental, cognitive and psychological functions, multiple disability or other incapacitating health dysfunction."*
However, vulnerability and disablement do not overlap.
Disablement is the consequence of a health problem that has permanently and persistently limited physical and/or mental aptitudes, and thereby seriously impaired participation in community life. It is tangible, ongoing, the consequence of a prior morbid phenomenon. Disablement is the after-effect of a previously endured pathology.
In contrast, vulnerability designates the potentiality of the risk a person is running if a situation to which he or she might be exposed were to occur. "Elderly" people consuming benzodiazepines with a long half-life with the result that their arterial blood pressure drops sharply when they stand up (orthostatic hypotension) are vulnerable because these factors increase the risk of a fracture after a fall and therefore the probability of long-lasting limitation in the future of their functional capacities (so that it becomes a disability).
You can be vulnerable in the presence of a potential risk.
You can be disabled as a consequence of a health problem that happened some time ago and which restricted once and for all physical and/or mental capacities.
It is important to understand that vulnerability combined with "normal" ageing can be amplified by vulnerability as a result of the after-effects of past disorders and/or related to one or several more or less evident, progressive and incapacitating chronic diseases.

But because of medical advances, more and more people are living longer and longer, in some cases with several diseases and disabilities affecting them simultaneously[50]. So medical progress can contribute to an increase in the number of vulnerable people while it also lengthens the period during which they are vulnerable[51].
In this way society and modern medicine combined generate vulnerability and dependency. But at the same time, shouldering the responsibility for doing so and taking dignified care of the vulnerability it facilitates, and even generates, are not so easy.

Herr M, Robine J-M, Pinot J, Arvieu J-J, Ankri J. Polypharmacy and frailty: prevalence, relationship, and impact on mortality in a French sample of 2350 old people. Pharmacoepidemiol Drug Saf. 2015;24: 637–46. doi:10.1002/pds.3772

Herr M, Grondin H, Sanchez S, Armaingaud D, Blochet C, Vial A, et al. Polypharmacy and potentially inappropriate medications: a cross-sectional analysis among 451 nursing homes in France. Eur J Clin Pharmacol. European Journal of Clinical Pharmacology; 2017; doi:10.1007/s00228-016-2193-z

[49] Law 2005-102 of 11 February 2005 for equality of rights and opportunities, participation and citizenship of disabled persons (*pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées).*

[50] Chaudhry SI, Murphy TE, Gahbauer E, Sussman LS, Allore HG, Gill TM. Restricting symptoms in the last year of life: a prospective cohort study. JAMA Intern Med. 2013;173: 1534–40. doi:10.1001/jamainternmed.2013.8732

Quiñones AR, Markwardt S, Botoseneanu A. Multimorbidity Combinations and Disability in Older Adults. J Gerontol A Biol Sci Med Sci. 2016;0: glw035. doi:10.1093/gerona/glw035

[51] See on this subject: Sieurin A, Cambois E, Robine JM. Les espérances de vie sans incapacité en France. Une tendance récente moins favorable que dans le passé. Document de travail – INED – 170 Janvier 2011

From a medical point of view, managing "multimorbidity" is a new paradigm challenging the very organisation of the health system[52]. Due to medical hyperspecialisation, treatment for different organs are compartmentalised. Each failing organ or function is treated and alleviated, but the lack of a systemic approach generally gives rise to neglecting the person as a whole and losing sight of what would be a desirable state of physical, mental and social wellbeing. In a word, of health. An obvious consequence is inadequate polypharmacy prescribed by several poorly coordinated specialists. Prescriptions can be, and often are, contradictory or even paradoxical and iatrogenic[53].

4) People do not die of old age (unless they let themselves die...). They die of disease (myocardial infarction, pulmonary embolism, cancer, stroke, etc.).

And yet, the distinction between normal ageing and pathological ageing is not obvious. This is particularly true as regards the decline in mental function which is not always easy to differentiate from the onset of neurodegenerative disease. This raises two issues:

- Since ageing is differential, what threshold marks that ageing has begun? (When a hip replacement is needed for osteoarthritis? Once many deep wrinkles change the look of a face?...), where does ill health begin (after one fall or two in the street... when there is an (irrepressible) urge to urinate...)?
- Since several pathologies afflicting the aged can be treated effectively (high blood pressure, medical replacement devices, some cancers, etc.), what is the future in store for the vast numbers of "elderly people who feel healthy" (*EVSI - Espérance de vie sans incapacité*/disability-free life expectancy) that the continued increase in life expectancy would seem to forecast (which should probably not extend beyond 105 years saving exceptions)?

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[52] Barnett K, Mercer S, Norbury M, Graham Watt, Wyke S, Guthrie B. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. Lancet. 2012;380: 37–43. doi:10.1016/S0140-6736(12)60240-2
Wallace E, Salisbury C, Guthrie B, Lewis C, Fahey T, Smith SM. Managing patients with multimorbidity in primary care. Br Med J. 2015;350: h176–h176. doi:10.1136/bmj.h176
[53] Any medical or non medical healthcare action having a detrimental effect on health is said to be iatrogenic.

Annex 2. Facts and data

1. ***Societal changes have altered the possibility for family carers or nearest and dearest to look after their parents, grandparents and other loved ones in their own homes.***

The historic and emblematic image of a carer for the elderly or, more generally for disabled or dependent people, is a woman[54]. But three essential socio-economic factors have to be considered as regards the increased need for services to individuals[55]:
1) Women aged 45 to 69, who are the ones mainly burdened with looking after elderly parents, are less available since they are still fully employed professionally.
2) Increases in the number of women gainfully employed in administrative, industrial and commercial professions, with correspondingly strict working hours.
3) An increased number of divorces after 40 years of age, so that there are more single-parent families (with less time to spare) and more second families (with a loosening of relations between daughters-in-law and parents-in-law)[56].
Tri-generational family homes living in property belonging to the "senior citizen" have gradually disappeared as society changes, so that older people are increasingly isolated from loved ones and have become more solitary[57].

2. ***Solitude, distress and suicide among the elderly***

According to a recent report by Fondation de France[58]: today one in four of elderly people over 75 years of age lives alone. "*50% of people over 75 no longer have any real active network of friends. 79% have little or no contact with their brothers and sisters. 41% have little or no contact with their children. 52% have no contact with neighbours. 64% are not active in any club, association or other group.*
This is particularly noticeable, and is a growing trend, in big cities: 33% of old people living in cities of over 100,000 inhabitants are isolated as compared to 21% in rural communities".
A risk factor connected to solitude is loss of independence and/or of autonomy: people who consider themselves as suffering from a disabling physical handicap are twice as exposed to relational isolation than the average (22% compared to 12%).

Disability or loss of autonomy is mentioned in 10% of cases as the root cause of solitude. The impact of disablement is all the harder since people losing their autonomy are more frequently living in poverty (18% have incomes of less than €1,000 per month, compared to the average of 8%) and in precarious circumstances (54% report that their financial situation has worsened in the last two years, compared to the average 40%).

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[54] Noel F. La problématique familiale dans le maintien à domicile des malades en fin de vie. Th: Med: Besançon; 2002. 02-023 Prix de thèse de la SFAP en 2004
[55] Services à la personne : état des lieux de l'Observatoire Caisse d'Epargne 2006. http://www.senioractu.com/Services-a-la-personne-etat-des-lieux-de-l-Observatoire-Caisse-d-Epargne-2006_a5535.html
[56] Les services à la personne en Europe. Les cahiers de la santé. Hors-série (Think Tank européen Pour la Solidarité)
[57] Audirac PA. Les personnes âgées, de la vie de famille à l'isolement. In: *Economie et statistique.1985;*175:39-54.
[58] La Fondation de France (étude réalisée par TMO Politique Publique). Les solitudes en France. 2014

That this solitude is distressing is very probable. *"Institutionalising elderly people is a risk factor for depression. In EHPADs, 40% of residents present with a depressive syndrome; 11% are suicidal. Depression is often trivialised; healthcare professionals and carers lack training for this situation. As a result, depression is underdiagnosed and insufficiently treated"*[59].

Nor can it be denied that in a place where residents are all people in the same situation of old age and dependency, where death is a frequent occurrence, this experience of institutionalisation and form of internment is bound to be traumatic for those who are subjected to it. It can cause behavioural and emotional disorders that the medical world will try to regulate and control with the help of devices and treatments... which will have no effect on the factual situation.
Distress is intrinsic to the inmates of EHPADs — places of full and generally final residence — as several authors have pointed out[60].

Although life expectancy in France is one of the highest, both at birth and at 60 years of age, the suicide rate for all age groups is one of the worst in Europe. The suicide rate of the elderly is no exception.

As was already noted in one of CCNE's previous reports[61], France has the unenviable privilege within the European Community of having the largest number of suicides in the over 75 age group. Every year in France, 3,000 people over 65 years of age end their life. This is nearly one third of the total number of suicides in this country, but does not seem to be much of a cause for concern[62]. After 85 years, the suicide rate is the highest of the whole population.

The mortality rate by suicide increases with age: the incidence per 100,000 inhabitants of 70 years age and over is more than 30[63] (compared with 6.5 for the 15-24 years age group). There does seem to be evidence that there is a link between the suicide rate and depression (70% of people who die following suicide were suffering from undiagnosed symptoms of depression, more often than not unknown to and/or untreated by the medical profession). The feelings of solitude and isolation, real and/or perceived by the elderly, are aggravated by excessive medication, hospitalisation and institutionalisation, cutting them off from their usual family and social environment and inducing reactive depression disorders. [64] [65]

When, to this already impressive list by its sheer numbers of "successful" suicides, are added the numbers of unidentified suicides (for instance, aged people who "starve" themselves to death), those which are "unsuccessful", as well as victims of "suiciding" as described by the

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[59] Hearing of Prof. Pierre Vandel, Psychiatrist; specialising in geriatric psychiatry. 25 April 2017.
[60] Trepied V. La médicalisation pour souffrance psychique des comportements déviants. Retraite et société 2014. 1 :93 -110.
[61] CCNE. Report on Ageing N°59 - 25 May 1998
[62] Charazac-Brunel M. Le suicide des personnes âgées. ERES; 2014. doi:10.3917/eres.chara.2014.01
[63] Observatoire national du suicide. Suicide : connaître pour prévenir : dimensions nationales, locales et associatives. 2è rapport. Février 2016
[64] Prévenir le suicide, Dunod, 2002, 259 p.,
[65] Casadebaig F, Ruffin D, Philippe A. Le suicide des personnes âgées à domicile et en maison de retraite en France. Revue d'Epidémiologie et de Santé Publique 2003. 51 (1) : 55-64

psychiatrist Jean Maisondieu[66] ("*...to be rid of an irksome presence, it is enough to negate the existence of a fellow creature, by negating that creature's humanity"),* then the indicator lights for elderly people's existential sufferings are flashing the brightest of reds.

3. *Our society's rejection of ageing is evolving into a "modern" form of segregating people because of their age: ageism[67].*

Several studies[68],[69] have clearly indicated that our western society regards age as not a pretty sight and therefore prefers to keep it hidden from the public at large. And so it is that millions of elderly people are ignored, particularly in social rhetoric as reported by the media.
The reasons would seem to be "the modern and shared fear of growing old" and the no less shared dialectical valorisation of "the youth culture", of the fantasy that it is imperative to stay young in order to continue being included in society.
We are confronted with an ideology lauding individualistic and activist values for active and productive citizens in the name of a sacrosanct economic vision so that each one of us is, above all, a consumer, a player in the process of economic growth.

Our society appreciates action; it constantly intensifies its demands on citizens for performance and profitability; this constant striving for "more, for faster, for better, for cheaper" is in direct opposition with the psychomotor deceleration characteristic of ageing.
It would not be out of place to consider people who have reached a certain age as individuals whose age, precisely, carries with it a form of wisdom and perspective. Once the more dynamic period of life is over, retirees can still play a leading economic role and participate actively in creating the nation's wealth.
But in our modern society, the vision of old age as a form of wealth does not seem to be acceptable.
Excessive value attached to action and performance means that the elderly are ill adapted to the demands and constraints of our health system and of society.

- To sum up, society sometimes sees an ageing population as being a "problem". The acceleration of advancing technology in recent decades forces upon everyone an increase in their capacity to adapt to such changes. The most typical illustration of this is probably the upheaval caused by the appearance of electronics into every kind of object in daily use together with the dominance of the computer and its applications in our daily life. But it is precisely the difficulty in adapting to change which is one of the more common characteristics of later years...
- And, because our society is significantly typified by a sharp increase in the numbers of people who are now "inactive" (i.e. retirees), we end up with a marked tension between the social demand of universal adaptation to the modern world and the simultaneous progressive reduction of the capacity to adapt of a growing fraction of its

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[66] Maisondieu J. L'autruicide, un problème éthique méconnu. Laennec 2010. 1 (58) :18-29.
[67] Saint Jean O, Somme D. Age et restriction d'accès aux soins. Gérontologie et société 1999 ; 90 : 109-120.
[68] See on this subject Yannick Sauveur's thesis. Sauveur Y. Les représentations médiatiques de la vieillesse dans la société française contemporaine. Ambiguïtés des discours et réalités sociales. Th : Sciences de l'information et de la Communication : Université de Bourgogne ; 2011
[69] Colella R. Le paradoxe du vieillissement dans notre société moderne : inacceptable vieillesse, refus de la mort et désir d'immortalité. Mémoire de master HPDS : Lyon 1 ; 2013.

population. This factual paradox should most certainly be taken into account in any formulation of policies to care for the elderly.

- But, more often than not, this same paradox is more likely to be a reason for stigmatising the elderly because of this difficulty accessing and adapting to change.

Carried to the extreme, it is this form of ageism which sometimes leads to extracting a person from a familiar environment, to be isolated in a place (often an EHPAD) where are voluntarily concentrated together all the elderly, in other words, "the problem cases". In a place which is almost always far away from the sight (possibly guilt-laden) of those who are not yet old but will most certainly become so.

The result is a situation combining isolation and concentration which generates a *de facto* social exclusion.

- In our health system, the "slowing down of functions" (sensory, cognitive, etc.) in elderly people is in direct opposition to the demands and constraints of ever more efficiency, productivity and profitability required of members of the medical and non-medical professions.

One example: when a health worker puts a question to an EHPAD resident at the start of personal services, it happens quite frequently that the resident's reply — often pertinent as it happens — only comes to mind once the professional has finished and has left the room, so that the answer cannot be given. This is how in some cases is born a confusion or an assumption that "not understanding fast enough" is the same as "not understanding at all"!

Similarly, an "old person's tempo" is often rather incompatible with the very tight schedule of a doctor who has a number of patients waiting to consult: it is quite frequent that since older people "take too long" to get undressed, they end up not removing their clothes in direct opposition to normal clinical practice and are "examined" (if you can call it that!) through their clothing. This failure to conform to good practices may lead to ignoring clinical signs that could have served, if observed earlier, to diagnose major disorders. Sometimes very advanced cancers are missed in older patients although they were regularly seen by a doctor in recent years.

In our society, the slowing down of sensory, motor and cognitive functions causes the loss of a social life for the elderly, leading in turn to the isolation which is such a torment for them.

Isolation is also the cause, *inter alia*, of malnutrition which itself gives rise to oral and dental disorders and disinclination to effort so that, in a vicious circle, there is a reinforcement of isolation. This isolation of the elderly is the cause of frailty, vulnerability and ultimately, dependency.

With this in mind, early screening for signs of presbycusis (loss of hearing) and presbyopia (loss of vision) and for dental damage should be one of the predominant components of a systematic follow-up policy to prevent "substandard ageing". And yet, these essential and common sense measures are not priorities in the eyes of the sickness insurance system. This is also true of other preventive medical action.

It cannot be denied that current public health financing policies are not geared to the effective preventive management of age-related pathologies.

Another example: emergency services practise a certain degree of segregation of the older members of the population. The least one can say is that members of the medical professions does not tend to see them as a priority.
Older people, already very upset when they are taken into a hospital as they understand that this means that they have a serious health problem, find it difficult to describe their symptoms and the objective signs that caused them to be referred to the emergency unit and are sometimes exasperatingly slow as they try to explain.
These complex multiple pathologies and long case histories[70] are completely at odds with the necessary speed of decision required of an emergency physician. What doctors need to do in such circumstances is to assess in a short time the signs and symptoms with which to formulate the various diagnostic possibilities as quickly as they can and then act with speed and efficiency. Furthermore, they are often confronted with a large number of anguished people in pain and in sometimes immediate danger arriving at the same time as elderly patients referred to them by institutions. The result of this mismatch in timespans and humanity is that the older sufferer, not being in any immediate danger, is set aside and frequently has to wait for a very long time on an uncomfortable gurney in the emergency department. Admission is then delayed, as is treatment, and sometimes when the patient is finally assigned it is not to the department which is best indicated for the dominant pathology so that diagnosis is delayed and there are even cases of inappropriate prescription. As a consequence and not infrequently, there is an aggravation of morbidity generating in some cases further life-threatening vulnerability.

This ageism is all the more dangerous for being rarely a "conscious decision" on the part of health professionals and because it is reinforced in a context of economic and budgetary constraints placing a burden on the health system where there is a tendency to suppose that "the old are costly".
Are the old the reason why our health system is imperfect and are they a drain on the health system's already inadequate resources as we are often told?
The report of the *Haut conseil pour l'avenir de l'assurance maladie* (advisory board for the future of the sickness insurance scheme), under the heading of *"Vieillissement, longévité et assurance maladie"* (Ageing, longevity and sickness insurance), adopted on 22 April 2010[71] would seem to dispel quite a few stereotypes on this subject. For instance *"...health expenditure for the elderly ... does not weigh as heavily as it is often said to on the budgetary scales. The "over 75 age group" is responsible for approximately a fifth of the total health expenditure of the population as a whole, that is just about the same as is consumed by the "under 30s"; the "over 85s " expenditure is about the same as that of the "under 10s".*
Similarly, the notion that most of the healthcare is given in the last months of a person's life is not altogether correct: "*...it is true that the last third of a life does represent, roughly speaking, two thirds of the person's health expenditure; but the last year of life only represents on average 7% of it."*

[70] The real reasons for admission to the emergency unit are often multiple: medical, a consequence of frequent multiple pathologies, but also social.

[71] Can be read and downloaded on the HCAAM website: http://www.securitesociale.fr/institutions/hcaam/
See also an article by Denis Piveteau : Piveteau D. "*Le vieillissement de la population est-il une menace pour l'assurance maladie* ?" (Is the ageing of the population a threat for the sickness insurance system?), Laennec 2011 ;2(59) : 18-30

It is still true however, that with increasing age and an increasing number of elderly people there is a proportional average increase in health expenditure per person. And in fact, the over 75 years age group will represent 16% of the French population in 2050 (the figure is currently 8%)... The HCAAM report points out that the average healthcare expenditure per person and per year is less than 2,000 Euros up to the age of 50, but increases to about 6,000 per year in the 75-79 age group.
According to Holcman[72], in fact extended life spans are — and will be even more so in coming years — the source of a notable production of wealth through (but not exclusively) the development of a market for personal services.
The financial impact of longer life spans must compare the cost of healthcare, medication and assistance from paramedical professionals and social insurance schemes with the production of wealth created by care given, personal assistance and all that it involves.
The expected production of wealth includes three components:

- an extension of productive capacity by the concomitant raising of the retirement age;
- the consequent conservation of consumption capacity;
- the creation of wealth related to employment in the health sector, the production of medical goods and services and the creation of professional structures for accommodation and treatment.

Similarly, the extension of the life span will increase the need for equipment and various sports, socio-cultural, commercial and urban services specifically geared to the needs of elderly citizens regardless of whether they choose to live at home or in special institutions.

The findings of this report and of later publications[73] were that it was not so much advanced age that is costly, but rather ill health.
Indeed, *"... past the age of 75, varying with the study, 6 to 8 disorders on average are noted per person (excluding problems with eyesight and teeth). The effects of age on expenditure are therefore first and foremost an effect of disease."*
However, more than illness and even more than age, it is dependency — and therefore solidarity — which is costly: *"...over 10,000 Euros annually of medico-social expenditure on average per person at 90 years of age: ten times as much as between the ages of 20 and 25."*

What these observations and statistical data are in fact telling us is that our health and home help systems are not adequate to cope with this "new deal". The logic of this system (but is it a system?) dates from a time when multimorbidity and chronic diseases did not exist or were nowhere as prevalent as they are now.
This "system" is very rigid and incoherent. It is excessively compartmentalised and incapable of adapting to changing needs. It generates unstructured and sporadic service. It does not fit in with the logic of health trajectories. It is dependent on budgetary allocations that are inconsistent with the growth in the number of users that depend on it.

As we reach the close of these thoughts about ageism, let us attempt for a moment to put ourselves in the place of the aged: this negative outlook on ageing is probably the cause of possible internalisation with the frequently reported feelings of "being a burden", "being unwanted", "no longer existing". It is true that some elderly people actually made an informed decision to go and live in an EHPAD and are reasonably happy there. But they are

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[72] Holcman R. Les enjeux économiques et financiers de la fin de l'existence. Journal d'Économie Médicale 2011, 29, (3), 79-91

[73] La fin de vie des personnes âgées. Rapport 2013 de l'Observatoire National de la Fin de Vie, Paris, La Documentation Française, 2014. Pages 62-71

far and away not the majority. Others, more numerous, did not necessarily take this deliberate decision; despite this, they enter into resilience and resign themselves to their sad fate, adapting through thick and thin to life in an institution. Some of them did not take the decision, develop a reaction depression and let them themselves die or welcome a death which puts an end to indignity...
Progressive deterioration allied with a lack of stimulation of sensory, organic and cognitive functions for the elderly, together with scarcity of resources, of space, of time, of attention and recognition concur to exclude any empathic projection of the future and to even more isolation.
The apparent paradox is that, the end result of this concentration in one single place of people all afflicted with the same feeling of ill-spent ageing is a *de facto* exclusion from the social group but also from family and friendship. And this is in flagrant contradiction with the laudable intentions of the people who care about them and the institutions who want to care for them, treat them with more compassion, keep them safe and protected.

4. The overmedication of aged and ageing people is a cause of frailty

Excessive medication of the aged has some justification. Before the time when geriatrics was recognised as a medical discipline, age and its ills were seen as a fatality. Older adults did not receive much, if any, healthcare. They were simply "placed" in so called "long-term hospital care" when they became ill and/or dependent[74]. Nowadays, geriatric services are regularly confronted with at least two complex problems: how to respect the wishes of a sick and elderly patient when decisions regarding treatment need to be taken while attempting to secure properly informed consent? How to achieve some kind of therapeutic balance without harmful consequences when a person suffers from not just one, but several diseases progressing simultaneously?

Providing care and treatment are not just and not always prescribing and administering medications: does just because "you know how to" mean that you must *always* medicate and treat? Caring and healing are above all about respecting the individual, respecting the patient's choices, which are not necessarily identical to those of either healthcare providers or of loved ones. So it is that we see that sometimes, the elderly who have expressed time and again that they do not wish to be medicated, nor to be the object of futile and aggressive therapy, are put into hospital against their wishes — often because it is impossible for an institution to act otherwise — and medicated against their will.
It is true that the elderly express somewhat ambiguous wishes, but this ambiguity or indecision is sometimes rather hastily interpreted as a form of incompetence or incapacity; the indecision very often results in "someone else doing the choosing" and choosing medication.
So the decision tends to be systematic; it is probably insufficiently called into question and even less anticipated. It sometimes also leads to a paradox: because medicine has made so many technical and scientific advances it helps to generate situations of survival that are incompatible with respect for what the aged person had expressed the wish for. It then happens that some institutionalisations become an "obligation". And then that some people, that doctors struggled desperately to save, say that they want to die...

[74] Nicolas Foureur. Médicalisation de la vieillesse : un juste équilibre ? Retraite et société 2014. 1(67)

In the end, everything happens as though ageing was a pathology that doctors are duty bound to prevent or cure[75]. It is probably this rejection of ageing together with overmedication which contribute or even create this new image of "multimorbidity", in fact elderly people suffering from several simultaneously occurring pathologies, failing organs and disabilities. This factual situation leads to polypharmacy which is not supported by any scientific reference as we are told by pharmacologists[76]. The issues of priorities and of selecting treatment should be addressed systematically. They should be the subject of discussion with the patient and between the different specialists. In fact, this absence of interaction leads to overmedication although everyone knows that it is not necessarily sound and that it generates iatrogenic effects and excessive frailty[77]. And yet, it persists.

5. *A tendency to negate elderly people's autonomy*

Continuing with these thoughts, reference to the definition of autonomy would be useful: "*auto nomos*", making one's own laws, which does not mean absolute liberty, but rather the opportunity and the freedom to be one's own "legislator", to set one's own laws, to follow them, in a social environment which also has its rules and prohibitions. From this stems the principle of self-determination, the possibility of deciding on one's own behalf.
The model for autonomous life follows — wrongly — the pattern of a "normal" life, that is a life which refers to a "standardised" vision (biologically and socially) of human life.

In medical matters, autonomy is often referred to when raising the issue of informed consent: a sick person is not consenting to a scientific demonstration but to the match between medical possibilities or proposals as clearly explained to the patient and the patient's own vision of a good and appropriate life at a given point in time.

For autonomy to be exercised, a person needs:
- to be informed: which requires a lengthy process of communication with one or several healthcare professionals; this is a work of patient progress and repetition, respectful of the patient's capacity of understanding, including the speed and limitations of that understanding;
- to be able to hear: which means that before imparting any information there has to be a check that there is no hearing problem... A particularly frequent problem for the aged... But deafness can also be "psychological", an attempt on the part of the psyche to resist the violence of words or of their meaning, so as not to listen to what a person prefers to be left unheard.

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[75] Kaeberlein M, Rabinovitch PS, Martin GM. Healthy aging: The ultimate preventative medicine. Science. 2015;350: 1191–3. doi:10.1126/science.aad3267
[76] Stevenson J, Abernethy AP, Miller C, Currow DC. Managing comorbidities in patients at the end of life. Br Med J. 2004;329: 909–912. doi:10.1136/bmj.329.7471.909
Richardson WS, Doster LM. Comorbidity and multimorbidity need to be placed in the context of a framework of risk, responsiveness, and vulnerability. J Clin Epidemiol. 2014;67: 244–6. doi:10.1016/j.jclinepi.2013.10.020
Scott I a., Hilmer SN, Reeve E, Potter K, Le Couteur D, Rigby D, et al. Reducing inappropriate polypharmacy: the process of deprescribing. JAMA Intern Med. 2015;175: 827–34. doi:10.1001/jamainternmed.2015.0324
[77] Mallet L, Spinewine A, Huang A. The challenge of managing drug interactions in elderly people. Lancet. 2007;370: 185–91. doi:10.1016/S0140-6736(07)61092-7
Spinewine A, Schmader KE, Barber N, Hughes C, Lapane KL, Swine C, et al. Appropriate prescribing in elderly people: how well can it be measured and optimised? [Internet]. Lancet. 2007. pp. 173–184. doi:10.1016/S0140-6736(07)61091-5

- to be capable of understanding the information given, to make a critical analysis of that information, i.e. be capable of discernment, discrimination, critical evaluation and hierarchisation of the information.
- to be able to integrate efficiently the options between which to choose and take a decision which meets a person's true preferences.
- to persevere, or not, in choices made over time and in interaction with a number of different discussants.

It is therefore rather obvious that the time constraints prevailing in the healthcare environment are hardly favourable to the exercise of this form of autonomy.

The agreement given by an elderly person to the medical staff's proposals for tests and treatment is often appropriate to circumstances. However, when the aged refuse their consent to what is proposed, it is frequently considered that they are incompetent to make a decision, that they find it too difficult to understand so that refusal would be "uninformed".
While it is true that an older person's refusal of treatment must be analysed, so should an acceptance of treatment and to the same extent: "consent obtained" cannot therefore be seen as absolutely synonymous with personal autonomy.
An older person's rejection of proposed tests or treatment should not, as is all too often the case, be seen as equating inability to understand and act autonomously.
Taking this line of reasoning one step further, how real is "informed consent" from people who are being asked about entering an EHPAD when there is every likelihood they will reside there until they die? Will the EHPAD always be the best place for them to be?

What of the autonomy of elderly people whose cognitive faculties are impaired? Is "relative autonomy" a valid concept in such a case?
Between on the one hand, the desire and the duty of loved ones and care providers to respect everyone's psychological autonomy (the concept of autonomy seen in its philosophical sense, also from the viewpoint of clinical ethics and as an essential principle upheld by law) and, on the other hand, the complex reality of existence as experienced by very sick people and those of advanced age with cognitive disorders, there are grave contradictions in some cases.
There is a considerable risk that — as the law incites — the "principle" of personal autonomy is seen as a simple dichotomy: a person is/is not autonomous.
In point of fact, being completely autonomous when suffering from serious ill-health or cognitive disorders is no easy task.
Nor is it easy to see oneself as a sick person and yet to be still capable of analysing the disorder and deciding on the best course without anyone's help.
In this sense, autonomy is consubstantially relative since it is dependent on others — health carers and loved ones for instance with which a trustful relationship has been built up — who may be applying an emotional influence, or even one of competence, to the decision. A decision which should really, *in fine*, belong to the sick or elderly person, the person mainly concerned.

In reality, medical decisions taken *with* someone (in the better case), or *for* someone (far from unheard of) are partly conditioned by the responsibility of the "co-decider" (for instance family or health professionals) and this is particularly true when the decision is related to an accurate evaluation of the hoped-for-benefit to the probable-risk ratio. It is easy enough to understand that, in the circumstances, the fear of risk (depending on whether the person concerned is a risk for self or for others) will be likely to tip the balance in favour of the safe

option, thus limiting autonomy by another notch. So, in the name of "the elderly person's best interests" and the ethical principles of not doing harm, of pertinence and benevolence, it becomes possible to override autonomy and violate a person's wishes. Dependency then is unethically opposed to the exercise of autonomy.

Respect for a person and for that person's wishes, or even perhaps decisions, should make it possible to have respect for the right to take a risk, as a facilitator for autonomy, akin to the dynamics of empowerment, but it should also lead to intergenerational solidarity (in the literal meaning of human interdependence).
Reasoning in terms of respect for an elderly and vulnerable person, retaining some degree of intellectual autonomy, relative perhaps but existing none the less, it should be possible to see to it that the person involved has a predominant voice in choices which are of direct concern. In such cases, elderly patients must absolutely be able to rely on the assistance and caring solicitude of family and caregivers to support them in the taking of difficult decisions and through frequently traumatic events, rather than try and persuade them.

Conversely, when considering in the absolute the exercise of autonomy by elderly persons who have become dependent, it may be argued that since they are dependent, institutionalised and suffering from invasive cognitive disorders, they have become so dysautonomic that there is no alternative to choosing for them what one hopes they would have wanted. Such a situation in fact refers rather to a situation where exercising relative autonomy is an impossibility. To be convinced of the very relative autonomy — relative but not totally absent — persisting in elderly people with advanced Alzheimer's disease, an analysis of their reactions when their medical condition is explained to them is very revealing: they often react emotionally; it is true that we cannot fully understand the meaning of their reaction, but this does not signify that they have understood nothing, contrary to what is frequently said or thought.
What it really means is that we do not understand their reaction and that its meaning remains a mystery for us, but it should be clear that people whose cognitive capacities are severely impaired may have retained a degree of autonomy.

It is indeed difficult to be in poor health and yet preserve autonomy absolutely. But it is only seldom that all autonomy is lost because of ill health. Similarly, it is difficult to be dependent and totally autonomous: dependency, pain, anguish in the expectation of death and the unknown, together with the deterioration of body image impair a person's capacity to exercise autonomy to the full.
And it is also true that the way in which the social and family environment regards the person concerned necessarily alters, conditions and constrains the exercise of autonomy.

Autonomy is neither abstract nor absolute; it is existential. It is circumscribed by a life history and an environment. It is essential to take meticulous care of it.

6. Impediments to organising assistance for keeping elderly people in their own homes

In some cases, it is not possible to keep elderly people living at home, for reasons "caused" by themselves, although they have expressed the earnest wish to stay there: anosognosia, a refusal to recognise the somatic and mental effects of ageing and the loss of independence, fear of becoming a burden on loved ones, refusal to have someone looking after them at home, etc.

Or sometimes carers have reached "the end of their tether".
Because of a changing social environment and evolving habitat, there is a shortage of nearby helpers (collective housing, lack of knowledge of the situation, indifference to solidarity, etc.). There is also a lack of "natural" helpers (because of age in the case of the spouses of elderly people, or fear of getting involved, other personal problems, family conflict, etc.)[78]
Care providers (all ages and in all circumstances) number some nine million people in France. Twenty percent of them are not family members (neighbours, friends, etc.). Twenty percent of care providers devote over fifty hours per week caring for a sick or disabled loved one. One out of every two carers are still actively employed. Twenty percent of carers die before the person they are caring for.

If carers stopped caring, 164 billion Euros would be required to compensate the loss so as to ensure that the people they were keeping alive, stay alive.

Caring may be meaningful and generate satisfaction and transcendence. It may also cause the carer's exhaustion (one million carers are overworked); carers and their charges may become mutually abusive and create a sadomasochistic relationship[79].
However, there is no sense in being blindly optimistic about carers and turning a blind eye to the possibility of property strategies, or even of requests in contradiction with the wish of the person concerned as regards the cessation of life-prolonging treatment[80].

As regards the professional care providers, whose task it is to make keeping a patient at home[81] possible as part of the SSAD (*services de soins à domicile* - home residential services), there are staff shortages due to budgetary problems in the social services' departments of the territorial communities involved and also because salary scales are very inadequate and totally unrelated to the workload expected of the home carers.
This is also true of the SSIAD (hospital nursing care at home) services and therefore of the availability of their auxiliary nurses although the SSIADs receive funding from the ARS (*agences régionales de santé* - regional health agencies) whose budget depends on central government or the national public health system. It would appear that the number of jobs on offer in the SSIAD system would have to be doubled in order to respond to the needs of the population concerned. Failing which, this population will have to be placed in EHPADs without reference to their preferences in that respect.

Another solution to the problem would be to pool SSIAD and APA (*aide aux personnes âgées* - assistance to the elderly) working hours, but experiments to this effect ran into difficulties because of conflicting regulations in social and health departments and also because different government departments are paying for the service. SSIAD does not leave any remaining cost to be paid for by the beneficiaries covered by the sickness insurance scheme, while APA does invoice beneficiaries for a part of the expense and the amount varies geographically and this

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[78] This data is mainly drawn from hearing Monsieur Jérôme Pellerin. *Centre René Capitant,* 5 April 2017
[79] This data is mainly drawn from hearing Monsieur Henry de Rohan Chabot. *Fondation France-répit* on 17 May 2017
[80] This data is mainly drawn from hearing Madame Anne Caron-Déglise, Magistrate, former President of the Chamber for the legal protection of adults and minors at the Paris appellate court, on 15 June 2017.
[81] This data is mainly drawn from hearing Madame Marie Paule Belot, General Director of a home care association (ELIAD) and member of UNA (*Union Nationale de l'Aide, des Soins et des Services aux Domiciles* - national association for home assistance, care and services), on 25 April 2017.

is sometimes very disproportionate to the income of people whose pension is situated below the poverty line.
Furthermore, SSIAD personnel is paid on a daily lump sum basis while for SSAD pay is based on a hourly rate. If the elderly patient also needs nursing care, the lump sum system sometimes results in a bias in the preferences by the organisms managing the services, so that they avoid the most needful patients, leaving them with no other option than to enter an EHPAD.
It is true that a large number of home care and services (*services de soins et d'aides à domicile* - SSAD) have been organised by private organisms in recent years, generally on a non-lucrative basis and more or less adequately funded by departmental regional administrations. Those created for commercial purposes have mostly failed to survive. The professionals they recruit are very exposed to difficult and thankless work, are insufficiently trained and paid (minimum wages) and their working conditions have deteriorated because of performance constraints incompatible with a caring mission.

Public financing has not increased in proportion to increasing dependency, despite law n° 2015-1776 of 28 December 2015 on adapting society to ageing (*Adaptation de la Société au Vieillissement - ASV*). As a result, actions were brief and fragmented which is inadequate to ensure high quality care and assistance for elderly people who are still in their own homes, particularly in rural areas.

The consequences for employees are totally disheartening. The accident rate is much too high, close to that observed in the construction industry. Unhappiness at work translates into unceasing personnel turnover as workers suffer unduly from burnout. For those in need of home care, the result is a constant change of carers from one day to the next, which induces a feeling of intrusion and violation of privacy which can become intolerable.
Moreover, as the regions do not apply the ASV law identically, there is an easily observed geographical inequality of access to services, which is further aggravated by the APA (personal autonomy allowance) applied by CNSA (*caisse nationale de solidarité pour l'autonomie* - National solidarity fund for autonomy) whose resources are insufficient (although its budget is large) to cover the needs of the population concerned.

The system for assistance to elderly dependent people has already overstepped the bounds of acceptable limits. The situation is such that carers can no longer make any sense of what they do; the consequences for the elderly have become disastrous.

Finally, the absence of territorial governance for SAAD, SSIAD, HAD and EHPADs whose systems for the management, care and nursing of patients are at variance (social/medico social/healthcare), together with above all the added complication of different financing systems (ARS/*Départements*) is very obviously the cause of dysfunctional healthcare of the elderly.

7. Some facts and figures concerning people living in residential long-term nursing homes for dependent elderly people (EHPADs)

By the end of 2016, 577,708 elderly people were permanently housed in residential nursing homes in France and the Regional Health Agencies (ARS) are planning to build 12,320 more long-term residential units in the 2017-2021 time period[82].
Three quarters of residents who were interviewed said that they would have preferred not to end their lives in an EHPAD[83].
According to DREES[84], three quarters of EHPAD and retirement home residents are women. Their average age is 85 (10 months more than in the 2007 report). Average age of entry is increasingly late (an average of 84 years and 5 months). Average duration of stay is two and a half years. Residents are affected on average by 7.9 disorders. Nine out of ten are afflicted by organic or functional neuropsychiatric pathologies, often in reaction to their lifestyle.
In institutions, 86% of people aged 75 or older are dependent, as against 13% of people of the same age living in their own homes. 68% suffer from cognitive disorders[85] which are more or less invasive for those around them.
The median rate (accommodation + reimbursable portion of fees) as calculated by CNSA is 1,949 Euros per month and represents the equivalent of 114% of the average monthly income of a retiree, excluding social allowances.

At least one EHPAD resident out of five was sent to an Accident and Emergency hospital department in 2011[86]. There are twice as many unscheduled visits to hospitals as there are scheduled ones.
Every year, 90,000 EHPAD residents die, 40% of which following an "end of life" decision (limited or cessation of treatment). 25% of deaths occur in a hospital[87].

Breakdown of residential care homes for elderly dependent people (EHPADs) according to legal status

	Number of institutions and percentages			
Types of homes	*2007*[88]	*2011*[89]	*2014*[90]	*2015*[91]

[82] APM. Dépêche. - 05/07/2017 - *Personnes âgées: 6.800 places installées en 2016 selon la CNSA* (Elderly people: 6,800 units created in 2016 as reported by CNSA).
[83] Observatoire National de la Fin de Vie. *La fin de vie des personnes âgées.* (The end of life of the elderly. 2013 report by the l'Observatoire National de la Fin de Vie, Paris La Documentation Française, 2014
[84] DREES. Etudes et résultats 2014; 899
[85] Calvet L, Pradines N. *État de santé et dépendance des personnes âgées en institution ou à domicile. Etudes et résultats.* DRESS. 988 ; 2016 (State of health and dependency of elderly people living in institutions or at home. Studies and results).
[86] Makdessi Y, Pradines N. *En EHPAD, les résidents les plus dépendants souffrent davantage de pathologies aiguës. Etudes et résultats.* (In EHPADs, the most dependent residents present with more acute disorders. Studies and Results) DRESS. 989; 2016
[87] *Observatoire National de la Fin de Vie. La fin de vie des personnes âgées.* (end of life of old people). *Rapport 2013 de l'Observatoire National de la Fin de Vie, Paris, La Documentation Française, 2014*
[88] Perrin-Haynes J. *« Les établissements d'hébergement pour personnes âgées »,* (Residential homes for the elderly) *Document de travail série statistiques février 2010*, n°142, Drees.
[89] Ramos-Gorand M, Volant S. *« Accessibilité et accès aux établissements d'hébergement pour personnes âgées dépendantes en 2011 ».* (Accessibility and access to residential homes for elderly dependent people in 2011). Drees . Études et Résultats 2014,891.
[90] Beffy M, Roussel R, Solard J, Mikou M, *« Les dépense de santé en 2014, édition 2015 », Résultat des comptes de la santé* (Health expenditure in 2014, 2015 edition. Results of healthcare accounts.)
[91] Beffy M, Roussel R, Solard J, Mikou M, Ferretti *C. « Les dépense de santé en 2015, édition 2016 »,* Résultat des comptes de la santé (Health expenditure in 2015, 2016 edition. Results of healthcare accounts.)

Public	3 471	3 800	3 303	2297
Private non-lucrative	1 952	2 271	2 237	2208
Private commercial	1 432	1 681	1 738	1756
Total number of institutions	6 855	7 752	7278	6261
	2007	*2011*	*2014*	*2015*
Public	50,6 %	49 %	45,4 %	36,7 %
Private non-lucrative	28,5 %	29,3 %	30,7 %	35,3 %
Private commercial	20,9 %	21,7 %	23,9 %	28%

8 . Home care services in France

The law dated 29 January 1996 and the implementation decree of 24 June that same year modified the range of home care services *("aide à la personne").* The certification procedure, created in 1991 specially for structures depending on voluntary associations was extended to commercial outfits. In 1996, a system called "*titre emploi service - TES*" was created whereby firms were authorised to partly finance services on behalf of their employees.
The law dated 21 July 2001 instituted the APA (*Allocation personnalisée d'autonomie –* personal autonomy allowance) which aims to make a contribution towards the care system for people who are losing their autonomy by paying for the assistance they need to cope with everyday needs. The regional administrations (*conseils généraux*) are tasked with allocating and managing this social benefit.
Another law, n° 2002-2 of 2 January 2002, was introduced to renovate social and medico-social action and added a new article L. 312-1 to the *Code de l'action sociale et des familles* (Code for social and family-related services). The new article regulates all the home care service structures, but not establishments and services concerned with families.
It can be summed up under four main headings:

- It reinforces the rights of "users",
- It provides a legal framework for home care, hitherto non-existent.
- It improves planning operations, based on two supporting structures: authorisations and the Higher Council supervising social and medico-social establishments based on organisational outlines.
- It should bring about better coordination between decision makers and players (concerted analysis of requirements, conventions, multiannual contracts for planning and budgeting, etc.).

The 11 February 2005 law introduces an allowance for the compensation of disability (*prestation de compensation du handicap - PCH*) which will be gradually replacing another benefit called the *allocation compensatrice tierce-personne - ACTP* (allowance for third party compensation).
The so-called "Borloo law" dated 26 July 2005, sets out two payment systems:

1) Users call on an organisation and pay for a service (*le mode prestataire*). This is mainly used by non-profit associations and commercial firms.

2) Users are the employers of the employee providing the home care service. This is called "*le mode mandataire et l'emploi direct ou gré à gré".)* They call on an organisation — the *service mandataire* (agents) to help them in their duties as employers. These agents take

on all the administrative tasks relative to employment and employment contracts. (See: [*Les services d'aide à la personne en France, par l'UNA (union nationale de l'aide, des soins et des services aux domiciles* - Personal services in France, UNA, National Union for assistance, care and home services].

9. The impossibility of having people live where they want to leads to their isolation and exclusion from a place to live which is meaningful to them and to their concentration in places they often do not want to live in.

Since both society and medicine reject ageing, the result is often overmedicalisation which in turn gives rise to cases of excessive frailty and vulnerability. Such situations open the door to dependency. The word "dependency" should be understood to mean the appearance of a series of disabilities, which is the meaning given to it by the 24 January 1997[92] law in Article n° 2 on the specific allowance for dependency: "...*dependency... is defined as being the status of a person who, despite any treatment that can be provided, has to be helped with essential needs of day-to-day life and/or requires regular supervision*".
When dependency is assessed as being too prevalent[93], it fairly systematically gives rise to institutionalisation for an elderly person. Assessment of dependency is skewed by the financial cut-off point affordable by those concerned since those limits are easily reached when financially assisted services to stay in the person's own home are limited as regards their number and the time allocated, or are even ill-suited.
The administrative and popular consensus of most people preferring to stay in their own homes combined with the core intention of the law are not sufficient to counter the perverse effects of this appraisal which is in fact quite arbitrary.
And so it is that, in spite of the repeated, time-worn and consistent wishes expressed by the overwhelming majority of French men and women to the effect that they prefer to stay in their own homes until the end of their natural life, and even though law n° 2015-1776 of 28 December 2015 on adjusting to an ageing society does contribute some obvious improvements in the right direction, there is still today in France no true will to implement coherently a policy to secure the assistance required if people are to age in their own homes [94].
The legal upper limits set on APA prevent the medical and social services run by the local administrations from offering possible waivers so that, in certain cases, it would be possible to provide the assistance keeping people in their own homes.
Paradoxically, it may be observed that, for lack of the necessary staffing and funding, the social aid services in local administrations cannot offer adequate care and assistance. In such cases, despite the clear reluctance of the persons concerned, a decision may be taken to force

[92] Law n° 97-60 of 24 January 1997 for the purpose of creating a specific allowance for dependency to respond more adequately to the needs of the elderly, until a law is voted to create an allowance for autonomy in dependent elderly people.
[93] The Autonomie Gérontologie Groupes Iso Ressources (AGIR) grid is used to assess functional status. Dependency is evaluated in terms of the level of care required (called "Groupe Iso-Ressource (GIR)". There are 10 items in the grid, called "discriminating variables". An algorithm classifies the response combinations to discriminating variables into 6 "Groupes Iso-Ressources" (GIR). This grid is in regulatory use for the setting up of the personal autonomy allowance (APA) and for the pricing authorised by their institutional governing bodies whose beds are partly reimbursed by social services.
[94] Ennuyer B. *Repenser le maintien à domicile*, Paris : Dunod, « Santé Social » ; 2014
Morin L, Aubry R. Où meurent les personnes âgées ? Une étude nationale en France (1990-2010). Médecine Palliat. 2015;14: 179–190.

them out of their homes and enter an EHPAD. The consequence for the local authorities is that they have to spend more on social aid than an APA allowance would have cost them, even if the allowance had been raised beyond its upper limit.

The 2013 ONFV (*Observatoire national de la fin de vie* - National end of life observatory) report[95] demonstrated the degree to which the end of life of elderly people is disrespectful of the will and wishes of those concerned and was even in some cases in total contradiction with them. The ONFV enquiries have shown that frequently people who are already irremediably engaged in the process of dying are taken into hospital. They then die in the discomfort of a stretcher in the emergency department or immediately upon admission into another hospital department.
The lack of any alternative to staying in their own home, the medicalisation of the extreme end of life, the tendency on the part of the medical profession to deny human natural finitude and the relative nature of life has the effect of forcing a significant number of people into an inhuman end to their lives.

Do social security contributions provide us with the means of acting differently? Is it really possible in today's world to avoid forcing people who are elderly and dependent to live and end their lives in an institution (EHPAD)? If the person concerned is old and frail because of ill health and disabilities, and more specifically if that person is alone, or is a man or no women are available to help[96], is it legitimate and ethical to force upon them what may be seen as a humiliating indignity?

In 2013, the ONFV report produced some edifying conclusions on this subject: our health system is so contrived that it forces — mainly for lack of trained staff — elderly people into going to end their lives where a large number of them never wanted to go. And to top it all, they are requested to pay a large amount of money, much of which is not reimbursed by social security benefits to go into EHPADs, exactly where they did not want to go... It is true of course that some people actually "choose" to enter an EHPAD, but probably among them quite a few only choose to do so because there is no alternative.

And so it is that elderly people are systematically excluded from places where life has meaning for them, i.e. their own homes; this exclusion also adds up to isolation as related to what used to be their social environment. Moreover, once they are institutionalised in an

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[95] La fin de vie des personnes âgées. Rapport 2013 de l'Observatoire National de la Fin de Vie, Paris, La Documentation Française, 2014.

[96] See on this subject the INED publications: Gaymu J. et l'équipe FELICIE. *Comment les personnes dépendantes seront-elles entourées en 2030 ? Projections européennes. Population et sociétés 2008* : 44.
Bonnet C, Cambois E, Cases C, Gaymu J. *La dépendance : aujourd'hui l'affaire des femmes, demain davantage celle des hommes ? Population et société 2011* ; 43
The population of dependent people aged 75 years and over is likely to increase by more than 70% in Europe between now and 2030 if the health conditions prevailing today continue on the same lines. In the same time period, the portion of the population without a spouse or a child should diminish as compared to people with at least one relative (child or spouse) who can assist them. "*Because there are more of them and they live longer than men do, and are therefore, more often than men, in a situation of dependency in their extreme old age, at this point women are the main beneficiaries of home assistance and care. They are also the main providers of assistance within the family: it is women mostly who go out of their way to help parents and spouses. In the next decades, there will be more elderly people and among them, more of them men who are either dependent or potential caregivers. Will we be observing evidence of a shift in family roles, and if so, of what kind? A development of professional home care? Will the cost of it be borne individually or collectively?*"

EHPAD, in a context where staffing is inadequate and medical care is "rationalised", residents' feeling of solitude is in fact reinforced[97].

Furthermore, the increased numbers of people who have become dependent "ultimately", partly because of improved healthcare and medical progress, recent societal developments in access to work for women and its generalisation, the gradual disappearance of "intergenerational housing", the organisation of the public health system and the limitations on the possibility of care in people's own homes, all lead to a "concentration" of elderly people all housed together in the same place, mainly in EHPADs. This *de facto* concentration isolates them from "other people". In addition, this one place itself bundles together elderly people suffering from incapacitating cognitive[98] disorders, debilitating for themselves but also extremely disturbing for fellow residents.

This situation has an obvious impact on the vision we have both from "inside" and from "outside" of these structures, but also on the way we view the elderly and, more generally, the ageing process which is all too often seen through this prism as a defeat, a fall from grace (as General de Gaulle remarked). This contributes emphatically to a modification of how our society today views old age. In truth, this system is the cause of furthering the exclusion of elderly people.
On what logic is based the reduction of an elderly person's living space to the size of a monk's cell or the concentration of elderly people all together in a single type of accommodation? Are not arguments based on economic rationality, ergonomics and safety now being allowed to take precedence over the capital importance of respecting people's wishes as to where they want to reside, over including the elderly into the social fabric in the diversity of ages and beings consubstantial with a definition of society? Is this exclusion in the guise of concentration not the materialisation of a collective denial of the inexorable reality of the future of each and every one of us?

[97] Trépied V. Solitude en EHPAD. *L'expérience vécue de la relation soignante par les personnes âgées dépendantes », Gérontologie et société 2016* ; 38 (149) : 91-104.
[98] Morin L, Aubry R. *Fin de vie et démence dans les établissements d'hébergement pour personnes âgées dépendantes (EHPAD). Médecine Palliat.* 2015;14: 191–202.

10. How could elderly people exercise their existing rights in the face of total opposition to the exercise of these rights? How to focus better on the capacities of people who are said to be vulnerable and not just only on their vulnerabilities?

Laws on the protection of vulnerable people are not in short supply. For that matter, one could say that France is probably one of the countries with the most legislation protecting their rights[99].

In fact, a fair number of measures for personal protection exist:

- Proxies, power of attorney given to a third party to interact with banks or managers of benefits.
- A mandate for future protection, i.e. a contract allowing people to organise in advance their own protection and that of their possessions and to designate a proxy who will be tasked with acting in their stead when their state of health no longer allows them to act for themselves.
- A trusted person, designated as a kind of spokesperson for vulnerable people who can no longer express their own wishes.
- When the state of a person's health warrants it, a magistrate acting in supervision of guardianship in district courts can be called upon to issue legal protection measures (court custody, guardianship, trusteeship, etc.). This protection mainly aims to safeguard a person's environment or assets, for example.

But how could elderly persons exercise such rights — for example the right to choose where they want to live or in fact end their lives — when the result is an impossibility?
How could elderly persons exercise their rights when they are isolated and that their slowness in responding or their participation in the life of society are not respected?

The drawing up of advance directives, for example, is a true illustration of the non-respect for personal autonomy. Law n° 2016-87 of 2 February 2016 that created new rights for patients and people whose lives are ending, has recently reinforced the value of these advance directives by making them binding. The legislators intended the advance directives to be a tool to facilitate the expression of people's wishes, be they sick or healthy, regarding the end of life and to reinforce the value of those wishes when medical decisions have to be taken although the sick persons concerned can no longer express their wishes themselves.

For the directives to be binding on the medical decision makers, advance directives must be written, signed and dated by the person concerned. In the case of an elderly person, this written document can only be the consequence of having foreseen their current condition. This advance planning requires on the part of members of the medical professions, and also on the part of relatives and friends of the patient, time to spare, willingness, authenticity and competence for sensitive communications. It means entering into a dialogue which will touch upon the end of life and the death of the elderly person concerned before perhaps getting down to the drafting of the advance directives. To sum up, the point of advance directives is not so much whether they were drafted by all those involved, but whether they are the result

[99] Laws: dated 4 March 2002 on patients' rights and the quality of the public health system; dated 11 February 2005 on the rights of disabled people. dated 5 March 2007 reforming the legal protection of adults, dated 28 December 2015 on adapting society to the ageing process, dated 2 February 2016 creating new rights for patients and people reaching the end of their lives.

of a dialogue helping the person concerned to see things more clearly and expressing as faithfully as possible an autonomous decision[100]. Who nowadays has the time to spare and the willingness to discuss these subjects at leisure with an elderly person so as to ensure the exercise of that person's autonomy?

It is a proven fact, in EHPADs in particular, that the one subject that members of the medical professions and residents prefer to avoid is that of the end of life and death[101]. The so-called "life planning forms", which are to be filled in when entering an EHPAD, strangely enough often exclude the fact that these are plans for the end of life; they could be an opportunity to talk about the end of life and about death and they could be a good lead-in to discussing possible advance directives.

As regards the protection of vulnerable people, French society has a full legal framework for the assistance and support of people who have become particularly vulnerable because of their state of health[102]. And yet, compared to the large number of people placed under the protection of the public community (this concerns 700,000 people) and, as pointed out in a recent report by the Cour des Comptes (Court of Auditors), "... the resources the State provides 'seem insufficient, in particular in comparison with those available for the judicial protection of children. There is no government department dedicated to supervising the actions taken in favour of vulnerable adults. Families are poorly informed and imperfectly supported. Professionals do not have any identifiable contact or organism to speak to. Competent administrations stay strictly with the area of their core missions and do not consult among themselves. The guardianship magistrates each have an average of 3,500 protection measures they are supposed to monitor regularly and the court registries are unable to check the accounts for assets belonging to adults that guardians and trustees submit every year..." [103].

[100] *Espace éthique de la Fédération Hospitalière de France (FHF). Avis sur les contraintes éthiques des directives anticipées contraignantes concernant une personne atteinte d'une maladie grave.* 2016. (Opinion on the ethical constraints of binding advance directives for persons suffering from serious disease. Can be downloaded on www.**fhf**.fr/

[101] Morin L, Johnell K, Van den Block L, Aubry R. Discussing end-of-life issues in nursing homes: results from a nationwide Sentinel Network of nursing home physicians in France. Age and Ageing 2016; 0: 1–7

[102] Laws: dated 4 March 2002 on patients' rights and the quality of the public health system, dated 11 February 2005 on the rights of disabled people, dated 5 March 2007 reforming the legal protection of adults, dated 28 December 2015 on adapting society to the ageing process.

[103] *Cours des Comptes. La protection juridique des majeurs. Une réforme ambitieuse, une mise en œuvre défaillante. Communication à la Commission des finances, de l'économie générale et du contrôle budgétaire de l'Assemblée nationale*. September 2016

Annex 3. International comparisons and how the way in which the elderly are viewed is evolving

1. ***The major principles adopted by the social security systems in different countries for coping with the protection (old-age provision) of the elderly*** [104]

This annex is a comparison of the guiding principles for the coverage of the elderly by the old age provision in the social protection systems of various countries.

Reasons for choosing certain geographical areas:

- The European continent was the birth place of social protection and the principal systems prevalent worldwide were developed on this continent. A study of the systems in place in several European countries therefore provides useful insight.
- Considerable demographic change is a characteristic of the African continent: increased younger population, accelerated ageing of the current population. As the continent is composed of a number of developing countries, it is interesting to study the presence (or absence) of state-governed projects for the protection of the elderly.
- The United States has a system which covers 96% of the population, so that a study of the American system throws light on the various problems in this respect regarding coverage and what proportion of the population is covered.
- Japan is currently the country where an ageing population is most prevalent and where people live longest. It is therefore a major challenge for the Japanese government.

1. Provisions for the aged in Europe

1.1 Germany

The German system is primarily based on a Bismarckian model, so that the pension scheme is mandatory for employees and certain self-employed workers. The financing model it generates is an illustration of the central place given to a work culture in the German social system. Funding is based on contributions by both employers and employees. Various voluntary corporate or private schemes come as a complement to the state scheme.

Access to pension rights is acquired upon reaching a certain age and the set length of time contributions have been served. There are also provisions for early retirement. In administrative terms, pension funds (employees, manual workers, miners, etc.) are autonomous but supervised by the Ministry of Works and Social Affairs.

The amounts paid are calculated taking into consideration earnings while the individual is employed and serving contributions, based on contributory and non-contributory components. There are minimum and maximum limits and a possibility of combining entitlement to a pension and an income from employment.

1.2 Belgium

The system is inspired by the Bismarckian model involving mandatory professional cover and funding *via* social contributions. The government finances support for the elderly. Administratively, the system is managed by a national social security bureau which collects contributions and redistributes them to the institutions concerned (in this instance, the national pensions bureau). This bureau reports to the Ministry for Social Affairs and is directed by an autonomous committee whose members are nominated by the King.

[104] This paragraph was produced by Gauthier Kieken, trainee with CCNE.

Old age pensions are served upon reaching a certain age and the time during which a pensioner has been affiliated is a factor only in the determination of the rate of benefits. The amount depends on salaries earned (although certain non-contributing periods of time enter into the calculation), family status and duration of insurance. In this country also, early retirement is a possibility.

1.3 Spain

Spain has adopted an insurance-based model. This is also true as regards unemployment. The system is funded by contributions, also single-purpose since one contribution covers all the risks. As everywhere else in Europe, funding is dual with a substantial contribution from the State.

The social security system is governed by a single administration, the Ministry for Social Affairs and Employment. Management is tripartite with input from the State, employers and workers. Old age insurance is mandatory. Pension amounts depend on salaries and how long people were paying into the scheme. A minimum time of insurance is mandatory and there is a legal age limit for retirement. There are possibilities for early retirement and for combining pensions while continuing to be gainfully employed.

1.4 France

The French system is complex. It is often said that it combines Beveridge's principles with Bismarckian methods. Its founding principles are also universality, solidarity (at several levels as regards old age: intergenerational, professional and national). And yet, professional insurance is mandatory, with a strong dualistic component, albeit in the main based on contributions. There are about a hundred different pension plans. The general social security scheme is the most prevalent and covers mainly salaried employees. The pension insurance is run by a national fund (CNAV) and a network of organisms (CARSAT, CGSS, CSS). It manages the general social security scheme, that is the basic pension of employees in industry, trade and services.

The complementary insurance schemes are mandatory with joint management. There are also supplementary, non-mandatory pension schemes, regulated by the codes for social security, mutual benefits or insurance.

Benefits are relative to contributions, as served during the contributing or non-contributing periods of time.

1.5 Greece

The Greek system aims at universal coverage and co-existence with the professional schemes whose funding is provided by contributions and government subsidies.

Administratively, there are a great many insurance institutions, each of which is governed by different legislation, under the aegis and authority of the Ministry for Health and Contingency Planning.

The legal age for retirement, at which time pensions can be served, is 65 years and the rate depends on the length of time contributions were paid in to the scheme. In parallel, there is a minimum pension scheme. Insurance is mandatory and occupational. The Institute for Social Insurance (IKA) manages the old age provision. There are also a number and variety of early retirement schemes. However, because of successive reforms the system has become a little obscure.

1.6 Italy

Based on a tradition of Beveridge principles progressively modified in the direction of universality, old age pensions are occupational as regards affiliation in parallel with a minimum old age pension system. Administrative management is complex as it is separately specific for the collection of contributions and the payment of benefits.

Although it was originally a pay-as-you-go system, it has progressively moved in the direction of virtual full-funding. Pension benefits are contingent on retirement at the set legal age. The system is mandatory, based on predominant occupational principles because of the existence of different mechanisms depending on the sector of activity and, therefore, governed by different institutions. Pensions depend on the length of insurance and the sum total of salaries. Early retirement possibilities exist. Currently, both the old pay-as-you-go system and the new notional accounts system are in use.

1.7 The United Kingdom

The Beveridge system's cradle, it is based on unity, uniformity and universality and is State-managed. The State also manages some of the complementary insurance schemes although some of them are independent. Funding is ensured via mandatory and voluntary contributions on a joint (employee/employer) parity basis.

The pension scheme is mainly on a pay-as-you-go basis, supplemented by some capitalisation. Basic pensions are identical for all but there is also an additional benefit which is proportional to earnings. This duality persists in schemes and conditions, but it is the quantification of conditions that change, in particular as regards legal retirement age and length of time contributing.

Source: EUROPA, Les services publics et l'Union Européenne, « La protection sociale en Europe », 2011.

2. Provisions for the aged in Africa

Support for the elderly will be a major challenge for the African continent because of two problems:

- The proportion of over-60s was 5.5% in 2015, but it will be 8.9% in 2050. This is fairly low in comparison to other continents, but it will triple in the space of 35 years [1].
- State investment is much too low, restricted by limits to solidarity.

In today's Africa, family solidarity is the preferred social protection method. However, with recent epidemics and increasing urbanisation, its limits are becoming apparent [2], [3], [4].

As noted by Muriel Sajoux, Valérie Golaz, and Cécile Lefèvre, it is mainly a panAfrican reaction which has stepped in, in the form of State investment, to come to the aid of family solidarity:

- The Pretoria Declaration on Economic, Social and Cultural Rights in Africa (2004)
- The Africa Union's Social Policy Framework for Africa (2008)
- The Yaoundé Tripartite Declaration

These documents reaffirm the need for, and the right to, social protection for African populations.

Current social protection models are mostly inherited from former colonial systems. Currently social insurance is the mainstay with contributory pension schemes. Which supposes that the individual is working and enrolled in a social security system. In

Cameroon, for example, the labour Code stipulates retirement at an age set by law and a minimum length of contributory employment [5].
According to ISSA (2015), this only concerns 5.9% of the active Sub-Saharan population and 23.9% of North Africa. Such social insurance, inspired by Bismarckian principles, which includes *inter alia* survivors' benefits, is not the same as a provident fund which is mostly to be found in English-speaking Africa and is based on a system of capitalisation. However, these schemes are progressively giving way to Bismarckian models, as was the case in Nigeria in 1994 and Malawi in 2011.
A few non-contributory, fully Beveridge-type universal protection schemes still survive. They function via the payment of a flat-rate pension and are based on a residence requirement. This is the case for Botswana, Lesotho, Namibia.
As African States are becoming aware of the need to support both young and elderly sections of the population, minimum old age pensions are emerging in a number of countries, such as Lesotho (2004) and Swaziland (2005).

Despite a growing number of developments in social protection, there are still significant disparities between men and women as well as urban and rural situations. This is true of the payment of pensions and the system is also severely contaminated by the existence of an informal, largely unreported sector. The situation is aggravated by the lack of healthcare provisions for the elderly; in 2010 the International Labor Organization reported that only 1% of the African population was involved.

3. Provisions for the aged in the United States [6]

The most salient fact in the United States is the quasi-absence of any pension scheme. It is first and foremost through capitalisation and savings (denying oneself consumption now in order to save for future consumption) that the population finances its pensions.
In the few cases where they exist, pension schemes are based on pay-as-you-go and distributive. They are topped up by a number of complementary schemes. The system includes a majority of people but benefits are small. It is a part of the Social Security scheme and is called the "Old Age and Survivors Insurance, which is a federal programme.

Funding is provided by tax revenues of the current year. Workers in both the public and private sectors pay a contribution for Social Security from which they will receive pensions calculated according to the level and duration of contributions. Employers and workers contribute to the fund on a parity basis. Similarly to European systems, access to full pensions are conditioned by retirement at an age set by law.
Complementary schemes are occupational and left to the discretion of employers. As reported by Philippe Vilas-Boas, there are two separate schemes: the Defined Benefit Pension and the Defined Contribution Pension.

4. Provisions for the aged in Japan [7]

There are two types of system in Japan to cover old age: one for salaried employees ("Kosei Nenkin") and the national, mandatory scheme for other workers ("Kokumin Kenko Hoken").
The first of these two systems pays out pensions which are proportionate to salaries. The system is compulsory and administered by the government. Employers (for companies with more than 1000 employees) can create pension funds, whose creation requires the agreement of employees, trade unions and the government. Once in existence, employee participation is mandatory and government funded pensions are adjusted accordingly.

The employee system is funded by insurance contributions, equitably shared between worker and employer. Insurance stops when employees reach the age of 70 although they may continue to be insured if they are willing to pay the whole contribution themselves. The amount depends on the employee's category, age, number of years insured. There is also a possibility of exemption from pension scheme enrolment and a basic disability pension ("Shogai Kiso Nenkin").
The national system is funded by worker (wage-earners and others) and State contributions. Pension is a flat rate. The private schemes are based on pensions adjusted according to the worker categories.

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[3] Sajoux M., Amar M.; *"Vieillesse et relations familiales au Maroc. Des solidarités fortes en proie à des contraintes multiples » ;* Vieillir dans les pays du Sud, Paris, Karthala, 187-209 ; 2015
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[6] Philippe Vilas-Boas ; *« Etats-Unis : petites retraites pour tous ? »* ; Apériodique Focus, n°13/40 ; Montrouge ; mai 2013.
[7] Centre des Liaisons Européennes et Internationales de Sécurité Sociale ; *« Le régime japonais de sécurité sociale (salariés) »* ; www.cleiss.fr/docs/regimes/regime_japon_salaries.html;

2. A comparative analysis of the perception of elderly people in industrialised and developing countries respectively[105]

The issue of ageing, beyond the institutional problems, and of emergent pathologies, is also a social issue. Jacques Fernand Ouakam[106] highlights a discrepancy between the perception of elderly people in the industrialised and developing countries, although lately the contrast is attenuated.

In Europe, the way this perception has evolved has gradually given rise to elderly people's isolation. As an example, the IPSOS-Senior Association Institute[107] notes regarding one of the fears entertained about ageing in France, that in reply to the question "What frightens you particularly about ageing?", 29% of people mentioned social isolation and loss of loved ones in second place after physical deterioration. Jacqueline Trincaz[108], in a study of the successive definitions used to qualify the aged, notes that perception has evolved from "wise" to "a burden". Industrial societies besides France segregate the elderly by their behaviour, their practices and their perceptions, as underlined by J. Maisondieu, psychiatrist, when he writes: "...age-related apartheid, with a ferocity which is all the more fearsome because it is subconscious, even in the minds of its victims"[109]. Moreover, in industrialised societies, the role of the family, insofar as it concerns its elderly members, is dwindling. And so, older people are a "surplus to adults immersed in their work and other demands on their time". With increasing maturity, the elderly bring other concepts to mind: banker, but also "burden" and "hanger-on". The lack of social and institutional consideration gives rise to marginalisation, passivity and dependency[110]. They are sometimes perceived as "blameworthy victims", a product of political economics[111].

At the opposite end of the range, in so-called developing societies, as illustrated for example by African families (in a system where societal stratification was based on age groups), young people are aware of their youth and lack of experience. They see "the ancients" as a source of maturity, living history, initiator to life in society and culture, the venerated teachers. However, this concept too is past its prime since there are signs of a new current of opinion that tends to draw together the two society models. Parents cling to tradition and there is an emerging social disconnection[112]. Lessault[113] also notes that in Dakar the late departure of youngsters from home is due to economic dependence on their elders. From these two

[105] Paragraph by Gauthier Kieken, trainee with CCNE

[106] Jacques Fernand OUAKAM OUAKAM, thesis « *Autonomie, dépendance et santé des personnes âgées cas du district de Bamako (Mali) », Université de Bamako 2005*

[107] An IPSOS survey of a sample of 900 people aged 50 to 70 years, published in l'Express (9 September 1999 n°2514). *Question: « qu'est ce qui, dans le vieillissement, vous fait particulièrement peur ?* » (Question: what frightens you particularly about ageing).

[108] Jacqueline Trincaz: *« Personne âgée : quelles représentations sociales ? Hier et aujourd'hui » ,LIRTES EA 7313, Université Paris Est Créteil Val-de-Marne, Créteil*

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[112] Dembelé C. Oumar *: « Le conflit de génération dans quelques romans négro africains » 1976 Mémoire de lettre, ENSUP, 76-A-9 (« Autonomie, dépendance et santé des personnes âgées cas du district de Bamako (Mali) », Université de Bamako 2005)*

[113]Diagne et Lessault *« Émancipation résidentielle différée et recomposition des dépendances intergénérationnelles à Dakar ». Paris, CEPED, Collection « Regards sur », 41 p., 2007*

findings emerges a point they have in common: relationships between generations are a reflection of economic and social transformation.
According to the figures in M. Ouakam's thesis, 76.67% of aged people questioned feel that they are respected by youngsters, 91% consider that this is due to their upbringing, 71.1% consider that the relationship has evolved (100% of the 150 people who were asked what this might be due to, replied that they thought it was upbringing. 87.62% of those asked consider that they are no longer important in the eyes of the community, although 53.3% of them are active carers. 61.9% of the people surveyed are "depressed". These figures illustrate a modification of the way elderly people are regarded in Africa, and they are confirmed by a CEPED 2007 report on " *Les relations intergénérationnelles en Afrique, approche plurielle*" (Intergenerational relationships in Africa, a multi-faceted approach) by Ph. Antoine, with reference to studies by V. Hertrich[114] outlining the finding that among the Bwa population in Sub-Saharan Africa, modification of people's perception of the aged goes hand in hand with a reduced appreciation of their legitimacy as regards their traditional domains of competence. Attané[115] and Vinel[116] arrived at similar conclusions in their analysis of matrimonial practices in Burkina Faso where it would appear that the prerogatives formerly granted to the elderly are fast diminishing.

3. Study on changes in the way elderly people are regarded[117]

In the Bible, in the Book of Daniel, there is "only one episode associating not virtue but vice with great age, in the often quoted account of Susanna and the two elders who hide in a garden to observe the woman they lust after as she bathes[118]". Conversely, damnation and celestial punishment were visited on old age in Greek and Roman myths. "Pandora visits the earth to bestow upon it the cruel pestilences that old age brings to humans"[119] .

This accursed old age also featured in Euripides, when Hecuba "aged, childless and enslaved" became a prisoner of the Greeks, and also in the *The Phoenician Women*: "...we the old, but a roaming host of dream-like apparitions, common sense lost, however quick-witted we believe ourselves to be..." [120]

In Greek comedy, old men were an object of ridicule, as in *Plutus* where an old man used cosmetics as he sought to wed a much younger partner[121]. Their situation in society was precarious. "The history of institutions seems to show that the authority of the head of the

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[114] Hertrich V., 1996 – *« Permanences et changements de l'Afrique rurale : dynamique familiales chez les Bwa du Mali »*. Paris, CEPED, Les Études du CEPED, n° 14, 548 p.
[115] Attané A., *« Choix matrimoniaux : le poids des générations… », « Les relations intergénérationnelles en Afrique, approche plurielle » de Ph. Antoine, CEPED, p168-196, 2007.*
[116] Vinel S., 2000 – *« Comment les alliés sont aussi des parents. Endogamie locale et relations familiales dans un quartier moose sikoomse (Burkina Faso) ».* L'Homme, 154-155 : 205-224
[117] Paragraph by Marc Bongiorni, CCNE documentalist
[118] Simone de Beauvoir, *La vieillesse.* (The Coming of Age) Gallimard, pp. 117.
[119] Hesiod, Works and Days, quoted in Minois, *Histoire de la vieillesse. De l'Antiquité à la Renaissance,* Paris, Fayard, pp. 72
[120] Euripides, quoted in Minois, op. cit. pp. 81.
[121] Georges Minois, op. cit. pp. 84.

family gradually diminished in Greece from the 7th century onwards and conflict between generations was quite heated, heightened as children seized greater legal independence[122]. The repetition of a number of Athenian laws on the obligation to respect elderly parents would seem to indicate that they were not greatly observed. [123]

There were twice as many old men as there were old women in the Roman Empire, mainly as a consequence of death in childbirth, which is why there were few elderly women characters in the literature, but "... above all the sex imbalance at the top of the pyramid is owed to the large number of marriages between an old man and a young woman, or at least a considerable difference in age between spouses. The literary paradigm of the libidinous old man in love with the same woman as his own son is more comprehensible in such a context (Plautus, Terence). There are not many women to be wed of the same age as the older Romans and rare indeed are elderly couples or spouses growing old together. Old men frequently enter into new wedlock with excessively young wives only too ready to make fools of them with young lovers. [124]"

From the 4th century BC onwards, the eldest male, the *pater familias*, was invested with an essential role at the head of his family. His absolute powers (he could sell his children into slavery abroad, exclude them from the family, etc.) gave rise "to feelings of pure hatred for old men who refuse to die"[125], as depicted in Roman comedy. Up until the 2nd century BC, "the Republic is conservative, order reigns, governed by an oligarchy favouring old age whose conservative inclinations conform to its own. It is only at a fairly advanced age that a man can aspire to be a high ranking magistrate. The "career of honours" is carefully regulated to prevent meteoric progress. Moreover, the Roman voting system is slanted in favour of elderly men. This political outlook is based on an ideology rooted in a rural economy with peasants wary of novelty. The essential virtue in Rome was *permanence*. The customs of ancestors had the force of law and postulated belief in age-old wisdom. Ancestors remained as a presence within the family: the Manes returned from the underworld on certain days and sacrifices were offered to appease them. They had to be obeyed and tradition had to be respected." [126]

As Roman antiquity drew to an end, with the Barbarian invasion and the triumph of Christianity, "little is known about the status of the old among the Barbarians. But a specific fact tells us that in the 6th century, there was a devaluation of the individual: the monetary compensation demanded in the event of the murder of a free man. Visigoth law set 60 pieces of gold for a one-year old child, 150 for a boy aged 15 to 20, 300 for a man 20 to 50, 200 for a man 50 to 65, 100 for a man over 65, 250 for a woman of 15 to 40 years, 200 for a woman 40 to 60 years old." [127]

[122] Jacques Ellul, *Histoire des institutions de l'Antiquité,* PUF, 1961, pp. 44, quoted in Minois, op. cit. pp. 97.
[123] Encyclopaedia of Religion and Ethics, éd par James Hastings, Edimbourg, 1917, art. "Old Age", pp.471, quoted in Minois, op cit pp. 97
[124] Georges Minois, op. cit. pp. 123.
[125] Ibid. pp. 124.
[126] Simone de Beauvoir, op. cit. pp. 141.
[127] Ibid. pp. 155.

Elderly men did not feature very prominently in the literature of the High Middle Ages[128]. The harshness of the times keeps them out of active life. In most European countries, a son replaced his father at the head of the household. As he attained a certain age and was too weak to till the soil, the father left the land to his eldest son. "Once in receipt of this heritage, the son took wife; the young woman replaced her mother-in-law and the old couple moved into the room that was traditionally given over to them, the "west room" as it was traditionally referred to in Ireland. Old people whose families could not take care of them were helped by the feudal lord or a monastery, but generally such assistance was meagre and the old ones were reduced to begging. Their position, at every level of society, seems to have been particularly underprivileged. Physical prowess was of prime importance for noblemen and peasants alike: weaklings were scorned. Youth was an age group of considerable importance but there was no such thing as an old man's age group. In the arduous and challenging circumstances of the times, communities were mainly interested in children who, having survived childhood ailments, represented the future in a society where a child was treated from the start like a small adult, working in the field or training to be a soldier." [129]

A study of the demography in the works of the Bordeaux poet Ausonius, at the chronological hinge between the Late Roman Empire and the High Middle Ages, provides examples of longevity comparable to those of today, but corroborates the limited role of the older generation within the social fabric as evidenced by their absence in sources.[130]

The primacy of son over father was confirmed in the 11th century. It is the son's effigy that is sculptured on the church tympanums. All the illuminated designs, paintings and sculptures were evidence of the same development in popular Christian representations, glorifying the Son to the detriment of the Father. Paintings represented Christ on the cross and God as an old man with a white beard, "Master of the celestial fortress"[131].

The popular imagery created by the Middle Ages and which persisted after many a century is not as serene as the "learned old man with a beard, sitting at his work table, in front of the hearth. It was replaced by Old Father Time, winged and wasted, holding a scythe. Although the association of the two notions seems to be obvious, old age as the result of an accumulation of years, the link had not always existed. In Antiquity, time is shown as a dual imagery. The first concept underlines the swift passing of time. This is Kairos, god of the opportune moment, marking a time of change in the life of men or of humanity. The second set of images insists on the fecundity of time: this is Aion, the creator, the symbol of infinite fertility. Time passes, but in passing, it creates. The ancients underlined the ambivalence of time. The plastic representation of time in Antiquity never refers to deterioration or destruction. Plutarch is the first to point out the contamination that had occurred between the Greek name for time, Chronos, and that of Kronos (or Kronus) the most fearsome of the deities. Kronus, who devoured his children was, as seen by Plutarch, the personification of Time and the Neo-Platonists accepted this assimilation while giving time a more optimistic

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[128] Yannick Sauveur. *Les représentations médiatiques de la vieillesse dans la société française contemporaine : Ambiguïtés des discours et réalités sociales. Sciences de l'information et de la communication. Université de Bourgogne*, 2011.

[129] Simone de Beauvoir, op. cit. pp. 162-166

[130] R. Etienne, *« la démographie de la famille d'Ausonne », Etudes et chroniques de démographie historique*, 1964, pp. 15-24, quoted in Minois, Histoire de la vieillesse. *De l'Antiquité à la Renaissance,* Paris, Fayard, pp. 211

[131] Simone de Beauvoir, op. cit. pp.166

interpretation. In their eyes, Kronus is the *Nous*, the cosmic understanding, the "wise old builder". Kronus was always depicted carrying a sickle, which at the time was considered to be an agricultural implement, a symbol of fertility. In the Middle Ages, this image was revisited: and time was seen as the cause of decline[132]".

After the 11th century, there were direct references to age in written works, "describing age and seeking for its causes and also its remedies. There is a return, particularly in the 13th century, to certain aspects of the thinking of antiquity. The elderly, who had almost vanished from theological writings and chronicles, reappear as literary characters[133]."

The status of age in medieval literature "seems rather ambiguous, situated between the two poles of wisdom on the one hand and, on the other, physical and moral decrepitude[134]." Saint Bernard mentions a notion that is familiar to clerical thinking in the Middle Ages when he states that true age is in wisdom and virtue, the actual number of years being almost extraneous[135]". But in popular belief, "folklore still associates age with death and suffering. In the German tradition, all old women are evil and, in some villages, the effigy of an old woman is burnt to drive away ageing. In the Roussillon region of France, the symbol of the time of penitence, Lent, is represented as an old woman, the *patorra*, who is burnt on Easter Sunday[136]."

The elderly featured much more prominently in the 14th and 15th centuries. They were more successful in surviving the plague epidemics which killed more than a third of the European population and flared up again repeatedly for over a century. "The elderly could represent up to as much as 15% of the population and are therefore the living embodiment of withstanding the ravages of time[137]." "As a consequence of this recurrent selective devastation, the economic and political power of elderly men was reinforced. Fathers stayed longer at the head of family fortunes which they sometimes transferred directly to their grandsons. As time went by, they were able to amass more capital and monopolise powers of decision to a greater extent than in the past[138]."

Although it was not a brutal break from the Middle Ages, the Renaissance was "like a process of acceleration for changes to the world, a dynamic evolution that soon swept through the whole of Europe. The new generation around 1500 was the first in two centuries not to die abruptly slain by the tragedies of the time. Epidemics were less virulent, famine subsided. There were proportionately more young people than in the previous century and youth was enamoured of life, luxury, art, culture, discovery and adventure... The humanistic times of the Renaissance could not be favourable to the elderly. After the thousand-year indifference of the Middle Ages, came two centuries of pessimism and sarcastic hatred of age[139]".

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[132] Ibid. pp.170
[133] Georges Minois, op. cit. pp. 228.
[134] Bernard Ribémont, *Sagesse ou folie ? Être vieux dans la littérature médiévale, Gérontologie et Société, septembre* 2005.
[135] Saint Bernard, Œuvres complètes, trad. Par l'abbé Dion, 8 vol., Paris, 1867, t. IV, *Traité du règlement de la vie et de la discipline des mœurs,* pp. 59-83, quoted in Minois, *Histoire de la vieillesse. De l'Antiquité à la Renaissance,* Paris, Fayard, pp. 236
[136] Georges Minois, op. cit. pp. 242.
[137] Yannick Sauveur, op. cit. pp. 68.
[138] Jean-Pierre Bois, *Histoire de la Vieillesse.* PUF, 1994, pp. 317.
[139] Ibid. pp.45

"Pluck, pluck your youth, since, as with this flower, age shall tarnish your beauty".

"Be they his predecessors, or Ronsard's imitators, all the 16th century poets sang the same lines, whose echoes permeated every level of society in all the far-flung corners of the European Renaissance. As always in times of rebirth and awakening, the era celebrated youth, the plenitude of life and the bloom of beauty and shunned all tokens of decline, decrepitude and death. As in Greek antiquity, the Renaissance instinctively harboured feelings of disgust with old age. The unprecedented violence of attacks against age in the 16th century was the expression of the impotent rage felt by this generation of worshippers of youth and beauty. The face of age appeared in the guise of a death mask[140]".

The representations of the 17th century were mainly abstractions in multiple forms: "In these Counter-Reformation times, there were the elderly in the major religious compositions whose idealisation was always timeless. Literature exploitded the themes announced by authors at the end of the 16th century, at first simply to accentuate the more striking characteristics, as in the description of the weak old man (Don Diègue in Corneille's *Le Cid*) or the uselessness of old age as typified by Cyrano de Bergerac. And again by Molière with the backdrop of the notion that age accentuates all the failings of men. The acid humour of Jonathan Swift in Resolutions *When I Come to be Old* summed up the anxieties of a time when age was synonymous with distress[141]."

In the Age of Enlightenment, the world "discovered the individual, hence the child, tenderness and emotion in family relationships and also heartfelt sentiments for old age and the old ones. Age was less defined in terms of power or dependency and more as a new factor identifying a person. This favourable evolution was the true transition between medieval civilisations and those of today, a cardinal event composed of the passage from community societies to governed societies identifying the individual within a state structure. In the 18th century there was a complete renewal of previous demographic preoccupations with an introduction to a time of realistic survey and exact calculations. Old age was categorised in actual years and ceased to be an abstraction. As a result of less early death and the improvement in living conditions, sixty-year olds counted for over 7% of the European population in the early part of the century and thereby crossed the threshold of perceptibility. With a smaller proportion, there was less awareness and unpopular old age was not perceived as a social reality nor integrated as a moral philosophy; but now the elders became a non-trivial component of the population. Representations of age, in both the visual arts and in literature, broke away from the pessimism and disenchanted irony of the 17th century, suddenly showing old age in a positive, just short of optimistic, light. This was particularly evident in the latter part of the century, with two excellent witnesses of their times: Denis Diderot and Jean-Baptiste Greuze. The representation of old age became more compassionate and social. The 18th century was also a time when the elderly were seen as living at a time in their lives when age had left room for the acquiring of qualities, allowing the kindly old man, with not only moral but political virtues, to enter the scene. Policies for assistance were set up in most European countries with the object of compensating the impoverishment brought on by increasing years. Invalidity pensions created by Louis XV evolved into military pensions under Louis XVI, thus emerging as the first retirement pensions in the kingdom. Other pension schemes were created in other government departments in France and the rest of Europe. The scale of the

[140] Georges Minois, op. cit. pp. 340.
[141] Jean-Pierre Bois, op. cit. pp. 54.

French scheme created a new figure on the social scene, old, inactive, honourable and honoured, to whom a pension brought independence, dignity and, finally, esteem. To this rehabilitation of age, the Revolution added glorification. Having destroyed all the ancient props, the Revolution was forced into seeking new roots for new values, and the elderly became the living examples of public-spiritedness and morality[142]." A the 10th of August 1793 celebrations, "86 old men bore the banners of the 86 *départements*. In the Federation's festivals, the elderly were held in high honour, presiding ceremonies[143]."

In the 19th century, the demographic situation was characterised by "the simultaneous collapse of infantile and infectious mortality, a steep increase in life expectancy and a drop in the birth rate, setting off the first irrevocable thrust of ageing in the European population. In the 18th century, the elderly first appeared and their numbers grew in the 19th century at a time when the rural exodus and the industrial revolution accentuated their precarious foothold, except perhaps in the bourgeoisie whose new-found prosperity and conscientious Christianity were at variance with failure to take care of the older members of the family group. For the first time, old age was perceived as a societal issue instead of just the fate of a single individual. After the first censuses in England and in France in 1801, the exact figures became known and demographic statistics revealed significant ageing throughout Europe. In France, life expectancy rose from 39 years around 1820-1830 to 48 years for men at the end of the century. For women the corresponding figures were 40 and 52 years. A reasonable estimation based on approximately 180 million Europeans around the year 1800, and a rate of 5 to 10% of individuals aged over 60 years, would add up to between 12 and 15 million senior citizens in Europe at that time. A century later, the population numbered 400 million inhabitants, with everywhere 7 to 13% of inhabitants over 60 year of age, and a total of 35 to 40 million old ones.

In this context, old people's health and medical science of the subject made remarkable progress. Charcot made a study of disorders characteristic of old age, of ailments affecting all age groups that take on specific traits when they affect the elderly and of pathological immunities brought on by age. This first rational approach to the subject of senile pathology was one of the outstanding features of the century's medical progress, culminating in the creation of geriatrics by its founder, an American, Dr. Nascher[144]".

At the time of the industrial revolution, traditional structures fell apart. "As a result of the rural exodus, children who go to live in the cities leave their parents behind to grow old unattended. In all of Europe, almost half of elderly couples in rural areas live alone in the second half of the 19th century[145]". For others, the cohabitation of generations was not always harmonious. In 1804, the director of an old people's home in Montrichard stated indignantly that: "Old people must take their belongings with them to the home, but their stone-hearted offspring bring their parents in and before they leave, strip them of even their clothes[146]."

Any attempt at summing up is precarious, "as the hierarchic structure in working class and bourgeois families is exceedingly complex. There are identifiable multiple-level families in

[142] Ibid. pp. 75.
[143] Simone de Beauvoir, op. cit. pp. 226.
[144] Jean-Pierre Bois, op. cit. pp. 87.
[145] Ibid. pp. 91.
[146] Historical study of Montrichard by M. l'abbé C. Labreuille, quote in Simone de Beauvoir, op. cit. pp. 239.

northern France, in the Lyons region, in the Meuse valley, where old people still able to work are kept within the family. Families become nuclear in areas where the textile and light manufacturing industries have given way to heavy and mining industries needing strong young male workers, so that pauperised grandparents are left behind. In the lower reaches of the bourgeoisie, the machines born with the century made family apprenticeship obsolete while the development of schooling made many a grandmother redundant. Thus vertical relationships within families are broken off but with the violence characterising the industrial and agricultural workers' worlds. In more moneyed circles, family becomes a bourgeois ideal with links between grandparents and grandchildren. It was in the bourgeoisie that certain family traditions are born, celebrating golden weddings or anniversaries. And so the general image of ageing takes many forms, content and the object of devotion for some, dispossessed for others[147]".

Perceptions of age were contradictory, even though "the general trend is to be much more kindly disposed towards age than at any other time in history. Up to the 18th century, reactions to age are mainly passionate and abstract, therefore open to moral, philosophical and religious vagary. At a time when ageing becomes an almost universal fate, authors finally distinguish between old age and adulthood and attribut specific values to each[148]."

In the 20th century, old age "has lost much of its prestige because the concept of experienced old age is discredited. Today's technocratic society no longer considers that knowledge accrues with passing years; on the contrary it is outdated. Age gives rise to disqualification. Only the values of youthfulness are appreciated. The old — with a few exceptions — no longer *do* anything. They are defined by *exis*, not by *praxis*. Time sweeps them towards an end that is not defined by an intention. Which is why they appear to active individuals in the likeness of "a foreign species" from which they are estranged[149]."

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[147] Jean-Pierre Bois, op. cit. pp. 93.
[148] Ibid. pp. 96.
[149] Simone de Beauvoir, op. cit. pp. 258-266.