

EDITORIAL

Wishes for 2016

The Administrative Council of the Crescendo Network wishes you a very Happy New Year 2016. May it bring you the blessing of a happy life, the joy of your personal or shared plans accomplished and the conviction of working for the Common Good and the announcement of Jesus Christ. We hope as well, that in the year 2016, the world will be less violent, more serene, constructive and the bearer of greater hope than was 2015. It is important that each one of us works toward this goal.

We are offering you a long article, non exhaustive, on the end of life in Europe, followed by a testimony. The end of life is a preoccupation for us, even if we are wishing that it comes as late as possible. In Europe, in the context of the laicization of society, mentalities evolve, convictions are being asserted and are confronted by the questions of euthanasia, assisted suicide, of the end of life with dignity. Politicians, governments and parliaments reflect and vote on updated laws which will result in future practice. Churches are vigilant about the respect of life and the dignity of the person until the very end. They insist on the increase of availability of palliative care.

We cannot remain disinterested. On the contrary, it is the very dignity of man which is in question. Living fully one's last years bears witness to our transcendence. "For believers in God, this final stage is not nonsense but another meeting. While respecting our freedom, God, the Lord of life, invites us to take care of each other with love, tenderness and an appropriate, fraternal support, worthy of the incredible greatness of every human being turned toward eternity."¹ The testimony of the Little Sister reveals the richness of a closer accompaniment of persons

Dominique Lemau de Talancé

We are seeking information regarding legislation and procedures as well as testimonies coming from other countries, other continents.

¹ End of life: Do not take the problem backwards! Bishops' Conference of France, January 20, 2015

POST

Current events regarding the end of life in Europe

Dr. François Blin
President of FEAMC

On April 17, 2015, the Executive Committee of the European Federation of the Catholic Medical Associations (FEAMC) organized a Colloquium entitled "The End of Life in Europe" which brought together some sixty participants from 15 European countries.

Legislation varies greatly from one country to another: penalization for euthanasia and assisted suicide range from being authorized (The Benelux) to 15 years in prison (Estonia, Lithuania). In several countries, notably Germany, advanced directives are still "open to challenge". In the great majority of countries, there are calls for the reinforcement of palliative care. In Russia, there is no ethical code. If the patient has the right to refuse treatment, the hospital has the right not to take this refusal into account. Therapeutic harassment such as euthanasia behind closed doors seem to be a usual practice. Palliative care is only at its beginning.

In November, 2013, The Council of Europe published a [Guide on the decision-making process regarding medical treatment in end-of-life situations](#). Leaning strongly toward consent of the parties, it recommends that only required treatments be dispensed, that useless or disproportionate treatments be stopped and that access to care be guaranteed. It mentions neither suicide nor euthanasia and avoids taking a position on three important subjects: advanced directives, hydration and

artificial nutrition, heavy sedation at the end of life.

The communications focused on three subjects:

Binding advanced: they exist in Germany since June 2010. The formulas vary and can be changed on the internet; both Catholic and Protestant churches are offering them. They can be given to the doctor or to an attorney. In the majority of cases, they are associated with the designation of a person of trust. These directives are valid for five years and up-dating them is recommended every one or two years. Because they are not always easy for the doctor to execute, one must sometimes have recourse to an ethics committee or even to the legal system. They are revocable at any time, even verbally, even with gestures, if the patient cannot speak. They are still not widespread enough. It would be desirable that they be applied in a climate of dialogue and not limited to being an administrative document.

Deep-sedation in the terminal stage. It had already been mentioned in Pope Pius XII's speech on February 24, 1957 to Anesthesiologists: *"Is the suppression of pain and of consciousness by the means of narcotics allowed when it is demanded by a medical indication ... even with death approaching and with the knowledge that the use of narcosis will shorten life? The answer will be: if there is no other means and if, in the given circumstances, that does not prevent the fulfillment of other religious and moral duties: Yes."* The new law being discussed in France limits deep-sedation "until death" only in cases when, at a short term, a life threatening prognosis is involved. Jean Leonetti, the reporter of this law, considers that this text is not ambiguous, but this opinion is not shared by all commentators. This communication, presented by a Parisian palliative care doctor, has drawn attention to the possible requests of the families who - sometimes more than the patient himself/herself - wish that the terminal phase be shortened. Now, the ultimate phase of life is sometimes the occasion of particularly moving relational times.

Nutrition and Hydration of patients in a chronic vegetative state: Dr. Leonetti defends the principle of the new law where it states that "Artificial nutrition and hydration constitutes a treatment" while considering that it is a question of artificially maintaining one of the most important vital functions, and that what applies to artificial ventilation applies as well to artificial nutrition. In his speech, Father Verspieren, a specialist in bioethics, defends the church's position affirmed by Pope John Paul II in his speech on April, 2004: "I should like particularly to underline how the administration of water and food, even when provided by artificial means, always represents a *natural means* of preserving life, not a *medical act*." It remains that categorizing artificial food as care or as treatment is without doubt not the heart of the



Jean Léonetti

Internet

debate. Perhaps the best possible notion would be that of "proportionality" of the care or of the treatment, without of course, forgetting the eventual position of the patient!

In France the new law stresses the need for increasing the development of palliative care units and to give more importance to the advanced directives of patients thus becoming compulsory to doctors. This new law shall establish the role of the person of trust capable of making decisions, should the patient become unable to do so.

Recently in the Bundestag, debates took place on Assisted Suicide in Germany. Since 1871, legislation has neither forbidden suicide nor the assistance to commit suicide as long as this aid is not "active" (furnishing a cocktail of deadly medications is not a crime, as long as it is the patient who self-administrates the poison.) But, in 2010, the creation in Hamburg of an association for assisted suicide in exchange for financial contribution opened a controversy. In 2015, Chancellor Angela Merkel and the Minister for Health upheld the Gries-Brand law, suggesting the ban of any organized assistance to commit suicide. Cardinal Reinhard Marx, president of the German Episcopal Conference, and Bishop Heinrich Bedford-Strohm, president of the Protestant Church, also indirectly supported this interdiction.

tion by publishing their common position for “the prohibition of organized assisted suicide”. The Catholic and Protestant Churches have gone further by extending access to palliative care. A law in this sense was voted on November 5, 2015. “The Griese-Brand Law was adopted by the Bundestag on November 6, 2015 and was included in the penal code. It is very short: “Commercial help with suicide”:

- 1- One who, with the intention of assisting a suicide by way of a third person direction, procuring for him, or serving as mediator with the commercial possibility of doing so, will be punished by a prison sentence of up to 3 years or a severe penalty.
- 2- The participant who does not act commercially, whether a relative of the third person named in §1, or one who is a close relative, remains unpunished.

The ethical code of the German Medical Association is clearly opposed to all forms of medical assistance in suicide: “Doctors must help patients while respecting their dignity and their will. It is forbidden to help patients kill themselves. One is not authorized to help a patient kill himself or herself. The deontological code requires doctors to furnish help to live, not to die.” Thus, a doctor (or relative or someone near to the patient) who will have helped in the suicide, would not be punishable by law, but could see oneself stripped of the right to practice medicine. All the same, one can question oneself on §2 of the law, which underlines the authorization for assisting a suicide by one’s close relatives.

In Switzerland, the penal Code, which prohibits euthanasia (Art.114), prohibits assisted suicide only in the case of a “selfish motive” (Art. 115): “Whoever, from selfish motives, induces another to commit suicide or assists him therein shall be punished, if the suicide was successful or attempted, by confinement in a penitentiary for not more than five years or by imprisonment.” This law might appear more restrictive than the German law (the son who encourages or helps his father to kill himself in order to obtain the inheritance falls under the scope of the law). One can, however, be surprised that in Switzerland as well as abroad, Swiss associations “for the right to die” *Exit* and *Dignitas*, have increased the number of assisted suicides every year. On November 6, after the vote of the German Law, the Geneva newspaper *La Tribune de Genève* headlined: “...Many more Germans could still come to Switzerland to die...”. On the whole, one can ask if, more than the law itself, it is not the manner in which it is applied that is important.



Cardinal Marx Internet

Assisted suicide is forbidden in all the other European countries (except in the Benelux). On September 11, 2015, the United Kingdom rejected the project of a law authorizing patients for whom hope for life does not exceed six months, to end their life. Prime Minister David Cameron, as well as those in charge of large British religious communities opposed this project.

In France, neither assisted suicide nor euthanasia is mentioned in the law under discussion. The only incitation to suicide is mentioned in the French Penal Code (Art.223). In France, the frequency of suicides is very high with one death in 50 a suicide. Considering these statistics and under the leadership of Mrs. Marisol Touraine, Minister of Health, who had supported a proposed law for assistance in “active death” in 2009, the National Observatory of Suicide was created on September 9, 2013.

WHO HELPS WHO?

Little Sister of the Poor, nurse in “Ma Maison” (EHPAD), I have the privilege of living with the residents and of being able to accompany them while they are with us.

Whether crippled by illness, perhaps disoriented, conscious or not, this is the same person I knew on her arrival in the home and with whom we have lived moments of joy and sorrow ..., near whom I will try to be present until the ultimate moment.

More and more, I have perceived the importance of the presence of someone she recognizes. A living presence which gives her the chance to be alive... “Stay with me, don’t leave me alone!” says the look in her eyes that follows us, the nurse-aide and I, as we leave her room.

The quality of care is essential. It takes priority for evaluating and easing her pain at all times, not just at the end of life! One must know the person in order to discern if her suffering is physical or rather in the affective or spiritual realm ... But we, the care-givers, can be too preoccupied with the care that we forget communication. The person who is dying is still alive. We must speak to her, tell her what is happening around her, talk of those who love her, of Minou, her cat, that she had to entrust to her neighbors!...

For 3 to 4 months Mrs. T. appeared to be dying... During her morning care, Sonia, the nurse-aide, says to her: “I met Maria and she says hello!” Mrs. T. who is half conscious, opens her eyes and reacts... Maria is her sister-in-law. “Maria was the daughter of John or Laurence?” Her face wrinkles in every direction... “Don’t worry!” Suddenly she responds: “The wife of John!”

“Do you want to stay in bed or sit in the arm chair? – In the arm chair, near the window”. There she can look outside... I turn off the television. She opens her eyes, unhappy! Especially if it is “Questions for a Champion”! She eats practically nothing. Sometimes, we tell ourselves: “She is sleeping so we won’t wake her up to eat...” Later, I come back: “Would you like a little pudding?” She opens her mouth very wide!... No, she is not yet ready to die...

One must discern an expectation, words hardly audible and short moments of intimacy when I pray briefly with her. I know that her faith is profound, but discreet.

We can never get used to it. Each person is different; death is unique for each one of us, for the Little Sisters and the staff. Day after day, we accompany her (or him) until the ultimate moment where, I hope, we can say good-bye to one another. But, if it is otherwise... she has always done what she wanted!

Accompanying in daily life, being very human. A passage from the Gospel enlightens me: “What do you want me to do for you?” In fact, it is God himself who asks the question to this dying person... Especially to be delivered from fear. Our role is to bring God’s peace by our presence, our care, our humanity thus joining to its humanity. In these moments, I feel God’s presence very near, at her side, ready to take her in His arms...

That the end be “natural”. We wish that birth be de-medicalized. Should we not desire this also for death? That would remove this fear from the elderly and their families. Mr. F. was very anxious: “I am not afraid to die, but I fear the manner in which I am going to die...” He had difficulty breathing. “Have confidence!” Sister B. held one hand and his son who was present took the other... he was gone... All of that would not have been possible had we put the patient under deep-sedation.

We live in a hurried world, with many requirements regarding health care. Are not laws being proposed as a way of “getting rid” of weak or dying persons...? We may pass beside something essential to life itself.

Nowadays, we speak of the “end of life” too much! Isn’t it not more urgent to accompany life! So that the elderly may live their last years in the best way possible.

After 65 years of a happy marriage, the death of her husband and no children, what keeps Mrs. T. alive? Maybe because she loves us? She is a source of joy for us, despite her weakness and the work she gives us... “She recognized me”, exclaimed

Maryline, on her return from vacation. Yes, she is precious in my eyes; she relies on me. She also counts on Sonia, and the others. Weakness has much to teach us. A great lesson for us. They are the ones, the sick and the dying who touch something in us.

Who helps who?

Sr. Marie Barnes, Little Sister of the Poor, Nurse

■ INTERGOVERNMENTAL ORGANISATIONS

UNITED NATIONS – General Assembly 70th Session Third Committee:

Work of the 2015 Open-ended Working Group on Ageing on the Follow-up to the Second World Assembly on Ageing.

Following the meeting of the OEWG on Ageing, the UN GA's Third Committee was drafting a resolution that could have significant impact on the way the OEWG takes its work forward. As the OEWG has been the main forum for UN Member States to discuss promoting the better protection of the rights of older persons, it is essential that this group continues to meet annually and stays focused on its core mandate.

Open Letter to the Members of the Third Committee of the NU General Assembly. Therefore "AGE International" drafted an open letter to the members of the Third Committee of the UN General Assembly. NGOs were being asked to join in as signatories so the letter could be sent out on November 2 : " We look forward to the UN's continued engagement on these urgent human rights matters and anticipate that the resolution of the Third Committee will reinforce the message that the UN is firmly aware of and supportive of protecting the rights of older persons, and most importantly is willing to take action."

UN GA Resolution on Measures to enhance the promotion and protection of the human rights and dignity of older persons A/RES/70/164, 17 December 2015, adopted by consensus.

Acting on the recommendation of its Third Committee, the General Assembly adopted by consensus the Resolution A/RES/70/164 on 17 December 2015; it considered that such an instrument was needed as no international legally binding instrument existed on the rights of older people and that the modalities of protecting the human rights of older persons at international and national levels are not effective enough to define the responsibilities of States on this matter. The General Assembly requests the Member States to continue contributing to the works of the Open Ended Working Group on Ageing notably in presenting practical measures, optimal proposals and lessons drawn from experience, as well as by drafting concrete proposals related to the preparation of a multilateral legal instrument.

WORLD HEALTH ORGANISATION - WHO Report (November 2015) - Revised Draft Global Strategy and Action Plan on Ageing and Health Strategies – Online consultation took place between 28 August and 30 October 2015, including 4 regional pre-meetings and the global consultation in Geneva on 29-30 October 2015 with almost 200 participants among which 35 NGOs.

THE GLOBAL GOALS – In September 2015, World Leaders committed to 17 Global Goals to achieve 3 extraordinary things in the next 15 years: End extreme poverty, Fight inequality and injustice, Fix climate change. Most of these goals have a direct effect on the well-being and defence of the human rights of older persons.

17 goals : No poverty, Zero hunger, Good health and well-being, Quality education, Gender equality, Clean water and sanitation, Affordable and clean energy, Decent work and economic growth, Industry, innovation and infrastructure, Reduced inequalities, Climate action, Life below water, Life on land, Peace and justice strong institutions, Partnerships for the goals

**HUMAN RIGHTS COUNCIL
30th Session.**

The Annual Report of the Independent Expert on the Rights of Older Persons gave rise to a lengthy discussion in Plenary, which was very positive. Her annual report can be seen on <http://www.ohchr.org/EN/OlderPersons/IE/Pages/Reports.aspx> **The Mission of Austria** organised, during the Council session, a Side-event: "The human rights of older persons : best practices in the implementation of existing laws. <http://www.ohchr.org/EN/Issues/olderPersons/IE/Pages/Bestpractices.aspx>

NON GOVERNMENTAL ORGANISATIONS

International Association for Hospice and Palliative Care –

Katherine Pettus (Advocacy Officer for Human Rights and Palliative Care at IAHPC) expressed her satisfaction at the report of the IE who released a statement with the Special Rapporteur on Health concerning the lack of access to pain medicine for older persons. More than 70% of the world's population has no access to such medicine.

Next year a Special UN Session on Drugs will be organised in Vienna, hence the importance of the report of the IE on Ageing. Ruth Dreyfus, Kofi Annan and other important personalities have been promoting medication for avoiding pain relief.

The African Union prepared an optional protocol to the African Charter of Human and People's Rights on the rights of older persons; but the Organisation omitted any mention of palliative care although in Africa less than 5% have access to appropriate pain relief beyond paracetamol. Katherine Pettus has requested the IE and WHO to write to the OAU.

■ NEWS OF MEMBERS

AIC: - September 27, anniversary of our Founder, Saint Vincent de Paul - Launching of the Facebook page AIC International

- In Columbia AIC volunteers in Ibagué initiated a project aiming at the social integration of elderly persons, thanks to their participation in activities producing vegetables and flowers as well as in recreational activities.

- In Haiti, Port au Prince, urgent help remains a high priority following the terrible earthquake of 2010. AIC Solidarity continues to finance a monthly food assistance program for 350 elderly who have no means of subsistence.

- In Bolivia, La Paz, AIC volunteers meet weekly with a group of elderly who live in a situation of extreme poverty. These meetings, as well as the many recreational activities proposed to them, have enabled these elderly to create new social links which often were lacking to them. Collaboration with some young students from a nearby school, in organizing some activities, promotes the strengthening of intergenerational bonds. Belonging to the same community as the recipients, the volunteers ensure that their customs and their traditions are respected, which the elderly particularly appreciate.

- L'AIC Syria celebrated 398 years of its association as well as the Feast of the Immaculate Conception of Mary with a beautiful Mass in the Church of Our Lady of Damascus, followed by a friendly gathering. Some one-hundred AIC volunteers were able to assist at the celebration, despite the ever dangerous situation in the area.

CICIAMS: CICIAMS held a restricted office meeting on November 18-19, 2015, to prepare the Congress in Swaziland. The next full office meeting will take place on February 22-23, in Rome at San Callisto, in the Vatican City. A year ago CICIAMS rented several places for its reunions.

MIAMSI: At the end of the year MIAMSI participated in a colloquium organized on November 20 - 22, 2015, by the European Relais in Pozzallo, in Sicily, on the following theme: "The Mediterranean, a Way in the Ocean": After hearing different testimonies, we called on all our network to reflect on this subject, to sensitize the persons around us, particularly where we exercise our responsibilities". (See the communiqué on the site of MIAMSI).

Elsewhere the president made a trip to Lebanon to support the existing teams, share the realities of their countries and notably welcome the numerous Syrian and Iraqi immigrants who represent 30% of the population living in Lebanon.

Little Sisters of the Poor: During the preparation for the World Days of the Family, 2015, the elderly, volunteers and friends of our Home in Philadelphia participated in the creation of a huge mural painting commemorating the visit of Pope Francis, entitled: "The Sacred today, faith and the family in the 21st century". The 153 panels, which composed it, were painted by the inhabitants of Philadelphia and also by the participants in the World Meeting of Families. The elderly Residents worked on several of these panels with great intensity, proud to participate in the creation of a work destined to cover the facade of a Catholic school in northern Philadelphia. It was beautiful to see the

members in charge of this Art Mural Program so patiently showing the Residents where to paint... and where not to paint... On the festive evening of Saturday, September 26, the designer of this fresco, Cesar Viveros, presented one of these panels to Pope Francis to sign.

VMI: The Steering Committee who secures the spirit of the movement's unity will meet from the 22nd to the 28th of May, 2016, in Lisieux (France). It is composed of an executive committee and continental delegates.

A little more than a year after the international meeting in Namur, it has as objective to define the work of the coordinators and to follow up on the reflection engaged on the challenges posed for the elderly in a changing world.

■ **CRESCENDO: WEBSITE:**

www.reseau-crescendo.org

Visit it regularly!