



## **Report on the Activities of the Charitable Organization "Association of Palliative and Hospice Care" for 2022 — May 2024**

### **Actuality**

In Ukraine, there remains a high number of elderly individuals and those suffering from severe incurable illnesses. In the conditions of martial law, the mortality statistics in our country for the years 2022-2024 remain undisclosed. However, available data also indicate general trends. For instance, in 2017, the total number of deaths was 583,600 individuals, and in 2021, including the consequences of the Covid-19 coronavirus, it was 714,263 people. The number of deaths from neoplasms in 2019 was 61,289, in 2021 it was 53,012, and in 2022 it was 42,660 (excluding temporarily occupied territories). Thus, the number of individuals in need of end-of-life care is significant. Palliative and hospice care can be provided to such individuals. This type of assistance is not only relevant in the field of healthcare and medicine but also generates practical interest in related fields such as social work, psychology, political science, economics, and others.

### **General Principles of Activity**

According to its Statute, the Association of Palliative and Hospice Care aims to develop palliative and hospice care in Ukraine. To achieve this, it conducts educational, advocacy, and scientific activities. The target groups of the organization include medical and social workers, educators, researchers, and, in a broader context, all individuals who have encountered the problem of severe illness. The Association relies primarily on ethical principles rooted in Christianity.

The Association's staff consists of highly qualified professionals. In its work, various theoretical approaches are utilized, including a socio-ecological approach. According to this approach, social work and assistance can be provided at the individual, community, and state levels, considering the "ecological" connection between individuals and the environment, which mutually influence each other. In its practical

activities since 2011, the Association has relied, for example, on the "Life Model of Social Work Practice" developed by C.B. Germain and A. Gitterman.

For this model, the following are important:

1. Harmony and interaction between the individual and the environment. The "Life Model" asserts that people and their social surroundings can develop positively when their respective needs, abilities, rights, and desires are optimally aligned.
2. Individual coping resources. These resources include, among other things, communication skills, competence, self-esteem, and self-regulation.
3. Social factors related to coping processes.
4. The "Life Model" in practice involves awakening individuals' strengths and potential and changing the surrounding environment so that well-being for individuals becomes possible within the context of optimized relationships between people and the environment.
5. Ethical requirements of social work.

For the Association of Palliative and Hospice Care, it is important to consider the individual in the context of the environment in which they live, namely socio-cultural aspects, taking into account human rights, desires, and needs. The education and advocacy work conducted by the Association are directed towards this goal.

Supporting the family and, in a broader sense, the relatives and friends of the patient (client) before, during, and after admission to a hospice or other institution providing palliative care is one of the main tasks of this organization. The Association strives to involve not only medical workers but also social workers, psychologists, rehabilitation specialists, and occupational therapists in the field of palliative and hospice care. The dying process can last for several months, and therefore, the quality of life in this final period directly depends on the activation of the patient (client) and the support of their self-esteem and assistance in socio-psychological self-regulation. The Association relies on professional standards of social work, including those of the International Federation of Social Workers and the European Federation of Social Work.

In the context of socio-ecological theory, social work includes working with individual cases, families, groups, and communities, as well as working at a higher level (state), namely social policy. The Association of Palliative and Hospice Care carries out its activities at all these levels (providing assistance to individual citizens, organizations, and institutions and, where possible, participating in the formation and improvement of the state's social policy regarding seriously ill individuals).

## **Scientific Activities**

In 2022, scientific research and the preparation of recommendations continued for the Ministry of Health, healthcare institutions, patient non-governmental organizations, and leaders of other non-governmental organizations based on the results of the project "Monitoring of prescribing, use, and storage of drugs used in the treatment of cerebral palsy in Kyiv and the regions, in the Zhytomyr, Dnipropetrovsk, Kharkiv, and Zaporizhzhia regions." Specialists from the Association, O.Volf and S.Augunas, participated in the project.

From 2021 to 2023, Oleksandr Volf was a member of the department's team implementing the scientific initiative-search topic: "Scientific substantiation of the concept of organizational, medical, and psychological support for primary health care professionals to provide palliative care to patients and their family members in outpatient settings." The term of the topic has been extended until 2025.

From 2022 to 2024, general scientific and scientific-practical development of palliative and hospice care in Ukraine continued. General theoretical developments are being prepared, which are reflected in a series of scientific publications.

### **Research Methodology.**

#### **Research Directions and Objects:**

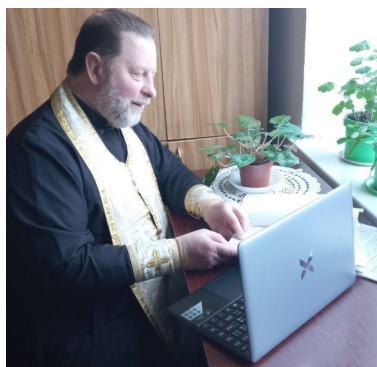
The general state of development of palliative and hospice care in Ukraine is being investigated; the availability of services for the population of Ukraine; compliance with the standards of care provision; the degree of society involvement in grassroots level changes aimed at improving services; ways of interaction between the government and society in the context of implementing palliative and hospice care. Both theoretical and empirical methods are used in combination. Specifically, expert assessment methods, qualitative and quantitative data processing methods, heuristic forecasting methods, morphological analysis methods, methods of semantic analysis of information, etc., are utilized. In particular, interviews with medical professionals, managerial specialists, representatives of patient non-governmental organizations, etc., are conducted. Scientific research by other researchers is studied. Observations and measurements are made. Document analysis is carried out (including using triangulation method).

Among the main results, it has been found that overall, general population are insufficiently involved in the development of palliative and hospice care.

Predominantly, there is a lack of understanding of palliative and hospice care among the population in different regions of Ukraine. Among specialists (medical workers), there is a simplified, general understanding of palliative and hospice care, which does

not perceive hospice care as a philosophy. According to the Ministry of Health of Ukraine, "as of 2024, general palliative care is provided within the framework of the Package of Medical Guarantees 'Primary Medical Care,' and specialized care is provided within the frameworks 'Inpatient Palliative Care for Adults and Children' and 'Mobile Palliative Care for Adults and Children.' In 2024, 751 healthcare facilities were contracted for specialized inpatient palliative care, and 1210 providers for mobile palliative care." According to expert surveys of medical workers, such a quantity is conditioned in part by the fact that medical institutions, especially in rural areas, are "renamed" to "hospices" to avoid closure (reduction). Some institutions consider "palliative and hospice care" as assistance that "complements" activities in other medical packages and does not require significant funds for implementation. Despite the requirement of the National Health Service of Ukraine regarding, for example, cooperation with social services, close cooperation between the medical institution and social workers (who are supposed to be members of the so-called multidisciplinary team of the palliative care institution), the majority of such institutions have such cooperation only on paper. Overall, requirements for multidisciplinary cooperation, teamwork, etc., are ignored. Often, multidisciplinary cooperation is understood as cooperation between a general practitioner and an oncologist. Social work specialists, volunteers, or members of the patient's family are not considered as team members or, are not invited to the team meetings. Other international standards regarding hospice care (bereavement support, work with the patient's family, spiritual care, work with volunteers, enlightenment activities, etc.) are not implemented. According to research by the Association of Palliative and Hospice Care, patient non-governmental organizations are not involved in the majority of discussions on "changes" to existing regulatory acts. These changes are primarily implemented by representatives of the medical community. As a result, there is "overtaking" in terms of the number of "hospice institutions" compared to the UK, Poland, and Germany combined.

In 2022-2024, the Association of Palliative and Hospice Care implemented a project on the introduction of telehospice (online) palliative care (multidisciplinary online consultations). Thirteen institutions from 8 regions of Ukraine were involved in the project. Processing of institution reports is being carried out. The information was systematized and in 2023 was provided to the Ministry of Health in the context of developing the Strategy for the Development of Telemedicine in Ukraine for 2023-2025.



Research into the possibility of implementing social services based on healthcare facilities continues in 2024.

In 2018, O.Volf was a member of the editorial board of the international journal *Sociálno-zdravotnícke spektrum* (Austria / Slovakia).

Since 2020, O.Volf has been a member of the scientific council of the public organization "Academy named after St. Edith Stein" (Slovakia).

### **Educational activities:**

Since 2021, the charitable organization "Association of Palliative and Hospice Care" continues to be registered by the Ministry of Health as an official provider of educational services for medical professionals (provider registration number 1094).



The experts of the Association, O.Volf and D.Vitvitsky, continued their cooperation with ISAR "Unity" in the implementation of the project "Building Civil Society Opportunities," supported by USAID, as consultants and experts. Within the framework of the project in 2023, they conducted 8 trainings on the basics of project management and strategic planning for non-governmental organizations working in

the field of healthcare and palliative care in the Kyiv region. This activity takes place in the context of organizational development. This term refers to a set of measures that help organizations become more effective and sustainable. It is long-term work to increase the organization's ability to renew itself, solve emerging problems, and quickly respond to external and internal changes. Therefore, the experts of the Association have been conducting such activities since 2019. The main goal is to develop and initiate bottom-up projects aimed at improving the situation regarding the development of palliative and hospice care. Despite the fact that most communities are not ready for full cooperation on palliative care (lack of local leaders, or lack of understanding of the need for social development, or weak infrastructure, or communities with low human development potential, or other factors), the Association finds adequate and willing communities for cooperation. One of the main prerequisites for the development of palliative and hospice care at the local (grassroots) level is the presence, including, of adequate and open-to-cooperation medical professionals.

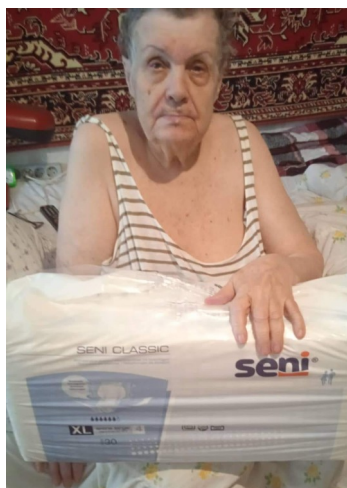


O.Volf is an assistant at the Department of Palliative and Hospice Medicine of the P.L. Shupyk National Medical Academy of Postgraduate Education and actively participates in the educational process. The target group of the educational institution primarily includes doctors and specialists with secondary medical education. In 2023-2024, the search and establishment of partnerships with a number of palliative and hospice care institutions in the USA, Poland, Germany, Slovakia, the Czech Republic, the Netherlands, and several other countries continued. During the ongoing monitoring of the development of palliative and hospice care in Ukraine, a number of educational needs of doctors and specialists with secondary medical education have been identified. Among these needs are: international standards of palliative and hospice care; basics of multidisciplinary cooperation; patient rights; ethical principles of care for seriously ill individuals; deontological principles in working with seriously ill individuals, and others.



## Material humanitarian assistance

In 2022-2024, the Palliative and Hospice Care Association received 20 tons of humanitarian aid provided by the Polish Palliative and Hospice Care Association, the Hospice of the Lesser Poland Voivodeship, the Irish Palliative and Hospice Care Association, several organizations from the Netherlands, the Slovenian Palliative and Hospice Care Association, as well as hospices from Germany. The cargoes consisted of equipment, hygiene products, food products, and were distributed among medical institutions and individuals in the Kyiv, Chernihiv, Sumy, Zaporizhzhia, and Mykolaiv regions. The total number of recipients of this type of assistance is approximately 1200 individuals.



## Implemented projects:

- "Targeted assistance to seriously ill citizens by providing products and hygiene items", donor - "Nova Ukraine", February-May 2022, budget 100,000 UAH. The total number of aid recipients was approximately 310 individuals.
- "Assistance to children and elderly persons by providing products and hygiene goods", donor - International Red Cross Committee, April-June 2022, budget 317,000 UAH. The total number of aid recipients was approximately 420 individuals.
- "Implementation of a pilot project for telehospice assistance in 7 communities in Ukraine", donor - Danish Christian Aid, September-December 2022, budget 380,000 UAH. The total number of consultation recipients over 4 months was approximately 450 individuals, with approximately 100 online consultations provided steadily each month.

- "Direct assistance to seriously ill and palliative care recipients", January 2022 - December 2023, budget 1,200,000 UAH, assistance was provided to over 1100 individuals.
- "Support for healthcare institutions in implementing palliative care", Palliative and Hospice Care Association, New York, January 2023 - February 2024, budget 170,000 UAH. Approximately 100 online consultations are provided steadily each month.
- "Support for healthcare institutions in implementing telemedicine palliative care", State University of Texas, January 2023 - February 2024, budget 160,000 UAH. Approximately 100 online consultations are provided steadily each month.

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