

HOSPICE MOVEMENT IN CROATIA

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INTRODUCTION:

We live in a world of major cruelty and disturbed human relationships, however we can see more and more societies and individuals developing sympathy for the suffering, we meet persons able of developing empathy – i.e. having the possibility of feeling what the other person feels, without expressing it in words. According to some actual world criteria that would mean that our cultural level is rising. The population of patients that especially needs our sensitivity to suffering and ability for empathy is the population of people at the end of their lives. The attention we give to the little people entering life should be granted to the human being leaving life.

The modern hospice movement accepted in over 120 countries worldwide is starting in our country, too. It is not well developed yet... Much has happened, initiatives were given, especially in the premises of the Croatian Medical Association (HLZ), but also at the Medical School in Zagreb, in the School of Public Health „Andrija Štampar“, in the Community Health Centres Zagreb – East, Hirčeva 1 and West, Baruna Filipovića, in Karlovac, Virovitica, Koprivnica, Rijeka, Varaždin, Bjelovar, Pula etc.) News from the war front and later turbulent reformations of reformations alongside with denial of everything accomplished by predecessors have most certainly significantly slowed down the news of peace, tolerance, understanding, respect of the human dignity and different opinions. The author divides the development of the hospice movement, led by the Croatian Association for Hospices / Palliative Care at the Croatian Medical association (HDH/PS, HLZ) into 4 stages.

- The first stage 1994 to 1999... the beginnings.
- The second period 2000 to 2005... period of great hopes and first goals.
- The third period 2006 to 2008... stagnations period.. decomposition – “burnout” syndrome, search for new ways, new people, way out of problems...
- The fourth period 2009 to...? This will hopefully be a new period of fight for an idea that won in so many places! Hope stays... hope in the existence of positive forces among the citizens of the Republic of Croatia.

I will only mention the most important data in this paper. I have to omit listing the many lectures, the numerous events throughout Croatia, publications in several books and newspapers. We will not mention the various educations (lasting from several days to a month) in the USA, Canada, Great Britain, Poland, Hungary, Austria, Switzerland, Norway etc. We will not talk about the great number of foreign guests from Great Britain, the USA, Canada, Italy, Germany, Switzerland, Poland, Hungary, Romania, Bulgaria, Israel etc. These data will once maybe also appear in a monograph...

I. PERIOD: 1994 - 1999

In the year **1994** the First Congress „Hospice and palliative care“ was held, lasting for two days. Anica Jušić founded in the

autumn of the same year the Croatian Association for hospice / palliative care of the Croatian Medical Association in order to maintain and develop the achieved effects. The publishing of the first three books followed immediately - Anica Jušić: „Hospice and palliative care“ (picture 1) and translations from English - Cicely Saunders and Nigel Sykes: „Palliative care in the terminal stage of malignant diseases“, and Robert Buckman: „I don't know what to say“ (picture 2).

In the year **1996** the four-day Second congress “Hospice and palliative care” is organized.

In the year **1997** the “Association of friends of hope Zagreb” was founded, as a logistic support to the roof Association, on the city level. The BULLETIN for palliative medicine/care was published for the first time in the same year, as the official paper of the Association, being issued twice a year since. The editor-in-chief was Anica Jušić, and the technical editor Boris Adamek. The first branch of the Association was founded in Virovitica. Numerous meetings will be held there, even an annual assembly of the HDH/PS,HLZ. The first one-day Congress on malignant pain in Karlovac was held that year, becoming an annual event, until recently under the leadership of prim. Marijana Persoli – Gudelj.

In the year **1998** the Third four-day Congress Hospice and palliative care in Zagreb is organized together with the first three-day education for nurses in the Nursing School in Mlinarska street led by Virginia Gumley (UK).

In the year **1999** the Croatian Association of hospice friends is founded as logistic support to the Association on the state level. The first interdisciplinary course for volunteers in the palliative care is organized, lasting for five whole Saturdays. The first house call was made in December (Anica Jušić and Stana Lovrić). The second Electoral Assembly of HDH/PS held in Karlovac sees the founding of three sections within the Association: for pain treatment, for psychological support and for volunteer's activities...

The Ministry of Health has asked Anica Jušić for the first time an opinion concerning the recommendation of the European Council on the protection of human rights and the dignity of terminally ill and dying patients. Although the answer was promptly provided, no reply has ever come. The Ministry of work and welfare however signs the project “Founding of hospices” and provides significant financial support. Significant help arrives from the Open Society Institute (OSI), first from Croatia, then from New York, and so we were able to employ our first employee, the administrator Gordana Špoljar.

II. PERIOD: 2000-2005

In the year **2000** the Centre for house calls begins „de facto“ its work situated in the private apartment of Anica Jušić, at 49 Gundulić street. The first weekly meetings of the interdisciplinary hospice team of house calls are held here, as well as the first supervisory meetings of non-health-care-professionals,

who have supervised trainings once a week in the Home for the elder and the frail at 14 Crnatkova street, serving as practical education for later house calls. The material resources, the archive and the telephone are situated in the Gundulić street, the city control comes to these premises. The first doctor engaged in hospice house calls together with Anica Jušić, was Ankica Prugovečki from the Zagreb "Emergency ward" (persuaded by Biserka Valjak). Later on Ivanka Kotnik joined the team, followed by Matija Rimac, both from the "Emergency ward". During its first year, the "centre" took care of 57 patients and their families. 18 volunteers of different professions paid 771 house calls, supported by numerous doctors' and nurses' telephone consultations. 23 volunteers regularly visited 20 patients in the Home for the elder and frail on a weekly basis, for a total of 10.880 visits within a year.

The Croatian Association for pain is founded and the first postgraduate interdisciplinary course starts – Chronic pain in malignant processes, diagnosis and treatment (lead by: Višnja Majerić-Kogler, Anica Jušić and Marijana Persoli Gudelj). The second branch of the Croatian Association for Hospices / Palliative Care at the Croatian Medical Association is founded in Koprivnica. A very promising activity started its development here, thanks to the MMF project of health care reform, which was later unfortunately reduced to the individual activity of the hospital's head nurse Žarka Zalar in the education of nurses and the introduction of the profession „discharge nurse.“

The press witnessed the promises of Milan Bandić, the mayor of Zagreb and Zvonimir Šostar, head of the city health department, given on the Cvjetni trg square promising free land plots for the construction of a hospice and the exemption from paying construction permits and electricity, water and sewage contributions. Talks about the draft of the Initial document for the construction of the Regional hospice centre – Zagreb (in Dubrava), start in the Gundulić street (picture 3).

We participated for the first time in the world wide action „BT Voices for hospices“ with a humanitarian concert of the Zagreb philharmonic orchestra and the Collegiate choir „Ivan Goran Kovačić“ held in the Concert Hall "Vatroslav Lisinski". The concert was organized by Biserka Valjak and Boris Adamek.

The first two-day international conference on hard decisions in palliative care was organized: Spirituality and Grief, in Zagreb, in the CMA, in the „Mimara Gallery“ and the Museum for Arts and Crafts.

Somewhat later the First Zagreb conference on neurological palliative care was organized in the CMA and the cooperation with David Oliver started, developing in many forms throughout these years.

In the year **2001** a project was realized in Koprivnica, funded by the MMF, on the defining of the health care reform in the Republic of Croatia, with special attention to palliative care. Jeremy Keen (UK) suggested that two interdisciplinary teams be formed, for hospitals and primary health care respectively, led by doctors who should first spend 6 months in an English hospice and then continue their education with long distance learning. The suggested doctors refused to leave their current positions for 6 months. The whole reform project failed at the

negotiations with the Croatian Health Insurance Institution and the change of the Health Care Minister. Jeremy Keen still insists today on this minimum for the leaders in palliative care. The first five-day English interdisciplinary course for palliative care was organized managed by David Oliver in the premises of the CMA. A second course was organized for non-health-care-professional volunteers in palliative care. It was held every Tuesday afternoon through three months. These courses are still organized, sometimes even twice a year. The Fourth three-day congress Hospice and palliative care, CMA, Zagreb was organized. Kathleen Foley and Nessa Coyle from the Memorial Sloan-Kettering Cancer centre (N.Y.) held lectures at the First Croatian Oncology Congress in Zagreb in the session for Palliative medicine. The supplement of the 1st BULLETIN was issued with texts from the session. Both guests visited together with Slobodan Lang, Desa Grubić-Jakupčević and Anica Jušić the Croatian Health Care Minister Andro Vlahušić, who then reached the decision on the founding of a Ministry Committee for palliative care including eight international members. They receive English translations of each session's protocol and provide their extensive comments.

The first of three translations of WHO editions is issued – „Relieving cancer caused pain and palliative care of children“. The following year saw the publishing of two further translations: „Relieving symptoms in the final stages of illnesses“ and „Relieving cancer caused pain“, by the same publisher.

In the year **2002** David Oliver was named guest professor (picture 5) at the ceremony session of the Scientific and academic board of the Medical school in Zagreb, the same honour was awarded later to Kathleen Foley (she is one of the creators of basic principles in world algology). The Academy of medical sciences of Croatia awarded a laureate diploma to Anica Jušić, who had founded the Committee for palliative care of the Academy Senate back in 1995 having the same tasks that were later overtaken by the Committee for palliative care of the Ministry of Health. The Regional hospice centre was opened in 1 Hirčeva street, in the former laundry of the Community Health Centre Zagreb – East with the support letter of the Ministry of Health. The ribbon was cut by the representative of the Ministry of Health Dunja Skoko-Poljak. The main activity of the Centre is the development of hospice house calls. The three-day „Conference on key problems in palliative care and solutions in the primary health care“ was organized, with the participation of Mary Callaway (N.Y.) and David Clark (Sheffield, UK). The one-day „Conference on the suspension of unfounded treatment“ was organized in search of a consensus of specialists regarding the solution of this increasingly important problem.

2003 The project „Palliative care in the community“ has received positive evaluations from the expert teams of the Croatian Health Insurance Institute and the application is awaiting the new budget. The „National programme of palliative care“ by Anica Jušić and Dunja Skoko-Poljak is in its final phase. This booklet was planned to be issued by the Committee for palliative care and financed by the Ministry of Health. The BULLETIN was replaced by www.hospicij-hrvatska.hr. Two brochures are issued: „Messages of a seriously ill person“ and „Pain treatment“.

The new Act on Health Care mentions for the first time the term palliative care and includes an article making it possible to found an independent „Institution“ with hospice house calls, ambulatory services and day care. The second suggestion of the Committee for palliative care - „special hospital – hospice“ was not accepted. The new government abolished the Committee for palliative care at the Ministry, without explanation, and imposed Regulations inappropriate for hospice / palliative care (the first edition included even volcanic mud and paraffin wax for the treatment of terminal patients – obviously for the indication „chronic patients“, and not „dying“). The two-day First congress on Palliative care for children was organized with Tomasz Dangel from Warsaw. The first two-day course for the employees of Homes for the old and frail in Zagreb was also organized. The course was repeated as a one-day-session in Bjelovar. The first two-day course was organized for family doctors in the primary health care, repeated in Požega and Karlovac. It was later transformed into a postgraduate course lasting for three Saturdays in a row since participants from all over the country applied to attend.

In the late spring of 2004 the Committee for palliative care was unexpectedly named for the second time, again without explanation, this time without international members, with a reduced number of members, with the former president. The president Anica Jušić was included in the new National bioethical board for medicine at the Ministry for Healthcare and Welfare.

The translation of Recommendation Rec. (2003) 24 was issued of the Ministers of the European Council 2004, the edition will be repeated in three years. David Oliver holds his first lecture on palliative care at the Medical school in Zagreb. The courses from Zagreb are transferred to Rijeka, Dubrovnik, Varaždin and Koprivnica in shortened form.

The tenth anniversary of the beginnings of an organized hospice movement in Croatia was celebrated with the Fifth congress Hospice and Palliative Care. The Congress was organized under direct auspices of Jadranka Kosor (picture 6). Nigel Sykes, who held the introductory lecture 10 years before at the First congress, participated again stressing out one more time the fact that “a hospice is made of specially trained staff, and not a building,„

In the year 2005 the first five-day course of palliative care was festively opened in the undergraduate English studies (picture 7). The lecturers included the four-member team of David Oliver with Melita Stipančić and Marijana Braš. At the same time, the postgraduate course for the certificate of the Kent University with English guest lecturers was organized. Other previously started courses were continued.

A humanitarian concert was organized with pop singers and the symphony orchestra of the Croatian National Television in the Concert Hall „Vatroslav Lisinski“ as an aid for the construction of the Hospice of St. Luke (idea). The head organizer was Egidije Čepulić.

In Rijeka and in Pula promising activities are being developed. A special interest for palliative care was shown by the head of the Social sciences department of the Medical school in Rijeka, Ivan Šegota and his associates. He published chapters on hospices in his „Bioethical volumes“, he included single

lectures first and then a full day of reports with international attendance on the organization of palliative care in his annual “Bioethical days” in Rijeka. He edited the translation of Pessini’s book *Distanazia* from Portuguese. The “Lošinj days of bioethics” under the leadership of professor Ante Čović included at first single lectures and then a whole session dedicated to palliative care. Julijana Franinović-Marković formed an interdisciplinary group in Pula (picture 8) working in hospice house calls, visiting patients in the Home for the elder and frail, in ambulatory counsellings with oncologists and in the organization of numerous educational meetings and contacts with the city and regional authorities. The group will attend a course in St. Christopher’s hospice in London in the year 2008.

III. PERIOD 2006 - 2008

In the year 2006 David Oliver and Stjepan Krajačić were elected honorary members of the Croatian Association for Hospices / Palliative Care.

Jadranka Mustajbegović creates the slogan ... a zbogom?! (... and goodbye?!) and starts promotion activities by e-mail and through a press conference at the First congress of palliative care in Croatia. The Congress lasted for three days, the first day was dedicated to lectures of representatives in palliative care from Slavic countries who were able to organize specific units for palliative care and enter the health care system at least partially. They were in the first line our known guest lecturers Jacek Luczak (professor of palliative medicine and oncology) and Piotr Krakowiak (clergyman of the hospice movement in Poland), leading persons in the “network” of hospice units (Poland holds the fifth place in Europe in the distribution of palliative institutions). Mirjana Adžić and Miroslav Bojadzijeovski presented the activities of a very successful mostly geriatric institution in Skopje, Macedonia. Nataša Miličević participated too, oncologist, head of the Belhospis in Belgrade, later also the representatives of an especially successful palliative complex within the University clinical centre in Tuzla, Bosnia and Herzegovina. We raised the question why this is possible in Poland, Macedonia, Serbia and Bosnia and Herzegovina, but not in the Republic of Croatia. We have stopped comparing ourselves with Great Britain and the USA. A book was issued comprising papers from the First Congress and the Fifth congress under the title “Palliative care in Croatia and worldwide“. In the year 2007 an international meeting on pain treatment in cancer patients and the communication of bad news was organized in the CMA. The meeting was organized by Christine Drummond, Adelaide, Australia. Another meeting was organized where geriatrics professor Emese Somogyi- Žalud held a lecture on the organization of palliative care in Honolulu, Hawaii. The undergraduate course on palliative care was repeated, where the cooperation contract between the Kent University and the Medical school of the Zagreb University was emphasized. The postgraduate course on palliative care for the certificate of the Kent University was repeated. “Voices for hospices“ and „The world hospice day“ were celebrated with a concert of Cantus Ensemble and the pianist Zrinka Ivančić. Anica Jušić warned in the professional part of the programme that Croatia not only does not have hospice units, but also lacks modern chronicaria, geriatric wards were shut down, pensioner’s homes from the 1980s

were transformed into Homes for the elder and frail, declared as social institutions, consequently having employees for such institutions. These institutions however, have up to 70% of bed-ridden users and up to a 30% mortality rate, i.e. they are health care institutions in the first place, pleading for reforms. Regular house calls of family doctors are more than ever limited (according to some information, house calls account only for 1,5% of the total medical examinations of general practitioners) so that hospice house calls have nothing to build on, but have to rely solely on themselves without the support of medical institutions for the most serious cases. A major problem is the reconstruction of older institutions, where palliative/hospice care can be added to, as a new dimension of care. The president transferred most activities in the year 2007 to the Committee for palliative care. As suggested by Health Minister Ljubičić, a lawyer at the Ministry for health drafted the Act on palliative care with criteria for the creation of a network of hospice units. A letter was drafted too, addressed to the present Minister with the demand to allow leave and remuneration for the nursing of dying patients, similar to the one allowed for the nursing of a newborn or seriously ill small child. No answer arrived. The new Act on Healthcare was forwarded to the Parliament, without consulting anybody from the Committee, not even in these two especially important points. And the creation of normative and standards for the palliative care is of utmost importance. I presented my suggestion to be discussed within the Committee, supplements were discussed with a representative of the Croatian Health Insurance Institute, but no answer arrived.

Croatian Association for Hospices / Palliative Care at the Croatian Medical association also published the „Croatian declaration on palliative care“. It was already signed by over 800 persons: some of them are very prominent – people on leading positions from Croatia and from abroad, even whole organizations.

The complete text was published in the Pharmaceutical bulletin and in an on-line paper edited by the Hungarian association for palliative care, the European association for palliative care and OSI, NY.

The Second Congress on Palliative Care in Croatia was held October 10-12 under the motto „Hospice and palliative care are a basic human right“. The intensive need for the reformation of existing institutions caring for chronic patients was stressed, as well as the role of psychological and social factors in the development of diseases and the importance of civil associations and the activation of medical students. The publication under the title Hospice and palliative care – basic human right was issued.

Anica Jušić and the Croatian Association for Hospices / Palliative Care at the Croatian Medical association were awarded the prize “Medicine” for humanity and ethics on December 17 at the ceremonial session of the Scientific and academic board at the occasion of the Day of the Medical school.

IV. PERIOD 2009 TO?

Unfortunately, the misunderstandings within the Regional hospice centre in 1 Hirčeva street are increasing and the cooperation projects with the Kent University are struggling with financial problems.

The Fifth Elective Assembly of the Croatian Association of Hospices / Palliative Care held on January 10, 2009 welcomed a new president and Management board of the Croatian Association of Hospices / Palliative Care. The young are our future... we can only hope that the newly elected people will be able to solve the old problems, that the former ones were not able to solve. Unfortunately, there are still many in the present medical structures. Maybe the model of palliative care will be able to recover them, as suggested at the assembly of the European Council in late 2008.



Picture 1 Cover of the Proceedings of First Congress Hospice and palliative care. The cover shows the logo of the hospice movement in Croatia – a bird flying out of a cage. The author is Božidar Jušić, painter.



Picture 2 Robert Buckman at the promotion of the Croatian translation of his book „I don't know what to say“. He is between Anica Jušić and Melita Stipančić, the translator.



Picture 3 Meeting in 49 Gundulić street: in the middle from left to right prof. Vesna Lopina, architect Ivana Turković-Ostrogović, mr.sc. Stjepan Krajačić.



Picture 4 Visiting Ministry of Health; in second line Kathleen Foley and Nassa Coyle, Anica Jušić and Andro Vlahusić (Minister of Health) in the middle. Front Slobodan Lang and Desa Grubić-Jakupčević.

Picture 5 David Oliver (on the left) receives from Davor Ježek (on the right) the guest professor diploma.



Picture 6 Jadranka Kosor, Prime Minister, inaugurating the Fifth Congress Hospice and Palliative Care, organized on the tenth anniversary of the hospice movement in Croatia.





Picture 7 Opening ceremony of the first graduate course of the Medical school, in the English study section. From left to right: David Oliver, dean Nada Čikeš, Sir John Ramsden, the British ambassador in Croatia and Anica Jušić



Picture 8 Three representatives from the Pula, Irena Grahovac, Julijana Franić-Marković, Milka Radetić with David Oliver and Anica Jušić in the Large hall of the Croatian Medical Home.

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