

HUMAN RIGHTS OF TERMINALLY ILL

PROJECT: ADVOCATING FOR HUMAN RIGHTS OF TERMINALLY ILL



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Authors:

Protopresbyter Prof. Dr Vladimir Vukasinovic, Faculty of Theology, University of Belgrade

Rev. Vladislav Varga, Director of Caritas Serbia and Montenegro

Prof. Dr Djordje Jevtovic, Director of the Centre for HIV/AIDS of the Institute for Infective and Tropical Diseases of the Clinical Centre of Serbia

Prof. Dr Violeta Besirevic, Professor of Medical Law, Union University Belgrade

Prim MSc Marija Tasic, MD, Institute for Gerontology, Home Treatment and Care, Belgrade

Dragana Radovanovic, Head of the Department for International Cooperation, European Integration and Project Management, Serbian Ministry of Labour and Social Policy

Editor:

Dragan M. Makojevic, MDiv MTh

Director of Philanthropy, Charitable Fund of the Serbian Orthodox Church

Translation:

Milica Jovanovic

Cover illustration:

Todor Mitrovic

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1.

HEALTH AND HUMAN RIGHTS

Rights referring to health do not only represent a significant segment of human rights, defined by international legal norms and the legal system of Republic of Serbia, but are also grounded in numerous aspects of Christian doctrine, especially in Christian anthropology and Church tradition.

Rights in the sphere of health, as integral part of human rights, had been set as fundamental ideals in traditions of Christian peoples much earlier than they had come to be thought about in the secular world. Unfortunately, human selfishness and negligence for others, with numerous excuses but also without them, destroyed and violated them then as they are doing it now.

There are a few basic points in understanding this aspect of human rights in Christianity. The most important of them is the common origin of the whole mankind, set by the creation and strengthened in a new way by the incarnation of the Son of God. They encourage solidarity among people and indicate the deepest inner connection of mankind. Therefore any discrimination on the level of basic human rights is against God's will, and is an act with not only historical, but also eschatological consequences. This is also obvious from Christ's words, with which he explained the importance of human solidarity, to his disciples, and thus to us as well: "Truly I tell you, whatever you did for one of the least of these my brethren, you did for me."

Christianity is not content with the cold social and legal conclusions of the existing human rights. It calls upon the inner feeling of them, the revelation of their content, which lies not in legal principles but in the human heart. All people are, as St. John the Theologian taught, obliged to love each other. And to love others, as apostle Paul showed, means *to serve each other out of love* thus fulfilling the commandment of Christ who said: *It is my commandment that you love each other.*

Lord Jesus Christ healed every illness and every disability. He then transferred this *authority and power* but also *obligation to heal* onto his disciples, that is, onto the Church – to heal every illness and every disability, and that is what they have done, starting with the apostles Peter and Paul. The following fact is of crucial importance: both Christ and the Church healed *all those who were in need* without any discrimination. That is weaved into the very foundations of the Christian attitude towards healing and the right to be healed. One must know that Christianity has brought a new understanding of an illness. The body (that is, the *whole being*) is the temple of Lord, and health is the Lord's gift. Therefore in a way *health becomes a social welfare entrusted to everyone* and everyone should participate in its maintenance and have to right to it.

International legal acts and laws of the Republic of Serbia defining human rights in the sphere of health: *UN Universal Declaration of Human Rights* from 1948 in its article 25 defines that: "Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control." and that "Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection."

The International Covenant on Economic, Social and Cultural Rights of the United Nations, from 1966, defines in its article 12 that "The States Parties to the present Covenant recognize

the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.” and that “The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for: (a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child; (b) The improvement of all aspects of environmental and industrial hygiene; (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases; (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.”

Revised European Social Charter, adopted by the Council of Europe in 1996, quotes in article 11 that “With a view to ensuring the effective exercise of the right to protection of health, the Parties undertake, either directly or in co-operation with public or private organizations, to take appropriate measures designed inter alia: 1. to remove as far as possible the causes of ill-health; 2. to provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health; 3. to prevent as far as possible epidemic, endemic and other diseases, as well as accidents.”

In *The Preamble of the Constitution of the World Health Organization* it is written that: “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, and political belief, economic or social condition.”

Article 68 of *The Constitution of the Republic of Serbia* also defines issues related to health: “Everyone shall have the right to protection of their mental and physical health. Health care for children, pregnant women, mothers on maternity leave, single parents with children under seven years of age and elderly persons shall be provided from public revenues unless it is provided in some other manner in accordance with the law. Health insurance, health care and establishing of health care funds shall be regulated by the law. The Republic of Serbia shall assist development of health and physical culture.”

It can be concluded that according to relevant international and national legal and strategic acts the key aspects of rights to protection of health imply a wide spectrum of factors helping us lead a healthy existence. Contributing determinants of health are: unpolluted potable water and adequate sanitation; uncontaminated food; adequate diet and housing; healthy working environment and surroundings; health education and information; gender equality. The right to health protection includes freedom, as well as the right to a system of medical care that gives equal chances to everyone to enjoy the highest possible level of medical care; right to prevention, treatment and control of illnesses and availability of essential medicines; protection of mothers, children and reproductive health; equal availability of health services; ensured health education and information; participation in decision making linked to health on national and local levels. Health services, goods and capacities must be disposable, available, acceptable and provided to everyone without discrimination.



KEY ISSUES IN REALISATION OF RIGHTS LINKED TO HEALTH IN SERBIA, THEIR GENESIS AND CAUSES

The right to health protection of the population of Serbia has been endangered in the past ten years, especially in the first couple of years of this period. The healthcare system, as one of elements significant for realisation of rights to health protection, was mostly incapable to address the population's needs. The most important issues were: a) *unavailability and inequality in use of medical care* (long waiting for making an appointment for checkups; checkups by doctors, admission into hospital and diagnostic procedures; difficult realisation of home treatment and care; impossibility of palliative care; inaccessibility of numerous medicines and opioid analgesics; difficulties in hospital treatment of geriatric patients. All these problems are even more pronounced in rural territories, and elderly, people with disabilities and terminally ill people have been the most threatened), b) *poor quality of provided health services*, c) *realisation of the right to urgent medical assistance, especially for elderly*, d) *discrimination, most often in relation with age – the elderly – and illness stadium – people in terminal illness phases* (this was mostly notable in cases of need for urgent interventions and/or admission into hospital care, e) *problems with families of patients*.

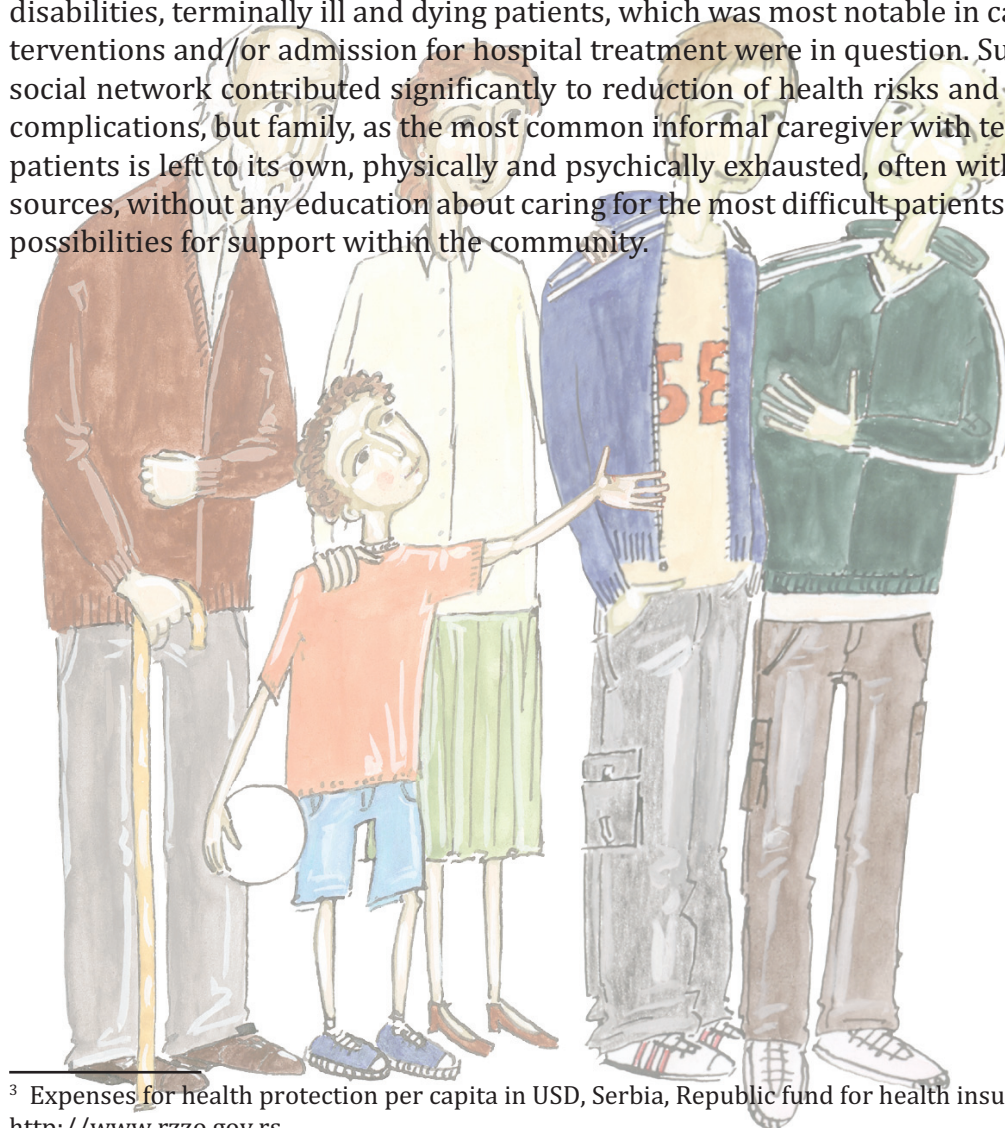
Realisation of the right to health protection, which is a complex social phenomenon itself, depends on numerous political and socio-economic elements, and the creation of indispensable preconditions for it is a task for the whole community. In the past period the right to health protection existed more on the rhetoric and declarative level than in reality. In the past ten years our state was faced with numerous problems that lingered from before and deficient resources which reflected invariably on functioning of health system and other structures responsible for realisation of citizens' rights to the highest attainable standard of physical and mental health protection. In 2000, Serbia entered a transition period with a heritage from the 1990s, marked by wars, sanctions and economic crisis, with extremely negative effects in all segments of society, thus in health care system as well, where health care was directly responsible for respect of the rights to health protection and dignity of every individual. In conditions of extremely limited resources and transitional processes once a huge and expensive health care system, which was free and relatively available to the population, became unsustainable. Former legal acts remained in power in the following couple of years, and financing of health care system was centralised and directed at financing of capacities, only later to become directed at financing of services. Moral values started to decline in very difficult social circumstances, and often a lack of humanity left the most vulnerable members of the community uncared for. Number of employees in health care was reduced in the transitional period, which caused overburdening of medical staff in certain segments of the system. Morbidity and mortality rates increased due to exposure to higher risk of illness occurrence. In the period 1997-2007 mortality rate of all malignant tumours increased by 11.7% for men and by 7%¹ for women. Health protection is a fundamental human right and therefore reaching of the highest attainable degree of health protection is the most important social objective in the realisation of which both social and economic factors take part.² The state is obliged to enable realisation of this right at the highest possible standards, in accordance with its economic possibilities. Health care system, however,

¹ Health of population in Serbia, Analytical study 1997-2007, Institute of public health of Serbia "Dr. Milan Jovanovic Batut", Belgrade, 2008

² Declaration of Alma-Ata. International Conference of Primary Health Care, USSR, 6-12 September 1978

can fulfil its obligations if it has the means to function properly. Expenses for health care per capita in Serbia were \$82 in 2001 and \$336 in 2007.³

Causes for the situation described are numerous and complex. Health service is badly organised, with little coordination between various levels and underdevelopment of certain segments (e.g. home treatment and care, palliative care, and caring for the dying). Part of the laws in force is outdated and not harmonised with existing conditions. Material means are insufficient, and infrastructure is underdeveloped in rural areas, with a lack of medical staff and technical support. Provision of medicaments is inadequate, and the list of medicaments which are attainable on prescription through the Health Insurance Fund is restrictive, so the citizens were forced to buy them. Corruption is also present among medical staff. The health care system entered into transition impoverished, with bad, outdated and defective medical equipment, shortage of sanitary materials and bad infrastructure – outdated and non-maintained facilities and vehicle fleet. Health care workforce is insufficiently motivated due to poor work conditions, overburdening and low income, but also insufficiently educated and organised, which influences their professional ethics negatively. Therefore, stigmatisation and discrimination of certain population groups in wider social community influences the occurrence of these, even among healthcare workers. People who were mostly discriminated were elderly, persons with disabilities, terminally ill and dying patients, which was most notable in cases where urgent interventions and/or admission for hospital treatment were in question. Support of families and social network contributed significantly to reduction of health risks and possibility for illness complications, but family, as the most common informal caregiver with terminally ill and dying patients is left to its own, physically and psychically exhausted, often with limited financial resources, without any education about caring for the most difficult patients or information about possibilities for support within the community.



³ Expenses for health protection per capita in USD, Serbia, Republic fund for health insurance (RZZO): <http://www.rzzo.gov.rs>

ATTEMPTS TO ADDRESS KEY ISSUES IN REALISATION OF RIGHTS CONNECTED WITH HEALTH IN SERBIA SO FAR, THEIR POSITIVE AND NEGATIVE RESULTS

Responsible authorities and stakeholders tried to solve or abate the problems that have been described. Among other *legal regulations and bylaws*, the following *acts* were passed: on health care, insurance, health workers' chambers, medicines and medical aids, on protection of population from infectious diseases, waters, health supervision of foodstuffs, sanitary supervision, ban on smoking in closed spaces, *strategies* for public health, against drugs, palliative care, development of mental health, development of health of youths, tobacco control, against HIV/AIDS, health care quality and patients' safety improvement, as well as the Ethical codex of the Medical Association of Serbia. Health Care Act (The Official Gazette, 107/05) for the first time dealt with the issue of human rights in the field of health and rights and obligations of patients in more detail, and the institution for protection of patient's rights was introduced as well. Patients, their families, and health workers themselves are still not familiar enough with these legal provisions, and therefore they mostly do not adhere to them. *Passed legal measures are incomplete and often not harmonised enough with positive legislation of the EU, and their application is inefficient and most of them exist on the declarative level only.*

Apart from this, measures have been taken to provide medical equipment, reconstruct and repair health institutions, develop a permanent system to enhance quality of work and educate health workers. Situation has improved slightly, and waiting for checkups, operation and hospital treatment has shortened. Activities to prevent risky behaviour and prevent illness complications are being undertaken, quality of health care has improved, hospitals are generally in better state, and patients are being treated in better conditions and with newer medical equipment.

Adoption of the Strategy for palliative care⁴ (hereafter -The Strategy) presents an important advancement, but it does not foresee establishment of hospices for care of the terminally ill, but only hospital wards for palliative care, within wards for prolonged treatment, including geriatric wards. It is foreseen by the Action plan for The Strategy implementation that 300 hospital beds in Serbia will be provided for needs of palliative care, which is insufficient. Foreseen staff is insufficient in number, as well as the coverage of rural areas. Many problems linked to therapy prescribing in home treatment services and uses of pain therapy in home conditions have remained unsolved. Unfortunately, families of the terminally ill have been forgotten, as informal, but most numerous caregivers. The Strategy mentions them as team members, but neither the health nor social system have undertaken anything to ease the problems of families, educate them related to care giving, or inform them of their possibilities. The Strategy has introduced the right of the patient not to endure pain, but health workers still mostly do not estimate pain of the ill, are insufficiently educated for pain therapy, and opiophobia is present both among patients and doctors. Among measures that have been undertaken, widening of medicines for palliative care is of utmost significance as well as introduction of oral morphine, which is now also available on the market, thus improving the possibility of pain coping, but the issue of opioids in home conditions still exists. Coordination of various levels of the health system, social services and local community is still nonexistent, although it has been foreseen by the Strategy.

⁴ Strategy for Palliative Care, Republic of Serbia, the Official Gazette, 17/2009.

PROPOSAL OF STEPS FOR SOLVING KEY CHALLENGES IN PRACTICING HEALTH CARE RIGHTS IN SERBIA

It is essential that authorities and stakeholders undertake a number of actions in order to solve the problems that have been described.

Government and Ministry of Health should harmonise the legislation with EU regulations and recommendations to a higher degree, in order to direct the legislation towards exercise of human rights and vulnerable population groups, as well as towards people suffering from progressive, incurable diseases.

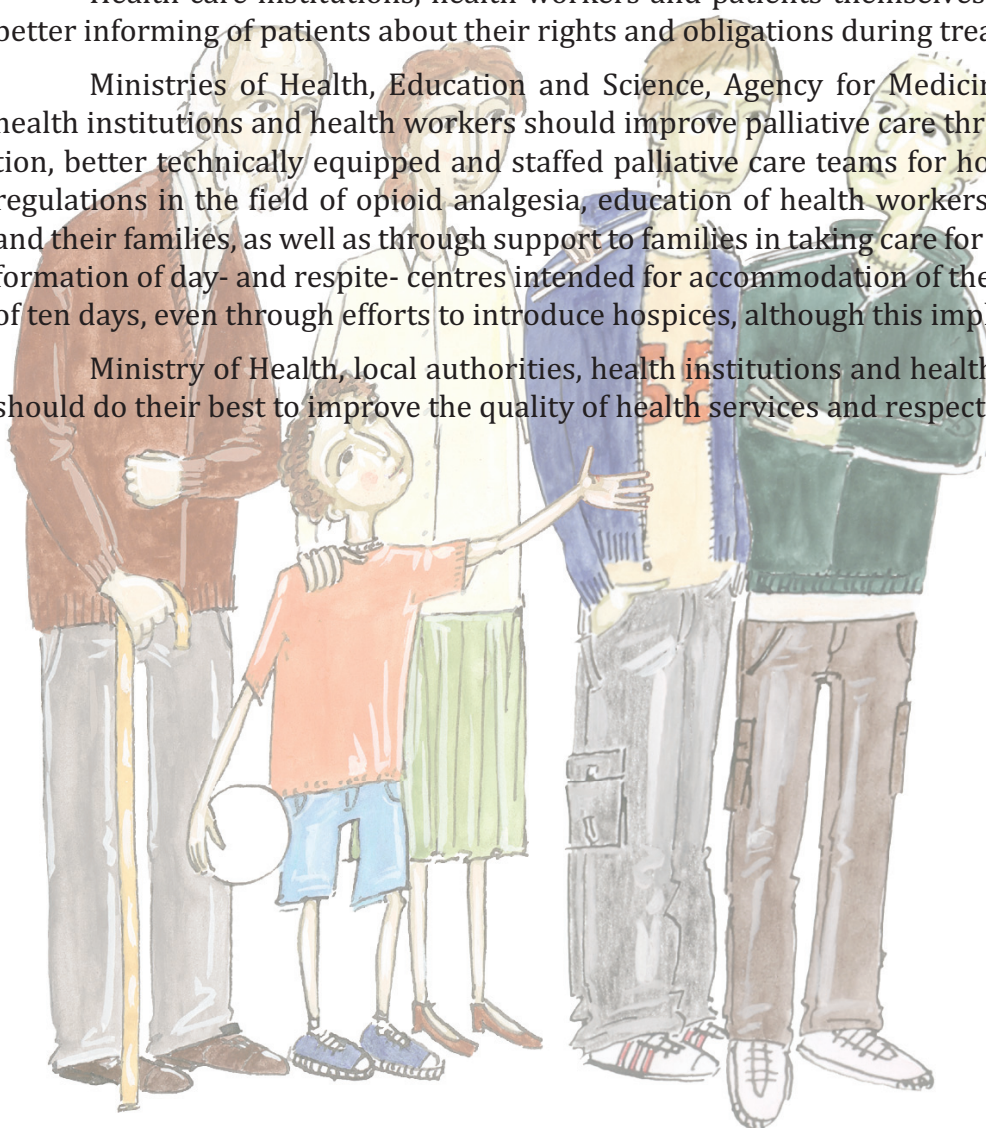
Government and competent Ministries (Ministry of Environment, Education, Infrastructure, Water Management, etc.) and local authorities should include all relevant segments of the society into realisation of the right to health protection of the population of Serbia.

Ministry of Health, health institutions, health workers themselves and local authorities should contribute to better organisation in institutions providing health care.

Health care institutions, health workers and patients themselves should contribute to better informing of patients about their rights and obligations during treatment.

Ministries of Health, Education and Science, Agency for Medicines, local authorities, health institutions and health workers should improve palliative care through better organisation, better technically equipped and staffed palliative care teams for home treatment, better regulations in the field of opioid analgesia, education of health workers, volunteers, patients and their families, as well as through support to families in taking care for terminally ill through formation of day- and respite- centres intended for accommodation of the ill for maximum stay of ten days, even through efforts to introduce hospices, although this implies huge expenses.

Ministry of Health, local authorities, health institutions and health workers themselves should do their best to improve the quality of health services and respect of ethical principles.



2.

HUMAN RIGHTS OF THE TERMINALLY ILL PEOPLE

Healing is not expected in people in terminal stadium of an irreversible illness, but death in the near future. Therefore improvement of quality of life is the fundamental objective in palliative care treatment, and this is accomplished through a comprehensive, holistic approach in treatment of symptoms, alleviation of suffering and enabling dignified dying.

Although suffering is a wider phenomenon than torment and a more complex experience than something that should be alleviated or abolished at any cost, in accordance to centuries-long experience of Church, Christians actively work upon alleviating the suffering of every human being in need. This alleviation firstly implies revelation of the deeper sense of suffering and teaching terminally ill to not only understand but also accept this sense. At the same time, it goes hand in hand with contemporary medical, psychological, legal and social ways of helping terminally ill patients.

Complete harmonisation of conditions of human rights of the terminally ill in Serbia with the highest European standards, e.g. those comprised in the recommendation of the Committee of Ministers of the Council of Europe does not seem realistic in a short period of time. However, a new approach in valuing every human being can be adopted even today, professional ethics in relationship with the terminally ill can be improved, as well as the understanding of their psychosocial and spiritual needs – their rights to dignified life, and dignified dying as well, and their need not to be left alone. It is also necessary to fulfil all the duties related to their closest ones during the illness and after death to the highest possible degree.

Serbia and its health system are in a difficult economic situation today, followed by shortage of medicines and accommodation facilities. However, it should not be acceptable for terminally ill patients to be released from hospitals or not to be admitted at all, because that means sending the message that they *are written-off for the society*. In a responsible society numerous historical and contemporary examples from the Churches of the East and West point out not only the imperative but also realistic possibilities to eradicate such practice. St. Basil the Great had, apart from his obligations as a bishop, opened centres for the sick and orphans and looked after them, St. John Chrysostom had taken care of the abandoned and poor people in Alexandria as a young priest, and St. Lawrence had spoken in 4th century about his protégés, the sick, as the greatest treasure possessed by the Church of Rome.

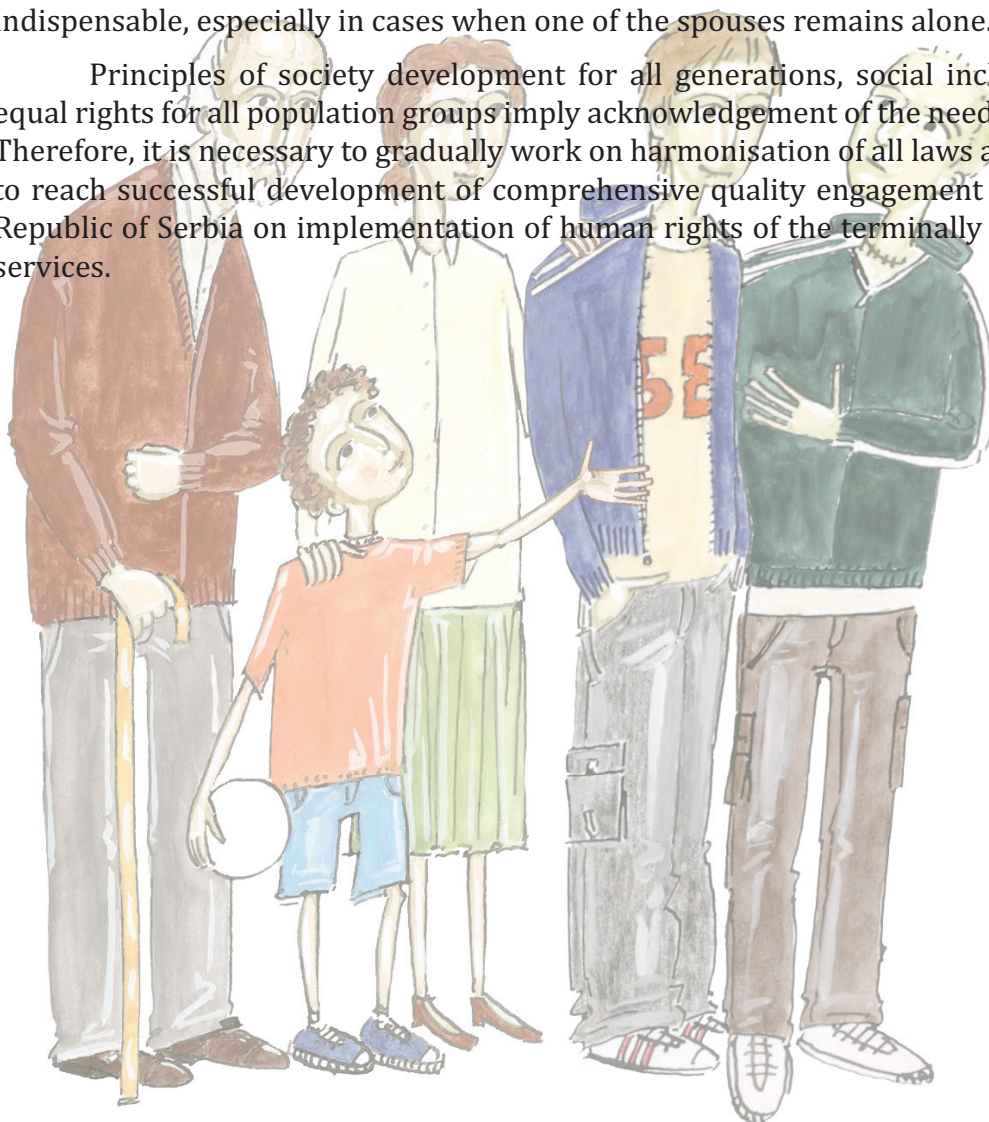
There are numerous examples of their spiritual heirs, ascetics and true Christians, who, through centuries until the present day, altruistically and devotedly served the most difficult patients in all phases of their illnesses. May it be the well-known example of Mother Teresa of Calcutta, who “swore the fourth oath” by serving “the poorest among the poor”, i.e. the dying of leprosy, AIDS, and other illnesses, or the modest nameless nuns of the St. Petka monastery near Ravanica, who see in their wards “the very icon of the suffering Christ”, their examples not only encourage and inspire but also oblige. This clear devotion of church structures, which are naturally not directed at bodily healing, sets high standards before other structures of humane society, for the construction of which there is agreement in Serbia today. The same people who are taken into someone’s hands with thrill and joy upon their birth, become undesired, unprotected and rejected, most often in case of a terminal illness. It is necessary, even in such situations, to advocate the fundamental rights of all people and provide them with special attention of medical staff, nearest of kin, friends but also people from narrow and wider community – volunteers.

A research made in the USA among AIDS, leukaemia and schizophrenia patients showed that those who have a person next to them who prays for or with them, no matter whether they themselves are believers or not, live longer and get special strength in fighting against their incurable illness. Although these results may be interpreted in various ways, they show that a person needs “a family”, in whose presence he/she feels best and gets energy from, whose union encourages him/her to accept the situation and “leave” in peace. Volunteers or other people who are with the terminally ill testify that all people are a big family, that no-one is undesired by society and community we all belong to, why volunteers need education for their work with the terminally ill.

It is often considered that preserving the illusion of good health does well to the patient, although the real state remains unsaid, while the patient himself feels worse and worse and becomes lonely in his illness. Knowing the truth calms the dying patient and prepares him/her to accept the existing state.

Often the patient’s family takes care of him, and the family is insufficiently educated, not only about physical technique (kinaesthetic, which should also be known), but also the illness development, and especially about spiritual support. Perhaps the least attention is dedicated to the family in time right before and after the death of the terminally ill person, although it is indispensable, especially in cases when one of the spouses remains alone.

Principles of society development for all generations, social inclusions and enabling equal rights for all population groups imply acknowledgement of the needs of the terminally ill. Therefore, it is necessary to gradually work on harmonisation of all laws and practices in order to reach successful development of comprehensive quality engagement of institutions of the Republic of Serbia on implementation of human rights of the terminally ill and palliative care services.

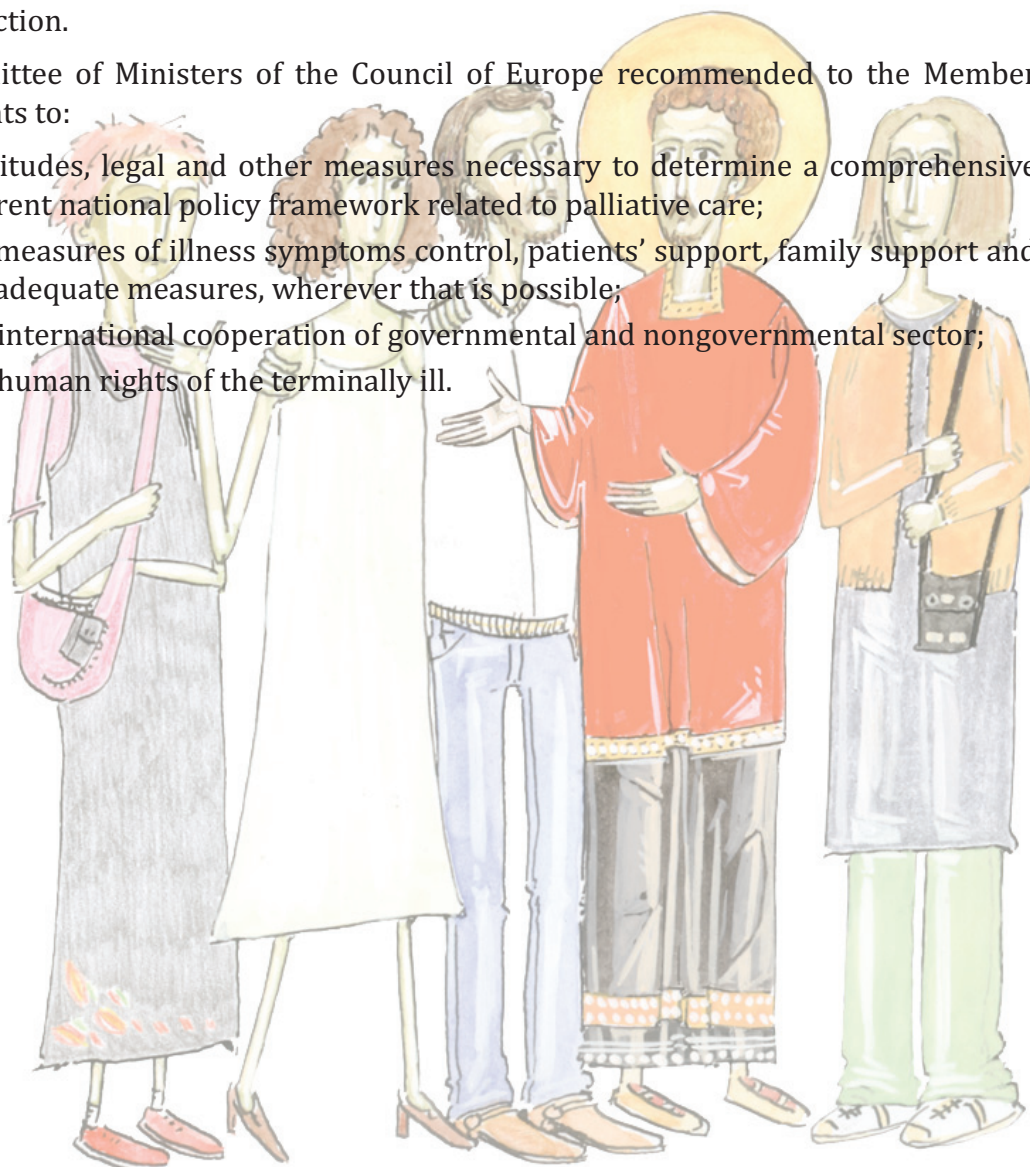


THE MOST IMPORTANT INTERNATIONAL LEGAL ACTS AND POLICY DOCUMENTS THAT DEFINE HUMAN RIGHTS OF THE TERMINALLY ILL

By insight into the documents and practice of the EU Member States, as well into the relevant documents of the Council of Europe (Recommendation of the Committee of Ministers of the Council of Europe no. 1418 on Protection of the Human Rights and Dignity of the Terminally Ill and the Dying, Recommendation of the Council of Europe no.89/13 on the Organisation of Multidisciplinary Care for Cancer Patients, the Poznan Declaration on Palliative Care in the Countries of Eastern Europe) define several fundamental rights of the terminally ill, on the base of which strategic documents are devised and support systems created: the right to a dignified treatment up to the moment of death; the right to truthful and timely information of one's health condition; the right to suitable psycho-social and spiritual support; the right to participation in making decisions related to one's treatment and destiny; the right to make decisions before surgical interventions; the right to pain relief; the right to visits by relatives; the right to express one's feelings freely; the right to a dignified death; the right not to die alone; the right to adequate protection.

The Committee of Ministers of the Council of Europe recommended to the Member States' governments to:

- adopt attitudes, legal and other measures necessary to determine a comprehensive and coherent national policy framework related to palliative care;
- pass full measures of illness symptoms control, patients' support, family support and all other adequate measures, wherever that is possible;
- promote international cooperation of governmental and nongovernmental sector;
- promote human rights of the terminally ill.



LAWS AND STRATEGIC DOCUMENTS OF THE REPUBLIC OF SERBIA THAT DEFINE HUMAN RIGHTS OF TERMINALLY ILL

A number of documents passed in Serbia (Poverty Reduction Strategy, Strategy for Social Care Development, New Health Policy Strategy, National Strategy for Accession of Serbia to the EU, National Plan for Integration of Serbia into the EU, etc.) determine the necessity for development of palliative care policy, harmonised with contemporary European and worldwide practice in the field of palliative care. In that sense, an intention to harmonise the social care system in order to satisfy the needs of this population group is notable.

In the adopted strategic document on social care development, it is emphasised that: the social care system should be more efficient and wholesome, especially for risk population groups, among which are terminally ill; the social care functions should be decentralised, and the role of the local community should be reaffirmed in caring for all population categories that need some kind of additional assistance and care; that preventive and therapeutic function of social care system should be particularly developed; that non-profit and private sectors should be more involved in choosing services; that new services should be developed and scope and quality of existing services should be enhanced.

In the New Social Care Law draft, Ministry of Labour and Social Policy determined the following principles in the field of social policy, which can be observed in a wider sense as creation of basis for further development and adjustment of policies in the domain of care for the terminally ill:

- 
1. Principle of humanity, respect for integrity and dignity of beneficiaries;
 2. Principle of non-discrimination;
 3. Principle of availability of social care;
 4. Principle of the least restrictive environment;
 5. Principle of social care efficacy;
 6. Principle of timely social care;
 7. Principle of continuous social care;
 8. Principle of enhancement of social care quality;
 9. Principle of publicity;
 10. Principle of the beneficiary's best interest.

The doctors' relationship towards the dying patients was defined for the first time in Serbia in 2006 by the Ethical Code, according to which dying and death of a patient is part of medical treatment, and a doctor is obliged to provide the dying patient in terminal illness phase with dignified dying conditions, as the continuation of intensive treatment in such a state would exclude the right of the dying person to a dignified death (Article 61, Paragraph 2 of the Ethical Code). Apart from the right of the dying person to assistance, care, information on health condition and measures that were undertaken, to presence of family and other close ones in the final moments, as well as to every kind of moral and spiritual help, the concept of dignified death also implies the doctor's obligation to undertake all measures necessary for meaningful treatment and relief in suffering, as well as to take into account the last wish of an informed, conscious patient in relation to the continuation of treatment. As to patients who are not capable of reason-

ing, the final decision on course or cessation of treatment is brought by the doctor, who could take into account a previously expressed wish of the patient. The doctor is forbidden to fulfil the dying patient's wish if it leads to active euthanasia.

Ethical Code strictly cites that deliberate shortening of life is in contradiction with medical ethics, and in expert public there are different attitudes towards use of medicaments with the intention of pain relief in doses for which it is known in advance that they might be lethal. Ethical Code refers to respect of the dying patient's last wish, but the doctor is allowed to disregard it if it is in collision with the doctor's ethical values and represents euthanasia. Provision of Criminal Law on deprivation of life out of compassion and accepted theories of criminal law on causality in crime of murder clearly point out that application of pain relieving substances to dying patients in potentially lethal doses is forbidden, regardless of the doctor's intentions.

Issues linked to euthanasia have been occasionally discussed in Serbia mostly by experts on criminal law, arguing on the necessity for existence of the criminal act of murder out of charity, and Serbian legislation and ethical standards on these issues are similar to those in most European states: passive euthanasia is legalised through the patient's right to reject treatment, while active euthanasia of any form is forbidden.



KEY CHALLENGES IN PRACTICING THE RIGHTS OF THE TERMINALLY ILL AND ATTEMPTS TO SOLVE THEM SO FAR

In spite of the aforementioned changes to the legislative framework and adoption of strategic documents, some of key aspects of right to health have been endangered in the past 10 years in Serbia, relating to spiritual support, health information, provision of health services, goods and capacities to all people without discrimination, as well as to the need that health services and other indispensable services, goods and capacities, be available, accessible and acceptable.

Although normative acts allow it, the presence of a spiritual guide in the most difficult moments for the terminally ill patients is mainly not effectively possible, due to organisational, logistic and other obstacles, thus violating fundamental human rights of the terminally ill and complicating mitigation of their suffering.

The concepts of palliative care and caring for the terminally ill, as well as consciousness on the attention and care of medical staff and society as a whole they deserve, are relatively new in Serbia. The Strategy for Palliative Care envisages palliative care and caring for the terminally ill within: (1) institutions of primary health care – health centres, where there are teams for palliative care and home treatment services, as well as the Institute for Gerontology, Belgrade, in charge for providing home treatment and palliative care for the elderly; (2) institutions of secondary health care – hospitals, which may have palliative care wards; (3) institutions on the tertiary health care level – e.g. some institutes within clinical centres (Clinical Centre Serbia – Belgrade, Clinical Centre Nis, Clinical Centre Kragujevac, Clinical Centre Vojvodina – Novi Sad) where formation of consultant teams is foreseen, as well as within the Centre for Palliative Care Development at the Institute for Oncology and Radiology of Serbia).

However, regardless of the recommendations of the Council of Europe, documents in force do not envisage formation of hospices with teams specially trained for palliative care, although such a way of comprehensive caring for patients is accepted abroad. Such institutions are organised by church, nongovernmental and governmental organisations, and financed by donations. Hospices improve the quality of life of patients in terminal illness phases and their families, through organisation of day-care hospitals, short-term care – “respite” centres, thus enabling dignified dying, but also giving considerable support to families during the illness and in period of bereavement.

Data show that in Serbia every year about 18,000 patients die of malignant diseases only, which only contributes to the claim that there is a need for caring for patients in terminal illness phases and dying patients. It is also a fact that most patients choose their natural social environment as the place where they wish to spend their last days, and that hospices are here described as “places to die in”, and therefore not accepted by the expert public in the first place, due to numerous social and cultural peculiarities of the community. On the other hand, it is also a fact that in-home caring for such patients is often not possible, because of numerous reasons, thus creating a big problem for all: the dying patient, his family, caregivers and health professionals.

In bad economic conditions in which the health care system in Serbia functions and with still insufficiently reformed legislation, the problem of availability of many medicines becomes even more distinct. Restrictive medications list that can be obtained on prescription through the Health Insurance Fund forced the citizens to buy e.g. pain relief medications (oral morphines

were not registered for pain relief). In this way the terminally ill patients were the most endangered, since not only their human right not to endure pain but their dignities as well were at risk.

Primary health care, the cornerstone of health care in Serbia, was transferred onto the “capitation” model and financing according to realised services, which disables health professionals to stay longer than the normative with a patient in the terminal illness phase, in order to consider all problems the patient and his/her family are facing, apart from physical and mental ones.

Existing legislation, which predicts caring for the most difficult patients in primary health care, disables a holistic approach in caring for such patients.

Inappropriate organisation of health care, bad coordination among its different levels and underdevelopment of some of its segments (in-home treatment and care, palliative care and care for the dying), lack of material resources and capacities, and underdeveloped infrastructure, lack of staff and technical support in rural areas, endanger the human rights of the terminally ill even more.

Lack of professional ethics and insufficient education of health professionals in the field of palliative care and caring for terminally ill and dying patients leads to discrimination of their rights.

Bad communication on the relation patient/doctor/family causes the patients and their families to be insufficiently informed of the inevitable course of illness, possibilities of treating various illness symptoms, as well as of possibilities for support and assistance that are partially existent in urban areas.

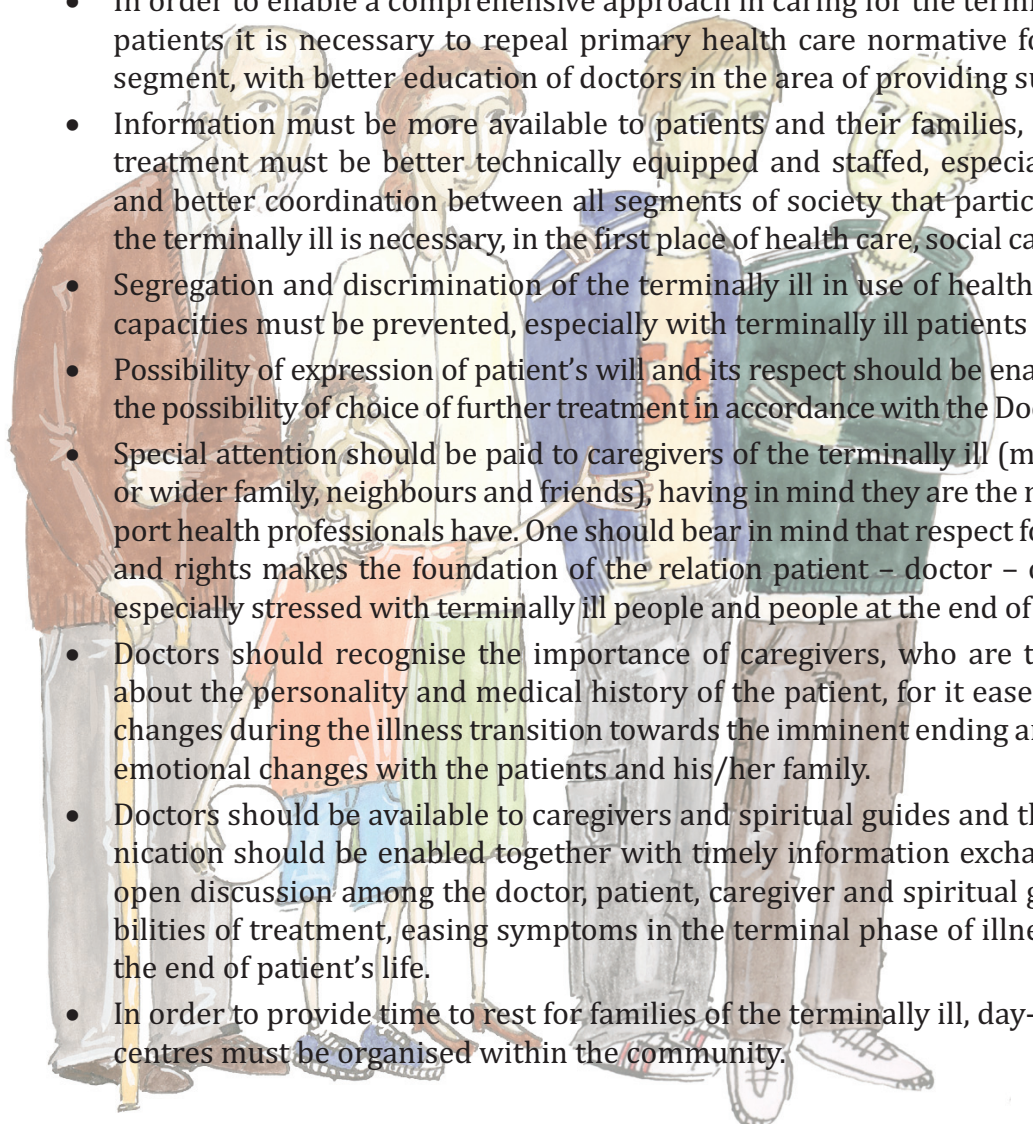
By engagement of authorities in charge and other actors these problems have been partially eased, which is reflected in:

- Registration of oral morphine on the market thus making it available for treating malignant pain;
- Better availability of medicines on the market;
- Adoption of the Strategy for palliative care in the Republic of Serbia and Action plan for its implementation;
- Education of health workers, health co-workers and volunteers on palliative care (project DILS);
- Adoption of National Strategy against HIV/AIDS.



PROPOSALS OF MEASURES TO SOLVE KEY CHALLENGES IN PRACTICING HEALTH RELATED RIGHTS IN SERBIA

- In order to secure respect of fundamental human rights of the terminally ill patients and ease their suffering to the highest possible extent, spiritual guidance in their most difficult moments must be effectively allowed not only by normative acts, but also with organisational and other measures.
- Legal and strategic acts regulating the issues of human rights of the terminally ill in Serbia must be harmonised to the highest possible extent with corresponding international regulations, i.e. those of the Council of Europe in the first place.
- Integration and good coordination of health care and social care is indispensable, together with linking all actors in holistic palliative care and caring for patients in terminal phases of their illnesses and dying patients, with the objective of creating preconditions for a comprehensive approach in caring for the most difficult patients.
- Formation of hospices is indispensable.
- In order to enable a comprehensive approach in caring for the terminally ill and dying patients it is necessary to repeal primary health care normative for this population segment, with better education of doctors in the area of providing support.
- Information must be more available to patients and their families, services for home treatment must be better technically equipped and staffed, especially in rural areas, and better coordination between all segments of society that participate in caring for the terminally ill is necessary, in the first place of health care, social care and volunteers.
- Segregation and discrimination of the terminally ill in use of health care services and capacities must be prevented, especially with terminally ill patients from rural areas.
- Possibility of expression of patient's will and its respect should be enabled, connected to the possibility of choice of further treatment in accordance with the Doctors' Ethical Code.
- Special attention should be paid to caregivers of the terminally ill (members of nuclear or wider family, neighbours and friends), having in mind they are the most common support health professionals have. One should bear in mind that respect for patients' dignity and rights makes the foundation of the relation patient – doctor – caregiver, which is especially stressed with terminally ill people and people at the end of their lives.
- Doctors should recognise the importance of caregivers, who are the source of data about the personality and medical history of the patient, for it eases the treatment of changes during the illness transition towards the imminent ending and all physical and emotional changes with the patients and his/her family.
- Doctors should be available to caregivers and spiritual guides and their good communication should be enabled together with timely information exchange, as well as an open discussion among the doctor, patient, caregiver and spiritual guide about possibilities of treatment, easing symptoms in the terminal phase of illness and support at the end of patient's life.
- In order to provide time to rest for families of the terminally ill, day-care and "respite" centres must be organised within the community.



3.

AVAILABILITY OF COMPREHENSIVE PALLIATIVE CARE – HOLISTIC APPROACH

IDEA, GOALS, CHARACTERISTICS AND HISTORY OF COMPREHENSIVE PALLIATIVE CARE

Palliative care is an approach in treatment which improves the entire quality of life of patients facing an active, progressive, advanced illness with limited prognosis and their families to the highest possible degree. Affirmation of life and death as normal processes is the basis of palliative care, without the intention to hasten or postpone dying, by actions aimed at relief of pain and other symptoms, by integration physiological and spiritual aspects of caring about a patient. Palliative care offers the support to live actively to the highest possible extent, until death, at the same time helping the family to understand and endure suffering. In cases of incurable diseases it is necessary to start the palliative process as soon as possible, before the terminal phase, with timely forecasting, prevention and treatment of suffering. Such an approach encourages the patient's autonomy, availability of information and the right to a choice, all of this in accordance with fundamental principles of bioethics (*primum non nocere* – first, do no harm, *salus aegroti suprema lex* – well-being of the patient is the most important law, *voluntas aegroti suprema lex* – will of the patient is the most important law).

A holistic approach to these patients therefore enables not only treatment of physical symptoms of the illness, but also care of the patient's whole being and his/her family through spiritual, emotional, psychological and social support. During treatment of a serious patient his/her illness, e.g. the sick organ, should not be at the core of attention, but the whole person, with all of his/her problems and needs. True compassion for the patient and his family should be connected to the highest medical achievements and the highest standards in the social protection domain. This can be done by early illness discovery, prevention and alleviation of illness symptoms, as well as relieving all psychical, emotional, social and spiritual problems that the illness brings.

As to the spiritual assistance given to patients, one should know that, in experience of Christian churches, it always implies several fundamental things that should always be kept in mind in order for their special and unique role to develop wholly and correctly in this important process: Churches, different to secular palliative institutions, do not view the patient's death as the final, ending state of his/her existence, but as a transition into a new and utterly different kind of existence. Therefore, the content of comfort they give to the dying is completely different from those offered by atheist/agnostic institutions and individuals of such beliefs; Churches give patients not only faith in future life, but also ways to feel and experience it here and now, everywhere, even in the hospital bed, through Sacrament life; Churches do not only set the patient into family-and wider social context in which/by which they prepare him/her for death, they offer the patient to heal those relations that should ease death/transition for him/her, through repentance, reconciliation, mutual forgiveness and renewal of broken links of love; Churches leave space for the importance of pain, although they have complete respect and consideration for secular techniques of psychological help and medicament pain relief therapy, this pain is not removed at any cost (if the patients wants and can do that), since it has a therapeutic, cleansing effect in the process of maturing of a human personality, that does not end on the deathbed but

culminates there; Churches, in the end, introduce heavenly physicians and protectors, healers and helpers, to whom they pray and ask them as intermediaries for help in the crucial moment of someone's life, into the group of palliative strivers, next to medical experts of various profiles, social services and spiritual guides.

One of the fundamental ideas of contemporary palliative care is that pain and other illnesses' symptoms have, apart from an organic, also an emotional-psychological, spiritual and social component, and their basic suppositions are that the patient and his family are the centre of all events connected to the illness and that the patient is in every moment a person who should be respected and who, within the limits imposed by the illness and basic ethic and professional norms, in the first place decides alone about everything connected to him/her.

Palliative medicine is one of the newer sub-specialist disciplines, and is the result of development not only of medical science, but advancement of humanist thought of the modern society, that implies a wider social reaffirmation of basic Christian postulates. Palliative medicine is applied when classical treatment methods have been exhausted or when the signs of illness advancement reached a degree that the patient endures with evident difficulties.

Palliative care slowly becomes a widely accepted kind of medical assistance and has been approved in 120 states worldwide. The beginning of modern palliative care dates from 1950s, when the attitude towards the dying began to alter significantly. Caring for them became an obligation of health staff, especially in the domain of new medicines' application that alleviate illness symptoms (pain in the first place), and of other actors within the community. In this period "good death" begins to be talked about, and that is not death in ICUs and other hospital wards, but in wanted family or similar environment.

1967 is considered to be the start of contemporary approach to palliative care, when St. Christopher's Hospice was opened in London. Two years later, the service for in-home care in the circle of the dying patient's family started to work within that institution, often comprised of the same interdisciplinary teams that follow the patient on both locations. Today the St. Christopher's Hospice is the most important, not only as perhaps the best model of holistic approach to patients and their families, rich in various facilities, but as an educational centre for palliative care practice. This model has been accepted in many countries, and it is often also accepted by the health insurance system. Cultural factors significantly influence forming of hospices; therefore in some areas a hospice is still regarded just as a "place to die in".

The most critical moments during an incurable illness are the discovery of first symptoms, diagnosis, beginning of therapy and its ending, in cases of some illnesses these include moments of temporary recovery and re-socialisation, and in the end the death outcome. The patient's family is involved in all patient's fears and physical and psychical sufferings, and the family itself faces numerous psychical, emotional and other issues. With advancement of illness, numerous symptoms and problems arise, that should be taken care of, from physical due to primary illness or applied therapy (pain, nausea, vomiting, cough, malnutrition), spiritual (facing imminent death) and psychological (anxiety, fear, anger, depression, insomnia, bad concentration) to social (loss of social network, role in society, financial support).

Numerous problems exist in the families of such patients, as well. They are faced with difficult problems during the illness duration and in the period of bereavement. Therefore the holistic method in palliative care for patients and their families, the largest possible improvement of their lives' quality, as well as dignified dying of the patients are provided by actions of multi-professional, interdisciplinary teams for palliative care, enabled for resolving various

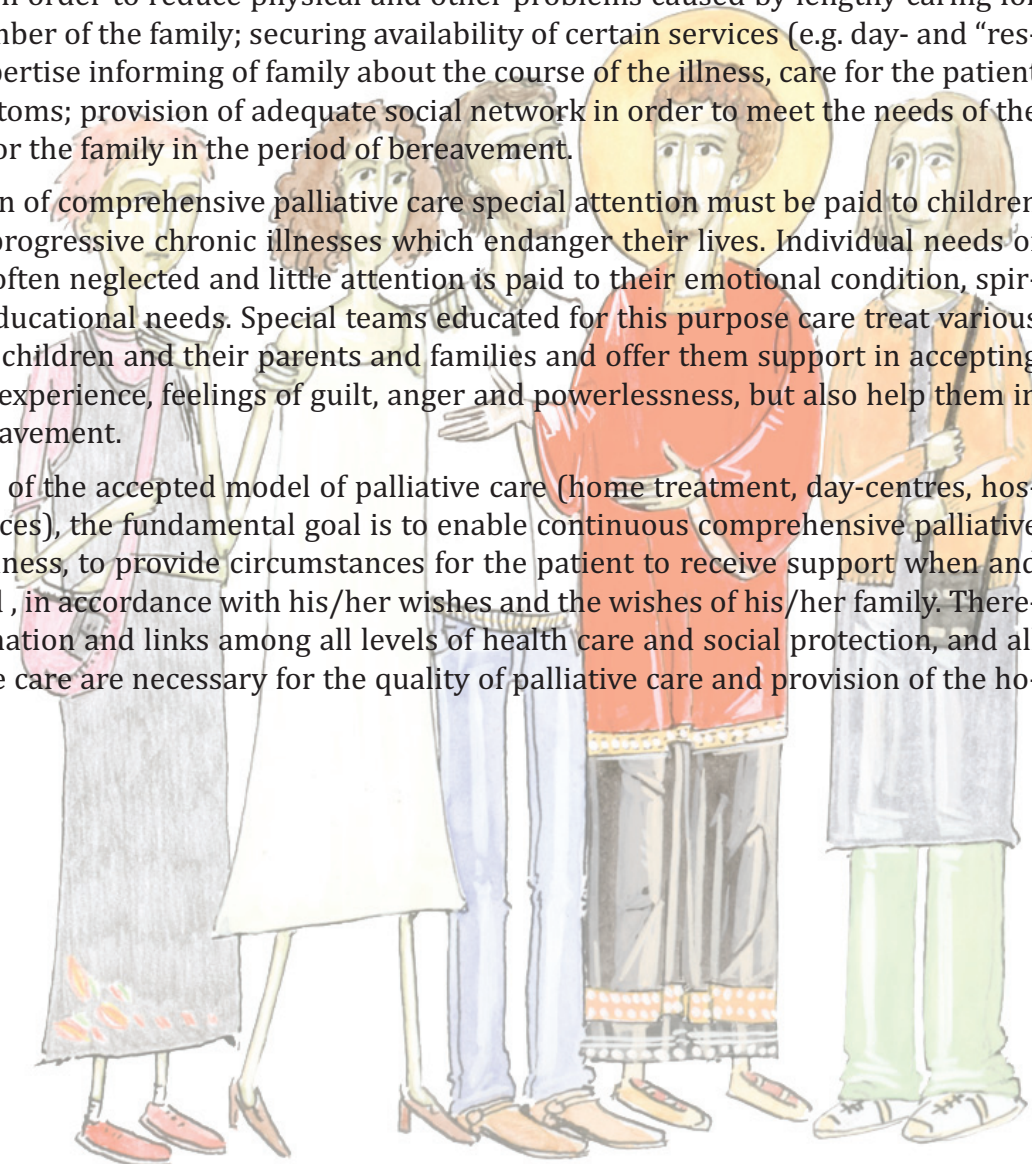
problems of the patient and his/her family. These teams are comprised by well educated nurses, doctors, spiritual fathers, social workers, psychologists and volunteers.

Palliative care on primary level of health care depends on the patient's family. Care in the terminal illness phase and dying at home is undoubtedly a good alternative to institutional accommodation, especially when one has in mind that the greatest number of people wants to be treated and die at their home, where the best possible life quality can be provided in accordance with their wishes. For such type of care, however, there must exist a family, that is, a constantly present caregiver, but the community must also have a well developed network of different services for assistance and support (in the first place, mobile teams, available 24/7). When we talk of family members as caregivers for persons in terminal illness phases, we must keep in mind that around three quarters of caregivers (who are mostly women) suffer from a chronic illness themselves.

Therefore, in order to implement palliative care at patients' homes, it is necessary to create certain preconditions and develop strategies to help caregiver, such as: provision of information on assistance and support services available within the local community; education on personal care in order to reduce physical and other problems caused by lengthy caring for a seriously ill member of the family; securing availability of certain services (e.g. day- and "respite" centres); expertise informing of family about the course of the illness, care for the patient and various symptoms; provision of adequate social network in order to meet the needs of the patient; support for the family in the period of bereavement.

In provision of comprehensive palliative care special attention must be paid to children who suffer from progressive chronic illnesses which endanger their lives. Individual needs of sick children are often neglected and little attention is paid to their emotional condition, spiritual, social and educational needs. Special teams educated for this purpose care treat various symptoms of sick children and their parents and families and offer them support in accepting the most difficult experience, feelings of guilt, anger and powerlessness, but also help them in the period of bereavement.

Regardless of the accepted model of palliative care (home treatment, day-centres, hospital wards, hospices), the fundamental goal is to enable continuous comprehensive palliative care during the illness, to provide circumstances for the patient to receive support when and where it is needed, in accordance with his/her wishes and the wishes of his/her family. Therefore, good coordination and links among all levels of health care and social protection, and all actors in palliative care are necessary for the quality of palliative care and provision of the holistic approach.



SITUATION AND CHALLENGES IN THE FIELD OF COMPREHENSIVE PALLIATIVE CARE IN SERBIA

In existing conditions in Serbia, hospital type of palliative care is possible, after suitable training in all primary, secondary and tertiary health institutions, where a number of beds would be reserved for palliative care. In such a system, perhaps the most important is training in primary health institutions, which would be carriers of ambulance palliative care.

Certainly, the initial factor in the analysis of palliative care concept in Serbia is its availability. Availability of palliative care is seen in organisation, accessibility of suitable medicaments and existence of trained teams for providing palliative care.

Development of palliative care is one of strategic goals of the Republic of Serbia in the domain of health system and specific forms of social protection. As palliative care potentially refers to total population, as citizens of different age and social and demographic characteristics could get sick from progressive, incurable illnesses that endanger life, apart from the Strategy for Palliative Care, other relevant strategic documents referring to palliative care have been brought in Serbia:

- *Social Protection Development Strategy (draft)*
- *National Aging Strategy 2006-2015*
- *National Strategy against HIV/AIDS*
- *Strategy for Development of Youth Health in the Republic of Serbia*
- *Public Health Strategy in the Republic of Serbia*
- *National Program for Integration of Serbia into EU.*

Relevant laws in Serbia for this field are:

- *Health Protection Act*, article 110 that refers to organisation of hospitals and article 88 that defines health service, and
- *Law on Social Protection and providing social security to citizens (draft)* in provisions relating to fundamental social protection rights – in the wider interpretation.

Principles of availability and continuity of health care are general principles that are applied to the obligation of accessibility of palliative care as well. As the maxim which does not single out availability of any health care segment at particular is acceptable on the level of guaranteeing general principles, lack of specific legislation that would refer to rights of patients in terminal illness phase and guaranteeing a holistic approach in palliative care provision is utterly unacceptable. Namely, the Health Care Act does not contain such specific guarantees, but the rights of patients in terminal illness phases are included in general category of patients' rights.

It should be pointed out that the Health Care Act does not guarantee the right to pain relief, but this right is mentioned in the Strategy for Palliative Care of the Republic of Serbia. Lack of guarantees for palliative care accessibility is visible in relation to the absence of special provisions that would regulate organisation of palliative care. Instead of that, performance of this segment of health services is subject of general provisions that regulate the issues of primary, secondary and tertiary health care.

GENERAL RECOMMENDATIONS FOR EMPOWERMENT OF HEALTH CARE SYSTEM IN SERBIA

Relevant international standards in the field of comprehensive palliative care that were taken into account when legislative and strategic framework in Serbia was changed are defined in the following documents:

- *Recommendation of the Committee of Experts* of the Council of Europe, from November 12th 2003, on organisation of palliative care, and
- *Study on Palliative Care in Europe*, written by the European Parliament Committee for Environment, Public Health and Food Safety. This document contains recommendations for all EU Member States to develop national plans for palliative care, promote integrated health care that includes suitable palliative care, start developing plans for medical staff training, and training for staff in social protection system, in order to provide them with necessary knowledge and skills to offer palliative care successfully. As membership in the EU is a strategic determination of Serbia, it is significant to harmonise appropriate systems in our country – health care institutions in the first place – with positive practice in EU states.

Contrary to the recommendations of the Council of Europe on palliative care organisation, our Health Care Act leaves no possibility for opening hospices where patients in terminal illness phases would be cared for. The Act has an additional drawback as there are no provisions on organising palliative care for terminally ill children.

Strategy for Palliative Care of the Republic of Serbia and Action plan for its implementation have foreseen teams for palliative care on primary level of health care within services for home care, as well as units for palliative care on the secondary level and consultant teams on the tertiary level of health care. Implementation of these documents in practice, however, has been accompanied by numerous challenges and shortcomings:

- Neither palliative care units nor consultant teams on secondary and tertiary levels of health care have been formed yet.
- Education of a small number of doctors and nurses of primary health care in the field of palliative care has yet been started.
- Teams for palliative care on primary health care level have not been formed, in spite of the fact that home care services available at health centres are not and cannot be teams for palliative care.
- There are no teams for palliative care of children (there is psychological support for children at the Institute for Oncology and Radiology of Serbia, but not for children suffering from other diseases).
- There is no sufficient coordination of actors in palliative care (Church, health care system, social care system, nongovernmental sector and other actors).
- Patients and their families do not have sufficient information on courses of illnesses, possibilities for choices and possibilities for care within the community.
- There are no teams for family support in period of illness as well as in period of bereavement.

- Strategy has not foreseen the formation of hospices, a widely accepted holistic approach in caring for the terminally ill and their families.
- Discrimination and stigmatisation of the terminally ill is still present, the elderly and AIDS patients in particular, both in the health care sector and other segments of society.
- Some hospitals, due to still present aggressive anti-Christian ideological consciousness, do not allow patient to have spiritual support, thus absolutely endangering one of their fundamental human rights.



RECOMMENDATIONS OF MEASURES FOR PROVISION AND AVAILABILITY OF THE HOLISTIC APPROACH IN PALLIATIVE CARE:

1. It is necessary to provide media support to development of comprehensive palliative care in order to achieve the widest possible social sensitivity and inclusion of various actors into securing the holistic approach, with the goal to improve the quality of lives of patients and their families and prevent discrimination and stigmatisation of patients in terminal illness phases.
2. In order to provide quality, availability and respect of the holistic approach in palliative care, it is necessary to determine standards and change the way of financing services which are provided for the patients and their families within the health system.
3. In order to secure availability of opioids necessary for palliative care, it is necessary to clearly state the scope and content of palliative care on the normative level, including the Strategy for Palliative Care and the Ethical Code, and differ them from borderline treatments such as active euthanasia, i.e. its indirect kind – use of medicaments with the intention to ease pain, but in doses known to be or might be lethal.
4. On primary health care level it is necessary to:
 - Secure education of doctors, priests, nurses, psychologists, social workers and volunteers in the field of palliative care.
 - Form palliative care teams, with provision of good coordination and establishing communication and cooperation on the local level (health centre – centre for social work – parish church – nongovernmental organisations – all other actors as needed, who could contribute to palliative care development and enable better life quality to patients and their families.)
 - Educate and form multidisciplinary palliative care teams for children, based on combination of family and home care, and where that is not sufficient, a special paediatric hospice should be available. Palliative care for terminally ill children should be based on the principle of protection of the child's best interests.
 - Educate and form patients' family support teams (especially for children and the elderly) in the periods of illness and bereavement.
 - Enable (through constant education) acquiring communication skills on the relation patient – family – palliative care team members, as well as mutual communication among team members.
 - Create preconditions for palliative home care.
5. On secondary and tertiary level of health care it is necessary to:
 - Form palliative care units and consultant teams (including those dedicated to children).
 - Educate palliative care actors on secondary and tertiary levels of health care.
 - It is necessary to secure good coordination and links both with other levels of health care and other actors in this care, in order to provide continuous care.
6. Coordination of health and nongovernmental sectors and other significant actors must be provided, with participation of volunteers in organised palliative care.

7. It is necessary to enable formation of hospices as one type of comprehensive palliative care, which has the goal to improve the quality of life and dying, and where different kinds of care are provided to patients and their families (day-care centres, home treatment, institutional accommodation, and various forms of counselling and family support) and peaceful and dignified death is enabled.
8. It is necessary to secure support and help for palliative care team members in order to prevent the “burnout syndrome”.



4.

EMPOWERMENT OF THE HEALTH CARE SYSTEM BY INTRODUCING A COMPREHENSIVE SYSTEM OF PALLIATIVE CARE SERVICES

STATE OF THE HEALTH CARE SYSTEM IN SERBIA, NORMATIVE FRAMEWORK AND STRATEGIC DIRECTIONS OF ITS EMPOWERMENT

Health system in Serbia is functioning in difficult conditions, endangered by problems remaining from the past and in bad material conditions, while its empowerment is at the same time made complex by multidimensional processes of transition.

Ministry of Health of the Republic of Serbia defined empowerment of the health system through improvement of health protection quality as one of the goals of its health policy, which has been monitored on the national level from July 2004. In February 2009, the Strategy for Constant Improvement of Health Protection Quality and Patients' Safety was adopted. Implementation of this Strategy has the objective to decrease:

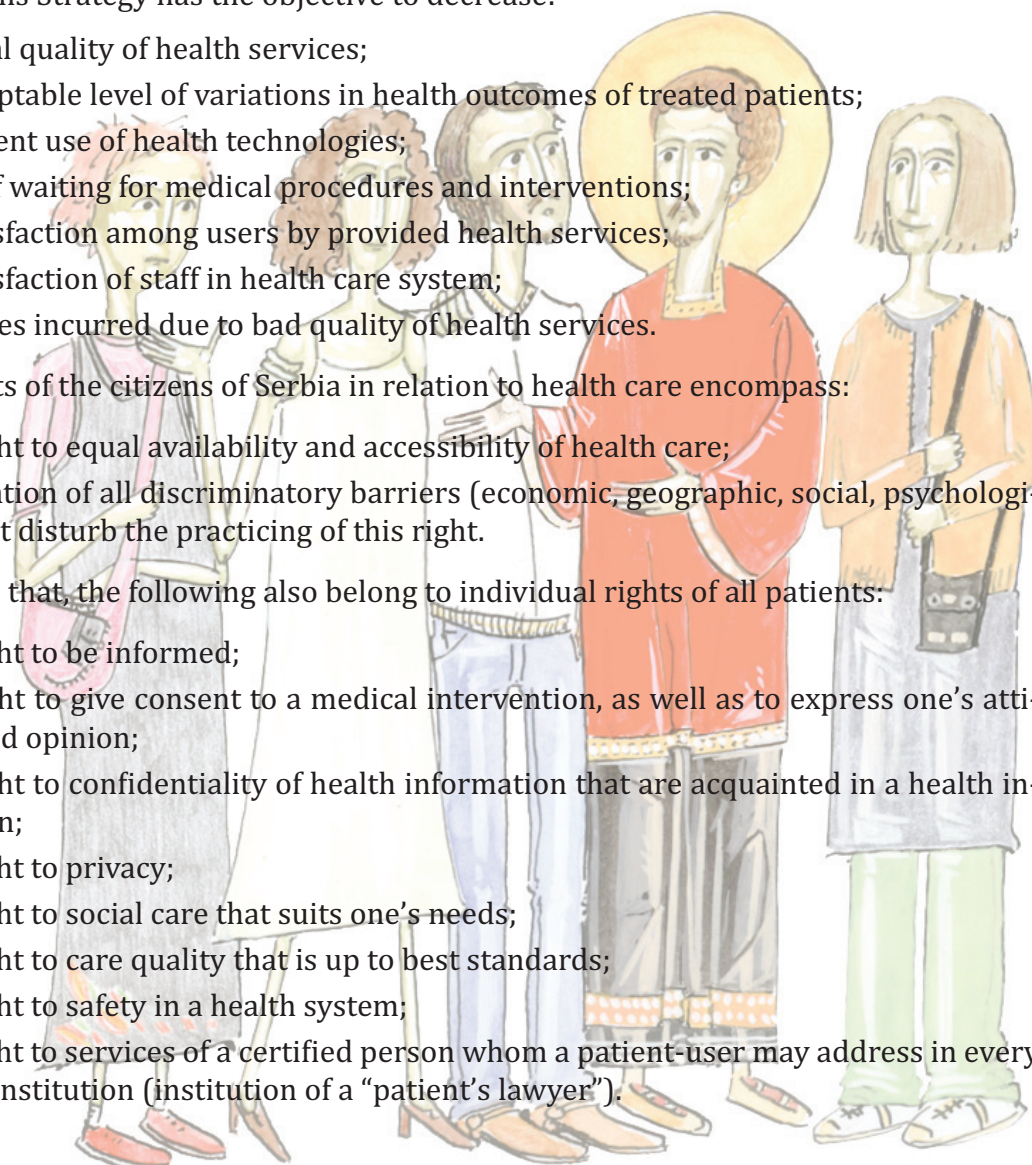
- Unequal quality of health services;
- Unacceptable level of variations in health outcomes of treated patients;
- Inefficient use of health technologies;
- Time of waiting for medical procedures and interventions;
- Dissatisfaction among users by provided health services;
- Dissatisfaction of staff in health care system;
- Expenses incurred due to bad quality of health services.

Social rights of the citizens of Serbia in relation to health care encompass:

- The right to equal availability and accessibility of health care;
- Elimination of all discriminatory barriers (economic, geographic, social, psychological) that disturb the practicing of this right.

Apart from that, the following also belong to individual rights of all patients:

- The right to be informed;
- The right to give consent to a medical intervention, as well as to express one's attitude and opinion;
- The right to confidentiality of health information that are acquainted in a health institution;
- The right to privacy;
- The right to social care that suits one's needs;
- The right to care quality that is up to best standards;
- The right to safety in a health system;
- The right to services of a certified person whom a patient-user may address in every health institution (institution of a "patient's lawyer").



The most significant strategic plans and programs of the Republic of Serbia directed at empowerment of health system are:

- Strategy of Public Health in Serbia;
- Strategy for Palliative Care;
- Strategy for Constant Improvement of Health Care Quality and Patients' Safety;
- Strategy for Youth Development and health in the Republic of Serbia;
- National Program Serbia against Cancer;
- National Program for Breast Cancer Prevention;
- National Program for Prevention and Early Detection of Diabetes Type 2;
- National Program for Prevention of Cervical Cancer.

International documents relevant for Serbia that regulate this field are:

- European Charter of Patients' Rights;
- Declaration on Promotion of Patients' Rights in Europe;
- Convention on Human Rights and Biomedicine;
- Recommendation of the Council of Europe on the development of structures for citizen and patient participation in the decision-making process affecting health care.



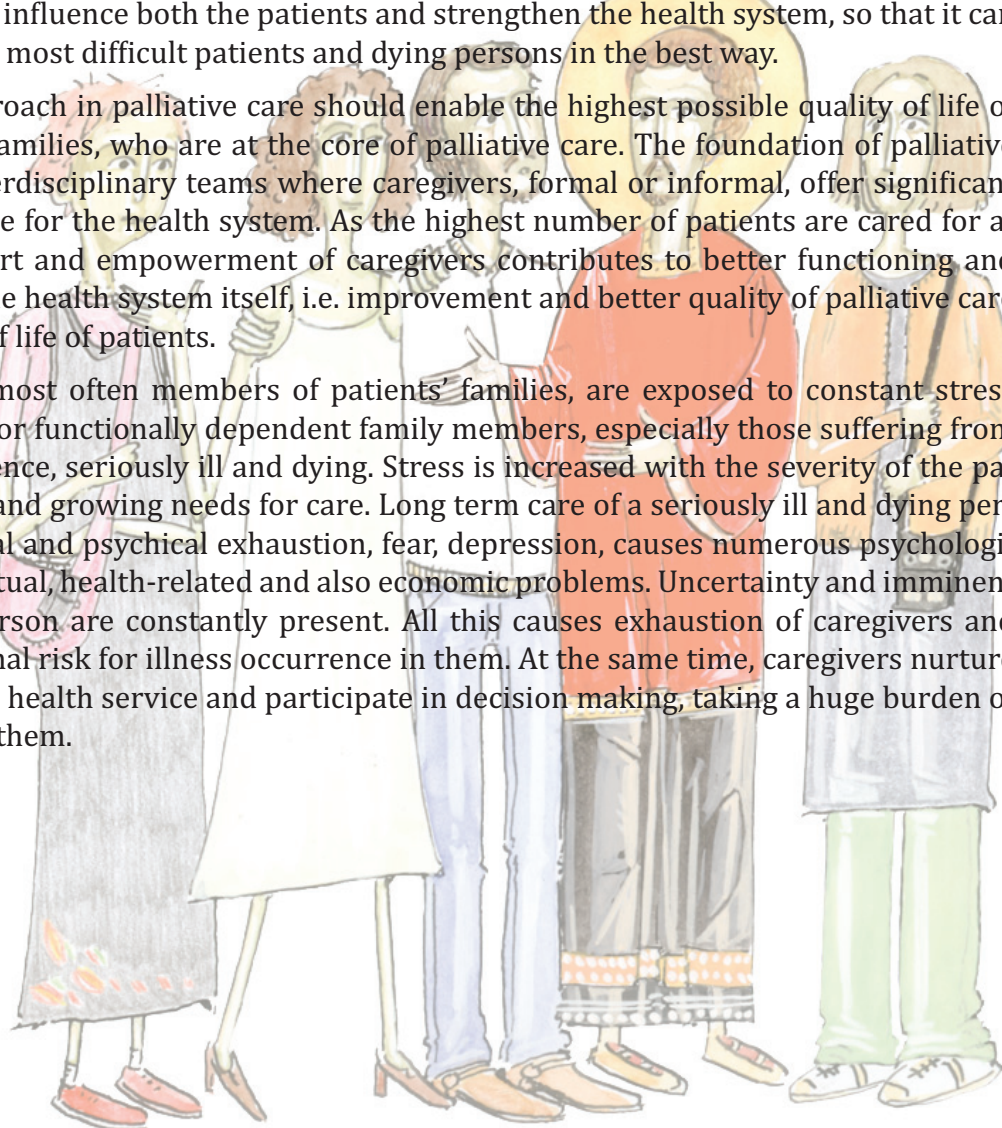
NECESSITY FOR HEALTH SYSTEM EMPOWERMENT IN THE SENSE OF PROTECTION OF HUMAN RIGHTS OF TERMINALLY ILL PEOPLE AND THE ROLE OF CAREGIVERS

When one speaks of respecting human rights within the health care system, human rights of terminally ill people are at highest risk, although they are guaranteed by the Health Care Act. With the Strategy for Palliative Care and the Action Plan for its implementation, the Government has chosen the development of palliative care model that leans on primary health care to the highest extent, i.e. on palliative care teams within services for in-home treatment in health centres.

Health system is comprised of capacities, i.e. equipment, and human resources in the first place, which are of utmost significance in comprehensive palliative care of patients suffering from active, progressive, advancing illnesses with limited prognosis. These patients need the highest possible quality of life in their remaining days, with respect of dignity and human rights. Therefore, support and empowerment of formal and informal caregivers is a two-way process that should influence both the patients and strengthen the health system, so that it can provide care for the most difficult patients and dying persons in the best way.

Holistic approach in palliative care should enable the highest possible quality of life of patients and their families, who are at the core of palliative care. The foundation of palliative care is made of interdisciplinary teams where caregivers, formal or informal, offer significant support and reliance for the health system. As the highest number of patients are cared for at their homes, support and empowerment of caregivers contributes to better functioning and empowerment of the health system itself, i.e. improvement and better quality of palliative care and better quality of life of patients.

Caregivers, most often members of patients' families, are exposed to constant stress linked with caring for functionally dependent family members, especially those suffering from dementia, incontinence, seriously ill and dying. Stress is increased with the severity of the patient's incapability and growing needs for care. Long term care of a seriously ill and dying person leads to physical and psychical exhaustion, fear, depression, causes numerous psychological, emotional, spiritual, health-related and also economic problems. Uncertainty and imminent death of a close person are constantly present. All this causes exhaustion of caregivers and imposes an additional risk for illness occurrence in them. At the same time, caregivers nurture a constant link with health service and participate in decision making, taking a huge burden of responsibility onto them.



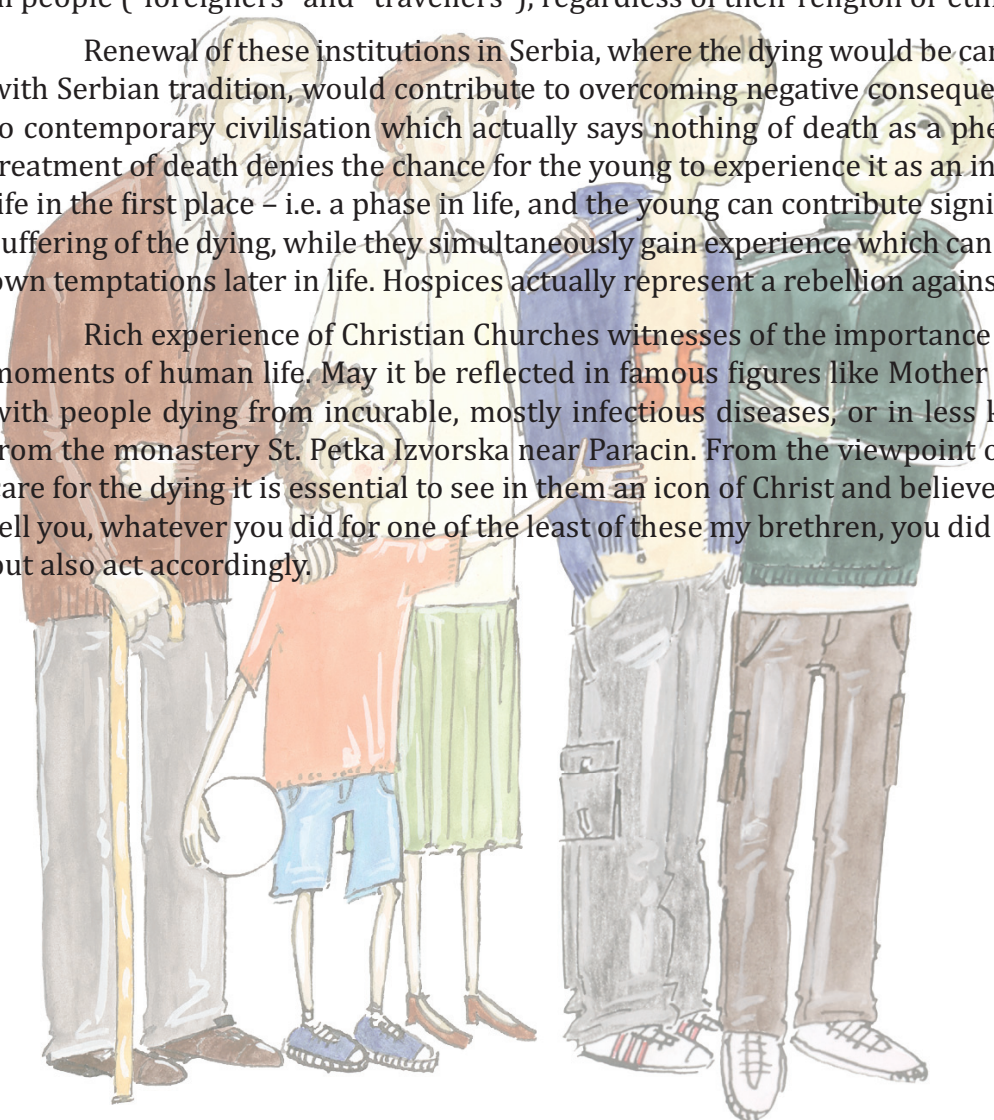
EXAMPLES OF THE ROLE OF SPIRITUAL GUIDES AND VOLUNTEERS IN CARING FOR DYING PATIENTS FROM THE PRACTICE OF CHRIS- TIAN CHURCHES

In all phases that dying patients pass, next to them they need persons capable of letting them know that death is imminent and help them accept reality. Therefore, the health system must be strengthened, i.e. teams should be engaged and educated to be capable to stay with the dying ones and follow them to their “peaceful” ending, when medicine surrenders. These teams should be comprised of priests, monks, nuns and volunteers.

Hospices, centres intended for caring for the terminally ill, whose advantages have been acknowledged in the most developed environments, represent one of the ways to care for these people. Activities of these centres are deeply rooted in Serbian tradition, as such institutions existed and were founded by Serbian rulers not only on Serbian territory (Studena, one of the first Serbian monasteries, bequest of Stefan Nemanja) but also abroad, e.g. in Constantinople, the capital of Byzantium. It is important to note that these hospices were open to all terminally ill people (“foreigners” and “travellers”), regardless of their religion or ethnicity.

Renewal of these institutions in Serbia, where the dying would be cared for, in accordance with Serbian tradition, would contribute to overcoming negative consequences of its belonging to contemporary civilisation which actually says nothing of death as a phenomenon. This tacit treatment of death denies the chance for the young to experience it as an integral part of human life in the first place – i.e. a phase in life, and the young can contribute significantly in easing the suffering of the dying, while they simultaneously gain experience which can help them with their own temptations later in life. Hospices actually represent a rebellion against denial of death.

Rich experience of Christian Churches witnesses of the importance of spirituality in last moments of human life. May it be reflected in famous figures like Mother Teresa, who worked with people dying from incurable, mostly infectious diseases, or in less known faces of nuns from the monastery St. Petka Izvorska near Paracin. From the viewpoint of Christian ethics, in care for the dying it is essential to see in them an icon of Christ and believe in His word: ‘Truly I tell you, whatever you did for one of the least of these my brethren, you did for me.’ (Mat.25:40), but also act accordingly.



GENERAL RECOMMENDATIONS FOR EMPOWERMENT OF HEALTH SYSTEM IN SERBIA

Due to aforementioned reasons empowerment of health system is necessary in many fields – from assigning more funds to health care that will enable better conditions for its implementation and better material conditions of health workers, through harmonisation of legislation with positive regulations in the EU, and their consistent implementation, to better education of health workers with the goal of constant improvement of health services quality.

Constant improvement of quality of services and patients' security is an essential part of daily activities of health workers and other employees within the health care system. Health of population is not a statistical category, but a dynamic process for the maintenance of which organised efforts on preservation and improvement of health and strengthening of health potential in all phases of life is needed. Specific activities are necessary in critical periods of life that represent special health challenges, such as early childhood, youth and old age. These activities are realised through:

- Intersectional cooperation and better connections with the community and its structures (both in state and civil sectors) on all levels of health system;
- Comprehensive, continuous and available health care;
- Health promotion concept.

Health promotion, together with its most significant component, education for health, has the goal to advance the capabilities of an individual, family and community to start activities connected to health improvement. In that sense, activities to achieve this goal should be directed at:

- Development of social and organisational capital for health improvement;
- Development of health communication based in the social marketing system;
- Creation of infrastructure that would enable promotion of health;
- Development of partnerships in the context of infrastructural development for promotion of health, especially partnerships among governmental, private and nongovernmental organisations;
- Encouragement (by better financing and valuing) of health-educational work as an indispensable component of engagement of every health worker, both in state and private sectors;
- Stimulation, by specific financing mechanisms, of implementation of prevention activities, which have been proved to lead to improved health condition of population and lifetime prolongation (health care based on evidence);
- Training in public health institutions, such as institutes and public health institutes and other relevant national institutions for specific fields in health care, in terms of human resources, material, IT, managerial and other qualification, as well as involvement in health promotion programs that are implemented in the EU member states.

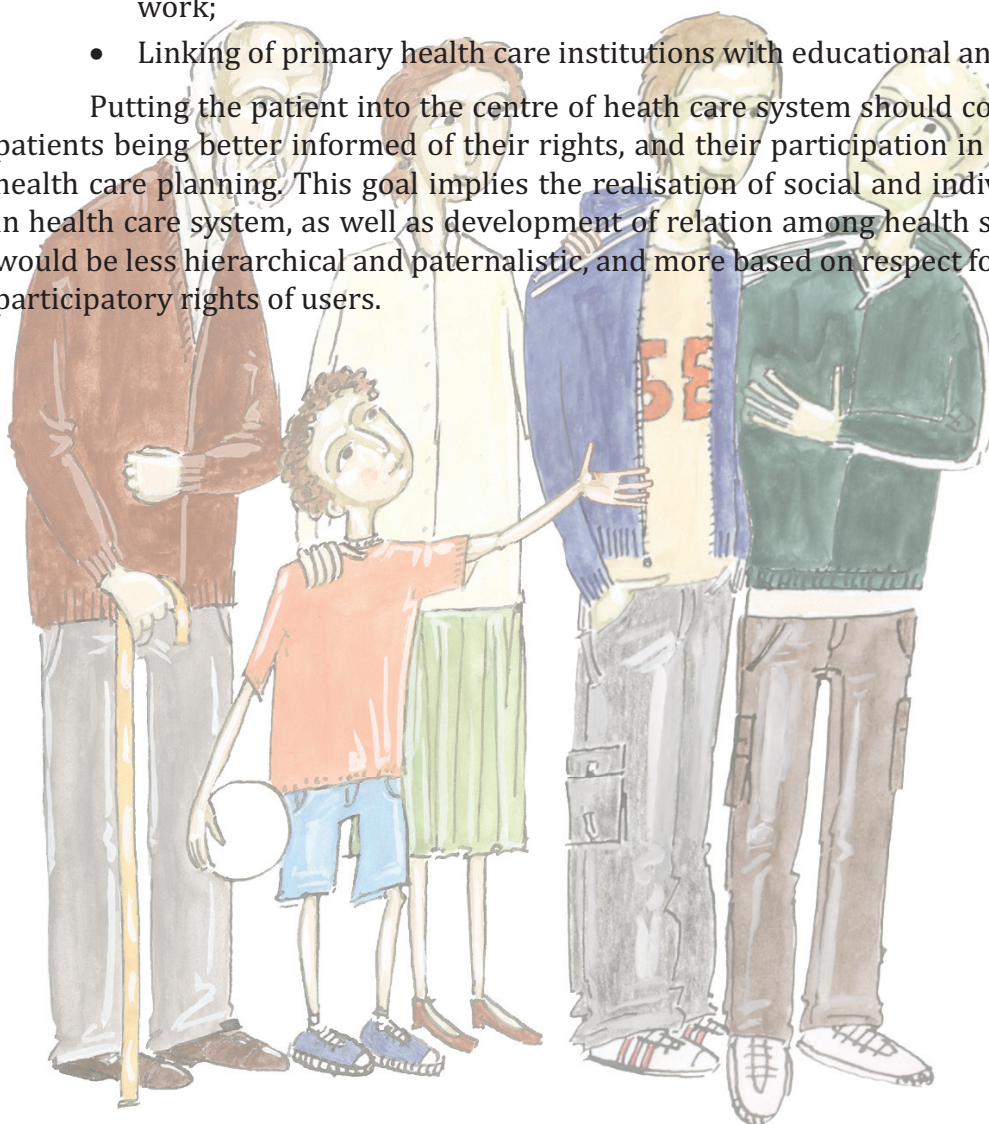
Inequality in health is usually manifested in the sense that the territories, groups and individuals whose health needs are biggest do not get health care, or they get it in shape and content that do not satisfy their needs. It is indispensable that mechanisms of equality, righteousness, and solidarity are applied in order to decrease differences in health condition and health care among:

- Urban and rural territories;
- Different social and economic, educational and other strata of population;
- Groups in underprivileged position and with special needs and other part of population.

Specially vulnerable population groups are numerous, but they differ by the cause of their position, such as poverty, insufficient education, unemployment, refugee status, old age, suffering from a system illness, belonging to marginalised, discriminated and socially isolated groups, and especially belonging to the group of people with disabilities. Health system has a significant role in preservation and improvement of health, as well as in prevention of illnesses within these groups, and this role should be realised through strong partnership with other community sectors, especially social ones. The most significant actions in this field are:

- Recognition of special health needs of these groups and their mutual connection with social needs, as well as adoption of program for simultaneous action on all community levels;
- Linking of institutions of primary health care – health centres, with social care institutions – centres for social work, as well as development of multidisciplinary teamwork;
- Linking of primary health care institutions with educational and other institutions.

Putting the patient into the centre of health care system should contribute to citizens – patients being better informed of their rights, and their participation in decision making and health care planning. This goal implies the realisation of social and individual rights of users in health care system, as well as development of relation among health staff and users, which would be less hierarchical and paternalistic, and more based on respect for the personality and participatory rights of users.



RECOMMENDATIONS FOR EMPOWERMENT OF HEALTH CARE SYSTEM IN SERBIA IN THE SENSE OF ACCOMPLISHMENT OF COMPREHENSIVE PALLIATIVE CARE

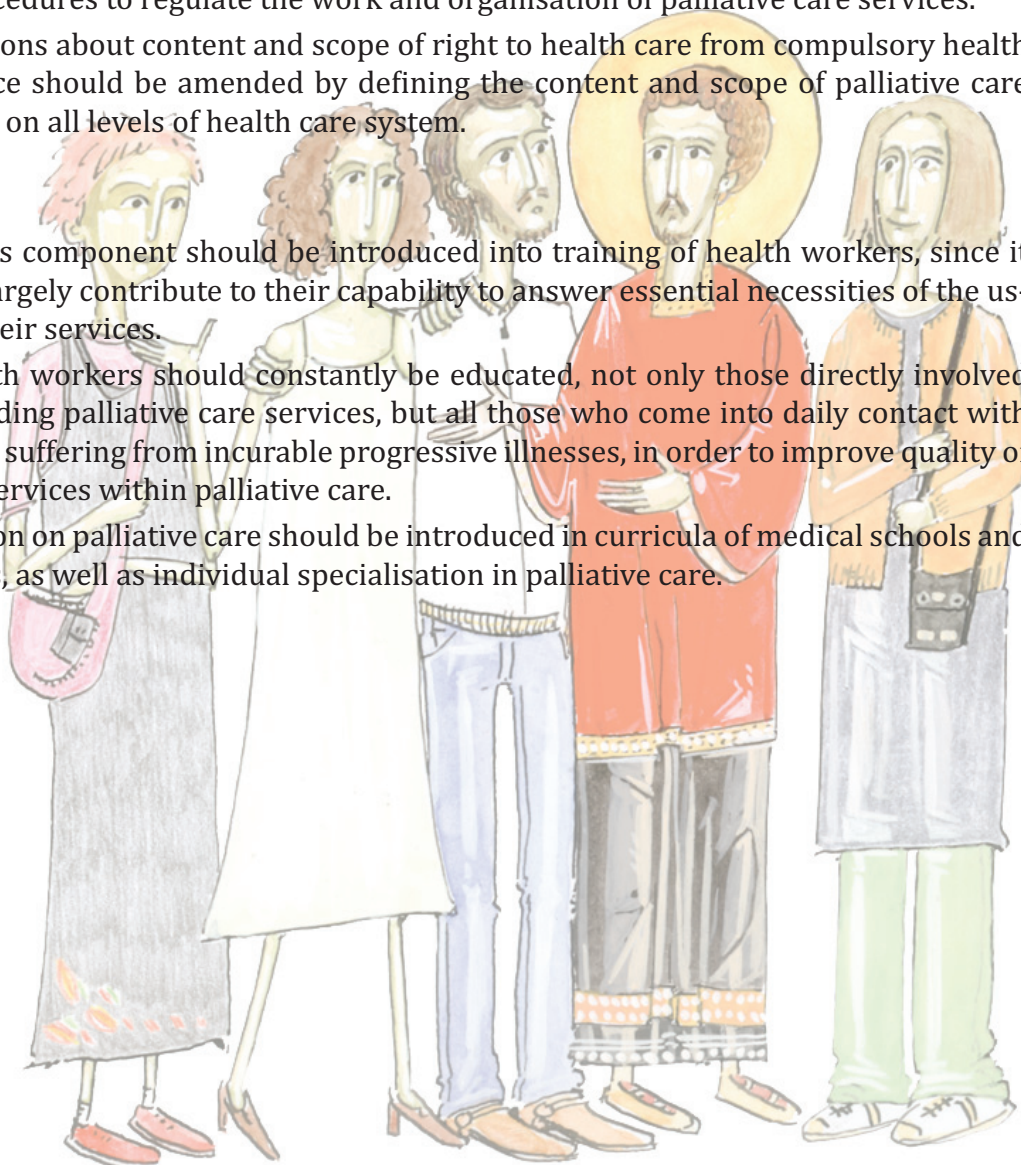
For the implementation of the Strategy for Palliative Care, apart from its observed shortcomings, it is necessary to create preconditions that were envisaged by the Action plan for its implementation that refer to:

1. Legislation

- Serbia ought to urgently ratify European Convention on Human Rights and Biomedicine, which it had signed. This document is one of the most significant for endorsement of patients' human rights, including rights of the terminally ill.
- Regulations about the requirements for performing health services in health institutions and other forms of health services should be amended by introducing systematic procedures to regulate the work and organisation of palliative care services.
- Regulations about content and scope of right to health care from compulsory health insurance should be amended by defining the content and scope of palliative care services on all levels of health care system.

2. Education

- Religious component should be introduced into training of health workers, since it would largely contribute to their capability to answer essential necessities of the users of their services.
- All health workers should constantly be educated, not only those directly involved in providing palliative care services, but all those who come into daily contact with patients suffering from incurable progressive illnesses, in order to improve quality of health services within palliative care.
- Education on palliative care should be introduced in curricula of medical schools and faculties, as well as individual specialisation in palliative care.



RECOMMENDATIONS FOR EMPOWERMENT OF THE ROLE OF CAREGIVERS OF TERMINALLY ILL PEOPLE

Apart from aforementioned measures, necessary for further development of comprehensive palliative care, development, support and empowerment of human resources, i.e. formal and informal caregivers that represent the foundation for this type of care also contribute to empowerment of health system as carrier of palliative care.

Therefore caregivers, as important co-workers and members of palliative care teams, should receive, apart from timely information on course of illness and prognosis, way to treat symptoms, plan and techniques for care, services that they have at their disposal, further support and education, etc, in order to as easily as possible overcome challenges they are facing during caring for seriously ill and dying members of their families. Special attention must be paid to parents of ill children. Apart from psycho-social support, development of capacities for short-term accommodation of patients can surely significantly contribute to family's reprieve and rest, before continuing with caring. Support to caregivers – members of families – given by the health system and good cooperation with them enable better quality of palliative care services and contribute to better quality of patients' lives. At the same time the health system will be empowered in providing comprehensive palliative care by relying on family members with whom it has good cooperation, built on foundations of trust, good communication and exchanging information necessary for holistic care for the ill and dying, especially those who are cared for at their homes.

Volunteers must be singled out among informal caregivers, as they play a significant role in supporting patients, their families and the health system. Currently, inflexible and hermetic health care system in Serbia has not yet recognised the importance and benefits that volunteers may have in a wholesome, holistic approach to patients and their families. Strengthening the capacities of volunteers and their role in palliative care will contribute to empowerment of health system and better quality of palliative care services. Well educated and organised volunteers can take over numerous roles in caring for and giving psychosocial assistance to patients, be of tremendous help to families and act as extremely important assistants and reliance to the health system. This can be of utmost importance in rural areas, as the Strategy did not foresee formation of palliative care teams in municipalities with less than 25,000 inhabitants, thus seriously threatening the rights of terminally ill people to whom palliative care services have been made inaccessible in this way.

Health workers involved in palliative care have also been exposed to increased risk and numerous psychological and emotional problems, which endanger their psychical and physical health. Therefore, it is necessary to work on promotion of caregivers' health and education on methods of stress management and psychosocial support, in order to overcome the possibility of creation of "burn-out syndrome".

When we talk of empowerment of health system in connection with the necessity of comprehensive palliative care, although the Strategy did not foresee formation of hospices, we cannot deny the importance they could have in improvement of quality of lives of patients and their families, as well as their influence on a holistic approach in caring for the seriously ill, and thus on the quality of whole health care for such patients. Numerous services that can be provided for the ill and dying and their families (from psychosocial support, day-care centres,

in-home visits, short-term accommodation for treatment of symptoms or support to family, to support to family in period of bereavement, which is particularly significant for parents of ill children), through and integrated and comprehensive approach, from diagnosis of a difficult progressive illness, until the death outcome, and later in period of bereavement, can significantly contribute to quality of life and dignity of the terminally ill.



5.

CONCEPT OF HUMAN RIGHTS OF TERMINALLY ILL PEOPLE

INTRODUCTION

Rights related to health are an important segment of human rights, defined by international legal acts and legislation in Serbia, and they are also founded in Christian doctrine, Christian anthropology and Church tradition. The most critical moments in an incurable disease are the revelation of the first symptoms, diagnosis, beginning and ending of therapy, sometimes temporary recovery and re-socialisation as well, and in the end – death as the outcome. The patient's family is involved in his/her physical and psychical suffering, faced with psychical, emotional, spiritual, social and other problems.

Palliative care is a treatment which improves overall quality of life in the highest possible degree to patients facing an active, progressive, advanced illness with a limited prognosis, together with their families. Basis of palliative care is affirmation of living and dying as integral processes of life, without an intention to fasten or postpone death, by causing relief of pain or other symptoms, integrating physiological and spiritual aspects of caring for patients.

Palliative care offers support for leading the most active life possible until the moment of death, also by helping the family to understand and endure suffering. Palliative approach should be started as early as possible, before the terminal phase of illness, with adequate forecasting, prevention and treatment of suffering. Such an approach encourages patients' autonomy, information accessibility and the right to a choice, in accordance with fundamental principles of bioethics.

Holistic approach to such patients enables treatment of physical symptoms of an illness, but also care of the whole being of the patients and their families, through provision of spiritual, emotional, psychological and social support. In the core of attention should not be only the illness, but the whole personality, with all his/her problems and needs, who decides upon things linked to him/her, within limits imposed by the illness and basic ethical and professional norms. True compassion with the patient and his/her family has to be connected with highest achievements in medicine and social protection standards, by early illness detection, prevention and relief of symptoms, as well as relief of all psychical, emotional, social and spiritual problems that the illness brings.

Palliative medicine, a new sub-specialist discipline, is a result of medical science development, advancement of humanist thought in contemporary society and wider re-affirmation of basic Christian postulates. It is applied when all classical treatment methods have been exhausted or when the patient has extreme difficulty in coping with the symptoms. Palliative care is now accepted in 120 countries, and in developed countries there are interdisciplinary services for home treatment of the dying, as well as specialized institutions – hospices, where trained doctors, nurses, spiritual leaders, social workers, psychologists and volunteers work, being a part of the health insurance system. Cultural factors also contribute to formation of hospices, thus in some cultures they are still considered to be just "places to die in".

Palliative care relies on the patient's family on the primary level of health care. Home care is a good alternative to care in institutional accommodation, as most people want to be treated and die in their own home, with the best possible quality of life. Basic condition for

this is existence of family or permanent caregiver, as well as the network of constantly available services for assistance and support. Around three quarters of caregivers (mostly women) are themselves ill from chronic diseases. Therefore, it is essential to create preconditions and develop strategies for helping caregivers: information about help and support attainable within the community; education and informing about personal care, course of illness and symptoms; availability of certain services and offices (e.g. day- and respite centres); provision of social network and support to family in the period of bereavement. Teams pay specific attention to terminally ill children, whose individual emotional, spiritual, social and educational needs are often neglected.

Regardless of the model accepted, the core objective is provision of continuity of holistic palliative care, provision of support when and where it is necessary, in accordance with the wishes of the patient and his/her family. Good coordination and links between all levels of health and social care and other actors in palliative care are indispensable.



VIEWS OF THE CHURCH

Rights in the sphere of health, as integral part of human rights, had been set as fundamental ideals in traditions of Christian peoples much earlier than they had come to be thought in the secular world. Unfortunately, human selfishness and negligence for others, with numerous excuses but also without them, destroyed and violated these rights then as they are doing it now.

There are a few basic points in understanding this aspect of human rights in Christianity. The most important of them is the common origin of the whole mankind, set by the creation and strengthened in a new way by the incarnation of the Son of God. They encourage solidarity among people and indicate the deepest inner connection of mankind. Therefore any discrimination on the level of basic human rights is against God's will, and is an act with not only historical, but also eschatological consequences. This is also obvious from Christ's words, with which he explained the importance of human solidarity, to his disciples, and thus to us as well: "Truly I tell you, whatever you did for one of the least of these my brethren, you did for me!"

Christianity is not content with the cold social and legal conclusions of the existing human rights. It calls upon the inner feeling of them, the revelation of their content, which lies not in legal principles but in the human heart. All people are, as St. John the Theologian taught, obliged to love each other. And to love others, as apostle Paul showed, means *to serve each other out of love* thus fulfilling the commandment of Christ who said: *It is my commandment that you love each other.*

Lord Jesus Christ healed every illness and every disability. He then transferred this *authority and power* but also *obligation to heal* onto his disciples, that is, onto the Church – to heal every illness and every disability, and that is what they have done, starting with the apostles Peter and Paul. The following fact is of crucial importance: both Christ and the Church healed *all those who were in need* without any discrimination. That is weaved into the very foundations of the Christian attitude towards healing and the right to be healed. One must know that Christianity has brought a new understanding of an illness. The body (that is, the *whole being*) is the temple of Lord, and health is the Lord's gift. Therefore, in a way health becomes *a social welfare entrusted to everyone* and everyone should participate in its maintenance and have to right to it.

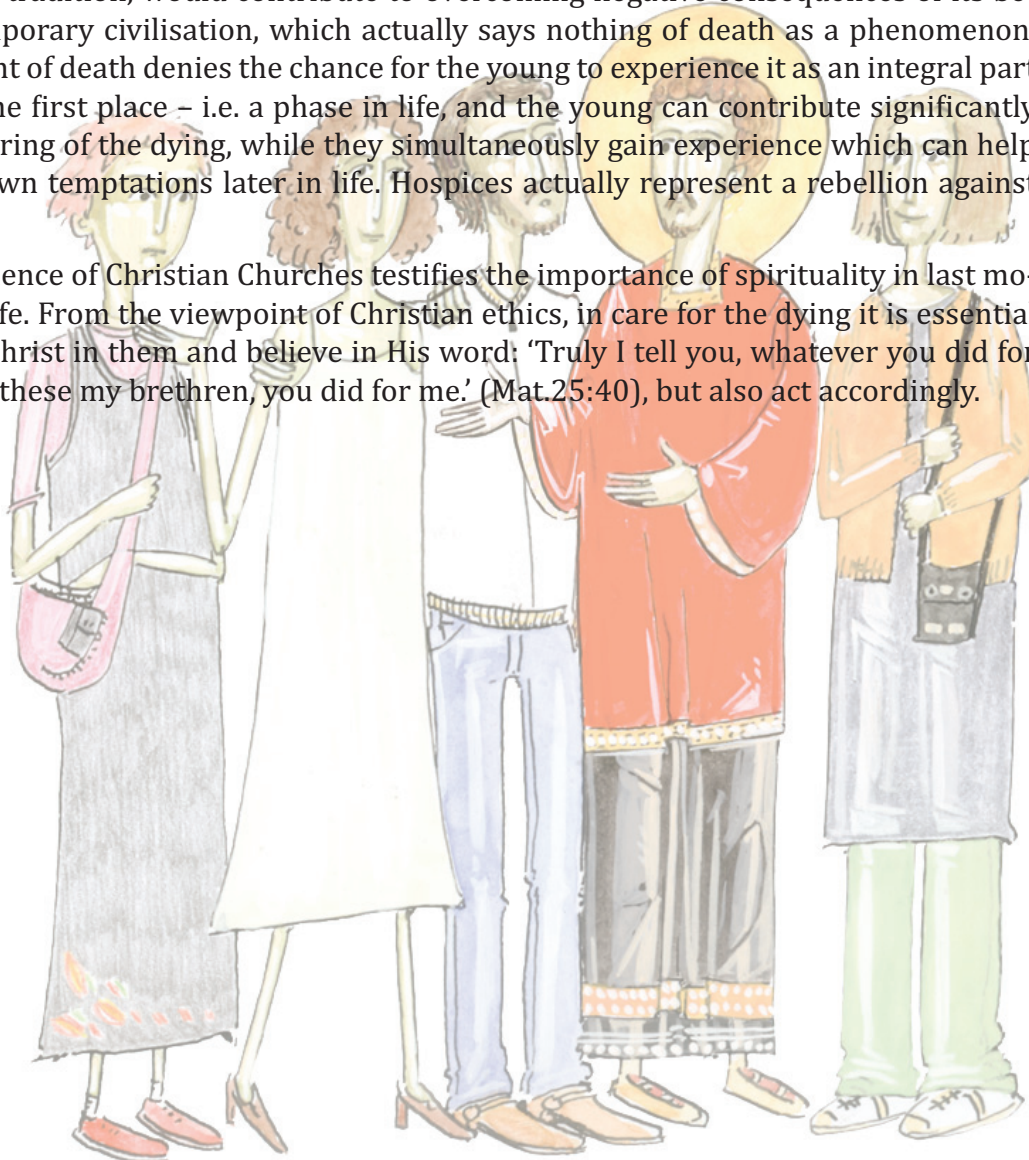
One should know that in the experience of traditional Christian churches spiritual support given to patients implies several fundamental things that should always be kept in mind in order to wholly and properly develop the special and unique role they have in this important process: Churches, different to secular palliative institutions, do not regard the patient's death as a final and terminal state of his/her existence, but more as a transition to a new and different form of existence. Therefore, the consolation they offer to dying patients is far different from what agnostic/atheist institution and individuals pertaining to those beliefs propose; Churches offer patients not only faith in future life, but also ways to feel and experience it here and now, everywhere, even in their sickbed – through the Sacrament life; Churches not only put the patient into a family and wider social context by which they prepare him/her for death, they offer patient the healing of those relations that should alleviate death/transition through repentance, reconciliation, mutual forgiveness and renewal of previously torn love connections; Churches, with respect for secular techniques of psychological help and the patient's pain relief by medicaments, still leave space for importance of pain, that is not to be removed at any cost (if the patient can and wants to do that) because they know for the therapeutic and purifying effect

of pain in the process of ending the maturing of a human personality, that does not cease but culminates on the deathbed; in the end, Churches introduce heavenly physicians and protectors, healers and helpers, to whom they pray and ask for their intermediary help in the crucial moments of a person's life, into the group of zealous palliative workers, next to medical experts of various profiles, social services and spiritual directors.

In all phases that dying patients pass, next to them they need persons capable of letting them know that death is imminent and help them accept reality. Hospices, centres intended for caring for the terminally ill, whose advantages have been acknowledged in the most developed communities, represent one of the ways to care for these people. Activities of these centres are deeply rooted in Serbian tradition, as such institutions existed and were founded by Serbian rulers not only on Serbian territory (Studena, one of the first Serbian monasteries, endowment of Stefan Nemanja) but also abroad, e.g. in Constantinople, the capital of Byzantine. It is important to note that these hospices were open to all terminally ill people ("foreigners" and "travellers"), regardless of their religion or ethnicity.

Renewal of these institutions in Serbia, where the dying would be cared for in accordance with Serbian tradition, would contribute to overcoming negative consequences of its belonging to contemporary civilisation, which actually says nothing of death as a phenomenon. This tacit treatment of death denies the chance for the young to experience it as an integral part of human life in the first place – i.e. a phase in life, and the young can contribute significantly in easing the suffering of the dying, while they simultaneously gain experience which can help them with their own temptations later in life. Hospices actually represent a rebellion against denial of death.

Rich experience of Christian Churches testifies the importance of spirituality in last moments of human life. From the viewpoint of Christian ethics, in care for the dying it is essential to see an icon of Christ in them and believe in His word: 'Truly I tell you, whatever you did for one of the least of these my brethren, you did for me.' (Mat.25:40), but also act accordingly.



RELEVANT NATIONAL AND INTERNATIONAL REGULATIONS

The most important international documents and regulations that define human rights in the sphere of health are: UN Universal Declaration of Human Rights (Art.25), The International Covenant on Economic, Social and Cultural Rights of the United Nations (Art.12), Revised European Social Charter (Art.11) and the Preamble of the Constitution of the World Health Organisation. According to these documents, among key aspects of right to health protection are rights to: health education and information, gender equality, equal possibilities for all to benefit from the highest possible level of health protection, prevention, treatment and illness control, essential medicines' availability, equal availability of health services, as well as participation in making decisions related to health.

Practice and relevant EU and Council of Europe documents (Recommendation no. 1418 of Committee of Ministers of the Council of Europe – Protection of the human rights and dignity of the terminally ill and the dying, Recommendation of the Council of Europe no. 89/13 on the organisation of multidisciplinary care for cancer patients, the Poznan declaration on palliative care in the countries of Eastern Europe) define the fundamental rights of the terminally ill, on the basis of which strategic documents are devised and support systems created: the right to a dignified treatment up to the moment of death; the right to truthful and timely information of one's health condition; the right to suitable psycho-social and spiritual support; the right to participation in making decisions related to one's treatment and destiny; the right to make decisions before surgical interventions; the right to pain relief; the right to visits by relatives; the right to express one's feelings freely; the right to a dignified death; the right not to die alone; the right to adequate protection.

The Committee of Ministers of the Council of Europe recommended to the Member States' governments to adopt attitudes, legal and other measures necessary to determine comprehensive and coherent national policy frameworks related to palliative care; to pass full measures of illness-symptoms' control, patients' support, family support and all other adequate measures, wherever that is possible; to promote international cooperation of the governmental and non-governmental sectors; to promote human rights of the terminally ill.

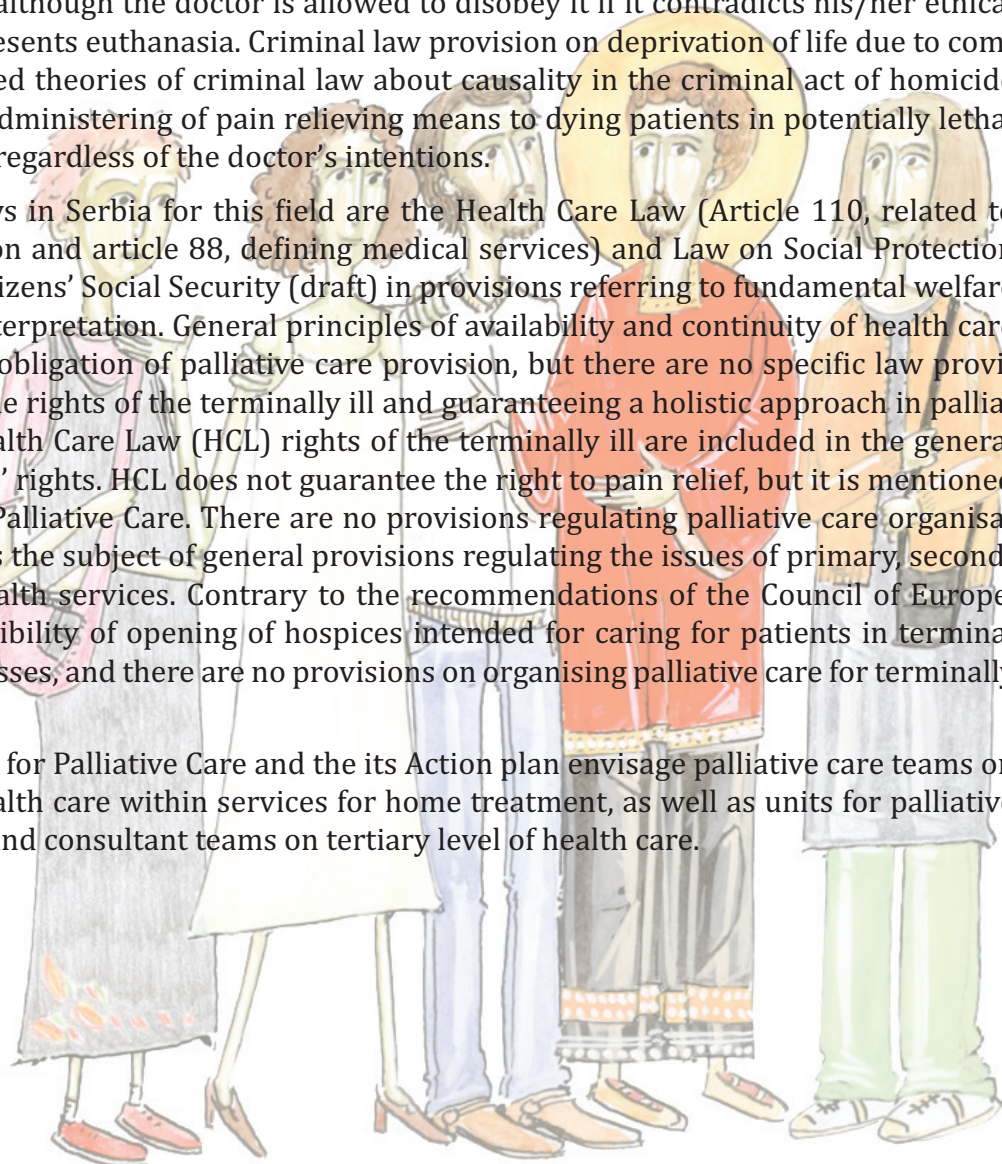
European Parliament Study on palliative care in Europe recommends Member States to develop national plans for palliative care, promote integrated health care that includes adequate palliative care, as well as to devise plans for training of medical staff and people working in social protection system in order to provide them with knowledge and skills necessary for successful palliative care.

A number of documents passed in Serbia (Strategy for Palliative care, Poverty Reduction Strategy, Social Protection Development Strategy, New Health-Care Policy Strategy, Public Health strategy, Strategy for Constant Health Care Quality and Patients' Safety Improvement, National Strategy on Ageing, National HIV/AIDS Strategy, Serbian National Program Against Cancer, National Strategy for Accession of Serbia to the EU, National Plan for Integration of Serbia into the EU, etc.) envision the development of palliative care policy, harmonised with contemporary European practice. This implies: adjustment of health care and social welfare system, to encompass risky groups and thus the terminally ill; decentralisation of these systems; reaffirmation of the role of local community; development of new services and improvement of the scope and quality of existing ones.

Relationship of doctors and terminally ill patients is defined by the Ethical codex in Serbia, according to which dying and death of a patient are parts of medical treatment, and a doctor is obliged to ensure a patient in the final stadium of illness dignified conditions to die in, since continuation of intensive treatment in this state would exclude the right of the dying patient to dignified death (Article 61, paragraph 2.) Apart from the right of a dying to assistance, care, information on health condition and undertaken measures, to presence of the family and other close people in last moments, as to all kinds of moral and spiritual help, the concept of dignified death implies the doctor's obligation to undertake all measures necessary for reasonable treatment and relief in suffering, and to take into consideration the last wish of the informed conscious patient, related to the continuation of treatment. As to patients incapable of reasoning, the final wish related to continuation or cessation of treatment is brought by the doctor, who can take into consideration a wish of the patient that was previously expressed. The doctor is forbidden to fulfil the patient's wish if it leads to active euthanasia. The ethical codex clearly states that intentional shortening of life is contradictory to medical ethics, and there are various viewpoints in the scientific circles on usage of medicaments with the intention of easing pain in doses anticipated to be potentially lethal. The ethical codex request respect of the dying patient's last wish, although the doctor is allowed to disobey it if it contradicts his/her ethical principles and represents euthanasia. Criminal law provision on deprivation of life due to compassion and accepted theories of criminal law about causality in the criminal act of homicide clearly states that administering of pain relieving means to dying patients in potentially lethal doses is forbidden, regardless of the doctor's intentions.

Relevant laws in Serbia for this field are the Health Care Law (Article 110, related to hospital organisation and article 88, defining medical services) and Law on Social Protection and Provision of Citizens' Social Security (draft) in provisions referring to fundamental welfare rights – in wider interpretation. General principles of availability and continuity of health care are also applied to obligation of palliative care provision, but there are no specific law provisions referring to the rights of the terminally ill and guaranteeing a holistic approach in palliative care. In the Health Care Law (HCL) rights of the terminally ill are included in the general category of patients' rights. HCL does not guarantee the right to pain relief, but it is mentioned in the Strategy for Palliative Care. There are no provisions regulating palliative care organisation as well, but it is the subject of general provisions regulating the issues of primary, secondary and tertiary health services. Contrary to the recommendations of the Council of Europe, HCL leaves no possibility of opening of hospices intended for caring for patients in terminal phases of their illnesses, and there are no provisions on organising palliative care for terminally ill children.

The Strategy for Palliative Care and the its Action plan envisage palliative care teams on primary level of health care within services for home treatment, as well as units for palliative care on secondary and consultant teams on tertiary level of health care.



THE MOST IMPORTANT CHALLENGES

Health system of Serbia functions in difficult conditions, endangered by problems left from the past and poor material situation. Multidimensional transition processes makes the empowerment of the health care system complex, hence the system failed to fulfil the population's needs in the past decade. Once a huge and expensive system of health care, which was free and relatively available to the population, it became unsustainable in conditions of scarce resources. Health service is quite badly organised, with poor coordination among its levels and underdevelopment of certain segments (e.g. home treatment and care, palliative care). Legislation has been inadequate and the health system was financed centrally and directed towards capacities, only later to become redirected to financing of services. In difficult social circumstances moral values declined as well, and the lack of humanity left the most vulnerable population groups uncared for. Health care staff decreased during transition, which overburdened certain segments of the system. Due to exposure to higher risk for illness occurrence, morbidity and mortality rates increased.

The most important problems in health care system are unavailability and inequality in using health care services (long waiting for scheduling checkups, medical checkups, admission into hospitals, diagnostic procedures, difficult realisation of home treatment and care, impossibility for palliative care, inaccessibility of numerous medicines and opioid analgesics; also in hospital treatment of geriatric patients. All these problems are more pronounced in rural areas, due to underdeveloped infrastructure and lack of health care staff and technical support, and elderly, people with disabilities and the terminally ill were at the highest risk), bad quality of health services provided, realisation of right to urgent medical aid, especially of elderly, discrimination – mostly related to age or stadium of illness (especially in case of need for emergency interventions and/or admission for hospital treatment) and problems with patients families.

Causes for the situation described are numerous and complex. Health care services are inappropriately organised, with little coordination between various levels and underdevelopment of certain segments (e.g. home treatment and care, palliative care, and caring for the dying). Part of the laws in force is outdated and not harmonised with existing conditions. Material means are insufficient, and infrastructure is underdeveloped in rural areas, with a lack of medical staff and technical support. Provision of medicaments is inadequate, and the list of medicaments attainable on prescription through the Health Insurance Fund is restrictive, so the citizens have to buy them (for example, oral morphine for pain coping). Corruption is also present among medical staff. The health care system entered into transition impoverished, with inadequate, outdated and defective medical equipment, shortage of sanitary materials and bad infrastructure – outdated and non-maintained facilities and vehicle fleet. Health care professionals are insufficiently motivated due to poor work conditions, overburdening and low income, but also insufficiently educated and organised, which influences their professional ethics negatively. Therefore stigmatisation and discrimination of certain population groups in wider social community influences the occurrence of these even among healthcare workers. Mostly discriminated groups are the elderly, persons with disabilities, terminally ill and dying patients. Family, as the most common informal caregiver of the terminally ill, is mostly left to its own devices, physically and psychically exhausted, often with diminished financial resources, without education on caring for the most difficult patients or information on support options within the community.

The concepts of palliative care and caring for the terminally ill and awareness on the attention they deserve are relatively new in Serbia. The Strategy for Palliative Care envisages

palliative care and caring for the terminally ill within: (1) primary health care institutions – health centres, with palliative care teams and home treatment services, as well as the Institute for Gerontology in Belgrade, which provides home treatment and palliative care for the elderly; (2) secondary health care institutions – hospitals, which may have palliative care wards; (3) tertiary health care institutions – e.g. some institutes within clinical centres (Clinical Centre Serbia – Belgrade, Clinical Centre Nis, Clinical Centre Kragujevac, Clinical Centre Vojvodina – Novi Sad) where formation of consultant teams is foreseen, as well as within the Centre for Palliative Care Development at the Institute for Oncology and Radiology of Serbia.

However, regardless of the recommendations of the Council of Europe, documents in force do not envisage formation of hospices with teams for palliative care, although they are worldwide organised by church, nongovernmental and governmental organisations, and financed by donations. The fact is that caring for such patients is often not possible at home, which from a number of reasons, becomes a big problem for the dying patient and his/her family and care providers, but for health professionals as well.

Additional problem is the transition of health care onto the “capitation” model and financing according provided services, which disables health professionals to stay longer than the normative with a patient in the terminal phase, in order to consider all problems, apart from physical and mental ones, that the patient and his/her family are facing.

Insufficient education of health professionals in the field of palliative care and caring for the terminally ill and dying patients leads to discrimination of these patients’ needs. Bad communication on the relation patient/doctor/family causes insufficient awareness of the patients and their families of the inevitable course of illness, possibilities for treatment of various illness symptoms, as well as of possibilities for support and help which are partially available in urban areas.

In circumstances existing in Serbia, hospital type of palliative care is possible, after adequate training in primary, secondary and tertiary health institutions, where number of beds could be ensured for palliative care. In such a system the key issue is training in primary health institutions, which would be carriers of ambulance palliative care. The outset in analysis of palliative care concept in Serbia is its availability. Availability of palliative care is reflected in organisation, availability of suitable medicaments and existence of trained teams for palliative care.

Implementation of strategic documents is followed by numerous problems and shortcomings. Formation of palliative care units has not started yet, nor formation of consultant teams on the secondary and tertiary health care levels. Education in the field of palliative care for a small number of doctors and nurses in primary health care was started. No teams for palliative care were formed on the primary health care level, in spite of the fact that services for home treatment in health centres, which mostly care for the chronically ill elderly, are not, nor can be teams for palliative care. There are no teams for palliative care for children.

There is insufficient coordination of participants in palliative care (the Church, health care and social welfare protection systems, nongovernmental sector and other actors). Patients and their families do not have enough information about the course of the illness, possibilities for choice and care within the community. There are no teams for supporting families during the illness and in period of bereavement. The Strategy has not foreseen formation of hospices as a holistic approach in caring for the terminally ill and their families. Discrimination and stigmatisation of the terminally ill, especially elderly and PLHIV, still exist. In some hospitals, due to presence of antichristian ideology and organisational and logistical obstacles, patients are not given spiritual support, despite normative acts that allow it, thus violating one of their fundamental human rights.

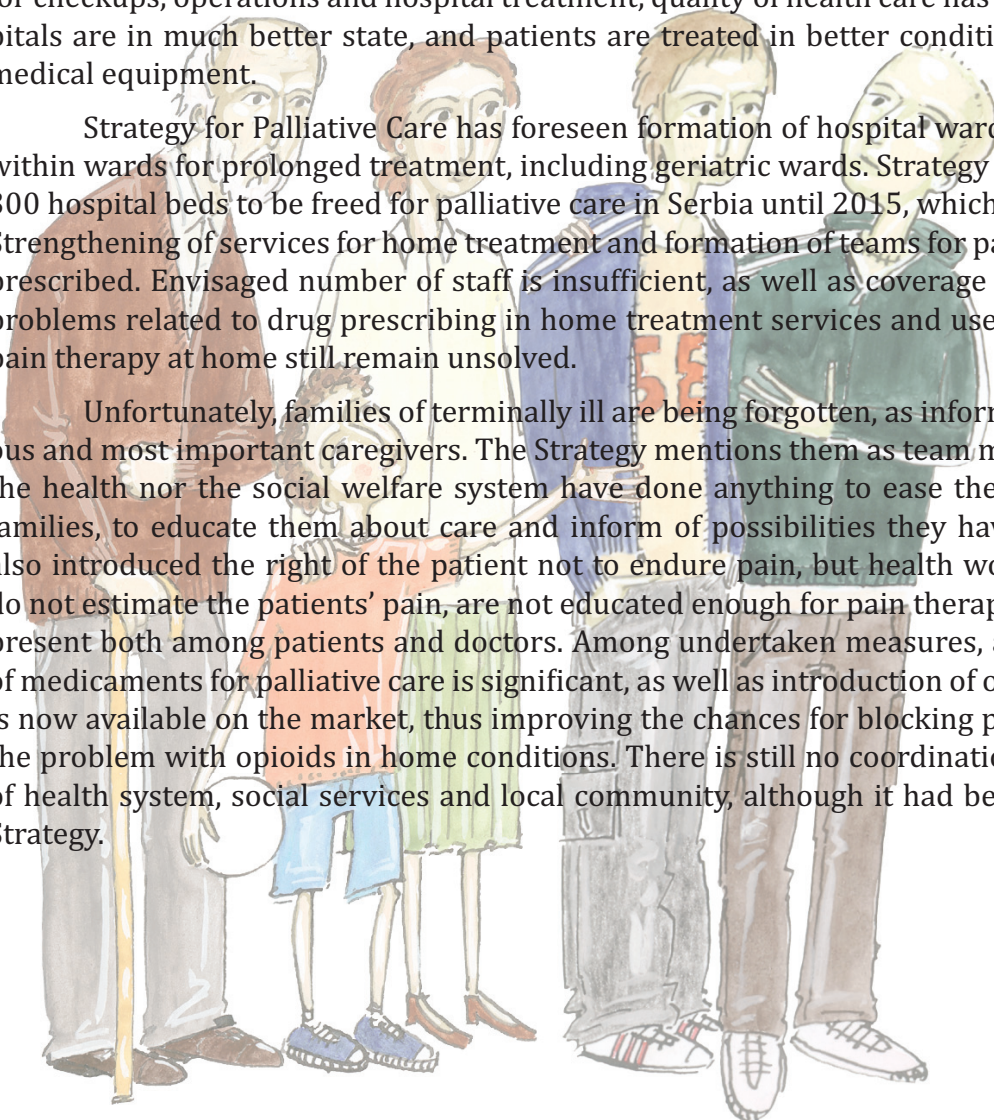
HITHERTO ATTEMPTS TO RESPOND TO CHALLENGES

The Ministry of Health defined empowerment of health care system through improvement of health care quality as one of health policy objectives. The Strategy for Constant Improvement of Health Care Quality and Patients' Safety seeks to decrease the unevenness of health services quality, outcome variation level in relation to patients' health, inefficient usage of health technologies, period of waiting for medical procedures and interventions, dissatisfaction of users with health services provided, dissatisfaction of the health care system employees and expenses incurring due to low health care services' quality.

By engagement of authorities in charge and other actors these challenges have been partly eased, which is reflected in better availability of medicines on the market, adoption of the Strategy for Palliative Care and its Action plan, education of health workers and volunteers on palliative care (project DILS), and adoption of the National Strategy Against HIV/AIDS. Measures have been taken to procure new medical equipment, reconstruct and refurbish health institutions, develop a continual system of work quality improvement and education of health workers. Situation has been somewhat improved also by shortening of the period of waiting for checkups, operations and hospital treatment, quality of health care has been improved, hospitals are in much better state, and patients are treated in better conditions and with newer medical equipment.

Strategy for Palliative Care has foreseen formation of hospital wards for palliative care, within wards for prolonged treatment, including geriatric wards. Strategy Action plan foresees 300 hospital beds to be freed for palliative care in Serbia until 2015, which is not close enough. Strengthening of services for home treatment and formation of teams for palliative care are also prescribed. Envisaged number of staff is insufficient, as well as coverage of rural areas. Many problems related to drug prescribing in home treatment services and use of medicaments for pain therapy at home still remain unsolved.

Unfortunately, families of terminally ill are being forgotten, as informal but most numerous and most important caregivers. The Strategy mentions them as team members, but neither the health nor the social welfare system have done anything to ease the problems for these families, to educate them about care and inform of possibilities they have. The Strategy has also introduced the right of the patient not to endure pain, but health workers in most cases do not estimate the patients' pain, are not educated enough for pain therapy, and opiophobia is present both among patients and doctors. Among undertaken measures, amplification of lists of medicaments for palliative care is significant, as well as introduction of oral morphine, which is now available on the market, thus improving the chances for blocking pain, but there is still the problem with opioids in home conditions. There is still no coordination of different levels of health system, social services and local community, although it had been envisaged by the Strategy.



RECOMMENDATIONS

The Ministry of Health, health care institutions, health workers themselves and local authorities should contribute to better organisation of health institutions.

Ministries of Health, Education and Sciences, Agency for medicines, local authorities, health care institutions and health workers should improve palliative care through better organisation, technical and human resources of palliative care teams within services for home treatment, better regulations in the field of opioid analgesia, and support to families in caring for the terminally ill through formation of day – and respite – centres intended for accommodation of patients for up to ten days, even through introduction of hospices, although this demands substantial material investments.

Ministry of Health, local authorities, health institutions and health workers themselves should undertake all available measures to improve quality of health services and respect of ethical values.

In order to secure respect and fulfilment of fundamental human rights of the terminally ill and ease their suffering to the highest possible extent, spiritual guidance in their most difficult moments must be effectively allowed not only by normative acts, but also with organisational and other measures.

Legal and strategic acts regulating the issues of human rights of terminally ill in Serbia must be harmonised to the highest possible extent with corresponding international regulations, i.e. those of the Council of Europe in the first place.

Integration and good coordination of health care and social protection is indispensable and necessary, together with networking of all actors in comprehensive palliative care and caring for patients in terminal phases of their illnesses, with the objective of creating preconditions for a holistic approach in caring for the most difficult patients.

Information must be more available to patients and their families, services for home treatment must be better professionally and technically equipped, especially in rural areas, together with better coordination between all segments of community that participate in caring for the terminally ill, primarily health care, social protection and volunteers.

Segregation and discrimination of terminally ill in using health care services and capacities must be prevented, especially with terminally ill patients from rural areas.

Expression and respect of the patients' will must be secured, when choosing the possibilities for further treatment in accordance with the Code of Professional Doctors' Ethics.

Special attention should be paid to caregivers of terminally ill (members of nuclear or wider family, neighbours, and friends), having in mind they are the most common support that health professionals have. One should bear in mind that respect for patient's dignity and rights makes the foundation of the relation patient – doctor – caregiver, which is especially stressed with terminally ill people and people at the end of their lives.

Doctors should recognise the importance of caregivers, who are the source of data about the personality and medical history of the patient, for it eases the treatment of changes during the illness transition towards the imminent ending and all physical and emotional changes with the patients and his/her family.

Doctors should be available to caregivers and spiritual guides and their good communication should be enabled together with timely information exchange, as well as an open discussion among doctors, patients, caregivers and priests about possibilities of treatment, coping symptoms in terminal phase of illness and support.

Support of media should be provided in comprehensive palliative care development in order to create wide social sensitiveness and participation of various actors in provision of a holistic approach.

It is essential to determine standards and change types of financing services which are provided for the patients and their families within the health system.

In order to ensure availability of opioids necessary for palliative care, it is essential to clearly state, on normative level, the scope and content of palliative care from borderline treatments like active euthanasia, i.e. use of medicaments with the intention of easing pain, but in potentially lethal doses.

On primary level of health care it is necessary to:

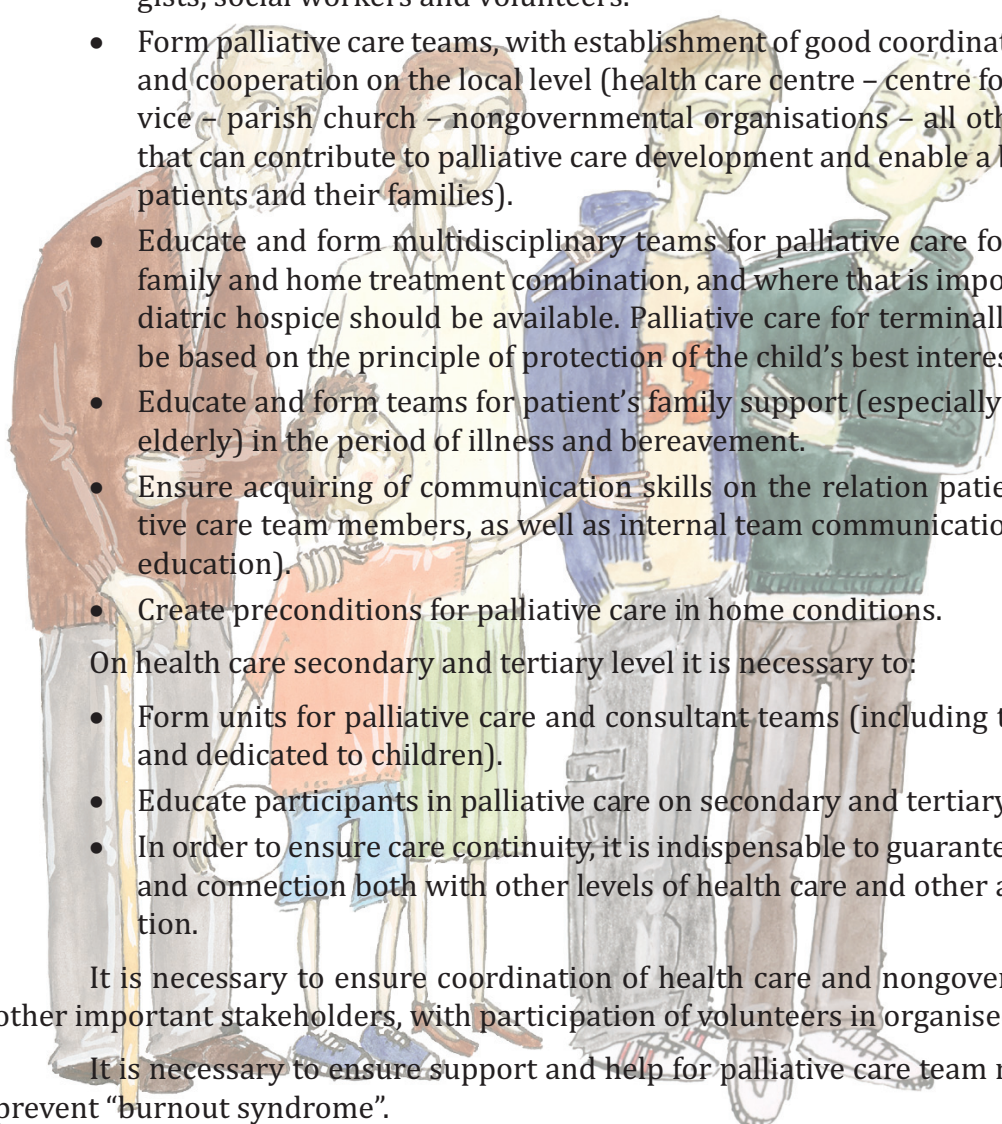
- Ensure education in the field of palliative care for doctors, priests, nurses, psychologists, social workers and volunteers.
- Form palliative care teams, with establishment of good coordination, communication and cooperation on the local level (health care centre – centre for social security service – parish church – nongovernmental organisations – all other necessary actors that can contribute to palliative care development and enable a better life quality for patients and their families).
- Educate and form multidisciplinary teams for palliative care for children, based on family and home treatment combination, and where that is impossible, a special paediatric hospice should be available. Palliative care for terminally ill children should be based on the principle of protection of the child's best interests.
- Educate and form teams for patient's family support (especially for children and the elderly) in the period of illness and bereavement.
- Ensure acquiring of communication skills on the relation patient – family – palliative care team members, as well as internal team communication (through constant education).
- Create preconditions for palliative care in home conditions.

On health care secondary and tertiary level it is necessary to:

- Form units for palliative care and consultant teams (including those specialised for and dedicated to children).
- Educate participants in palliative care on secondary and tertiary health care level.
- In order to ensure care continuity, it is indispensable to guarantee good coordination and connection both with other levels of health care and other actors in this protection.

It is necessary to ensure coordination of health care and nongovernmental sector and other important stakeholders, with participation of volunteers in organised palliative care.

It is necessary to ensure support and help for palliative care team members in order to prevent "burnout syndrome".



Institutions of primary health care ought to link with educational and other institutions.

Serbia should urgently ratify European convention on human rights and biomedicine, which it had signed. This document is one of the most significant for endorsement of patients' human rights, including rights of the terminally ill.

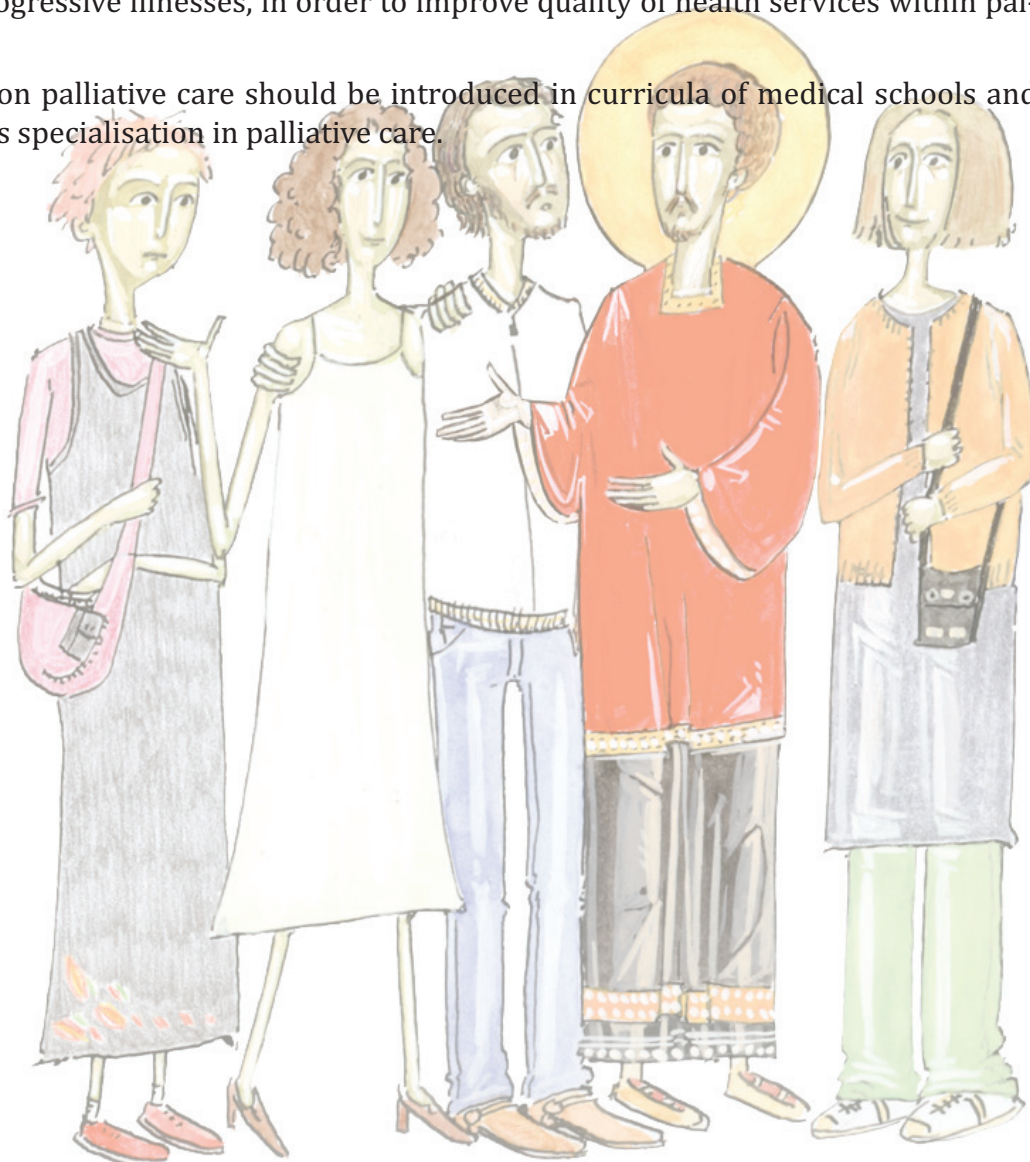
Regulations about the requirements for performing health services in health institutions and other forms of health services should be amended by introducing systematic procedures to regulate the work and organisation of palliative care services.

Regulations on content and scope of health care rights from compulsory health insurance should be amended by defining the content and scope of palliative care services on all levels of health care system.

Religious component should be introduced into trainings of health care workers, since it would largely contribute to their capability to answer patients' essential necessities.

All health workers and associates should be educated constantly, not only those directly included in palliative care, but all those who come into daily contact with patients suffering from incurable progressive illnesses, in order to improve quality of health services within palliative care.

Education on palliative care should be introduced in curricula of medical schools and faculties, as well as specialisation in palliative care.





PHILANTHROPY CHARITABLE FUND OF THE SERBIAN ORTHODOX CHURCH

4, Dr Ive Popovica Djanija street
11040 Belgrade, Serbia
Phone/fax: +38111/ 367 2970 and 367 2971
beograd@covekoljublje.org
www.covekoljublje.org

Philanthropy's Office in Kragujevac
The Orthodox Seminary "Sveti Jovan Zlatousti"
Vladimira Rolovica street
34000 Kragujevac, Serbia
Phone/fax: +381 34/ 371 176, 371 178
kragujevac@covekoljublje.org

Philanthropy's Office in Nis
5a, Janka Veselinovica street
18000 Nis, Serbia
Phone/fax: +381 18/ 512 144
nis@covekoljublje.org

Philanthropy's Office in Kraljevo
The Spiritual Center "Saint Bishop Nikolay"
3, Karadjordjeva street
36000 Kraljevo, Serbia
Phone/fax: +381 36/ 234 547
kraljevo@covekoljublje.org

Philanthropy's Office in Novi Sad
34, Maksima Gorkog street
21000 Novi Sad, Serbia
Phone/fax: +381 21/ 662 1990
novisad@covekoljublje.org

Philanthropy's Office in Belgrade
4, Dr Ive Popovica Djanija street
11040 Belgrade, Serbia
Phone/fax: +38111/ 367 2970 and 367 2971
beograd@covekoljublje.org
www.covekoljublje.org

Philanthropy's Office in Vranje
26, Ivana Milutinovica street
17000 Vranje, Serbia
Phone/fax: +381 17/ 414 919
vranje@covekoljublje.org

Philanthropy's Office in Banja Luka
8, Bana Milivojevica
78000 Banja Luka, Republic of Srpska,
Bosnia and Herzegovina
Phone/fax: +387 51/ 226 920
banjaluka@covekoljublje.org

Philanthropy's Office in Podgorica
7, Bulevar Revolucije
81 000 Podgorica, Montenegro
Phone/fax: +382 20/ 243 088
podgorica@covekoljublje.org

Philanthropy's Office in Knin
Krka Monastery, Croatia
knin@covekoljublje.org

