

# The Guiding Principles in the Hospice / Palliative Care and Introducing Practices to Croatia. Foreword to the Handbook 'Palliative Care in the Community'

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## Introduction

George Bernard Shaw once wrote: "The single biggest problem in communication is the illusion that it has taken place." I hope this introductory part will communicate what is important in the area which is often mentioned in our country, but the main problem is often missed due to the lack of systematic theoretical knowledge and practical experience.

Wolfgang Wodarg, MD, at the session of the Parliament of the Council of Europe, held in 2008, submitted a report which could have significant consequences. He warned of the central problem of highly sophisticated and expensive health care. This type of health care does not address the basic needs of people who suffer from chronic and rare diseases. As a model of reconstruction of Health and Social Policy, palliative care is offered. It is based on human dignity, autonomy, human rights and the rights of patients, solidarity and social cohesion. Thus the protection of human rights is a matter of state, not of individual political lobbies. Palliative care is a new addition to the curative, highly scientific medicine, where subjective feelings of patients come in the second place and the cure of the disease comes first, often causing a massive side effects. Medicine must be oriented to the man as a whole, with the inclusion of social, psychological and spiritual support.

The author further elaborates the theme. During their training, health professionals have to be informed how to treat patients who are facing the final stage of life, and how to deal with the members of family. The restoration of the role of primary care physicians must be supported, and solutions for the appropriate care of the chronically ill and the elderly should be found. The economic motivation should not be the only motivation for these activities.

We should change our attitudes to patients, but also the attitudes of the whole community. The patient is first and foremost a person, who among other things has a diseased

kidney, heart or legs; but patient is also a member of the family and larger community and the holder of a particular world view, a certain system of values. The appropriate conditions should be created and the support (emotional, social and spiritual) should be provided to plan a patient's life, without imposing views. The state should create conditions for the realization of such attitudes, first by reducing economic pressure on health professionals. The aim has to be maximum autonomy for those who must live with physical or mental disabilities or with an incurable disease. It should be avoided to make decisions about what is and what is not a life worth living. A particular problem is the demented person whose autonomy is reduced due to reduced awareness.

We must learn to respect other people's opinions if supported with arguments; the second opinion should be asked for, especially if it is from related fields, in order to broaden one's horizons of knowledge. Above all, we must learn to listen to the patient and colleague carefully and completely. [1. 2]

## From the history of a New Field of Medicine

Dealing with dying and death is as old as the human race. In primitive communities dying was even accelerated. Later Hippocrates represents "non-interference in the plans of the gods". With Christianity the principle of organized help begins to apply, primarily through monk communities. During the Crusades, "hospices" appear where exhausted passengers and dying could find shelter, but also the local population.

After World War II, life care was encouraged by the discovery of new drugs, especially painkillers and psychopharmacies. The reaction to the development of depersonalized "intensive care", where the patient becomes the object of technical intervention, was also important. Cicely Saunders was systematically and continuously building new profession in the relatively favorable environment of advanced English medicine and extensive tradition of volunteering actions. She gained her experience

in personal contact with many dying persons and studying the reports of the London doctor Howard Barrett about the individual destinies of the dying. He was the first doctor at the head of the institution which took care of the dying and the poor. He was also the first to start the application of opium in suppressing pain "on the clock" instead of "if necessary". Encouraged by Howard Barret, Cicely Saunders studied medicine.

By systematically developing her own experiences and experiences of others, Cicely Saunders defined the basic principles: Death is a natural occurrence as well as birth, and it needs to be talked about. The patient's wishes are important. The patient's religious, national, racial affiliations, and wealth status should be respected. The problems were divided into the four groups: organic, psychological, social and spiritual. In 1967, she opened the first modern hospice stationary and home hospice in 1969. She linked both to teaching and research. She was continuously developing the institution to which people came to learn from all over the world and the institution in which trained volunteers played an important role.

The beginnings of care for the dying in the vast majority of countries around the world are connected to volunteers and home care, close or occasional cooperation with primary care physicians, and rarely with specialist services. England and Poland, which have one of the largest number of hospice / palliative care services, also have currently strong, organized volunteer movement which covers almost half of the cost. The education and organization of volunteers have proved essential for the beginnings and sustainable development of the care at the end of life. Several decades ago those were essential for the U.S. as well.

### Definitions of Basic Terms

**The modern hospice** is not a well-equipped building, but a specific philosophy of care for people at the end of life, which can also be applied in their home. This is not a place for dying, but a place for the struggle for a better quality of life before its completion. It is important to create harmonious home atmosphere which corresponds to the current needs of a dying person, with suppression of symptoms and the presence of people who know and have the time to listen, often in a complete silence, but without fear.

**Palliative care** The name was created in 1975 by Balfour Mount for the department in Montreal, because in French Canada hospice is "house of mercy" for the elderly. The teams of this palliative department had advisory role both in hospital and in private homes, following the example of the Hospice of St. Christopher. The term has spread widely, and it is currently used in Croatia, even as a synonym for symptomatic care, which is needed in virtually every medical branch, as it is needed in supportive care.

**"End-of-life care"** Initially, indications for the accommodation in hospice / palliative care were mainly oncology patients. Neurological, cardiac, pulmonary, renal, and psychiatric patients have later been added to a group in need of hospice / palliative

care. A new specific group of patients has been gradually created, sharing the nearness of death. The causes are etiologically different organ failures, essential to sustaining life. "End-of-life" care is required sooner or later, or only on certain occasions. Particularities often develop with chronological age, either pediatric or geriatric. The care for the chronic has to be separated because it is a preparation for a better quality of future life. As residents prepare for the end of life in the stationary or home hospice, the effort has to be made to raise the quality of the last days of life. It is important to emphasize that hospital for the chronic incurable and hospice are not identical.

### Beginnings in Croatia

I have described the important memories of the beginnings in the article with the colleague and friend David Oliver [3]. I have described the documented details in my autobiography [4]. The main problem was how to help those at the very end of life, those who are approaching the end of life. In many international contacts I saw that the development of the profession was going chronologically backwards, i.e. from suppressing symptoms to preventing its development and later on its appearance. Dying should be experienced many times in order to come to terms with death. It is necessary to stop fearing death, because this is the only way to help those who are actually dying.

After a series of foreign contacts, I started organizing the First Symposium of Hospice and Palliative Care in 1994, and thanks to its success, in the same year the Society for Hospice / Palliative Care (within the HLZ - The Croatian Medical Association) was founded to promote education. In 1997, I launched the Society of Friends of Hope, and in 1999, the Croatian Association of Hospice Friends with a task to provide logistic support to the Croatian Medical Association (CMA). In 2000, I helped the development of the Croatian Society for the Treatment of Pain within the CMA. In 1999, the first course consisting of five modules was held preparing multi-professional volunteers to begin with the first hospice home visits at the end of the year. The starting point was my private apartment and my phone in 49 Gundulićeva Street. The archive and the storage of the first place to rent orthopedic devices was also situated there. This was the first place for the supervision of "students" and the place for organizing new conferences and symposia. The polygon where the first contacts with seriously ill people could be experienced was located in the neighbouring institution, the Home for the Elderly and Disabled. I personally led all these programs and institutions always defying problems and misunderstandings so widespread in our society.

Despite the problems I had faced, the Regional Hospice Center was opened in 2002 on the location in 1 Hirčeva Street, as a center for hospice home volunteers. In 2004, this center 'provided care for more than 200 residents and their families. In 2003, thanks to the Committee for Palliative Care (which I chaired) of the Ministry of Health, we entered in the Health Insurance Act. On the primary health care level it enabled the opening of the "Facilities for Palliative Care": 1. interdisciplinary team (doctor, nurse, social worker, physical therapist), 2. outpatients department for pain and palliative care 3. daily hospice stay. The proposal for the

hospice as a "special hospital" at the secondary level was not accepted then.

A regular collaboration with David Oliver and the University of Kent has developed in the form of a multi-specialist one-week courses in palliative care, which he held with three other associates. More important was the launch of regular classes in English part of the School of Medicine, Zagreb, as an elective subject "End of Life Care." We translated and published a number of books and booklets. I wrote over a hundred articles, some of them were particularly well-received abroad. It was primarily the article "Key ethical debate in hospice palliative care" [5]. We had been publishing a magazine "BILTEN for Palliative Medicine / care for five years, and later I launched a website, wrote a number of projects to financiers abroad and domestically, and prepared the Declaration on palliative care. I made a draft of a strategic plan, and a new section in the Law on Health Insurance, etc.

In 2009, exhausted, I decided to withdraw. I hope, however, that in 2017 we will reach the development of basic attitudes for

which I fought for so many years."In the hope we live, in the hope we die ..." It is important that we respect the truth in every day life, this respect inspires trust, which allows us to penetrate into the depth of the secret of life and death.

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