



## About the publication

It has not been long since the palliative care was introduced into healthcare system of our country. For a long time relevant resources were not available for persons in need of palliative care, including terminally ill patients. These resources imply medical personnel with proper qualification and forms of services to be offered to such patients.

Fortunately, likewise other countries, our country has also started development of the palliative care system and at a glance, it brought hope to “hopeless” patients – alleviation of pain and other insufferable symptoms, management of their psycho-social problems. Today this is done by professional personnel knowledgeable in palliative care. On another hand, it may seem that medical persons in any specialty should possess palliative care skills. They are required to know not only specific biomedical aspects and foster relevant skills, but also be educated in the ethical and legal issues related to this field. Present small publication aims at explaining exactly these issues.

The publication includes issues such as providing clear and comprehensive information to patient around his/her health condition and medical services, requirement for obtaining informed consent from a patient, right of the patient to refuse medical care, the role of family members and relatives in making decisions about the patient's medical care, inadmissibility of euthanasia, etc.



# Ethical and legal issues of Palliative care and Care at the end of life

Explanations and recommendations to healthcare personnel

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## Palliative care and General legal framework of patient's rights

It is assumed that today Georgia has the legislation on the rights of patients / health and human rights responding to contemporary standards. We imply the laws of Georgia on Healthcare, the Rights of Patient, Doctor's Professional Activity, The Council of Europe Convention on Human Rights and Biomedicine and its additional protocols, and other specific laws regulating different fields of healthcare – mental health, HIV/AIDS, transplantation, etc.

Clearly, the rights stipulated in these laws completely apply to the persons in need of palliative care. Besides, there are issues particularly important for patients receiving palliative care, including terminally ill patients. Georgian legislation and namely, the laws on Healthcare and the Rights of Patient<sup>2</sup> provide following definition of palliative care:

**“Active, multi-disciplinary care with the primary aim of relieving the pain and other pathologic symptoms, ensuring patient's psychosocial and spiritual support. It concerns the patients whose disease can no longer be cured; such type of care improves the quality of life of patients and their families.”**

It is also noteworthy that the first version of the law on Healthcare which was adopted in 1997, dedicates separate chapter to the issues<sup>3</sup> of medical care for terminally ill patients. The chapter emphasizes respect of dignity of a dying patient (Article, 147):

**“While treating / carrying out palliative care of terminally ill patient . . . his/her dignity shall be respected.”**

It is important that medical personnel master how to approach, how to behave in a variety, very often difficult cases, when it comes to provision of palliative care to terminally ill patients.

## Providing information – Ethical and legal dilemma

### *Telling the truth and informing the patient – general principles*

Telling the truth is one of the components of autonomy - the main principle of contemporary medical ethics. The doctor shall disclose truth to the patient about patient's health condition and proposed medical services. This norm is correspondingly envisaged in the legislation. Law of Georgia on Healthcare, article 7 stipulates:

<sup>2</sup> Amendments on Palliative Care issues to the laws on Healthcare and the Rights of Patient were made in May 8, 2007 with the effort of pioneers of palliative care in Georgia;

<sup>3</sup> Chapter XXIV “Critical Conditions, Death and Euthanasia”

**“All Citizens of Georgia enjoy the right to receive comprehensive and unbiased information in understandable form, also to seek for second opinion, about own health condition.”**

The law on the Rights of Patient describes in details what sort of information should be provided to patient (Article 18):

**1. The patient exercises the right to receive from the healthcare provider comprehensive, objective, timely and understandable information on:**

...

- c) Proposed preventive, diagnostic, therapeutic and rehabilitation procedures; potential risks and benefits of each procedure;**
- d) Results of medical examination;**
- e) Alternatives to the proposed medical procedures, their potential risks and benefits;**
- f) Possible outcome of refusal to proposed medical procedures;**
- e) Diagnosis and possible prognosis, ongoing course of treatment.**

Further, the same law pays attention to providing information to patient in an understandable language. Namely, the article 19 of the law states:

**“The information is provided to the patient or his/her relative or legal representative considering their capacity to understand. Use of specific terminology shall be minimized when explanations are given.”**

Thus, both of the laws entitle patient to obtain comprehensive information about own health. Besides, this information shall be provided to a patient in an understandable and simple language. Doctor is required to take into consideration above mentioned. This is clearly described in the law on Doctor's Professional Activity (Article 39):

**1. The healthcare personnel must provide comprehensive, true and due information in understandable to patient language:**

- a) About patient's health condition, including:**
  - a.a. intended preventive, diagnostic, therapeutic and rehabilitative interventions and its alternate versions, including accompanying risks and effect;**
  - a.b. Results of medical examinations;**
  - a.c. Possible consequences that may follow the refusal to medical intervention;**
  - a.d. Diagnosis and possible prognosis as well as the course of the treatment;**
- b) The factors promoting health maintenance or adversely affect health;**
- c) Available medical care needed for patient and opportunities for their application as well as the fee for offered medical care and the terms of payment.**

Thus, the legislation on one hand, gives right to a patient to obtain full information about own health; on another hand, it obliges a doctor to provide relevant information to patient in easy and understandable language.

It should be taken into account that it not easy to deliver information to patient about his/her health condition when it comes to an incurable disease and in doctor's opinion the illness will inevitably result in loosing patient's capacity or death. There are many recommendations on delivering unpleasant news to patient (e.g. the so called SPIKES model). Surely, such approach is not bound by law; however the professional ethics requires it. Many training programs for doctors offer a special module on skills for delivering "bad news".

Finally, the doctor should always take into consideration that the patient has a right to access own medical records. Article 17 of the law on the Rights of Patient states that the patient, also, in case of a patient's consent or incapacity, the family members or relatives, have right to access medical records and request copy of any of its parts.

### **Exception**

As mentioned above, it is difficult for a doctor to provide full information to patient about his/her health condition when it concerns incurable diseases, especially when the illness is fatal and the condition is terminal. It's not an easy case to communicate to the patient that the illness will inevitably result in death.

But still, to tell the truth remains the main principle. Besides, the legislation allows for exception when the doctor has founded assumption that telling the truth about diagnosis and prognosis will be harmful for patient's health.

The Law on the Rights of Patient entitles doctor to refrain from disclosing information about the health condition or provide part of information in cases when (article 18.2):

**"...there is a valid assumption that delivery of full information will considerably harm patient's health."**

Thus, in mentioned case the doctor has right to withhold information; however, this decision shall not be taken independently. The same article states that the decision on withholding information or part of it shall be verified by ethics committee. If such committee is not available at the hospital then the decision shall be attested by other doctor. In all cases the fact of withholding or curtailing information shall be recorded and attested by signature in medical records (medical history).

It shall be noted that this exception has its restrictions which doesn't allow the medical personnel to withhold or provide part of information to the patient when the latter insists on obtaining it. This norm is declared in the law on the Rights of Patient as well as Doctor's Professional Activity. The latter states (Article 39, paragraph 3):

**“If a patient insists on obtaining information, the healthcare personnel shall provide this information.”**

Therefore, upon insistence of patient the doctor is obliged to provide information to patient about his/her health condition, course of illness and prognosis, alternatives of treatment.

### ***Refusal to receive information***

Patient has the right to refuse to receive information about own health condition and proposed medical service (The law the rights of Patient, Article 20). This likewise applies incurable diseases. Surely, doctor shall ensure that patient has no desire to learn about own health condition and the details of proposed medical care. The best approach in this case is posing relevant questions to patient during conversation and hearing patient’s opinion.

It shall be taken into account that sometimes withholding information may be harmful for patient considering patient’s daily routine or profession. So, patient’s right to refusal to receive information is also subject to some exceptions. Namely, according to Georgian legislation<sup>4</sup>, the doctor must provide information to patient when:

**“...withholding information may incur serious harm to the patient or to the third party.”**

Withholding information from a patient may especially be a problem when due to diagnosis (for instance, cancer) it is necessary to perform treatment which bears some risk and requires clear and moreover, written consent. For instance, a written consent is required for surgical interventions, chemotherapy of malignant tumor, etc (see chapter “Informed Consent and Palliative Care”).

## **Informed Consent and Palliative Care**

Informed consent as the basic component of ethical principle of Autonomy is a prerequisite for any medical intervention. Sometimes the need for it is obvious (e.g. prior to surgical operation); sometimes it may appear less important (e.g. when there is almost no risk, pain and discomfort associated with routine intervention). However, according to legislation, obtaining informed consent in any case is a requirement (law on the Rights of Patient, article 22):

**“Informed consent of the patient or in case of his/her incapacity, of patient’s relative or a legal representative shall be a precondition for providing medical service to the patient. Informed consent shall precede the medical service.”**

Essential component of informed consent is provision of clear information to patient about proposed medical service or intervention. Surely, in case if s doctor decides on withholding informa-

<sup>4</sup> Law on the Rights of Patient, article 20, paragraph 2; Law of Doctor’s Professional Activity, Article 39, part two of the paragraph 2.

tion from a patient or the patient refuses to receive information (see chapter Informed Consent – ethical and legal dilemma), it is impossible to obtain full informed consent from a patient. This is particularly important when there is need for written consent prior to medical intervention, for instance prior to chemotherapy. The Law on the Rights of Patient includes list of interventions which requires written informed consent (Article 22, paragraph 2). This list contains some interventions which are relevant for incurable, including cancer patients:

- Surgical operation;
- Central blood vessels catheterization;
- Radiotherapy;
- Chemotherapy for malignancies.

In case of patient's refusal to receive information, agreement shall be made with patient about who should take decision about an intervention and who should provide comprehensive consent. Legislation provides no specific paragraph about this issue; however, it is clear that such decision shall be properly documented and attested in the patient's medical records.

Informed consent is obtained from patient's legal representative (closest relatives – spouse, children, parents, etc) when patient is legally incompetent or lacks decision making capacity.

At the same time it shall be emphasized that the law protects patients who are legally incompetent or lack decision making capacity from incorrect decision of their relatives or legal representatives (see "Euthanasia and refusal to treatment").

## Euthanasia and refusal to treatment

### *Euthanasia*

The topic of euthanasia has become quite popular in our society today. There are people who consider that the so called "Good Death" shall be accessible for persons, the aim of which is "to free from suffering" a person with severe disease. In our opinion it is far more important to be focused on introduction of new forms of care and support that can help patients in severe condition, alleviate pain and other symptoms and provide moral support. Surely, palliative care is implied.

Despite the fact that today issues related to euthanasia are widely discussed in the society, it is clearly regulated by the legislation – [Georgian legislation prohibits euthanasia](#). The law on Healthcare defines euthanasia as follows (Article 3):

**"Euthanasia – intentional termination of life of a terminally ill patient with incurable disease on his/her demand".**

Thus, contemporary legislation in defining euthanasia implies active participation of a doctor in terminating patient's life.

As for the prohibition of euthanasia, the Law of Georgia on Healthcare clearly states that any person, including medical personnel, is prohibited to conduct euthanasia or participate in it. Below is given the relevant article from the law (151):



**“Medical personnel, as well as any other person are prohibited to accomplish euthanasia, or participate in it.”**

Of worth noticing is that euthanasia is clearly prohibited by The Criminal Code of Georgia which establishes sanctions for such action. However this document mentions neither the term “Euthanasia”, nor medical personnel or patient. Namely, The Criminal Code states (Article 110 – Mercy Killing):

**“Mercy-killing on insistence of the victim and at his/her true will, administered in order to free the dying person from strong physical pain – is punished by imprisonment up to five years.”**

In fact, Georgian legislation implies the so called “active euthanasia” under the term “euthanasia”. Passive euthanasia, which earlier implied withholding life-saving treatment from patient at patient’s will today doesn’t imply euthanasia. Below it will be shown that this problem is discussed in terms of the patient’s right to refuse to undergo treatment.

### ***Refusal to undergo treatment and advanced directives***

Georgian legislation prohibits performance of any type of medical intervention without prior consent of the patient. If a patient is legally competent and is capable of taking conscious decision he/she enjoys right to refuse to any type of treatment including life-saving measures (Laws on the Rights of Patient and Healthcare). Moreover, Georgian legislation emphasizes that a dying patient also exercises this right. Below is given an excerpt from the law on Healthcare, article 148:

**“1) A terminally ill patient capable of taking conscious decision has the right to refuse to resuscitation, life-saving or palliative care.”**

Above mentioned right is bound by prohibition on conducting medical intervention without patient’s consent; this concerns medical personnel (law on the Rights of Patient), Article 23).

It is natural that very often patient’s relatives have to take decision about medical care of a dying patient; and besides in Georgia there is no tradition of patient’s written advance directives or oral declaration on what would be his/her will in case of terminal condition. However below we will see that Georgian legislation enables citizens to make advance directives on medical services.

According to legislation the relatives of a dying person have right to refuse to provision of medical care to patient if the refusal is based on respect for patient’s dignity. Another important condition for relatives to refuse provision of medical service is taking patient’s will into consideration. The second paragraph of above quoted article states (148.2):

**“2) In case of the unconscious state of terminally ill patient, patient’s relative, or legal representative has right to refuse to resuscitation, life-saving measure or palliative treatment or/and palliative care with the purpose of respecting dying person’s dignity and considering patient’s will.”**

While discussing the issue of relative's refusal to provide treatment to patient, we will touch upon the mechanisms which aim at preventing abuse of this right by relatives (for private interest). Georgian legislation entitles a doctor to disagree with the decision of relatives of patient lacking decision-making capacity if the doctor considers that this decision is against the interest of patient's health.

On one hand, doctor can address the court if the patient's condition allows this (the law on the Rights of Patient, article 25.1). In other cases, when a legally incompetent patient or patient lacking decisions-making capacity is in need of urgent medical care without which patient's death is inevitable and patient's relative or legal representative contradicts medical care, the law doctor has a right to act in the best interest of the patient (Law on The Rights of Patient, Article 25.2).

Further, citizens have right to express a living will about future treatment if they happen to be in a state unable to take conscious decision. Such a will may concern only terminal condition or disease causing severe disability (Law on The Rights of Patient, Article 24):

**1. Citizen of Georgia enjoys the right to express advance directive in a written manner (a consent or refusal) concerning “do not resuscitate order” or palliative treatment or/and palliative care in case of unconscious state or inability to take voluntary/conscious decision if mentioned states are caused by:**

- a) Terminal stage of incurable disease;**
- b) Disease that may inevitably cause grave disability.**

According to existing legislation, the medical personnel shall take into consideration the patient's living will upon deciding on delivering medical care to dying patient, when the latter has no capacity to take conscious decision (Law on Healthcare, Article 11).

**The provision of medical care to a legally incompetent patient or patient who lacks capacity to take conscious decision, patient's inclusion in the process of medical education and scientific research is acceptable only by taking into account patient's advance directive (when the patient was capable of taking conscious decision). If the latter is not available - under the consent of the patient's relative and/or legal representative.**

The legislation considers one more mechanism promoting respect for patient's will; particularly, the law on the Rights of Patient enables citizen to nominate a person who will take decision about his/her medical treatment in case of above described conditions – terminal state, disease causing grave disability.

## Confidentiality and informing family members

One of the oldest principles of the medical ethics - keeping doctor's secret - is clearly envisaged in contemporary legislation. It completely concerns delivery of medical care to a patient with incurable disease. Mentioned ethical and legal requirement is often violated. Information about the patient's health state and provided medical care is often incautiously provided to third person, including patient's relatives as well as medical personnel not related to patient's care, journalists, etc.

By the established tradition every visitor of a patient at the hospital requests detailed information from the doctor about the patient's health condition. As a rule, nobody considers patient's will about disclosing this information. Further, the doctor spends much time and energy to satisfy the curiosity of patient's relatives.

The law entitles the patient to take decision about who to inform and what information to provide. Namely, the law on the Rights of Patient, article 21 states:

**“Patient is entitled to take decision whether any person can receive information about his/her health status. If patient agrees, he/she should entitle the person who should be informed. The patient’s decision, as well as the identity of the person entitled, shall be entered in medical record of the patient.”**

Thus, without patient's consent the medical personnel are disallowed to disclose information about the patient's health condition. Only when the patient is legally incapable or lacks decision making capacity, the medical personnel have right to provide information to relatives or a legal representative. Besides, the law allows for disclosure of information when withholding information endangers life or/and health of other person or in cases required by the law.

## Palliative Care and professional standards

### *Instructions on Palliative Care*

Palliative Care in Georgia is a new direction in medicine and surely, there is a lack of knowledge and experience in this field.

Despite this, it is delightful that the professional standards in palliative care are approved by the law. Namely, “The Instructions on Provision of Palliative Care to persons with Chronic Incurable Diseases” was approved by the order N157/N of July 10, 2008 of the Minister of Labor, Health and Social Affairs.

The mentioned instruction as a guideline describes in details important following issues of provision of palliative care to patients with chronic incurable diseases:

- Aims, objective and components of palliative care;
- Criteria for selecting a patient for palliative care;

- Assessment of the state of a patient with chronic incurable disease;
- Management of symptoms at terminal stage of incurable patients, including pain management;
- etc.

It should be emphasized that these instructions are approved under a normative act through which the professional standards were recognized and legitimized. Further, according to Georgian legislation every certified doctor in Georgia shall conduct own professional activities in compliance with the “professional standards recognized in the country”. Therefore, palliative care in our country shall be delivered in compliance with above mentioned standards. Certainly, a doctor has to some extent professional freedom in taking decision about an individual patient. In addition, doctor’s decision shall be justified.

### ***Prescribing and issuing narcotic drugs***

Proper pain management constitutes an integral and important part of the palliative care. At certain stage it implies using narcotic drugs. Up to recent times the prescription and issue of narcotic drugs in relevant dose was restricted and sometimes even impossible.

The situation has changed after adopting above mentioned order<sup>5</sup> of the minister which together with the instructions defines the rule for prescribing and issuing narcotics. Namely, the order states:

- a) One prescription (form) issued to a patient with chronic incurable disease may contain dosage of narcotics sufficient for 7 days;**
- b) The responsibility for appropriate prescription of the drug lies with the doctor who writes prescription and the head of hospital or a responsible person officially appointed by a head of hospital, who performs monitoring;**
- c) If a patient’s state changes during the treatment that requires substitution of narcotic or changing its dose or form then the doctor has to issue a new prescription;**
- d) Prescribed narcotic drugs shall be issued during 5 business days. After which the pharmacist has no right to do so. In case of need a new prescription shall be issued.”**

Therefore, today a doctor can prescribe relevant amount of narcotics required for relieving the pain for patients with incurable diseases; the dosage shall be calculated for 7 days. Further, the doctor can change type or dose of narcotics before full usage considering the patient’s state.

## **Summary: Recommendations for Medical personnel**

Below is given the summary of above discussed legislation related to palliative care of terminally ill patient. The summary represents recommendations, in simple language and in our opinion, will help medical personnel provide palliative care to terminally ill patients in compliance with the requirements of contemporary ethics and legislation of Georgia:

<sup>5</sup> Order N157/N of July 10, 2008 of the Minister of Labor, Health and Social Affairs on approval of “The Instructions on Provision of Palliative Care to persons with Chronic Incurable Diseases”.

### **Recommendations**

1. Patients with incurable diseases at the terminal stage require special attention; it is necessary to provide explanations to them in simple, understandable language about their health condition and proposed medical care; as a rule, you should inform them about diagnosis and prognosis.
  2. Exceptions to this rule are allowed when you are sure that disclosure of full information may be harmful for a patient. In this case you should coordinate your decision with the ethics committee and in case of absence of such committee, with other colleague. The decision shall be always recorded in the medical history and attested by you and your colleague or a representative of ethics committee.
  3. Please, remember that if a patient capable of giving conscious consent (a person in the full legal age who is not assumed incapable by the court) insists on receiving full information about own health, you shall tell him/her the truth. In such case information about the health cannot be withheld from this patient.
  4. The patient's request to see own medical records or receive its copy shall be satisfied.
  5. Information about the patient's health condition shall be disclosed to patient's family members, relatives only by consent of patient; besides they should be given possibility to get familiar with the patient's medical records after agreeing this with patient;
  6. If the patient refuses to receive information, you should respect this decision. In this case a person shall be nominated who will take decision on behalf of the patient and declare consent on intervention;
  7. Informed consent shall be obtained from a patient who is in need of palliative care prior to any medical intervention. For some medical interventions a written informed consent is required (e.g. surgical operation, radiation therapy, chemotherapy);
  8. If the patient is legally incompetent or in a given moment is incapable of taking conscious decision (e.g. black-out or coma), you should obtain informed consent on medical care from patient's legal representative (spouse, child, parent, sister, brother, etc);
  9. Never perform and participate in euthanasia. Euthanasia is prohibited by the law and is punishable by The Criminal Code of Georgia;
  10. If a legally competent patient who at a given moment is capable of taking conscious decision, refuses to medical intervention, or has desire to terminate the intervention regardless of the type of intervention, do not perform this intervention or cease it;
- If you suppose that the patient is taking irrelevant decision, make sure that the patient is capable of taking conscious decision (through inviting relevant specialist or organizing consultations). If it is confirmed that the patient is capable of taking conscious decision, it is unacceptable to perform any intervention against his/her will;
11. When a dying patient has no capacity or due to illness (strong intoxication, coma, psychosis) has no capacity to take conscious decisions and patient's relatives request termination of medical intervention which cannot improve a patient's condition including alleviation of pain, then satisfy their request. However, if you suppose that the decision of patient's relatives is conflicting with the patient's interests (e.g. they refuse to perform treatment which may alleviate pain or improve the quality of life) then address the court;

When there is no time and the death is inevitable without intervention, when your intervention can indeed save the life and it will not prolong patient's suffering and the process of dying, you can intervene in the interest of patient, without consent from relatives;

12. When providing palliative care apply "The Instructions on Provision of Palliative Care to persons with Chronic Incurable Diseases" as a guide;
13. You can prescribe relevant amount of narcotic drugs for alleviation of pain to incurable patients with chronic diseases; this amount should be sufficient for 7 days;
14. If the patient's condition changes during palliative care and substitution of narcotics or its dose or type is required, issue the new prescription.

### **Useful resources:**

Below is given the list of the names and addressed of organizations and/or web-pages which will be useful for you in settling professional, ethical and legal issues arising when providing palliative care.

Name	Definition	Web-page
Georgian National Association for Palliative Care	One of the main goals of the association is to promote development of Palliative Care system in Georgia and to implement the internationally approved bioethical standards. Head of organization: Dymitry Kordzaia	<a href="http://www.palliativecare.org.ge">www.palliativecare.org.ge</a>
Palliative Care hospital of Cancer Prevention Centre	The first palliative care hospital in Georgia. Head of hospital: Ioseb Abesadze Tbilisi, Lake Lissi, National Centre of Oncology	web-page is being developed
Parliament of Georgia, Committee of Health and Social Issues: Palliative Care	Activities of Committee in Palliative care; web-page contains many resources including national program on palliative care	<a href="http://www.parliament.ge/index.php?zlang_id=GEO&amp;sec_id=619">http://www.parliament.ge/index.php?zlang_id=GEO&amp;sec_id=619</a>
The Parliament of Georgia: Legislation	Contains search engine for laws.	<a href="http://www.parliament.ge/index.php?lang_id=GEO&amp;sec_id=69">http://www.parliament.ge/index.php?lang_id=GEO&amp;sec_id=69</a>