

We are on this earth to be at home somewhere

**Voluntary Palliative Assistance of Senior to Elderly People
Grundtvig II Project**



Report 2006-2007

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The title of this Report is a quote from *"Abel in America"*, a book by Áron Tamási. The original in Hungarian reads: "Azért vagyunk a világon, hogy valahol otthon legyünk benne."



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Foreword

Because of the continually lengthening life expectance, a growing number of the elderly people are stimulated to take a new glance at their position in the society. Unfortunately not only positive but also negative changes are observed here. In Lithuania the satisfaction of the physiological needs of the elderly people is ensured under the laws and social insurance system. However the spiritual, self-expressional needs of the senior people are not fully satisfied, the equivalent participation of the senior people in the life of the society is not ensured. Most of them suffer from social isolation and loneliness. For a person in age, as well as in the previous steps of his/her life, it is relevant to remain an active participant of the social processes, i.e. to have a possibility to express oneself as an individual. Seniors and elderly people may use their valuable life experience and lifelong skills through the participation in the activities of non-governmental organizations, by doing voluntary work for the communities. They can help each other as well as begin activities attractive to them that correspond to their abilities and taste. Unfortunately the volunteering of the senior people, the inter-assistance activities in the communities and the palliative assistance is not developed enough in all European countries. In Lithuania there are only the basics of the voluntary activities and palliative assistance. Through the cooperation with social organizations from different European countries we have noticed that we have a common concern – to contribute to the assurance of welfare of the elderly people. This is how the idea of this project was born – to awaken the activity of the senior people, to involve them in to the process of life quality improvement based on the principle "Senior for Elderly".

We hope that sharing good experience with other countries, where voluntary activity and palliative care are much more

developed (the Netherlands, Hungary, Czech Republic) the preparation of the training materials and its adjustment to the actual needs will provide more possibilities for the senior and elderly people to participate in the community life. Also, involving them in the lifelong learning process and the creation of harmonious relations between the community members will positively influence their cultural life. This is particularly important for old and elderly people from new EU member countries, who lived in different political/social systems and need assistance to adapt to the quickly changing society.

We also expect that the different socio-economic and cultural aspects of the selected European countries and their representative organizations will positively influence the implementation of the objectives of this project, as well as the dissemination the project results in the geographically widely located participating countries.

In the first stage of the project "Voluntary Palliative Assistance of Senior to Elderly People" the partners from Lithuania, Hungary, The Netherlands, Czech Republic, Cyprus and Greece collected and presented data about the situation of senior and elderly people in the society, focusing on social, demographical, medical aspects and voluntary activity. The partners from the Netherlands and Hungary summarized the material, illustrating it with photos made during the project meetings in Lithuania, Czech Republic, Greece and Hungary to prepare the final version of this Report.

More information is available at the partners' websites:

- Lithuania: <http://www.sidmc.org/senior/index.php>
- Hungary: <http://www.pecsi-caritas.hu/seniors/index.html>
- Cyprus: <http://www.ikme.org/seniortoelderly/>

Danguole Boguseviciene
Coordinator of the Project

1. Introduction

1.1 Palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual¹.

This definition of the World Health Organisation on palliative care highlights:

- The active total care of patients whose disease is not responsive to curative treatment.
- Control of pain, or other symptoms and of psychological, social and spiritual problems is paramount.
- The goal of palliative care is achievement of the best quality of life for patients and their families.
- Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with for instance anticancer treatment.

The word Pallium derives from the Latin *pallium* meaning 'mask' or 'cloak.' This etymology indicates what palliative care essentially is about: masking the effects of incurable disease, or providing a cloak for those who are left in the cold, because they cannot be helped by curative medicine.

Therefore palliative care...

- affirms life and regards dying as a normal process;
- neither hastens nor postpones death;
- provides relief from pain and other distressing symptoms;
- integrates the psychological and spiritual aspects of care;
- offers a support system to help patients live as actively as possible until death;

¹ WHO definition 2002. source: <http://www.who.int/cancer/palliative/definition/en/>

- offers a support system to help patients' families cope during the patients' illness and their own bereavement.

It is a unique way of dealing with persons in their last phase of life and help that usually is not very long. It is unique while the persons themselves, their families and friends are involved in the care, the services are delivered by the principle of an interdisciplinary team, and family receives support even after the death of the patient. The cooperation strategy of the specialists from all the fields is to help the dying person to relieve suffering, to understand the realistic situation, and to search for ways how to manage problems.

Illness and death are now, and always will be an inevitable and integral part of the human experience. Since the beginning of time, societies have attempted to offer support and comfort to their ill and dying. Volunteers can play an important role in this caring society.

For this reason it is important to emphasize the cooperation between volunteers, informal caregivers and the professional carers. In the best way their efforts are recognized as equal and complementary but of different importance to the patient and the relatives. The input the volunteers give day-to-day is based on the psycho-social, spiritual and practical needs, adjusted to what the informal caregiver (family, friends, etc.) offers.

But palliative care in this sense is only one part of the "end of life care". For the volunteer part its also important to stress that the volunteer carer should also retract to the background if the person at his/her end of life needs privacy and solitude, and needs to "hide" his/her state of mind. Palliative care means a continuous readiness and presence, in the highlight or the background, depending on the needs of the patient.

1.2 Volunteering

Volunteering is the whole of activities done without payment by a volunteer for another person, group (without any blood ties), or the society as a whole within an organisation and without any obligation.

To prevent misuse of the term, some criteria are developed:

- the work has a common social aim;
- it is done without any profit;
- it is not replacing paid jobs;
- and it has a complementary character.

The International Association for Volunteer Effort (IAVE) proclaims² that volunteering brings to life the noblest aspirations of humankind – the pursuit of freedom, opportunity, safety and justice for all people. It is a means by which human values of community caring, service and participation are sustained and strengthened; individuals exercise their rights and responsibilities as members of communities; and connections are made across differences which otherwise can push us apart.

The IAVE emphasizes that volunteering...

- invites the involvement of the entire community in identifying and addressing the challenges, opportunities and problems which face it;
- encourages and enables people of all ages and from all sectors of society to take leadership through participation in service and social action;
- provides a voice for those who cannot speak for themselves;
- gives anyone the opportunity to participate;
- complements but does not substitute for responsible action by other sectors and the efforts of paid workers;

² IAVE Strategic plan 2007-2010

source: <http://www.iave.org/ResourceView.asp?ResourceID=87>

- enables people to acquire new knowledge and skill to fully develop their personal potential, self-reliance and creativity;
- promotes family, community, national and international solidarity.

Volunteering has two sides: one is about the benefits for the society, an organisation or an individual: devoting time, knowledge and energy with no or only symbolic consideration. The second part is about the benefits for the volunteers themselves: opportunity for everyone to use their abilities and experience, to gain new skills, make new friends, get into work and change their social life, in return of self satisfaction, regardless of sex, race, nationality, religion, political beliefs, age or health.

Volunteering in palliative care isn't totally different from this. On the other hand special skills, especially about self-reflection and communication are asked. This is because of the complex and vulnerable situation of the person in care, because of the emotions that have to be dealt with for the caregiver, the family who asks for the care and also for the volunteers involved, and because of the special needs in coaching the volunteers in this particular area.



Picture 1. The first Project Meeting in Vilnius, LT

2. Six different countries

This project is focusing on the voluntary palliative assistance of senior to elderly people. The main idea of the project is to improve and encourage through non-formal learning the participation of senior people, especially women, in the voluntary activities of NGO's, local communities and social work services, in providing moral and social palliative assistance required by elderly people. The project would also stimulate social participation of senior and elderly people thus improving their active quality of life on the basis of the principle "Senior for Elderly".

The project aims to share good practice among participating partners³ from LT, CY, GR, CZ, NL, HU through workshops, electronic connections and information placements on the project's web-site. The project will cooperate closely with NGO's, local communities, state institutions and government agencies. With this it will ensure both the understanding of the needs of the target groups as well as the dissemination of the results and products. The working language will be English so some participants will improve their language skills through language training.

The first project stage consists of the introduction of the participants, interchanges of project staff, accomplishment of some research, collecting and summarizing the material about each participating country's situation of the senior and elderly people in society, with regard to social, demographical, medical aspects, and voluntary activity.

The results of this research work are presented in this Report.

2.1 Demographic tendencies

In the six countries involved in this project, more or less the same demographic tendencies can be observed. The life expectancy is getting higher; the total population in each country is decreasing or is expected to decrease in the next decades; the percentage of persons of 65 years and older is increasing. In

³ See complete list of project partners in the *Appendix*.

some countries it will go up from 20% to 35% or even higher. This differs between the countries. For instance in Greece, the population 60+ increased between 1960 and 2000 from 30% to 39%⁴.

Also the number of persons living together in one household is of influence. The birth-rate is going down and therefore the households are getting smaller. For instance in the Netherlands it diminished from an average of 4-5 persons in the beginning of the last century to 2,3 persons in 2003, and the expectancy is that it will become 2,1 by 2050.

The third thing is the ratio between men and women. While women are getting older, they are overrepresented in the older age groups. For instance in the Czech Republic 56.260 persons are in the age of 70+. Only 15% of this group are men.

So, while the tendencies go towards the same direction in all of the countries involved in this project, the impact of these developments are different. The impacts can come sooner or later, and be mild or strong for the next few years in each country.

The living situation for the persons aged 65+ differs in the six countries. In the Netherlands older persons are living more on their own. In 2003 there were 2,5 million one-person households in the Netherlands and this will increase to 3,5 million by 2040. Because of the increasing age of people and the men/women ratio, these households consist mostly of women on their own. Homes for elderly are a place to go to only for a few percentage of the older people. In 1995, 8% of the persons 65+ lived in a home for elderly but this diminished to 6% by 2003. Above 85 years only a third of the people would go to homes for the elderly.

In Hungary you can see more or less the same when you notice that most of the persons of 60+ live on their own in a one-person household. And in the Czech republic only 1,5% of the persons aged 70+ are living with their spouse (i.e. not widows).

⁴ This is not a scientific paper but the examples we give are an illustration for the development we noticed. The figures are based on European statistic information by statline. Source: <http://statline.cbs.nl/>

In Lithuania the family ties are close and 20% of the adult children live together with their parents. Also 90% of the Lithuanians name their children as the most preferable source of assistance in daily life in old age. The adult children consider this both as a pleasure and as an obligation. Institutional care is considered to be the last option. But there are changes coming up. For instance there is a trend that people in the cities count more on state assistance than persons in the countryside do. The parent-child relationships are loosened in the cities.

Also in our project the partners from Greece found it normal to take care of their parents but wouldn't trouble their children with their lives when they're getting older.

Although the statistical figures differ between the countries in the project, the discussions about care for the elderly are more or less the same. The role of the family, the role of homecare, the role of institutional care is all changing. There are also the two sides of an ethical discussion and of a pragmatic approach to deal with the needs of the elderly.

At the end of this chapter there are some data about life expectancy (**Figure 5.**) and about people with terminal illnesses (**Figure 6.**) in the six countries examined.



Picture 2. Visit at Caritas Hospital of Nursing, Kaunas, LT

2.2 Some differences

2.2.1 Socio-economic differences

In the first year of this project we have visited Lithuania, the Czech Republic, Greece and Hungary. At the first sight the differences between the socio-economic situation in the different countries were huge.

Prof. dr. Johan Mackenbach (researcher at the Institute of Public Health, Erasmus University, Rotterdam, The Netherlands) did research⁵ on differences in mortality and socio-economic differences in Europe. He stated that differences in mortality everywhere in Europe were bigger in the nineties than they were in the eighties of the last century. On average everyone has an increasing life expectancy in years but higher educated people benefit more than the lower educated.

The health of the lower socio-economic groups is often diminishing. This means that the "unhealthy years" are increasing for these groups. They are suffering relatively more from heart- and vascular diseases and cancer. This has to do for instance with smoking habits but also with the availability of health services, medication and the costs for medical treatment. Smoking has a strong influence on differences in mortality between the higher and lower educated people in Northern Europe and even more in Southern and Eastern Europe. Till the sixties of the last century 70% of the male population was a regular smoker. The figure was a lot less in Southern Europe. Since then the higher educated population stopped *en masse*, while women started to smoke. Also in Southern Europe there was an increase in the number of smokers, especially in the lower economic groups. These changes have their impact on differences in health and mortality.

Mackenbach expects that overweight is the next social issue that has its impact on health and mortality differences.

In **Figure 1**. there is a comparison of the average income in the year 2003 of five of the six countries involved. There is a big difference between the lowest and highest average income.

⁵ NRC (Dutch newspaper), 05-05-2001

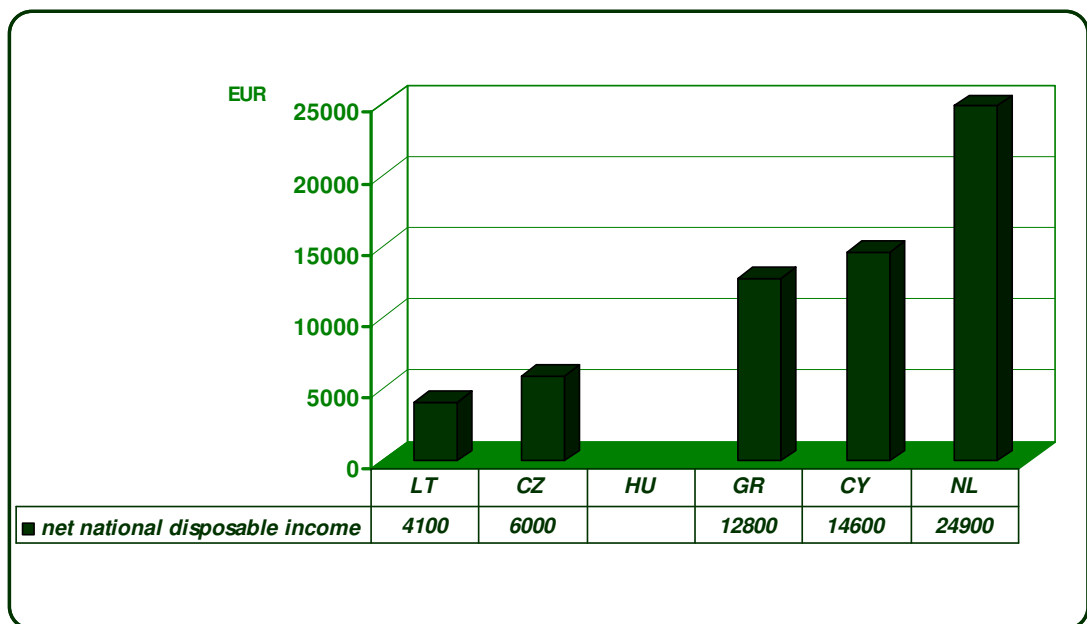


Figure 1. Average income per inhabitant in 2003⁶

In our visits to Lithuania, Czech Republic, Greece and Hungary we have seen the differences on the street and in the healthcare institutions as well as in the services for elderly people.

When we compare these differences with the life expectancy shown in *Figure 5*, we can see a gap between the Netherlands, Greece and Cyprus on one hand and Lithuania, Czech Republic and Hungary on the other hand. This means that socio-economic differences can explain the difference in life expectancy to some degree but also that there is a level above which these differences are less important.

2.2.2 Differences in the healthcare system

Also the healthcare systems and availability of healthcare services differs a lot in the examined countries. This has to do among others with the financial system on which the healthcare system is based. For instance in the Netherlands, the new insurance system for curative healthcare ("Zorgverzekeringswet", January 2006) is a private health insurance with social

⁶ source: <http://epp.eurostat.ec.europa.eu>

conditions. The system is operated by private health insurance companies; the insurers are obliged to accept every resident in their area of activity. A system of risk equalisation enables the acceptance obligation and prevents direct or indirect risk selection. Everyone with the same policy will pay the same insurance premium.

At the same time in Lithuania there is a National Health Care System (NHCS) that provides individual health care and public health care services and carries out pharmaceutical activities. Patient funds pay for family physician services. Currently the number of private Primary Health Care Institutions (PHCI) where one or more family physicians work is rapidly increasing. Private PHCI's make agreements with patient funds, therefore family physician services are free of charge.

This shows in short the differences between a market oriented and a state oriented system, although there are all kinds of situations inbetween within the countries themselves. The system - in combination with the financial accessibility of healthcare services - determines the possibility of free choice.

The entrance to the system is also an important factor. For instance in the Netherlands the GP has a central role in referring people to specialist healthcare services in non-acute situations. In Lithuania legal acts establish that each individual may freely choose a PHCI and a family physician (internist or paediatrician) that is closest to his/her place of residence or most convenient. They are the front door like the GP in the Netherlands but are located in the secondary healthcare.

The availability of services (based on the system) is another important issue. For this brochure we focus on the availability of palliative care services but these figures also represent the healthcare services situation in each country (see **Figure 2**).

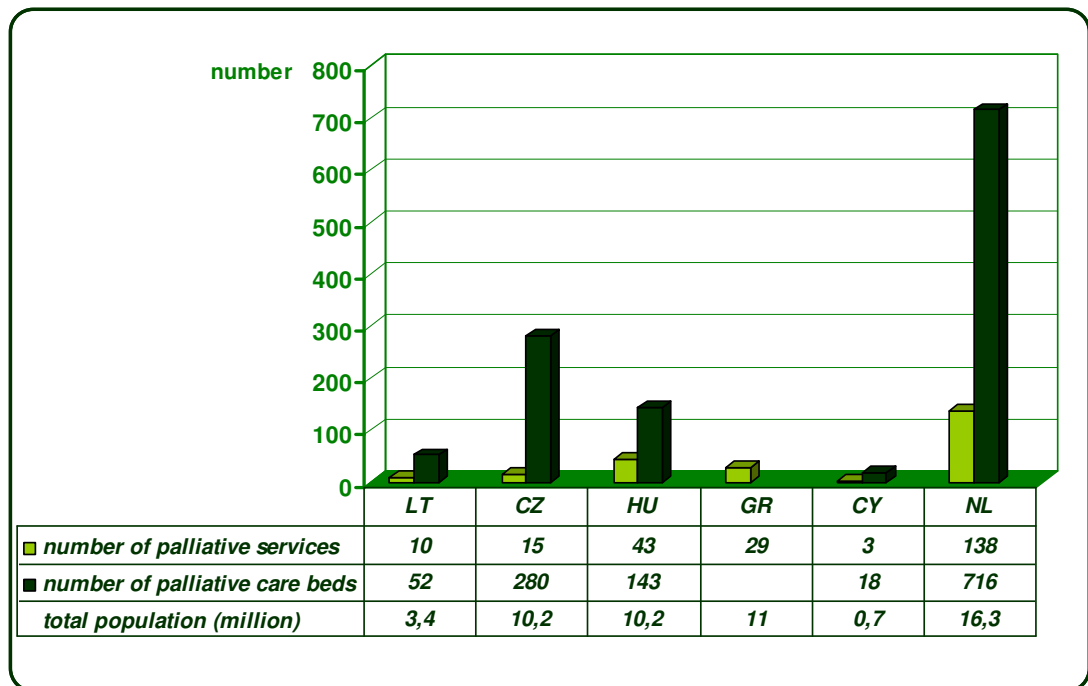


Figure 2. Overview of palliative care services in the participating countries⁷

2.2.3 Historical and cultural differences in volunteering

Third we'll mention the differences between the volunteer services and the volunteer organisations. This has also to do with the different historical backgrounds of the examined countries.

In the Eastern European, former communist countries the word "volunteer" has a totally different meaning than it has for the Southern and Western European countries. Although a stereotype, there's a difference between the partly forced (literally or emotionally) volunteer work in Lithuania, Czech Republic and Hungary (think of the phrases "public benefit work" and "communist Saturdays"); very informal volunteering in Greece and Cyprus (mostly family based – it is normal to do and there is no discussion about it) and the free choice to volunteer based on a long history in the Netherlands.

This also explains the differences between the organisations involved in this project.

⁷ source: EAPC Atlas of palliative care in Europe, IAHPCPress, 2007

- The Lithuanian Socialisation Vocational Training Centre (SVTC) was established in 2001 by a team of female managers with lengthy experience in the field of women and youth rehabilitation. It provides training and rehabilitation services and leads projects for combating unemployment aiming at the social induction of social groups who face social exclusion.
- Palliative Medicine Association of Lithuania was founded in 1995. It is a voluntary non-governmental organization uniting representatives of different professions: doctors with different specialities, nurses, social workers, rehabilitations specialists, and representatives of spirituals. It actively cooperates with the Ministry of Health and Government, and promotes the development of a unified national system of palliative care in Lithuania.
- The Cypriot Socio-political Studies Institute (IKME) was founded in 1996 as a non-profit institution aiming to contribute to the prevalence of freedom, democracy, socialism and the European values.
- The Greek Centre of Vocational Training (SBIE – CVT) was founded in 2000 by the Educational Organisation SBIE and offers high quality educational services in the form of intracorporal training seminars and consultation services.
- The Union of Catholic Women (UKŽ) is an NGO founded in Prague in 1992, operating on voluntary terms with a portfolio of successful credentials in implementing projects that disseminate their gospel into practical help for the Czech women in need. Its membership consists of women associations which are gradually being formed in the Czech and Moravian parishes. In targeting its mission UKŽ organises women into voluntary activity groups, provides legal and social consultation as well as psychological and practical support and counselling to its members and to the public with regard to social induction and employment rehabilitation of women that are mostly at a disadvantage in the labour market.
- The Catholic Caritas Foundation of Pécs Diocese (Caritas Pécs) is the official relief organisation of the Diocese of

Pécs of the Hungarian Catholic Church, which was reorganised in 1990 after the decades of communist banning. It is a regional organisation co-ordinating the work of 36 local Caritas groups and the work of more than 300 volunteer workers. The aim of its operation is engaging in all kinds of social helping activities, enhancing the equal rights of underprivileged social groups and providing charity activities focusing on ethnical minorities, poor families and the homeless.

- The oldest volunteer organisation for palliative homecare in the Netherlands was founded in 1980 and was followed in 1986 by founding the National Volunteers Palliative Terminal Care (VPTZ), the same year as the founding of the first volunteer hospice (almost-like-home house). VPTZ is a specialised volunteer organisation to promote the contribution of trained volunteers in palliative terminal care where it is needed and where people in the last phase of their life want it. Therefore VPTZ stands for the position of the volunteers in the palliative terminal care as well as in the health care as a whole. VPTZ is an association with 205 local members (65 hospices; 140 volunteer palliative care home services) with almost 7.000 volunteers and 400 volunteer coordinators⁸.

On the one hand there are young organisations (LT, GR, CY) in a specialised learning environment, older organisations (CZ, HU) with connections to old religious institutes and a specialised volunteer palliative care organisation (NL) with quite a lot of experience in this type of care. This gives the opportunity to look from different perspectives to the question what every organisation needs to fulfil their role in voluntary palliative assistance of senior to elderly people in each country.

Figures 3 - 6. present a statistical overview of the demographic data of the six participating countries.

⁸ VPTZ Registration report 2005, Bunnik, the Netherlands, 2007.

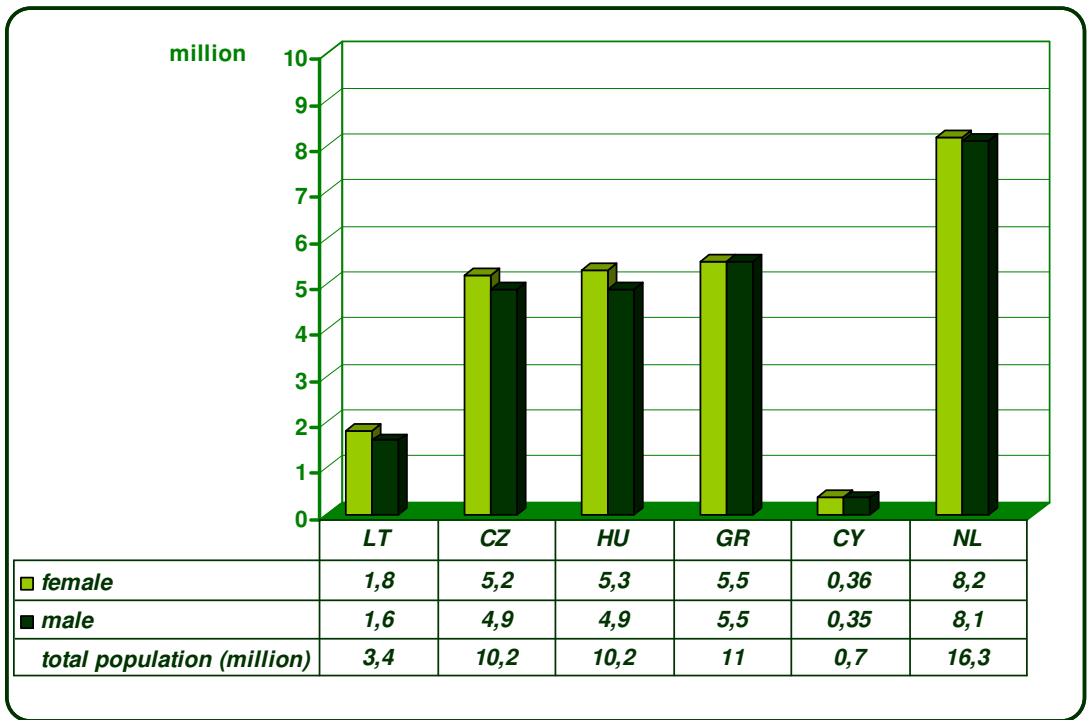


Figure 3. Total national population

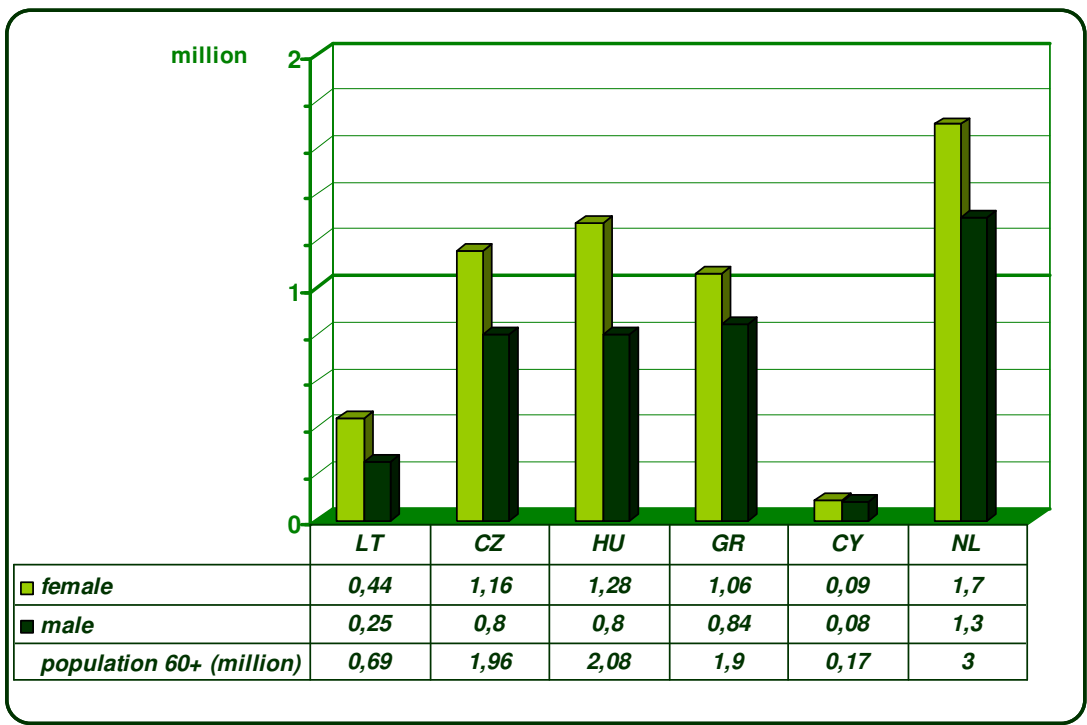


Figure 4. Population over the age 60

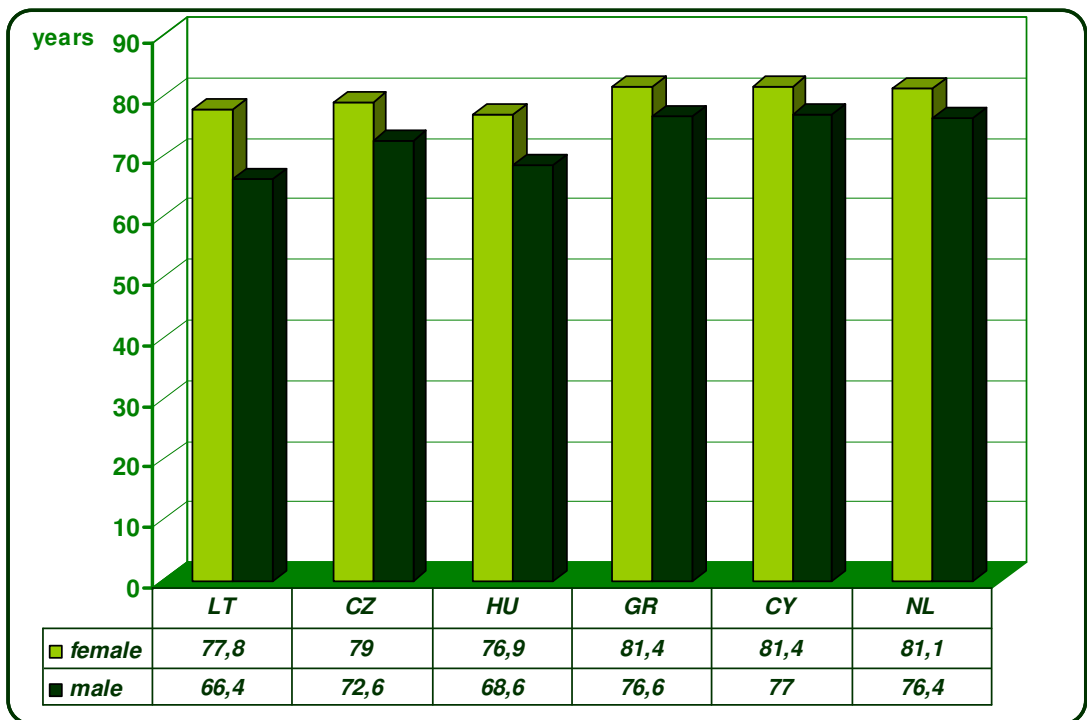


Figure 5. Average life expectancy

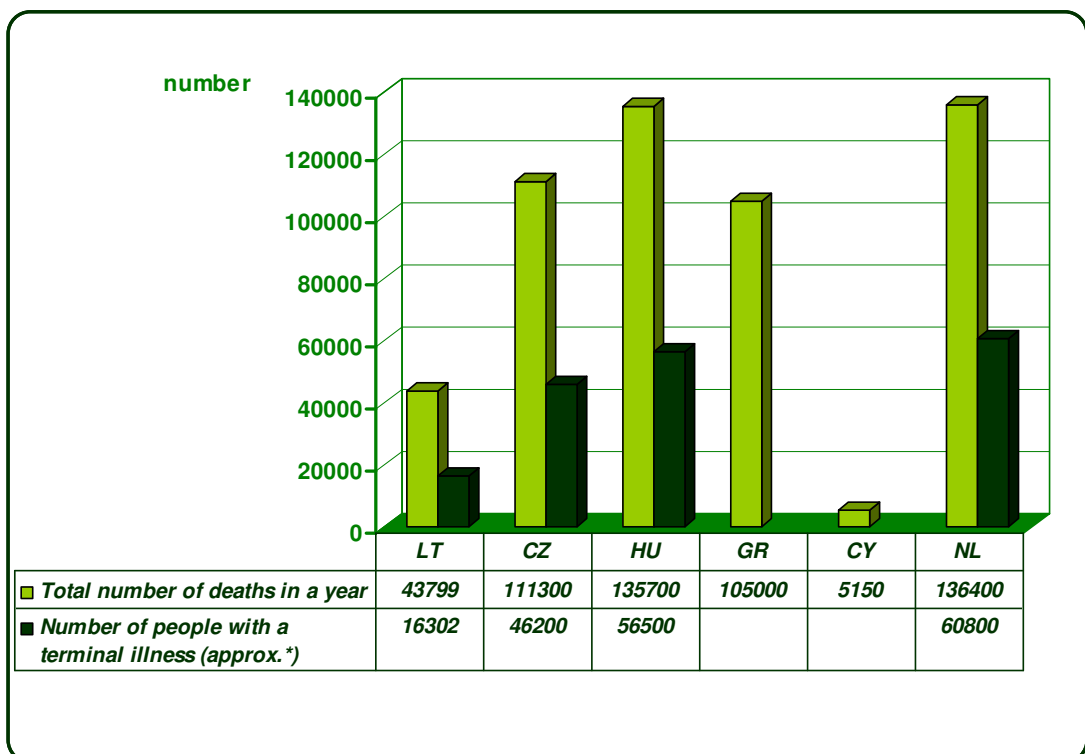


Figure 6. Deaths and terminal illnesses

*** Note for Figure 6.:** For this purpose we collected data for neoplasms, cerebral vascular diseases, chronic diseases of the respiratory system and diseases of the digestive system. The national figures found aren't completely comparable to each other. The percentage of people with a terminal illness, who die after a phase of palliative care, is by estimation about 40-45% of the total number of people who died in a year.

3. Volunteers in palliative care

3.1 The quality of the volunteers' work in palliative care

Quality is the adherence to standards and disciplines that are set for the performance of the volunteer services as well as for the learning and empowerment of the volunteers which is aimed by the associated training courses.

Palliative care is teamwork, with nurses, doctors, psychologists, priests, social workers and specially trained volunteers in the team. Teamwork demands an emphasis on communication and sensitivity.

The importance of communication is stressed by Marie Opatrná of the Institute of Humanitarian Studies in Medicine of the Charles University in Prague⁹.

Good communication skills are an essential part in all areas of health care, and as such, are not specific to palliative care. Communication involves much more than the delivery of information. It is a process involving many people where the objectives include information exchange, mutual understanding and support, addressing difficult and sometimes painful issues and dealing with the emotional distress associated with such issues. It involves time, commitment, and a genuine wish to hear and understand the concerns of one another. In part, it is about providing answers, in a greater part, it is about staying with the patients when there are no answers and trying to empathise with their pain. In the palliative care setting, patients and families are often under stress. Not infrequently, there is little if any

⁹ see presentation at: <http://www.pecsi-caritas.hu/seniors/material/MarieOpatrna-PalliativeCareandClinicalPastoralCare.pdf>

communication between the various parties involved. In such circumstances, there is enormous scope for misunderstanding and resentment.

Individuals may feel that they are carrying an unfair burden of the care. Old rivalries and jealousies may surface in the family or community, and the entire process may rapidly spin out of control.

The main effort for the volunteer is "to be there" – in a right mood, on the right place and at the right moment.

In that sense quality in volunteer work means for the participants of the project:

- the right attitude in terms of compassion, modesty, sensitivity for the needs of the patient and the family;
- good communication skills;
- dignity for the volunteer as well as the person and family that asks for care;
- reliability shown in terms of preciseness/punctuality;
- to be task oriented as well as relation oriented.

Quality thus means the scrupulous carrying out of a well-defined task and in a right sense. The tasks can be planned, since we can rely on the worker who carries it out and a good feedback system for the volunteer and the patient/family is part of the service that is provided.

In this part we emphasize the quality of the relationship between the volunteer and the patient and the patient's family. It is about who you are as a person and volunteer, about personal skills and about the organisational conditions of the volunteer to give time, attention and support. Most of the quality systems developed in the professional healthcare systems put a lot of effort in the quality of the organisation. Although this is an important issue, it doesn't say anything about the personal and relational part of caring. Volunteer organisations depend on the motivation of people to give their spare time and dedication to this particular organisation. Quality in this type of organisation is about the essence of the particular type of volunteer work and has an intentional character.

This is an important aspect of the training of volunteers and volunteer coordinators in palliative care.

3.2 The impact of volunteers in palliative care in the six different countries

For now there is little experience with specialised volunteers in palliative care in the six project countries, except for the Netherlands. This has to do with differences in historical backgrounds, the socio-economic differences, cultural differences (for instance the awareness of death and dying in a society), the state of the healthcare system and palliative care in each country. Some of these differences we mentioned in *Chapter 2.2*.

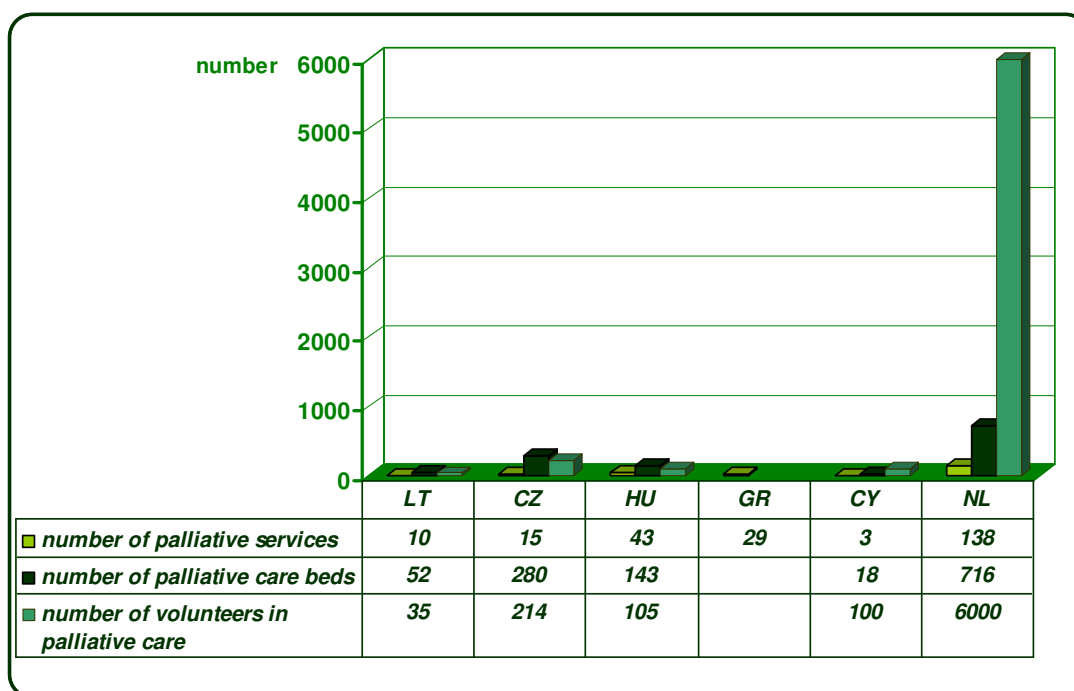


Figure 7. Overview of volunteers in palliative care in relation to the palliative services in the participating countries¹⁰

¹⁰ source: EAPC Atlas of palliative care in Europe, IAHPCCPress, 2007
(Note: these data are older than the data mentioned in *Chapter 2.2.3*, see **Footnote 8.**)

The official statistics don't say much about the real impact of volunteers in palliative care. In the Netherlands VPTZ uses a three-point declaration about the importance of volunteers¹¹.

- First, volunteers bring the human face of society into the healthcare system and can prevent the system from hospitalization and medicalization.
- Second, volunteers can be the linking pin between the patient and the family, and the professional carer because of their special position and the way they are trusted by the patient and their relatives.
- And third, volunteers are the ambassadors for palliative care in the society. They are the ones who speak up about death and "living till the end".

Volunteers are in this perspective not a replacement for professional workers, nor a way to cut the costs in healthcare. They have their own position and responsibility.



Picture 3. Visit at "Nea Thalpi" Long-Term Nursing Home, Athens, GR

¹¹ Long-term strategy VPTZ 2006-2010, Bunnik, The Netherlands, 2006 (in Dutch)

4. **Some impressions from the visits by the project partners**

As the results of the first project year's work showed, the selection of project partners is purposive, since great differences both in palliative assistance and voluntary work in this field are observed. This enables the continuation sharing the experience and learning from each other. Though the socio-economic conditions are different, the main purpose remains the same – to provide voluntary services, improving as much as possible the quality of life in the last step of life.

The example of Pécs has shown that palliative assistance is well organized there, and the presented lectures about nursing and the visits to the hospices confirm this. Voluntary assistance is provided both at home and in hospice. In Greece and Cyprus the voluntary inter-assistance is recognized as a widely accepted matter because it is based on the strong family and community relations. In Prague we have seen a well organized palliative assistance system, though voluntary work in Strasburk Hospice is not widely applied. We were particularly impressed by the activity of the Home Care Hospice Cesta Domů, providing nursing services at home.

Although the Czech Republic is quite advanced in the field of palliative care, still in comparison with the Dutch reality there is a lack of volunteers as well as a lack of palliative services with regard to the number of inhabitants. "Serving the poor is not a sacrifice, but a privilege" – said Mother Teresa of Calcutta (as the motto on the brochure of Caritas Pécs reads). The project may reveal the reasons and causes of having not so many volunteers as required. It may reveal the possibilities how to improve the work with volunteers and how to attract the potential volunteers, especially among the seniors.

This project stretches over Europe regarding the home of the project partners: North to South, East to West. From the Hungarian part we observed that some gradients and differences follow this geographic span. These differences can be seen in

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CZ

HU

the volunteer movement of the countries, the structure and development of the healthcare system, and the relation of the authorities and the society to palliative care.

The visits to institutions and the presentations by invited experts revealed innovative solutions and significant initiatives (e.g. at the Home Care Hospice Cesta Domù in Prague, CZ). This affirmed our choice of methodology that as the project evolves, we can and must learn from each other to reach our goals.

CY

From the Cyprus point of view, the visits to hospices comprised a turning point in our learning curve both on the problems revealed in the countries under review as well as the solutions given by the societies for taking care of the terminally ill people. We will promote this knowledge to cascade the experiences learned into the efforts towards emerging practices in this field.

GR

Visits to different hospices in different countries and the exchange of views between partners of different nationalities, experts and other relevant people revealed advantages or disadvantages of the systems adopted in order to offer palliative assistance to elderly people. Taking into consideration that palliative care is destined to improve the quality of life of patients facing problems associated with life-threatening illnesses, we can understand how crucially important it is to be able to offer high quality services in the healthcare sector. Greece keeps making stable steps towards providing better care, but still has to make serious efforts to follow the Hungarian and Dutch good practice in the relevant field.

NL

From the Dutch perspective there are three important impressions from the visits of the different services and institutions, the lectures, the discussions with each other and the overall experience.

First of all the differences in financial and economic possibilities between the countries are huge. The small room and the lack of privacy in the hospice in Lithuania in comparison with the Dutch hospices is one example. But this doesn't say anything about the

commitment and the loving care that caregivers provide. This shows the essence of what caring is about.

Secondly there are differences between the countries and the volunteer organisations in the way they perceive their own role in the healthcare system or just beside the system. In this perspective the Hungarian and Dutch organisations have more in common in the services they (want to) provide than the organisations that see themselves more as an assistance to the healthcare professional.

And at last we mention the different moods you can feel in each country. The Euro sceptic view in the Netherlands, a rich country which is anxious about losing things versus the look forward for the young members of the EU who are hoping to gain things and benefit from their partnership in the EU.



**Picture 4. Visit at Home Care Hospice Cesta Domù,
Prague, CZ**

5. Preliminary conclusions

At the end of the first project phase, some preliminary conclusions can be drawn. These are:

- 1.** There are more or less the same demographic tendencies in the six countries involved in the project:
 - the life expectancy is getting higher;
 - the total population in each country is decreasing or is expected to decrease in the next decades;
 - the percentage of persons of 65 years and older is increasing.
- 2.** The role of the family, the role of homecare, the role of institutional care is all changing.
- 3.** There are significant socio-economic differences (a "gap") between NL, GR and CY on the one hand, and LT, CZ and HU on the other hand. These socio-economic differences have a causal relation to the difference of life expectancy in the countries.
- 4.** There are great differences in the health care system of the countries from the financing issues to the availability of the health services and palliative care in specific.
- 5.** Concerning volunteer work, in the project there are young organisations (LT, GR, CY) in a specialised learning environment, older volunteer organisations (CZ, HU) with connections to old religious institutes and a specialised volunteer palliative care organisation (NL) with a lot of experience.
- 6.** We have defined coincidentally what quality in volunteer work and palliative care means for the partners. First of all palliative care is teamwork, and as such it demands an emphasis on good communication and sensitivity. Quality in volunteer organisations depend on the motivation and the dedication of the volunteer workers. Quality in this type of organisations is about the essence of the particular type of volunteer work and has an intentional character, in comparison to professional

healthcare systems which focus on measures and processes of the whole system.



Picture 5. Project Meeting at Catholic Caritas Foundation, Pécs, HU

7. As for the standing of the volunteers in palliative care: they are not a replacement for professional workers in healthcare nor a way to cut costs. They have their own position and responsibility:

- to be the human face of society in the healthcare system;
- to have a special, personal relation with the terminally ill patient and the family, which is based on trust;
- to act as the ambassadors for palliative care in the society.

8. As the quote in the title says: "We are on this earth to be at home somewhere." Volunteers in palliative care can help to provide for terminally ill patients to feel and be at home, even till the end.



Appendix

The project partner organisations and their representatives are:

SVTC – Socialization And Vocational Training Centre

(Lithuania - LT)

Ms. Danguole BOGUSEVICIENE

Palliative Medicine Association Of Lithuania

(Lithuania - LT)

Ms. Aukse NARVILIENE

Catholic Caritas Foundation of Pécs Diocese

(Hungary - HU)

Ms. Anna FORRAYNE

Mr. Pal CSONKA jr.

Association Volunteers Palliative Terminal Care

(The Netherlands - NL)

Mr. Hans BART

Czech Catholic Women Union (Czech Republic - CZ)

Ms. Marie BOHACOVA

IKME – Sociopolitical Studies Institute (Cyprus - CY)

Mr. Alecos TRINGIDES

Center of Vocational Training CVT SBIE Ltd

(Greece - GR)

Mr. Gavriil IORDANOGLU

