

# HUNGARY



The Republic of Hungary (population 10.08 million)<sup>1</sup> is a landlocked Central European country located in the Carpathian basin that covers an area of 93,030 square kilometres (1% of the size of Europe) with more than half the area being lowlands surrounded by mountain ridges and hills.<sup>2</sup> Hungary occupies a strategic location astride main land routes between Western Europe and the Balkan Peninsula as well as between Ukraine and the Mediterranean basin; the north-south flowing Duna (Danube) and Tisza Rivers divide the country into three large regions. Its land boundaries border Austria, Croatia, Romania, Serbia, Slovakia, Slovenia, and Ukraine.<sup>3</sup> According to the United Nations human development index (HDI), Hungary is ranked 35/177 countries worldwide (value 0.869).<sup>4</sup> This places Hungary in the group of countries with high human development.

## PALLIATIVE CARE SERVICE PROVISION

### Current services

At a board meeting of the Hungarian Hospice Palliative Association (HHPA) on 13<sup>th</sup> March 2007, it was revealed that, despite difficulties encountered in collecting data, 52/57 hospices had participated in the national statistical survey of the HHPA, *Hospice in Hungary* (2006). The figures for palliative care provision in Hungary presented here are based on this survey.<sup>5</sup>

In 2006 there were an estimated 57 palliative care services in Hungary, comprising of 21 inpatient palliative care services (one freestanding unit; ten hospital units; four hospital mobile teams; six nursing home units), 34 home care services, and two day care services. There were an estimated 215 palliative care beds allocated to adults: 10 beds in the one freestanding inpatient palliative care unit; 154 beds in the ten hospital units; and 51 beds in the six inpatient palliative care units in nursing homes. There are no paediatric palliative care services in Hungary - the palliative care service for children in Bethesda Hospital, Budapest worked from 1995 to 2003, but closed in 2003 because there were not enough patients. However, this service is expected to re-open during 2007.

There are a complex range of palliative care services offered in Hungary. For example, *Budapest Hospice House* provides an inpatient unit, hospice home care, hospital mobile team, day care centre, pain outpatient clinic, psycho-oncological outpatient clinic, telephone mental health service, bereavement service, and an education centre; *Elisabeth Hospice, Miskolc*, provides an inpatient unit, hospice home care, day care centre, telephone mental health service, bereavement service, and an education centre; *Pécs Irgalmas Hospice* provides an inpatient unit, hospice home care, hospice in the nursing home, and an education centre.<sup>6</sup>

Despite the fact that there are only two official bereavement support teams in Hungary, many psychologists and nurses working in palliative care have been trained in bereavement support, on courses of approximately 120 hours total duration.<sup>7</sup> At Budapest Hospice House, bereavement support groups are provided for ‘normal’ grief, whilst individual psycho-social support is provided for more ‘complicated’ grief.<sup>8</sup>

*Hospice inpatient units and bed numbers 2006 (date of opening)*

1. Gyula, Pándy Kálmán Hospital	20 beds (1994)
2. Budapest, Szent László Hospital	20 beds (1995)
3. Miskolc, Semmelweis Hospital	20 beds (1995)
4. Pécs, Irgalmas Hospice	18 beds (2004)
5. Pécs, county Hospital	15 beds (2004)
6. Eger county Hospital	20 beds (2004)
7. Esztergom county Hospital	10 beds (2004)
8. Budapest, MÁV Hospital	10 beds (2004)
9. Budapest, Jewish Charity Hospital	10 beds (2004)
10. Budapest Hospice House (freestanding)	10 beds (2005)
11. Nagykanizsa, Hospital	11 beds (2006)

*Total number of beds* *164 beds*

*Hospice beds in nursing homes 2006 (date of opening)*

1. Sóstó, nursing home	10 beds (1997)
2. Pécs, nursing home	4 beds (1998)
3. Szederkény, nursing home	5 beds (1999)
4. Tatabánya, nursing home	5 beds (1999)
5. Hajdúböszörmény, nursing home	15 beds (2002)
6. Debrecen, Szent Erzsébet Hospice	12 beds (2003)

*Total number of beds* *51 beds*

*Hospice home care 2006 (date of opening)*

1. Budapest, Hungarian Hospice Foundation	(1991)
2. Szombathely, Hospice Foundation	(1992)
3. Miskolc, Erzsébet Hospice Foundation	(1994)
4. Tatabánya, Hospice Szeretetszolgálat Foundation	(1994)
5. Debrecen, Szent Erzsébet Hospice	(1994)
6. Székesfehérvár, Help 17.Bt. Hospice Home Care	(1995)
7. Nagymaros, Pax Corporis Foundation	(1995)
8. Pécs, Social Net Association	(1996)
9. Óbuda-Békásmegyer Hospice Home Care	(1997)

10. Kecskemét, Ölelő Kéz Foundation	(1995)
11. Ruzsa, Bánfi Hospice Home Care	(1999)
12. Kaposvár, Nevitt Hospice Home Care	(1999)
13. Szegedi Hospice Foundation	(2002)
14. Pécs-Baranyai Hospice Foundation	(2004)
15. Békéscsaba, Csahó Hospice Home Care	(2004)
16. Mártély, Csernai Hospice Home Care	(2004)
17. Recsk, Rencia Hospice Home Care	(2004)
18. Eger, Agria 2000 Hospice Home Care	(2004)
19. Esztergom, Vaszary Kolos Hospice Home Care	(2004)
20. Mátraterenye, Koher Hospice Home Care	(2004)
21. Salgótarján, NRG-i Hospice Home Care	(2004)
22. Salgótarján, Tábita Hospice Home Care	(2004)
23. Nagykanizsa, Ápoló Kéz Hospice Home Care	(2004)
24. Zalaegerszeg, Mónika Hospice Home Care	(2004)
25. Budapest, Szent Rita Hospice Home Care	(2004)
26. Százhalombatta, Gondoskodás Hospice Home Care	(2004)
27. Szolnok, Morpheus Hospice Home Care	(2005)
28. Novaj, Menedékhely Foundation	(2005)
29. Szeged, Gondoskodás 2003 Hospice Home Care	(2005)
30. Ercsi, Benedikt 2001 Hospice Home Care	(2005)
31. Majosháza, Református Hospice Home Care	(2005)
32. Cegléd, Homecare 2002	(2005)
33. Váci Homecare BT	(2005)
34. Veszprém, Fehér Galamb Foundation	(2005)

*Hospital support teams 2006 (date of opening)*

1. Dombóvár, „Életet az éveknek” Foundation	(2001)
2. Dombóvár, Alkony-Támasz Foundation	(2001)
3. Budapest, Hungarian Hospice Foundation	(2001)
4. Sopron, Hungarian Maltese Service	(2006)

**Table 1 Palliative care provision in Hungary 2006**

		<i>Existing services (2006)</i>
<b>Adult/paediatric</b>	Inpatient palliative care units	20
	Inpatient hospices	1
	Consultant teams in hospitals	0
	Home care teams	34
	Day centres	2
	<b>Adult/paediatric total</b>	<b>57</b>
<b>Paediatric</b>	Inpatient palliative care units	0
	Inpatient hospices	0
	Consultant teams in hospitals	0
	Home care teams	0
	Day centres	0
<b>Paediatric total</b>	<b>0</b>	
<b>Grand total</b>		<b>57</b>

## Reimbursement and funding for services

In 2004, the National Health Insurance Fund (NHIF) and the Ministry of Health made an important decision to create the legal framework and financial foundations of hospice care as an integral part of the health service. On September 1<sup>st</sup> a two-year model programme started, under which the NHIF supported service givers and hospital wards which provided hospice care for cancer patients and their families from a monthly fund of HUF 100 million. This was intended to multiply the number of people who can have access to hospice care.<sup>9</sup>

Dr. Csaba Simko, medical director at Elizabeth Hospice (Otthon), and vice-president of the Hungarian Hospice Palliative Association stated:

‘From September 2004, there is a new, special hospice financing system which takes the whole hospice team into account. It provides a real possibility to maintain a hospice homecare team and covers about 70% of the expenses of an inpatient unit... Up to now non-profit organizations (foundations) [were] the main constitutional form but from this time for-profit organizations also started to work in this field.’<sup>10</sup>

Since 2004, 42 hospice services out of 57 have been financed as 'hospice services' by the NHIF (11 inpatient services, two nursing home, and 29 home care services). However, there is still not enough financial support from the National Health Insurance Fund.<sup>11</sup> The operation of the Hungarian Hospice Foundation, for example, depends heavily upon the donations of individuals and corporations, and in 2004, the National Health Insurance Fund provided only 6% of its budget. Dr Katalin Muszbek, Director of the Hungarian Hospice Foundation, suggests that whilst funding for education/training initiatives is not too difficult to obtain, the funding of daily activities within the hospice is considerably more difficult, particularly for psycho-social activities.<sup>12</sup> For many organisations, there is often not enough money to start and maintain palliative care programmes (especially inpatient units); this lack of acceptable financing has weakened many organizations, and some of them have changed the direction of their activity.<sup>13</sup>

Thus, despite the additional funding provided by the NHIF, hospice and palliative care initiatives still need to raise money from alternative sources. Katalin Muszbek suggests that this way of thinking is often difficult in post-communist Hungary:

‘...you know, some people are thinking in Hungary that everything should be covered by the budget because people are used to that coming from the organised health care system, that they are working in a hospital, they have the beds, they have the medicine, they have the salary, they have everything. But if anybody is working with hospices, we have to realise and we have to recognise that about 50 per cent of the money is coming from the budget but we have to add about 30 per cent of the money from different resources, and these resources can be different grants, different applications to the EU and other groups, and fundraising from the community – and also money from the churches and from other sources. So I think, and this is one of the tasks of our Foundation, because we are quite advanced in the management and in PR, that we will organise some courses for the Hungarian people [on] how to do management, how to, how to change the traditional management, how to [do] fundraising, how to make PR in Hungary to get more money or more resources – not only money but also human resources.’<sup>14</sup>

These sentiments are echoed by Dr Agnes Ruzsa, the second President of the Hungarian Hospice Palliative Association, speaking in 2004:

‘I think now I think it is a very important time, a very important point which occurred now in Hungary because the National Health Service can support the hospice and the palliative care units in this year, so I think never, ever was this such an important time, because now there is a possibility for every service who want to take care of dying patients to be supported by the government and to be financed by the government, but it is also important that it is only 50 or 60 per cent of the financial support, and I think that it is very important that the services have to look for other possibilities for charity and for, I think, for some tax support or anything else.’<sup>15</sup>

Since 1997, the Hungarian Hospice Foundation has secured funds to develop the home care service, to enhance the management of pain relief, to establish a volunteer programme and to develop the hospice house project. The hospice mobile team at the Jewish Charity Hospital was awarded funds to establish the service, to educate team members and to cover salary costs. The Hungarian Hospice-Palliative Association obtained grants to publish national palliative care standards, to translate those standards into English, to publish hospice news and to develop a national programme of palliative care education.<sup>16</sup>

Other sources of additional funding include: local governmental support; grants; donations; and the 1% tax law. The Hungarian tax system contains a paragraph allowing citizens to assign 1% of their salary to the support of local organisations, churches and foundations, which increasingly benefits hospice institutions.<sup>17</sup> The Hungarian Hospice Foundation is a special charity, and so anyone paying taxes in Hungary can donate 1 per cent of their income tax, an option of great value for both the Foundation and for those people who want to help.<sup>18</sup>

*NHIF financed hospice services that use other funding sources:*

Magyar Hospice Alapítvány  
Szombathelyi Hospice Alapítvány  
Miskolc, Erzsébet Hospice Alapítvány  
Gyula, Pándy Kálmán Hospice Osztály  
Debrecen, Szent Erzsébet Hospice Házi Beteggondozás  
Miskolc, Erzsébet Hospice Otthon  
Budapest, László Kórház  
Pécs, Szociális Háló Egyesület  
Kaposvár, Nevitt Cindy Szolgálat  
Sóstói Idősek Otthona, Hospice Részleg, Naplemente Alapítvány  
Tatabánya, Nefelejts Ápoló Ház  
Pécs, Betegápoló Irgalmas Rend, Hospice  
Eger, Markhoz Ferenc Kórház, Hospice  
Budapest, MÁV Kórház, Hospice  
Zalaegerszeg, Mónika BT  
Pécs-Baranyai Hospice Alapítvány  
Budapest, Szent Rita Szolgálat  
Pécs, Baranya megyei Kórház, Hospice  
Budapest Hospice Ház  
Szeged, Gondoskodás 2003  
Majosháza, Református Egyházközség Szolgálat  
Salgótarján, Tábita Szolgálat  
Váci Home Care

In 2002, Katalin Muszbek revealed an unexpected source of income - a charitable donation from events organised through the Charles Dickens Heritage Foundation, by a descendant of Dickens with a family connection with Hungary:

‘What kind of support could I get this year? Charles Dickens’s great-grandchild visited us: she has a Hungarian relation on the mother’s side, and she visited some Hungarian NGO’s looking to support a civil organization, because there is a Charles Dickens Heritage Foundation, and she visited a lot of groups, and she also visited our Hungarian Hospice Foundation. And I introduced our project, and the hospice house and she – her choice, or the choice of this Board, was the Hungarian Hospice Foundation. And they organized A Christmas Carol Ball and the income, the pure income was 10 million Forint, and all the audience were mainly British persons who are working here in Hungary, and you cannot imagine what they did – they put the 10,000, the 50,000, the 100,000 Forints into a pot and they offered [them to] us.’<sup>19</sup>

An imaginative promotional campaign raised funds from a wide variety of sources after support had been forthcoming from high profile Hungarian personalities. Katalin Muszbek describes the background to the campaign:

‘...it was a survey done by Katalin Hegedus in 1999 about the perception of hospice, the word hospice in the country; none of the people we asked knew the word so we started in 2001 with a huge campaign and in 2002 we repeated it... the aim of this campaign was to change the public mind about death and dying because it’s a taboo in Hungary, nobody speaks about it, and when the people are thinking about things like cancer everybody is very afraid of the suffering but nobody is saying ‘oh I can die’ or ‘what about death and dying’ so it was really a taboo...so we started with this publicity campaign involving three key persons, actresses and artists from Hungary who are very famous and a film of testimony was done by them...It’s a lovely film, its three really lovely films, and at the same time we put billboards on the street, indoor posters, and the publications in the newspapers, and for two weeks maybe at the beginning, one of the most well known actress was coming in and I was going to meet her every morning and every evening she gave interviews to different television stations because the people do not listen to me, but the people will listen to this young actress. So it was running for two months in five Hungarian spoken channels and in one year there were about 100 publications in the newspapers, television, radio and everywhere.’<sup>20</sup>

One of the key persons involved in the campaign, actress and film star Kate Dobo, describes her motivation to help the Hungarian Hospice Foundation:

‘Just like a lot of people in Hungary, I also went through a distressing and anxious period in my life: 2 years ago I lost my grandmother who died of cancer. During her treatment, we experienced how humane the care was where hospice was present... All the good things that have happened to me in the past four years...are actually gifts that I feel I must return. I am confident in saying that if you fail to give, life does take something from you...I adore my job, I love learning and I incredibly enjoy making films. All this, however, does not suffice. I realized it when I myself became involved in this sad topic by losing my grandmother. When hospice helped in her care, I promised I shall return the favour. That is why I am trying to help now. May I please ask for your help to let the first Hungarian Hospice House come true.’<sup>21</sup>

Since the television publicity campaigns relating to hospice and palliative care in Hungary that featured well-known Hungarian personalities were shown, there has been a substantial increase in the number of people contributing to the funding of the hospice via the ‘1% tax law’. Katalin Muszbek explains the possible reason for this increase:

‘I think it was the basis of our successes because our activity before was very nice clinical work and education, but it was recognised because the whole hospice programme, or the mission, mission of the hospice was not clear for anybody in the country, not even for the public. The people didn’t know what hospice means, and to some families whose relative was cared for in a hospice, they were very much for it, and they recognised it of course, but generally it was not recognised. So that was the reason why we decided to organise, to make this national publicity campaign, and it was a very high quality campaign so it was not a regular campaign, and the people who could see these spots on the television immediately opened their eyes and said ‘Look, it’s something special’...it touched everybody because although the people are not speaking about dying people, everybody has a relative who died...and a lot of interviews were done, and additionally we made a report about the last year, about our professional programme and about our budget, so we wanted to avoid that failure, not to be transparent, and we put it also into the newspapers and we advertised our final report about the previous year. So this different information was coming to the people and this resulted in a huge awareness increase.’<sup>22</sup>

Katalin Muszbek recalls the fame she encountered following the publicity campaigns and her subsequent appearance in *Cosmopolitan* magazine:

‘I can tell you a small story, after this campaign I was going into a shop and a 20 year old lady with long painted nails was asking for some paper. When I was asking for the bill she told me that she thought ‘this is the Hungarian Hospice Foundation!’ and she looked at me and said ‘you have this wonderful face on the television!’ and congratulated me on how nice it is and she wished me a lot of energy and for such a woman who is going just into disco’s and nothing is interesting, so for me it was really something I thought it was a success that such a young woman who does not care [about] anything [but] to dance and look good and she says ok, this is fantastic!’<sup>23</sup>

A number of charity concerts have also been held in the St. Stephen's Cathedral, the Kálvin Square church, the Óbuda Club and the Music Academy, featuring artists like Veronika Kincses, Márta Sebestyén, Zoltán Kocsis, Dezső Ránki, Gábor Presser, and the Hungarian Hospice Foundation patrons, the Amadinda Percussion Group. In October 2006, the Foundation organized the event *Hospice Voice* for the sixth time in a row, held at the church at Kálvin tér. The musical programme was presented by the Budapest Bach Orchestra conducted by István Ella. The Messiah by Handel was presented as a routine part of the programme. Besides their charitable purposes, such concerts have also helped to raise awareness of hospice and palliative care in Hungary. The purpose of this worldwide event is to attract widespread attention to the problems of cancer patients and the terminally ill and to accentuate the need for help.<sup>24</sup> However, Katalin Muszbek also suggests that although there is now a better understanding of palliative care in Hungary, the fear of pain and the concept of ‘hospice’ continues to play a major part in the public perception of cancer.<sup>25</sup>

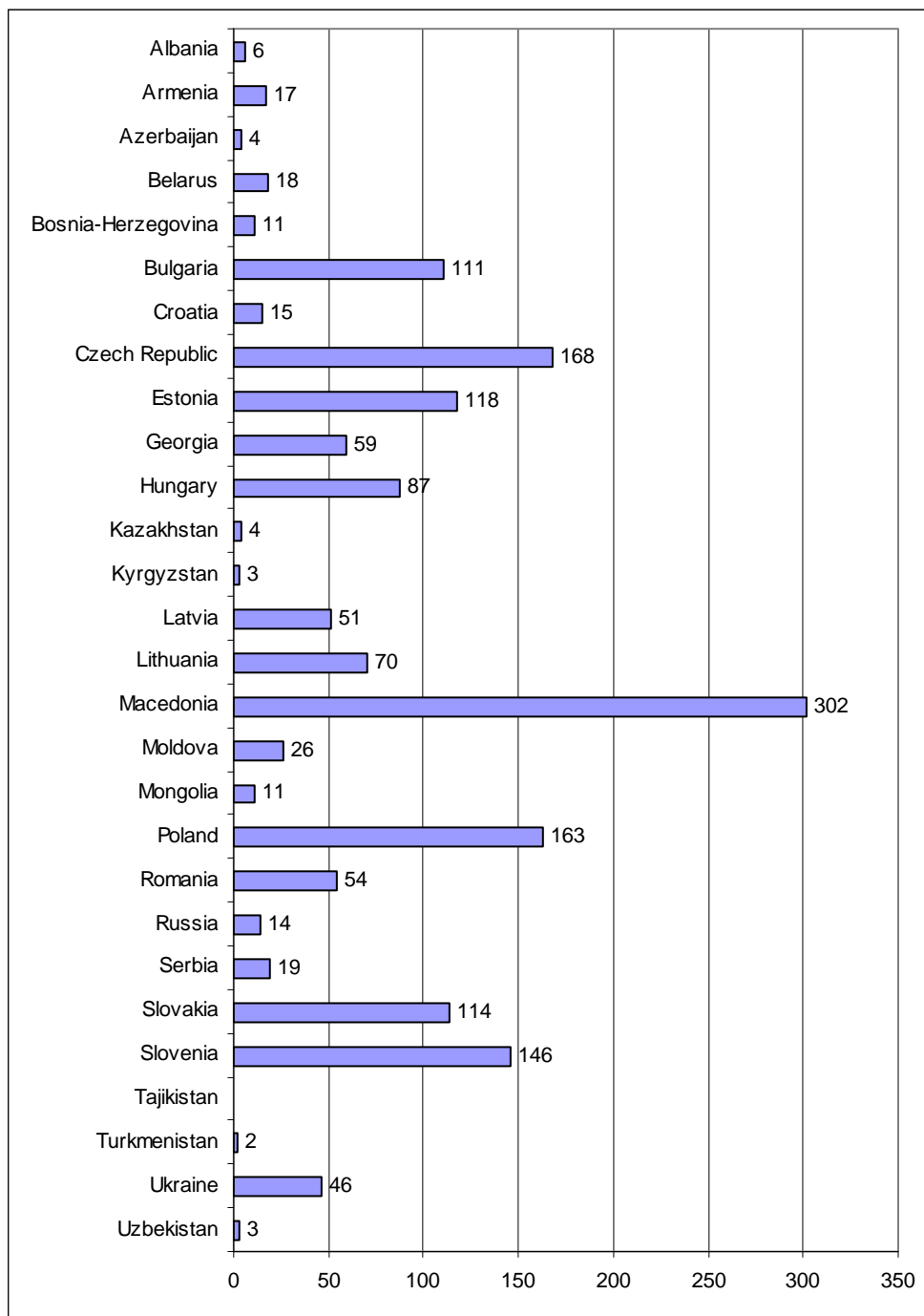
### **Opioid availability and consumption**

In 1994, oral slow release morphine, tramadol and dihydrocodeine became available free of charge to cancer patients, and transdermal fentanyl is also available without charge in outpatient settings. A wide range of opioids is available, including: morphine – immediate release, controlled release and injectable; methadone, oxycontin, pethidine and fentanyl. All are free to cancer patients except immediate release morphine and oxycontin.<sup>26</sup>

For the years 2002-2004, the average defined daily dose consumption of morphine for statistical purposes (S-DDD)<sup>27</sup> in Hungary was 87. This compares with other Central and

Eastern European countries as follows: Croatia 15, Romania 54, Serbia 19, Slovakia 114, and Slovenia 146 (Table 2).

**Table 2 Average daily consumption of defined daily doses (for statistical purposes) of morphine per million inhabitants, 2002-2004 Central and Eastern Europe/Commonwealth of Independent States (plus Mongolia)**



Source: International Narcotics Control Board *Narcotic Drugs: Estimated World Requirements for 2006. Statistics for 2002-2004*. New York: United Nations, 2006.

The International Narcotics Control Board<sup>28</sup> has published the following figures for the consumption of narcotic drugs in Hungary (2004): codeine 2907 kg (up from 2363 kg in 2003); dihydrocodeine 367 kg (down from 460kg in 2003); methadone 7kg (up from 5kg in

2003); morphine 26 kg (down from 31 kg in 2003); pethidine 11 kg (down from 12 kg in 2003).

There has been a lack of adequate knowledge and experience amongst many physicians in relation to the prescribing of strong opioids. This has resulted in a number of lectures that were given to attempt to improve the knowledge of physicians and nurses on the appropriate use of strong opioids and to reduce patients' fear of opioids<sup>29</sup>

Regional and nationwide campaigns against pain were organized by the Cancer League and Hungarian Hospice Palliative Association in 2000.<sup>30</sup> Yet Csaba Simko suggests that:

‘There were regional and nationwide campaigns against pain organized by the Cancer League and the Hungarian Hospice Palliative Association. The Cancer League delivered a survey amongst cancer patients in 2000, which gave a disappointing result about painkilling.’<sup>31</sup>

However, Agnes Ruzsa suggests that the attitude of oncologists to palliative care and opioids may be changing:

‘I think, erm, we have a lot of opportunity to use the new drugs in oncology and there [are] a lot of oncologists that were interested in the new protocols, the new chemotherapeutic agents, new chemotherapeutic drugs, but not in palliative care, but two years ago, or five years ago something changed and the oncologists are more interested in my work and in palliative care now, I think it's very important.’<sup>32</sup>

In September 2005, the Hungarian Government announced the National Cancer Control Program (NCCP) as part of the National Development Plan. Quality of life improvement and social and professional collaboration for fighting cancer were indicated as the main aims. A further aim was to 'accomplish a complex oncological approach and to form and operate an effective care system providing balanced patient care'. With this purpose, the NCCP followed the guidelines and recommendations of the World Health Organization's (WHO) National Cancer Control Program. In order to develop the program which was prepared by the Ministry of Health, the Hungarian Hospice-Palliative Association (HHPA) offered to construct the chapter of hospice/palliative care and recommendations/aims, since these were not present in the first plan of NCCP. Very useful relationships were formed between the Association and the Ministry's Department of Health Policy during the years while constructing the *Palliative Professional Guidelines* (2002) and the *Palliative Minimum Conditions* (2004) and while organizing joint conferences (2001; 2005). The first version was submitted for social-professional debate in November 2005. Katalin Muszbek recalls the haste with which the proposal was submitted:

‘We did not have more than two weeks because the Hungarian National Cancer Control Program was in process and the deadline was maybe two weeks and the members of the association immediately came together and we wrote it and we sent it, he sent it back, we re-wrote it etc and there was a one week conference organised for about 250 – 300 doctors, policy members, decision members, pharmacists and other researchers and other groups to have an open discussion on the development of the National Cancer Control Programme. There I had the opportunity to make a presentation about palliative care in the National Cancer Control Programme.’<sup>33</sup>

From 2006, palliative care was included in the *National Cancer Control Program* in Hungary.<sup>34</sup> The HHPA represented itself at debates within the professional colleges and via the member organizations it collected further additions and proposals. The final National

Cancer Control Program was introduced on the 3rd February 2006, in the National Institute of Oncology in the presence of the Prime Minister and the WHO representative Cecilia Sepulveda. Unfortunately a somewhat less detailed section was included in the final NCCP about palliative care than was in the first version.<sup>35</sup> Hospice provision was included in the NCCP with the explicit aim of creating a countrywide hospice network to improve the quality of life of cancer patients. Stage one of the program relates to the coverage of hospice and palliative care in Hungary to be achieved by the scheduled deadline of 31<sup>st</sup> December 2007. Yet Katalin Muszbek suggests that the target of meeting 70% of palliative care coverage is unlikely to be achieved: currently only approximately 50% of those requiring palliative care are actually receiving it.<sup>36</sup>

### **National and professional organisations**

The major umbrella, national organisation within Hungary is the *Hungarian Hospice Palliative Association*. Founded in 1995 by the *National Association of Cancer Patients* and 19 hospice organizations, it supports the development of palliative care through inviting applications from organizations that provide (or intend to provide) hospice care, and from individuals who wish to offer support. In 2007, there are 49 member associations of the Hungarian Hospice Palliative Association. It represents the interests of members in a variety of forms - including discussions with the Ministry of Health. Agnes Ruzsa recalls the formation of the association:

‘...we had to organise an association for the hospice teams and for the cancer patient, and in 1995 we and the other hospice teams, the 12 hospice teams decided to organise this association, the Hungarian Hospice Palliative Association which was working together. At this time the goals were first to ask for more pain control – to ask the government and the financial supporters for accreditation and minimum standards and so on.’<sup>37</sup>

The Association became affiliated to the European Association for Palliative Care (EAPC) in 1999 and is supported by The Open Society Institute, New York. The Association is involved in a broad range of activities. In addition to monitoring the progress and development of hospice organizations, it disseminates information to its members from the EAPC. Topics of interest are included in the Association’s annual conferences, in its quarterly newsletters, and in a series of publications entitled *Hospice Patient Care*. The Association encourages quality of life research and represents the interests of hospice within the national health care system. In 2002, the Hungarian Hospice-Palliative Association (with the support of the Soros Foundation) produced the document *Palliative Care of Terminally Ill Cancer Patients Professional guidelines: 2nd improved and extended edition*.<sup>38</sup> The 6<sup>th</sup> Congress of the Hungarian Hospice-Palliative Association (with the participation of the leaders of the EAPC, organised by the Elizabeth Hospice Foundation) was held on 23<sup>rd</sup>-24<sup>th</sup> April 2004, Miskolc, Hungary.

Hungary was a signatory to the Poznan Declaration (1998) and is a member of the Eastern and Central European Palliative Care Task Force (ECEPT). Its palliative care leaders subscribe, therefore, to the call for national policies, palliative care education, increased drug availability, a growth in palliative care services and an increase in public awareness. Hungary was represented on the Council of Europe’s (2000) committee of experts on the organisation of palliative care by Katalin Hegedus. A hospice and palliative care research group is associated with the Institute of Behavioural Sciences, Semmelweis University of Medicine.

A number of international collaborations have been established. Erzsébet Hospice, Miskolc, has developed links with Casa Sperantei (Romania) and Sir Michael Sobell House (UK).

Bethesda Children's Hospital, Budapest, has worked closely with Warsaw Hospice for Children; in 1999 these two hospices engaged in a partnership to organise the first paediatric palliative care conference for physicians in Eastern Europe, held in Budapest. Seventy-five representatives attended from 19 European and three non-European countries (Argentina, Australia, and Canada). A similar collaboration contributed to the second conference, held in Warsaw in 2001.<sup>39</sup> Budapest Hospice House has twinning arrangements with hospices in Ukraine, Moldova, Turkey, Romania, and Georgia. It had a five year (2002-2007) twinning arrangement with a hospice in Krakow through an EU/PHARE grant, and enjoys a twinning arrangement with Sir Michael Sobell House, Oxford (UK), and Buffalo Hospice, New York.<sup>40</sup>

### **Palliative care coverage**

Approximately 13% of all cancer patients have access to a specialist palliative care service in Hungary. In rural areas, coverage is provided mainly by home palliative care teams connecting to the regional (not palliative) home services.<sup>41</sup> Katalin Hegedus, President of the Hungarian Hospice Palliative Association, describes some of the problems relating to palliative care coverage:

‘...there are different counties in Hungary, there are 19 counties and Budapest and the coverage for home care, for home hospice care, you can see there are some counties where there is nothing, not anything.’<sup>42</sup>

Agnes Ruzsa expresses her desire for total palliative care coverage:

‘In the future we are working for the cancer patient but we want to cover all the country, all Hungary, we want to provide this care for all cancer patients and the next step we want to provide for the older patients too.’<sup>43</sup>

Katalin Muszbek describes the advances made in palliative care coverage in Budapest:

‘So we serve our patients here in 12 districts in Budapest, Budapest has 24 districts and we started to work in 12 because we had a small team and the city is huge so that's why we did not make a contract with all the districts of Budapest because some of them are far from here; we cannot do that and two years ago we applied for a European union grant to start with networking and we found a small district in north Buda that is south Pest and that's a very innocent area I mean without any type of hospice care and from this European grant we established an office, we found a senior nurse there and also the disciplinary team members they belong to us so this is under our authority...This group is working doing very well, every month they come here once to our meeting, regularly the senior nurse is doing the case discussion meeting every week as we do here, and the documentation or the administration comes here and we send it to the national health insurance and because this work had started there we decided to add two other districts from this south Pest region to this networking and we applied to the municipality and it was also successful and now it will be about 300,000 inhabitants in that district where we are able to provide care...Then we would like to go to the local hospital to ask them for their support to start with a ten-bed unit there. It should be step by step when we start the next region; the next year if it is possible an in-patient unit behind this region and then if we are successful with this we are going to the south Buda region so there may be three or four regions in Budapest that are able to provide good care for the whole of Budapest.’<sup>44</sup>

At a board meeting of the Hungarian Hospice Palliative Association (HHPA) on 13<sup>th</sup> March 2007, it was revealed that in regions outside Hungary (for example, in Transylvania, Romania), Hungarian nationals are advised to go to the local hospice, but many prefer to return to Hungary for treatment.<sup>45</sup>

In 2005, the ratio of hospice/palliative care services in Hungary was one service per 0.23 million inhabitants (see Table 3). This compares to one service per 0.37 million inhabitants in 2002.<sup>46</sup>

**Table 3: Ratio of hospice/palliative care services per million population; Central and Eastern Europe (2005).**

	<i>Ratio 1:</i>
Estonia	0: 1.34m
Poland	1: 0.09m
Slovenia	1: 0.24m
Bulgaria	1: 0.18m
Hungary	1: 0.22m
Latvia	1: 0.28m
Lithuania	1: 0.34m
Czech Republic	1: 0.61m
Albania	1: 0.61m
Romania	1: 0.59m
Slovakia	1: 0.76m
Macedonia	1: 0.29m
Bosnia-Herzegovina	1: 1.11m
Croatia	1: 1.48m
Serbia	1: 2.13m

*Source: EAPC Taskforce on the Development of Palliative Care in Europe (2005) A Map of Palliative Care Specific Resources in Europe. 4<sup>th</sup> Research Forum of the European Association for Palliative Care, Venice, Italy, 25<sup>th</sup>-27<sup>th</sup> May 2006/ Clark, D., and Wright, M. (2003) Transitions in End of Life Care: Hospice and Related Developments in Eastern Europe and Central Asia. Buckingham: Open University Press.*

Csaba Simko suggests that:

‘The main aim is to spread hospice/palliative care into those regions of the country, where there is no hospice team now. [This] should take care of about 50% of cancer patients in 10 years. The Hungarian Hospice Palliative Association has to control palliative care teams, [therefore] assuring the good quality of professional work.’<sup>47</sup>

### **Education and training**

In Hungary, education and training initiatives are regarded as significant contributors to the development of palliative care. The Hungarian Hospice Foundation was formally established on 29 April 1991, led by Dr Katalin Muszbek who recalls:

‘Our first activity was education. We didn’t work with patients at all. We organized courses – a lot of courses – here in Budapest, and those people who participated or attended our courses, they started their own group in the country to establish another small hospice group.’<sup>48</sup>

As a result, a number of grant applications was made during the 1990s to ensure the continuation of educational activities. These grants meant that key personnel could attend international conferences held outside of Hungary; they also guaranteed the presence of palliative care experts at conferences within Hungary. In addition, funds were allocated for the development of courses at postgraduate and undergraduate levels. Extension courses on the ethical and psychological problems of death and dying began at Semmelweis Medical University in 1993; a further series was offered in 1994. These courses proved to be popular, each course attracting between 100 and 120 participants. Arising from them, a monograph entitled *Close to Death* was published in 1994, followed by *Close to Death II* in 1995. Katalin Hegedus, Professor at Semmelweis University, has played a major role in the establishment of palliative care education. She describes how she became involved as follows:

‘My mother died of lung cancer [in 1990] and that’s why I began to deal with the problems of dying people. I went to France to learn about hospice and palliative care and I had a lot of study tours and different courses...First I was a sociologist, it’s my profession, the second one is a psychologist...at first I was a volunteer, but after I gave psychological care to hospice palliative patients, I organised a national education system of palliative care in Hungary.’<sup>49</sup>

To support the education programme, a series of textbooks has originated from Semmelweis University of Medicine, supported by the European PHARE programme. They include titles such as *Hospice basic knowledge*,<sup>50</sup> *Cultural anthropology of death and dying*,<sup>51</sup> *Psychology of death and mourning*,<sup>52</sup> and *Basic knowledge of palliative care*.<sup>53</sup> Another series of booklets is available for physicians, nurses, chaplains, social workers and physiotherapists, published by the Hungarian Hospice Association. In 1997, the thanatological journal, *Kharon Thanatological Revue*, began to include a section on palliative care and to accept papers on palliative care subjects.<sup>54</sup>

Curricula, guidelines and standards for palliative care (for example WHO- standards, Council of Europe documents etc.) have been translated into Hungarian. Additionally a one-year post-graduate educational programme for nurses exists, which, following a law decreed in June 2001 by the Ministry of Health, began in 2002. A national training program for Palliative Care, organized by the Hungarian Hospice-Palliative Association was accredited by the Ministry of Health and includes a basic course spanning 40 hours as well as an advanced course of 40 hours.<sup>55</sup>

Much hospice/palliative care education is organized by the Hungarian Hospice-Palliative Association, in association with the Institute for Basic and Continuing Education of Health Workers and the Semmelweis University of Medicine. A grant from the Open Society Institute supported the education programme from September 2000 until 2005, with Katalin Hegedus the grant holder and programme co-ordinator.

Hospice services can now draw from nursing personnel trained in standardised national basic and advanced courses and possessing at least a basic knowledge of palliative care. Yet while hospice and palliative care training for nurses is expanding, there is a severe shortage of doctors with palliative care knowledge, and palliative care content hardly exists within the medical curriculum.<sup>56</sup> Katalin Muszbek highlights some of the inherent difficulties in this area:

‘Well we have a barrier, a big barrier, it’s the doctors. Because the palliative care issue is not acknowledged in Hungary and not recognised in Medical Universities, it means that in the undergraduate medical courses there are only one or two sessions about it, whether it is called palliative care or not. So it is not built into the undergraduate

courses and there is no specialisation in it and that's why the doctors are not very interested in it...for me the undergraduate level is more important now because I know for all professors the communication will not change between the old professor and the patient, but for the young medical students I believe and I am sure because I have been working at the university for 20 years and I know it's more important now, and for the older physician I don't know exactly how we can involve them.<sup>57</sup>

At undergraduate level, hospice courses have been run for future health care workers (nurses, social workers, physiotherapists) consisting of 20 hour modules (accredited since 2002). Palliative care courses for medical students have also been run: 'Palliative care of terminally ill patients', consisting of 30 hour modules (accredited since 2003 by Semmelweis University and Pécs University), and attended by approximately 200 medical students.<sup>58</sup> Yet generally, under-graduate attendance on palliative care education and training initiatives remains insufficient, and Katalin Hegedus highlights the need for more physicians to attend:

'...we need physicians because physician, nurse and coordinator are the obligatory members in the team and the other team members are not obligatory but recommended. And the education they need to finish some palliative courses, for nurses it is obligatory 40 accredited hours, for physicians a palliative care course and for other team members too, and for the coordinator nurse there is a one year course, it is obligatory too...but I think that under this health authority scheme it will be obligatory to finish a one week course for every GP, in two years and I am sure that it will be a good result; for nurses it is excellent, for nurses, we have a very good post graduate accredited course with a lot of nurses and we have this one year course for the hospice nurse and coordinator.'<sup>59</sup>

At postgraduate level, 40 hours basic and 40 hours advanced post-graduate hospice and palliative courses, accredited by the Ministry of Health, and organized by the Hungarian Hospice Palliative Association and the Institute for Basic and Continuing Education of Health Care Workers have been run, attended by about 3,500 health care workers and volunteers. Other postgraduate courses, organized by the Hungarian Hospice Foundation, Budapest, Erzsébet Hospice Foundation, Miskolc and Social Net, Pécs have been attended by about 1000 health care workers and volunteers. At the specialist level, a skilled hospice nurse and coordinator course has been run, consisting of 750 hour modules (accredited since 2002), attended by approximately 200 nurses.<sup>60</sup>

At a board meeting of the Hungarian Hospice Palliative Association (HHPA) on 13<sup>th</sup> March 2007, it was revealed that access to training and education initiatives had improved drastically as a direct result of the 2006 National Cancer Control Program. It was also stated that at the forthcoming EAPC Congress to be held in Budapest (organized by the Hungarian Hospice Palliative Association), from a total of 1050 submitted abstracts, a record 200 had been received from Central and Eastern Europe, and 30 abstracts had been accepted from Hungary alone. Most of the plenary sessions were to involve an interpreter, so many health professionals from rural Hungary were expected to attend, although it was noted that the three day minimum registration fee for the congress had caused some financial difficulties for people from the Hungarian countryside.<sup>61</sup> Katalin Muszbek describes plans for the Congress:

'So first of all we are very proud of it as it is organised in Budapest and also because there are plenty of developments in Hungary and it seems to me that the preparation is going well, we have almost finished the scientific part of the preparation and a lot of local organisations are going now and we would like to make this meeting very remarkable...also what I am very happy about is that many Eastern delegates are going to come because its much cheaper for them to find cheap accommodation, and

now maybe there are 200 registered persons from Eastern Europe in the last meeting there were 60, so it's a big increase, and also I think that it will influence the Hungarian palliative care development because we will involve plenty of decision makers from Hungary.'<sup>62</sup>

By May 2007, there were 1934 registered participants for the Congress; 336 from Central and Eastern Europe/Commonwealth of Independent States (including 94 from Hungary).<sup>63</sup>

### **Palliative care workforce capacity**

In general, there is a lack of well trained full-time palliative care experts in Hungary,<sup>64</sup> as described by Katalin Muszbek in 2004:

'I have an excellent team of nurses, physicians – physicians are working part-time, this is the crucial point in any Hungarian hospice team, that's it's very difficult to get a physician who contributes completely to the hospice and we are suffering from this problem as well. But we have good part-time physicians so we have an excellent team.'<sup>65</sup>

Yet in a later interview, Katalin Muszbek suggests that the recent health reforms may lead to an increase in the palliative care workforce:

'Now there is a health reform in Hungary and now the government have decided to reduce the budget of the health care it means at the same time that until now there were few unemployed doctors but now there will be because active beds are reduced and maybe the interest towards our topic will increase and they may trickle in to palliative care by that method...I think that due to this health reform plenty of physicians will not find work, so maybe some of them will show an interest in our work and, so I am really optimistic so I think that in three years there will be at least twice as many services as there are now.'<sup>66</sup>

In 2006, an estimated 1093 people were working in palliative care in Hungary, including 104 physicians; 524 nurses; 41 social workers; 57 psychologists and mental health experts; 79 physiotherapists; 40 dieticians; 44 coordinators; eleven occupational therapists; nine bereavement counsellors; four ambulance personnel; 40 spiritual counsellors or leaders and an estimated 140 volunteers.<sup>67</sup> The relative lack of volunteers may result from Hungary's Socialist past, when voluntary structures were not supported and therefore did not exist. Another reason may be that the misuse of donated money by so-called charity organisations in post-socialist Hungary proves to be a hindrance for those organisations who wish to work on a voluntary basis.<sup>68</sup> Volunteer training courses comprise of 120 hours training, and volunteers tend to be mainly men, spanning a wide age range. Voluntary work averages approximately four hours per week.<sup>69</sup>

## **HISTORY AND DEVELOPMENT OF PALLIATIVE CARE**

### **Narrative history of palliative care**

Hungary's capital city, Budapest, has played a special role in the development of the Hungarian hospice movement. It was in Budapest that innovative pioneers were to be found at the end of the 1980s; a group that included the President of Hungary and other leading figures. A groundswell of interest arose that eventually led to the establishment of Hungary's first hospice and the Hungarian Hospice Foundation. Meetings with ministers and government

representatives ensured that in Hungary, hospice care became incorporated into the Hungarian National Health Service.

Palliative care in Hungary began with the collapse of the communist system. Prior to the political changes that began in 1989, issues dealing with death and dying were considered to be taboo.<sup>70</sup> The experiences of Alaine Polcz, one of the key figures in hospice development in Hungary, are noteworthy:

‘I worked for two decades on the department of paediatric oncology – leukaemia – and at that time leukaemia was doubtless considered as a terminal illness of swift course. We had immense losses. We tried to create more human and bearable conditions for the last days of the children. However, it was a very hard task – for everyone. I collected my experience about dying in the hospital and at home. I examined the various aspects of the issue and I wrote an article about it. I did not find a place to publish it. At long last, after months of hesitation, the periodical ‘Valosag’ published it. This publication was a battering ram – a pioneer work in Hungary.’<sup>71</sup>

As the 1980s drew to a close, two groups in Budapest, based at the National Institute of Oncology, began to collaborate and explore more holistic ways of dealing with patients.<sup>72</sup> From this collaboration emerged the first Hungarian hospice, known as the Hungarian Hospice Foundation. Alaine Polcz figured prominently amongst the seven founder members.<sup>73</sup> Well known in Hungary, she was associated with the liberal branch of Hungarian politics and had married the acclaimed writer, Miklos Meszoly. As a friend of both George Soros and President Arpad Goncz, her contacts proved to be helpful in the establishment and development of hospice.

The Hungarian Hospice Foundation was formally established on 29 April 1991. The hospice addressed its activities at first to making the public aware of palliative care, and to begin to change attitudes.<sup>74</sup> The concept of hospice was completely unknown to the public, the approach to death and dying a taboo. Consequently the Hungarian Hospice Foundation’s main concern was to bring this new form of care for the dying into the public and enlist relevant social organisations for support.<sup>75</sup> Led by Dr Katalin Muszbek, its aims were stated as follows:

- (i) Psychological and mental care for dying patients
- (ii) Pain and symptom control
- (iii) Public health and social services care
- (iv) Help and counselling for family members
- (v) Bereavement service for family members
- (vi) Establishing hospice houses and hospice care teams
- (vii) Organising a hospice education system

The service, which initially meant home care given by a few volunteers, is now provided by a variety of organizations, in various forms (inpatient unit, hospice home care, hospital mobile team, day care centre, pain outpatient clinic, psycho-oncological outpatient clinic, telephone mental health service, bereavement service, etc.). Hospice teams began to form in 1994 with the help of the Soros Foundation.<sup>76</sup>

In 1993, hospice care was incorporated into the Hungarian National Health Service and included in subsequent development plans. Entry criteria were defined and invitations issued to services offering hospice/palliative care who intended to be integrated into the service and subsidised by it.

In 1995, the Hungarian Hospice-Palliative Care Association was established by the National Association of Cancer Patients and 19 hospice organisations, and invited applications from organisations and individuals who provided or wish to support palliative care. The Association is heavily involved in education, alongside Semmelweis University of Medicine and the Institution for Basic and Continuing Education of Health Workers. It also organises annual conferences, disseminates information from EAPC, and publishes a quarterly newsletter.<sup>77</sup>

In 1997, Hungarian Health Law declared the human right of palliative care, and defined hospice care. The legal framework was made to conform to European standards and WHO recommendations when a new act on health services was created, which dedicated an entire chapter to patient rights, and a section to the definition of hospice treatment.<sup>78</sup> When the new Health Care Act of 1997 was being drafted, a 3-person committee made up of Bela Blasszauer, Ference Falus and Katalin Hegedus produced a document dealing with the care of the dying. This document has become an important reference base; a summary was incorporated into the Health Care Act to outline the principles of hospice care. Yet Katalin Muszbek recalls the difficulties in the legislation:

‘This Act involved the topic of hospice, so there is a paragraph, an Act, a part of an Act, I don’t know this is a paragraph on what does hospice mean? Everybody has the right in the terminal phase to have hospice care, the family members can stay with the patients in the hospice, etc, so this is very modern, and we were very happy in ’97 that we had this Act and we thought that it’s working. But this Act in Hungary in the Hungarian regulation or Hungarian legislation, the Act itself is not working, only if it has a special regulation. And this was missing, so it was not a hospice code. It doesn’t mean that when you made a hospice activity it was not registered as a hospice activity, it was registered as a normal home care service or a chronic bed activity in a hospital, because we had a code for those two, but we didn’t have a special code, a special regulation, for hospice...in the Act there is hospice but in practice it was not hospice care.’<sup>79</sup>

National Guidelines and standards for palliative care were established by the Hungarian Hospice Palliative Association and accepted by the Ministry of Health in 2002, and a detailed palliative care guideline was launched that dealt not only with professional but also constitutional and financial aspects of palliative care.<sup>80</sup> These guidelines – approved by the Health Department – were sent to all Hungarian hospitals.<sup>81</sup>

In 2003, there was a media campaign to establish human rights and patients rights organisations that initiated a parliamentary examination.<sup>82</sup> The Council of Europe report on palliative care (Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care) was translated and edited by the Hungarian Hospice Palliative Association in October 2004 with the participation of many journalists.<sup>83</sup> When interviewed in 2002, Dr Katalin Muszbek stressed the need for a Ministerial decree relating to the provision of hospice and palliative care in Hungary:

‘I would like a Ministerial Order...a Ministerial Decree Order is very important for the financial system; it’s the most important.’<sup>84</sup>

The lack of a Ministerial Decree to regulate the financing of palliative care began to affect the availability of funding from other sources, as Katalin Muszbek recalls:

‘One of the main barriers to the development of palliative care in Hungary was the lack of the decrees or regulations, the problem was that palliative care is not

recognised in Hungary...we were told that if we do not have any regulation in palliative care then we can not go on many of the Hungarian groups. The hospice groups are based in the civil background, they are NGO's or some of them are working in a hospital and the hospital manages the in-patient unit, but in general there is a foundation behind that which they built to raise money, or some charity managing the differences between the budget of the government and the real expenses.'<sup>85</sup>

By 2004, changes to Ministry of Health personnel and continuous lobbying from pioneers such as Katalin Hegedus and Katalin Muszbek had introduced fresh optimism about the possibility of a Ministerial Decree:

'...in the last year that there were some political changes and some personnel changes in the different Ministries, in the different authorities. One was that a psychiatrist, who is a psychoanalyst, and a very socially sensitised person, or a socially skilled person, became the Vice-Minister in the Ministry. The second one is that the Director of the National Health Insurance Fund became a person who was interested in creating or setting up a hospice. So these two key persons were the target of our lobby in the last two years...So we tried to approach first the Minister, the new Minister, and the different levels of the Ministry, and we got the promise that they are really willing to help us. And we prepared the, not only the Foundation, but the ... Association prepared material regarding what would we like to have in the regulations...So we prepared this, and then we formed, we lobbied it at this Minister, the two Vice-Ministers, and it seemed to be that they had open minds, they were open-minded and they encouraged us to do this.'<sup>86</sup>

Eventually, after many years of lobbying, publicity and educational work, numerous advertising campaigns and the organisation of charity events to spread the hospice philosophy, hospice and palliative care became an integral part of the Hungarian health care system:<sup>87</sup>

'...we were working at it, the Board of the Hospice Association, Palliative Association, but practically Katalin (Hegedus) and me were in the Ministry at the final preparation of this regulation, and we were there almost a day. And we finished it at about six o'clock and we...I begin to cry now to...we've got it!...so we embraced each other and we began to cry, because that was a historical point that we could not believe that after 13 years it's done, it is there, it's on the paper that there is a hospice regulation, there is a hospice code that means that it will be in the Hungarian daily practice.'<sup>88</sup>

In April 2004 the National Health Insurance Fund and the Open Society Institute organized a Palliative Care Policy Development Conference to set up a National Strategic Plan for Palliative Care. The Hungarian Hospice Foundation, University Clinics and professional medical societies were also invited to this conference in addition to policy makers, hospice and patients' right organisations. Participants accepted recommendations to develop policy, education and training initiatives, the final construction of financing, as well as a national strategy which relied on professional consensus. Recommendations were published in a special medical journal in November 2004. The conference recommended that by 2009, at least half of those requiring help should get it with 70% of all costs covered by the national insurance<sup>89</sup> Katalin Muszbek recalls the pivotal role that the Open Society Institute played during this time:

'Without their activity the whole region would be much, much poorer, and what I could see when I follow from 2000 to 2004 the activities of the countries in the region,

I could see in 2002 a huge development and in 2003 a much, much bigger development in this country, via the support of the Open Society Institute, because they organise meetings, they visit personally the countries and they organise some local meetings in the country. For example they realised in Hungary that the biggest need is now the policy; in another country it is how to set up the first step, home care; the third country how to [improve] education, etc.’<sup>90</sup>

The National Health Care Insurance Fund started a two-year financing pilot programme for hospice/palliative services in May 2004. The providers had to meet special requirements as elaborated in professional and financial plans, references, infrastructural, personal and material conditions and quality management. The main elements of the monitoring were the professional and operational indicator-system, bi-annual reports and process control. The NHIF stipulated the integrated form of provision: in-patient and home care services needed to operate in conjunction with each other.<sup>91</sup>

In 2004, the Health Ministry launched the Ministerial decree on the *hospice minimum condition* which gave official licences and special financing that took the whole hospice team into account. The ministerial decree for hospice minimum standards was passed providing: a definition of palliative care; description of forms of care (home care, inpatient unit, mobile team); objective and personal conditions of operation. The decree on the minimum requirements for hospice care provided for greater professional control and increased contribution from the state.<sup>92</sup> A lot of the existing inpatient and home hospice services applied, and also some ‘normal’ hospital departments and home care services, who fulfilled the application’s requirements (for example, they had nurses trained in hospice care or the service had a quality control system). Some of the other old hospices did not apply but continued their hospice work on the basis of other support. As a result, in addition to the existing hospice inpatient centres, some other hospitals that were not previously classed as hospices received financial support.<sup>93</sup> Katalin Muszbek recalls the importance of clearly defining a ‘hospice service’:

‘...the key element of this project is that, if a hospital opens a hospice inpatient unit, the minimum beds, the number of beds are 10. When they open it should be combined with a home care team ...so the first and the very important thing is that it is based on the minimum standards, so if a group is applying to get this money, this reimbursement, and they are not the minimum standards, they are asking just because this is good money, better money than regular, they cannot get it. It’s very important, because when we extend an activity, you know, all those people who see the money in the new project are applying for it, and we would like to keep the essence of hospice/palliative care...Because now we know what it means or it is written; what does it mean hospice and palliative care, what is its meaning, what kind of personal needs or minimal standards has it or any other kind of minimum standards are written in it?...And er that was very important because otherwise you know it was a higher amount of support from the National Health Insurance Fund and if we do not have these minimum standards and the groups are unable, the palliative care groups are unable to complete them then it became a business and not palliative care and that was one of the reasons why we strongly fought for only those groups to be supported financially that complete the minimum standards.’<sup>94</sup>

Katalin Hegedus elaborates further on the problem of definition:

‘Yes but the main problem for me for example, because in I am in the university and this university has a lot of clinics you know and opportunity we don’t have palliative care in the university clinics and now there is a project in my university to create a

hospice in the university but the head nurse of the university wants something not the professors and dean and physicians, oncological people, but if the head nurse wants to organise something its chronic, it will be a chronic department and not a real hospice you know, and for the other chronic wards and chronic departments it is the same problem because they don't know exactly what are the differences, what are the differences between chronic and palliative care.'<sup>95</sup>

The concept of palliative care as a basic human right was discussed during negotiations leading to the 2004 National Health Insurance Fund/Ministry of Health decision that created the legal and financial conditions for hospice and palliative care to become an integral part of the Hungarian health care system. Within this context, Katalin Muszbek suggests that the ministerial decree has improved access to palliative care<sup>96</sup>

At a board meeting of the Hungarian Hospice Palliative Association (HHPA) on 13<sup>th</sup> March 2007, it was revealed that the National Health Insurance Fund contract ended on March 31<sup>st</sup> 2007, but also that the contract was to be reviewed or extended on the production of a new tender that detailed revised hospice funding provision. Katalin Hegedus suggests:

'This decree is very important for us because without this decree it is impossible to develop the hospices in Hungary, and by this decree we could receive financial support from the national health insurance fund - without this it is impossible, and it was started in 2004 and it is a model programme for two years but for palliative care services who got this financial support it is very important that, after the 2 year programme they can continue this programme in the hospital or in the home care system, and I think that is the main aim of the municipal decree and the national health support.'<sup>97</sup>

Some hospitals will continue to receive hospice care financing, yet others will be terminated because although they began by providing hospice care, they eventually provided chronic care only and therefore do not now fulfil the relevant criteria. By contrast, other hospitals had undergone a complete reorganisation in order to satisfy the hospice funding criteria. The confusion surrounding the definition of a 'hospice' was of particular concern to the HHPA board, who felt that some organisations that did not really provide hospice care could receive NHIF funding, whilst 'genuine' hospices may face closure. A good example of the ethical dilemmas involved in the funding process was the application from a pulmonology institute to set up a 24-bed 'palliative care' unit – it was revealed that the person responsible for submitting the application was pro-euthanasia. It was stressed how important it was that such initiatives do not become part of the hospice and palliative care framework in Hungary. Within this context, Katalin Hegedus and Katalin Muszbek had made recommendations on the financing of hospice and palliative care to the supervisory board of the *National Authority of Public Health*, the *Ministry of Health*, the *National Health Insurance Fund*, the *Oncology Professional Supervisory Board*, and hospice and hospital directors throughout Hungary.<sup>98</sup> The NHIF have confirmed that they are to continue their financial support until at least 31st December 2008.

In 2007, quality control of hospice physician's work has been undertaken by the public health authority.<sup>99</sup> Professional guidelines have been published regarding the palliative care of terminally ill patients with malignant tumours. These standards address the concept and regulation of palliative care, its accessibility on the part of patients and issues of quality. Also stated are the tasks and responsibilities of team members, together with education and training requirements. Standards of documentation, cost analysis and research are also outlined.



*Hungarian Hospice Palliative Association Board Meeting (March 13<sup>th</sup> 2007)*

At a board meeting of the Hungarian Hospice Palliative Association (HHPA) on 13<sup>th</sup> March 2007, it was revealed that the new fee payable under the recent changes to the Hungarian health care system for visiting a GP is not applicable to cancer patients. However, a hospice consultation fee is payable up to a maximum of 20 days per year, whereby the hospice pays the state in advance, and the patient reimburses the hospice accordingly. No reimbursement is required if the patient dies within the 20 day period. There are no costs to home care patients. In reality this is often avoided by patients being transferred from one hospice/hospital to another. Indeed, in practice, only one person to date had been reported as having paid the fee. The HHPA board felt that it was a question of how the law was interpreted, but expressed some concern that this rule may inevitably result in reduced income for hospices and other palliative care institutions.<sup>100</sup>

### **Hospice success stories**

Hospice success stories in the form of palliative care ‘beacons’ are outstanding examples of hospice/palliative care in a particular region. These palliative care services provide illumination in the form of education and training; they are also recognised from afar for their innovation, enterprise and quality. Palliative care ‘beacons’ serve as an example and source of inspiration to others, indicating what can be achieved in difficult circumstances, when the correct ingredients are present for successful innovation, service provision and sustained development. Each palliative care ‘beacon’ faces both common and disparate challenges, and in responding to those challenges, has contributed to the development of palliative care regionally, nationally and internationally.<sup>101</sup>

### *Hungarian Hospice Foundation*

The Hungarian Hospice Foundation was formally established on 29 April 1991 by a group of seven founder members<sup>102</sup> - although at this stage it was more to do with ideas than a building. The prime movers included Dr Alaine Polcz and Dr Katalin Muszbek – who together sought a broader-based treatment of patients, coupled with better communication and the clarification of patient rights.<sup>103</sup> A major project of the Hungarian Hospice Foundation was to acquire and equip Hungary’s first free-standing hospice or ‘hospice house’. Premises

that once housed a kindergarten were obtained in a quiet part of the city within District 3. Once established, the pressing task of the hospice was to make the public aware of its provision for dying patients and to begin to change attitudes. While palliative care attracted widespread philosophical support and generated a lively ethical debate, there was general nervousness when it came to action.<sup>104</sup>

The new millennium brought far-reaching changes in the life of the Foundation. In 2001 the Hungarian Hospice Foundation was selected from 48,000 NGOs in Hungary to be awarded the 'NGO of the Year' Prize of the Non-profit Information and Training Centre (NIOK). After ten years of struggle, in May 2002 the first wing of the Budapest Hospice Home was opened, which was only made possible with substantial public support. The Foundation sought to establish a multi-source income structure to secure funding for its extensive operations, and to ensure that the necessary laws relating to hospice were created and that the state started subsidizing this segment of the health service.

In 2002, the Foundation launched a multi-phase programme to rehabilitate patients, to look after seriously ill people and to support the bereaved. The services of the *Psychosocial Support Programme* are not restricted to the terminal phase, but are available for cancer patients and their relatives from the moment the illness is diagnosed. In 2003, under a two-year psycho-social model project supported by the Bristol Myers Squibb Foundation, the Foundation had a unique opportunity to significantly widen the capacity of the service to support cancer patients and their families: the *Multi-Phase Psycho-Social Support for Cancer Patients and Family Members*. The main goal of this project was to provide psychological support for cancer patients and their relatives at various levels free of charge. The Foundation sought to turn the project into a model for a nationwide program and to spread the conviction that psychological health and well-being is as important in coping with cancer as is medical treatment. The program sought to realize the goals at three levels.

The first part of the project was *LifeLine*, a toll-free helpline was the first step in providing assistance. On-duty volunteers directed the caller to the psycho-oncological ambulance that was available free of charge, where they were received by psychiatrists and psychologists.

The second part of the project involved bereavement support. A bereavement group was launched each year for those having lost their loved ones. These groups mainly included the relatives of deceased patients who had been cared for by the home care team. Members of the group were selected with the help of psychologists, psychiatrists, nurses and volunteers. In the course of setting up the group, the foundation sought to select individuals with a similar bereavement process. The group had between 10 and 12 members and was led by two trained bereavement counsellors. They worked with structural techniques along a planned scheme which was then flexibly adapted to the group's needs. The aim of the group was to reduce the isolation of those in bereavement, to offer an opportunity to share the pain, to alleviate the burdens by getting to know the process itself, to provide practical support, to help recognize opportunities in experiences of others in a similar situation and to open perspectives towards new possibilities and new relationships.

The third part of the project was an assessment and research study conducted at five oncology departments in Hungary (Budapest, Debrecen, Kecskemét, Szeged, and Zalaegerszeg). The study sought to assess the psychological state of patients receiving oncology treatment, and it also included validation of assessment methods new in Hungary: *A validation study of the Hungarian version of the Hospital Anxiety and Depression Scale (HADS) on a large cancer patient sample*. The Hungarian Hospice Foundation commenced this research project in January 2004. In the first phase 130 non-terminal patients were studied. The goal was to establish their psychic condition, their degree of depression and anxiety, as well as to validate

the HADS questionnaire and the so-called Distress Thermometer on a sample of cancer patients. Preliminary results showed that the problems of the sample were typically physical and emotional, and that the anxiety and depression of the patients were in the range of 5-6, on a scale of 21. Thanks to this research, it is now possible in Hungary for professionals in psycho-oncology to use these up-to-date tools for assessing patients' status. Closely related to this study is a project by the *International Psycho-Oncology Society* (IPOS), under which an on-line curriculum is available for professionals working in cancer treatment as part of their daily routine. Their intention was to make them familiar with the most common psychological problems among cancer patients. The Hungarian version of this was completed with the work of the Hungarian Hospice Foundation.

Budapest Hospice House is considered to be the education and training centre for the whole of Budapest, organizing one week postgraduate courses for Eastern-European professionals (primarily for nurses, physicians, psychologists and physiotherapists) whose work is caring for incurable patients and who aim to develop hospice in their home countries. Theoretical lectures are complemented by intensive professional practice at the palliative unit of Budapest Hospice House. In September 2003, Budapest Hospice House hosted a national meeting of professionals, honoured by the presence of the President of the *International Psycho-Oncology Society*, Dr. Jimmie Holland. Participants included heads of professional committees and societies in oncology and psychiatry, university lecturers, the President of the *Association of Hungarian Hospitals*, and Hungarian practitioners of psycho-oncology. The short-term objective defined during the highly productive discussions was to work out the local standards of psycho-oncology. In October 2003 the Foundation organized a conference in Budapest, which was part of the *Open Society Institute Public Health Seminars* series. The aim of the conference was to further the integration of hospice care into the health services of Central and Eastern European countries. The participants were palliative treatment experts, decision makers in health security and government, local hospice leaders, and academics. Nineteen countries sent 72 delegates.

Also in 2003, with support from the Ministry of Interior, the Foundation started an experimental programme at the inpatient ward of the hospital of the Dózsa Avenue homeless shelter. A team of a nurse, physician, physiotherapist, psychologist and volunteer aide gave spiritual support to the patients and alleviated their symptoms. The programme was intended to become a model for a humane service rendered to homeless and incurable patients, one that ensured that the right to human dignity and hospice care, as outlined in the Health Act, are available for everyone.<sup>105</sup> The programme highlighted a number of problems associated with the provision of palliative care for the homeless: lack of volunteers; lack of family member support; lack of training and education for health professionals in this specific area; and late presentation and diagnosis.<sup>106</sup>

In 2004, Budapest Hospice House was substantially redeveloped, and Katalin Muszbek recalls the difficulties relating to the opening of the new inpatient unit:

‘Well we had to think, when we started to reconstruct the building where can we put the inpatient unit, we had to consider that without national budget support, National Health Insurance support, we cannot open it. We can work in the home care system because we can reduce the number of the patients if we do not have enough money, but when we have an inpatient unit it's a very money-consuming field, so we decided to reconstruct the building when we started our discussion with the National Health Fund...this new project was the nine-bed in patient unit and we had to apply for it, and we failed because this is the only hospice house in the country and it had only 10 beds and it was in the regulation by law that an independent hospital should have 20 beds

so they refused it so it was a very big problem because it was one year that this house was empty.<sup>107</sup>

In 2005 the inpatient clinic was finally opened. Referrals sometimes come from physicians, but the main source of referral is self-referral (approximately 70%). This is due to the fact that many GPs tend not to recognise palliative care - GPs are often visited by hospice staff to actually encourage referral. In 2006, Budapest Hospice House had 160 inpatients with an average stay of approximately 20 days per patient (91% bed occupancy).<sup>108</sup>



*The spirituality room at Budapest Hospice House*

The Hungarian Hospice Foundation established an integrative ISO Quality Assurance audit system in 2006. The issued certificate applies to the following activities: professional home care, home hospice care, inpatient care, mobile team service, education related to medical care, pain clinic, day centre and psycho-oncology service.<sup>109</sup>

#### *Mobile hospice team: Jewish Charity Hospital*

In 2001, the Hungarian Jewish Social Support Foundation (HJSSF) established a mobile hospice team based in the Charity Hospital of 'Mazsihisz' – the Federation of the Hungarian Jewish Communities (the Jewish Charity Hospital). The hospice was supported by a grant to the American Jewish Joint Distribution Committee from the Government of Luxembourg as part of their contribution to the Nazi Persecutee Relief Fund.<sup>110</sup>

The Jewish Charity Hospital caters for the health care needs of elderly Jews. In addition to physical care, spiritual, social and psychological care assumes a high priority. Social support identifies a variety of personal, financial and administrative tasks that need to be undertaken with the patient. Psychological support takes the form of discussions regarding anxieties and expectations. At the end of its first year of operation, the mobile team at the *Jewish Charity Hospital* produced a booklet in both Hungarian and English, giving details of its origins, philosophy and activities<sup>111</sup>

The mobile hospice team – located within the hospital – is seen to present a number of advantages. In particular, patients are able to receive palliative care without delay, as soon as

the need arises. Because patients remain in their usual environment, complications do not arise regarding the availability of beds or admission to special units. Cost effectiveness is thought to be high. However, much debate preceded the initiative. During a project interview, Dr Gyorgy Samuel (medical director) explained how in his opinion, hospice philosophy was ‘a human philosophy’ and not owned by any one group.<sup>112</sup> Before the hospice was established, a careful examination took place of Jewish beliefs surrounding death and dying. Eventually, supporters of the hospice prevailed.<sup>113</sup> Dr Katalin Hegedus recalls:

‘The Hungarian Jewish Foundation came to this hospital and they spoke about the hospice movement, but the hospital refused it. And they refused it because the hospice philosophy is against Jewish spirituality, because the Jewish philosophy is for life and not for death. But we spoke about hospice philosophy: it’s *not* for death, it’s for life also, for quality of life, you know – and during 5 months the hospital refused the service and the money also. But this January the American leader and some leaders from Israel came to the hospital to speak with the Director, and the Director accepted the service.’<sup>114</sup>

#### *Erzsebet (Elizabeth) Hospice Foundation, Miskolc.*

The Erzsebet (Elizabeth) Hospice Foundation, as one of the pioneers of the Hungarian Hospice Association, began the homecare of terminally ill cancer patients in 1994. The Foundation contributed to the opening of the Erzsebet Hospice in 1995, which is integrated into the Semmelweis Hospital in Miskolc.<sup>115</sup> The Foundation continuously assists the work of the hospice by obtaining medical and office equipment, as well as items to assist in the care and comfort of the patients. The winning of Dutch grant support in 1999 made it possible to create a day-care department. More volunteers are also getting involved in the work of patient care on a charitable basis.

So far, more than 1500 individuals – doctors, nurses, social workers, psychology and mental hygiene students, trainee priests and ministers – have participated in various training courses at the *Training and Resource Centre for Palliative Care*. Other hospice institutions, like the Jewish Charity Hospital hospice mobile team also send their members to Miskolc for training.<sup>116</sup> The aim of these courses is partly to pass on professional knowledge, and partly to publicize the humane way of treating the dying. In recognition of its educational work, the Erzsebet Hospice Foundation won the title ‘Education and Training Centre’ from the Open Society Institute in 2000.

The professional work of the service is well-known even beyond the borders of Hungary. The Foundation’s doctor represents Hungary on the ECEPT Task Force as a professional rapporteur. The care team received the city of Miskolc’s ‘Nivo’ award in 1999, the certificate of recognition of the Minister of Health in 2000; and the head nurse received the Order of the Golden Cross of the Republic of Hungary in 2002. A significant part of home care activity takes place on a charitable basis and does not enjoy social security support. The foundation attempts to provide the material pre-requisites for its work through gifts, charity events and grants.

#### **Life/oral histories**

##### *Interview with Dr Agnes Ruzsa – conducted by Michael Wright, Budapest (October 2003)*

In 2003, Dr Agnes Ruzsa, Second President of the Hungarian Hospice-Palliative Association (HHPA), was interviewed by Michael Wright in Budapest. In this interview, Agnes describes how she first became interested in oncology through a personal experience involving a family

friend, and how she eventually began working as a full-time oncologist and part-time hospice physician. Agnes details the events that led to the formation of the HHPA in 1995, and the challenges faced during this period, including the difficulty in providing comprehensive palliative care coverage, numerous financial barriers, and the absence of a minimum decree standard. Agnes also discusses the ethical dilemmas involved in the provision of palliative care in Hungary, particularly in relation to the concept of ‘truth-telling’ and the stigmatised and taboo status surrounding death and dying, and highlights the role that spirituality plays in relation to the provision of palliative care, with particular emphasis on the difficulty of maintaining religious and spiritual belief during the period of Communism.

*Interview with Dr Agnes Ruzsa – conducted by David Clark, Miskolc (April 2004)*

Agnes Ruzsa was interviewed again in Miskolc in April 2004 by David Clark. In this interview, Agnes discusses her role as President of the HPPA and her work as an oncologist at Zala County Hospital, and the ways in which these dual roles interact and intertwine with each other. She describes her increased involvement in developing palliative care education programmes for oncologists (for example, in ‘breaking bad news’) and also provides insight into the new quality-of-life research programmes that are being developed. Agnes describes the OSI meeting in Budapest, and the changes taking place at the policy level in Hungary (for example, the introduction of palliative care as an integral part of the *National Cancer Control Programme*).

*Interview with Katalin Muszbek – conducted by David Clark, Budapest (April 2004)*

Katalin Muszbek took her degree in Medicine in Budapest and her diploma in psychiatry in 1978. She was Assistant Professor of Psychiatry at the *Jahn Ferenc Hospital, Department of Psychiatry*, and Chief of Psychiatry at the *National Institute of Mental Health, Department of Psychotherapy*. Later, she was Chief of Psycho-Oncology at the *National Institute of Oncology*, and at St. Stephen Hospital, Gyneco-oncology Department. She is currently Director of the Hungarian Hospice Foundation.

Katalin was a founding member of the Hungarian Hospice Foundation in 1991, and was President of the *Hungarian Hospice-Palliative Association* from 1995 until 2001. At present, she is also honorary president of the *Hungarian Psycho-oncology Society* and Vice-president of the *Eastern and Central European Palliative Task Force* (ECEPT). Katalin is also an editorial board member of *Progress in Palliative Care* and her curriculum vitae lists numerous international presentations.<sup>117</sup>

In 2004, Dr Katalin Muszbek was interviewed by David Clark in Budapest. In this interview, Katalin describes the changes in the provision of hospice and palliative care in Hungary since she was interviewed in 2002. These include the recent National Congress, palliative care education and training programmes, and the continuous lack of finance.

Katalin details the lobbying activities that both she and Katalin Hegedus had been involved in over the last few years with the National Health Insurance Fund, involving the financing and regulation of hospice and palliative care. She recalls their delight at finally establishing a minimum decree standard following a lengthy and difficult administrative process.

Katalin speaks at length about the definition of hospice and palliative care in relation to funding; she also highlights the importance of obtaining funding from other sources and the ways in which this might be achieved. Finally, Katalin describes the difficulties in communicating the meaning of hospice and palliative care to the general public and the ways

in which the television publicity campaign featuring Hungarian celebrities improved public perception.

*Interview with Katalin Muszbek – conducted by Tom Lynch, Budapest (March 2007)*

In March 2007, Katalin Muszbek was interviewed by Tom Lynch in Budapest, and highlighted the importance of recent policy changes in the country and the impact these changes had on the provision of hospice and palliative care. These policy changes included: the 2004 Ministerial decree relating to the minimum standards for hospice and palliative care; the 2004 National Health Insurance Fund/Ministry of Health decision to fully integrate hospice and palliative care into the Hungarian health care system; and the 2006 Ministry of Health National Cancer Control Program. In addition, Katalin spoke about the public perception of hospice and palliative care in Hungary following the recent television publicity campaigns, and the ways in which the provision of psycho-social support provided to hospice and palliative care patients has evolved in recent times.



*Dr Katalin Muszbek, Budapest Hospice House (March 2007)*

*Interview with Professor Katalin Hegedus – conducted by Tom Lynch, Budapest (March 2007)*

Katalin Hegedus is President of the Hungarian Hospice Palliative Association and Associate Director at Semmelweis University, Institute of Behavioural Sciences, Budapest. Katalin took her MSC degree in Sociology in Budapest in 1976, and her PhD in 1994. She began working in palliative care in 1992 as a hospice volunteer at the Hospital of Újpest and after that in St. Stephan's Hospital, Budapest. Following completion of her psychological training in 1996, Katalin began work as a mental health specialist at St. Ladislaus's Hospital, Hospice, Budapest. From 2001- 2004 she was hospice mobile team leader at the Jewish Charity Hospital, before commencing her position at the University of Semmelweis.

Katalin has attended a number of training courses in Europe, the United States and Israel, and is generally acknowledged as having made a major contribution to the palliative care education and training system in Hungary. For the period 1997-2001, Katalin won the Szechenyi Scholarship for research activities into topics that included the rights of dying people, ethical aspects of euthanasia and ethical aspects of palliative care. Her research/development projects since 1992 have included: attitudes of physicians, nurses and medical students towards death and dying; introducing hospice/palliative care into the curricula of medical faculties; and the construction and development of professional palliative care guidelines for dealing with terminally ill patients suffering from malignant tumours.

Katalin is an expert member of the *Council of Europe: Committee of Expert on the Organisation of Palliative Care*, the national coordinator of the *European Association of Centres of Medical Ethics*, and a member editor for the *Hungarian Society of Thanatology*.

Katalin is also responsible for the *Central and Eastern European and Former Soviet Union Palliative Care Online Newsletter*, edited in English and Russian languages. This monthly newsletter covers palliative care activities in these regions and is developed by the *Hungarian Hospice-Palliative Association*, with the support of the *Open Society Institute Network Public Health Program's International Palliative Care Initiative* and the *European Association for Palliative Care*. The goal of the newsletter is to communicate the activities, diversity, challenges and progress being made in palliative care development, to foster networking, communication in Central and Eastern Europe and the Former Soviet Union, and also to inform those throughout the world about the regional effort.<sup>118</sup>



*Professor Katalin Hegedus, Semmelweis University Institute of Behavioural Sciences, Budapest (March 2007)*

In March 2007, Katalin Hegedus was interviewed by Tom Lynch in Budapest, and described a number of recent policy changes in Hungary relating to the provision of hospice and palliative care. These policy changes included: the 2004 Ministerial decree relating to the minimum standards for hospice and palliative care; the 2004 National Health Insurance Fund/Ministry of Health decision to fully integrate hospice and palliative care into the Hungarian health care system; and the 2006 Ministry of Health National Cancer Control Program. In addition, Katalin spoke about the ongoing development of hospice and palliative care education and training initiatives in Hungary, and discussed some of the ethical dilemmas associated with the provision of hospice and palliative care in the country. The forthcoming EAPC Congress to be held in Budapest in June 2007 was of particular relevance to Katalin, who has been on the board of the EAPC since 2003, and is the chair of the Local Organizing Committee of the Congress. During this interview, Katalin stressed the importance of being the first Eastern European country to host the Congress and the ways in which she hoped this would result in promoting an enhanced sense of inclusivity amongst the countries of Central and Eastern Europe and Commonwealth of Independent States.

## **ETHICAL ISSUES**

In a paper on legal and ethical elements of Hospice-Palliative Services in Hungary, Katalin Hegedus reports on the incorporation of patients' rights into Health Care legislation, and discusses the situation of those suffering from serious illnesses or dying.<sup>119</sup>

Incorporating such rights into the Health Care Act of 1997 followed strengthening of the democratic legal system, and a re-examination of the relationship between patients and doctors. Professionals stressed the need to include palliative care in the new legislation. A number of rights are detailed: the right to receive medical care, to human dignity, to personal contacts, to be informed and have self-determination, to refuse treatment, to be informed of the content of health documentation, and the right to professional secrecy. Significant areas

are those dealing with information and self-determination; building on previous work in the area of informed consent. The right to refuse treatment in some circumstances is an innovation of the new Act, for patients who are able to do this. The Act also allows for “Living Wills”. The earlier Health Care Act of 1973 had made it difficult to discontinue treatment, and in the early 1990s doctors were not always able to differentiate between the new concept of palliative care and passive euthanasia although the 1987 proposed Code of Ethics in Medicine recognised the suffering caused by unnecessary treatment. In 1993, a directive from the Ethical College of the Hungarian Chamber of Physicians disapproved of all forms of euthanasia. Their Code of Ethics passed in 1998 makes a clear distinction between euthanasia and palliative medicine.<sup>120</sup> Katalin Hegedus explains the situation:

‘In the health care act about euthanasia, passive euthanasia is not forbidden and we have the living will in our health care system but the problem is normally the patients don’t know about this opportunity, it is in the law but few people know about it. And there is not an obligation for the physician to tell this possibility to the patient...and active euthanasia is not possible you know but sometimes there are debates about it.’<sup>121</sup>

Hungary has not participated in any way in the Council of Europe discussions about euthanasia (the Marty Report). There are no initiatives in Hungary that seek the legalisation of euthanasia or assisted suicide.<sup>122</sup>

At Budapest Hospice House, a contract must to be signed by family member to ensure they understand that the hospice is not a place of ‘cure’ for their loved one. In Hungary, still often just ‘partial truth’ is told; relatives of a terminally ill person are always told of the patient’s prognosis – the patient is told only if they express a wish to know.<sup>123</sup> Agnes Ruzsa recalls the ethical dilemmas involved in ‘truth-telling’:

‘...when I became a trained oncologist I recognised that a lot of patients become terminally ill, and the hospital is not able to take care of this patient and we have to say to them, ‘Oh there is no problem, you can go home and your general practitioner will give you a pill and you will live in very good circumstances’, but it was not true.’<sup>124</sup>

Dr Julia Lohinszki, in her account of the issue of “truth-telling” describes the kind of culture change that became necessary in the face of the increasing numbers of patients treated by the hospice services:

‘Usually it was [the practice] not to tell the truth, not for the patient. And in this last ten years we tried – it is respect to tell the truth to the patients. It’s necessary, and of course we cannot start a treatment without telling what the illness is - at the first moment. So now the surgeons also began to tell the truth, because a lot of patients came to us and they didn’t know their problem - why they have to come in an Oncology Department...The problem is, we have to say that the disease is progressive, that we have to finish the curative treatment - so this phase of terminal illness is a little bit sophisticated. And we speak a lot about how to tell, when to tell, and in what depth to tell the truth. But it’s now general to tell, and if some patients come and the relatives ask us not to tell the truth, we can try to discuss also with relatives - that it will be easier to communicate with a patient if everyone can tell the truth, and not to hide the problem and leave the patient alone.’<sup>125</sup>

Katalin Muszbek provides a poignant example of the problems relating to ‘truth-telling’ in Hungarian culture:

‘...there is such a low education of the physician in psycho-social aspects that they do not know how to communicate, how to bring bad news, so they regularly say ‘ok it’s not such a big problem’. So I had a patient at 28 and that patient had a lot of metastasis in the bones and had big pain and he told me that he wants to die and he was asking the mother to bring the pills together and give them to him because he wanted to finish and then I told him it is just a short time that you have and he didn’t understand at first because in Hungary nobody told such a sadness to anybody and then the next day because I visited him everyday twice at least and he was in a very poor condition and I repeated and then he asked do you think that I am going to die and I told him yes I do, ‘how much time do I have?’ I said maybe seven weeks and then he told me ok, then I will say goodbye to everybody for a couple of weeks - I can survive no longer, and then he told me now he can understand why the young doctor is not coming and sitting with me everyday because the young physician does not know what to do or how to say it and really I was shocked by this communication because I never saw such a communication and I was a little bit worried that I did something wrong. It is more than 20 years since we had the first meetings on communication and ‘breaking bad news’ and I was so heated because this old professor told me ‘I am proud that I am [drawing my] pension and I did not tell anybody that they have cancer.’<sup>126</sup>

Yet Katalin Muszbek also suggests that there has been definite improvement in this area in the last fifteen years - for example, ‘breaking bad news’ training courses are now being run.<sup>127</sup> Agnes Rusza recalls the development of these courses:

‘...we organised training on palliative care for oncologists and also some training about how to break bad news because it was also very important to programme because oncologists don’t like to say the bad news to the patients and for the relatives too, so it was another training programme, breaking bad news, and something new, and to give them, to provide them with knowledge about palliative care, about painkilling and symptom control too.’<sup>128</sup>

Katalin Hegedus also suggests an improvement in this area:

‘I think telling the truth, its I think during these 20 years I am in health care in Hungary its changed a lot and about 60-70% of cancer patients are well informed. When I started to work in this field it was about 20% and now its changed...although it is the same problem that we spoke about relating to palliative education for young physicians - its normal to speak in a in a more empathic way and for medical students they have very strict communication skills about it but for older physicians nothing, unfortunately they don’t want to participate; we have a lot of communication training for physicians and there are many participants but only young people’<sup>129</sup>

Katalin Muszbek suggests that spirituality and religion were discouraged during Socialist times but hospice care and spirituality may have grown together since the collapse of Communism (although there is no firm no research on this to date). The hospice service at Budapest Hospice House is provided independently of spiritual/religious belief.<sup>130</sup> Agnes Rusza recalls the change in religious and spiritual belief amongst people at the end of life:

‘And in this period people began to go back to the chaplains – because in the Communist period people [turned] their back [on] the chaplains and also the whole spiritual aspects of afterlife and also the illness too, and they change their mind and a lot of people who were coming closer to their death are asking me for a priest or somebody who can provide them with spiritual care too. It was very important because I thought the spiritual need was very high among these people...But some

people don't like to speak about the religious aspects of their life, and they always told me that, 'It is not good for me because I am afraid to speak about this part of my life', so it was very hard work for those people.'<sup>131</sup>

Katalin Hegedus summarises the current relationship between palliative care and some religious groups in Hungary:

'In palliative care, after the communist era there were big changes in religion and spirituality, and during the communist era it was quite difficult to speak about it. And after the political changes yes we could speak about it. And there are only 40 priests for all the hospices in Hungary who agree to participate, and we wanted to contact with the Catholic University to get more contact with them and to get young priests involved in palliative care, but they don't want to come really, I don't know why. For example, there are two or three hospices in the Catholic Church who don't want to come to the National Association, but I don't know why, because sometimes you know there are a lot of National Congress conferences and we invite them and they don't want to come but I don't know why.'<sup>132</sup>

## **PUBLIC HEALTH CONTEXT**

### **Population**

In 1997, the population of Hungary was 10.1 million; around 5 million Hungarians also live in neighbouring countries or overseas. Budapest, the capital, has 1.9 million inhabitants. The population is decreasing, and figures for the year 2000 give the population as 9.9 million. Children under 15 years comprise 18% of the population; people aged 65 and over comprise 14%.<sup>133</sup> By 2050 the population is estimated to fall to around 7.6 million people.<sup>134</sup>

Hungarians trace their descent from Finno-Ugric groups from Central Asia. The largest ethnic minority group is the Roma, or Gypsy community. In 1996, the number of gypsies was estimated to be over 450,000. Other national minorities (Croatians, Germans, Serbians, Slovaks, Slovenians and Romanians) number 100,000 in total.<sup>135</sup>

Hungary's current population of around 10.08 million is made up of the following ethnic groups: Hungarian 92.3%, Roma 1.9%, other or unknown 5.8% (2001 census). Religious groups include: Roman Catholic 51.9%, Calvinist 15.9%, Lutheran 3%, Greek Catholic 2.6%, other Christian 1%, other or unspecified 11.1%, unaffiliated 14.5% (2001 census).<sup>136</sup>

### **Epidemiology**

In 1999 there were 143,210 deaths; 34,255 (24.4%) were from cancer, the second highest cause of death after cardiovascular diseases. Around 20% of deaths occurred at home.<sup>137</sup> In 2003, 132,833 people died in Hungary; 33,537 of these people died of cancer.<sup>138</sup> In 2006, there were 135,732 deaths in Hungary, of which 30,615 were due to cancer. An estimated 4,130 patients received palliative care in Hungary during 2006,<sup>139</sup> with the duration of hospice care averaging approximately 30 days.<sup>140</sup>

Rates for ischaemic heart disease remain high at 25.7 deaths per 1,000 population. Deaths from chronic liver diseases and cirrhosis also remain high at 6.2 deaths per 1,000 population; this compares with an average figure of 1.5 in the European Union.<sup>141</sup>

In Hungary, an *aging process* of society can be observed, although it nevertheless progresses markedly slower than in Western Europe and also in comparison with some countries in

Eastern Europe.<sup>142</sup> The WHO World Health Report (2006) indicates a life expectancy at birth of 69 years for males; 77 years for females (Table 4). Healthy life expectancy is 61.5 years for males; 68.2 years for females.<sup>143</sup> By 2050 the average age is expected to rise to 79.3 years.<sup>144</sup> Compared to the Western European population, the Hungarian population is in poor physical condition, and the quota of deaths from cancer is also the highest in relation to other countries of Eastern Europe or Central Asia.<sup>145</sup> The comparatively low life expectancy can therefore be ascribed to Hungary having the highest cancer rates Europe-wide.<sup>146</sup>

**Table 4: Population life expectancy at birth, Central and Eastern Europe (2004)**

<i>Country</i>	<i>Life expectancy at birth</i>	
	<i>Male</i>	<i>Female</i>
Albania	69	74
Bosnia- Herzegovina	70	77
Bulgaria	69	76
Croatia	72	79
Czech Republic	73	79
Estonia	66	78
Hungary	69	77
Latvia	66	76
Lithuania	66	78
Macedonia	69	76
Poland	71	79
Romania	68	76
Serbia	70	75
Slovakia	70	78
Slovenia	73	81

*Source: WHO World Health Report 2006*

The adult mortality<sup>147</sup> rate in 2005 is reported as 256/1000 population for males and 107/1000 for females.<sup>148</sup>

In 2006, UNAIDS reports:

‘The epidemics in Eastern Europe and Central Asia continue to grow and are affecting ever-larger parts of societies in this region. The number of people living with HIV in this region reached an estimated 1.6 million in 2005 - an increase of almost twenty-fold in less than ten years. AIDS claimed almost twice as many lives in 2005, compared with 2003, and killed an estimated 62,000 adults and children. Some 270,000 people were newly infected with HIV in the past year. The overwhelming majority of people living with HIV in this region are young; 75% of the reported infections between 2000 and 2004 were in people younger than 30 years (in Western Europe, the corresponding figure was 33%).’<sup>149</sup>

UNAIDS also specifically highlight the increase in HIV infections in Hungary:

‘By the end of 2004, there had been 1175 HIV cases reported in Hungary, in which 471 people were reported to have developed AIDS, including 266 who died. In the year 2004 itself, there were reported 71 new HIV cases, 22 new AIDS cases and nine AIDS deaths. The incidence of AIDS cases is relatively low and stable. Recent reductions in AIDS death are due to the introduction of HAART in the country.

Eighty-one per cent of the AIDS cases registered through the end of 2003 were among MSM and 0.5% in IDUs. Similarly, most reported HIV infections in Hungary have been among MSM and heterosexual women, with relatively fewer cases amongst IDUs (approximately 2%). A closer analysis of heterosexual cases reveals that in 2002-2003, 32% were imported from countries with generalized HIV epidemics<sup>150</sup>

There are very few HIV/AIDS patients in Hungary; people diagnosed with the disease are treated in a special HIV/AIDS Centre in Budapest that does not have any connection with mainstream palliative care services;<sup>151</sup> although they are accepted in Budapest Hospice House if requested.<sup>152</sup>

### **Health care system**

During communist times health care became a responsibility of the state and was administered through a hierarchical model that was highly centralised. Some improvements were made to the health status of the population during the 1950s but these slowed during the 1960s. As life expectancy improved in Western Europe during the 1980s, rates in Hungary worsened. The need for change was apparent, and by 1987 a package of reforms saw the establishment of the Social Insurance Fund and recognition of private providers. Following a reformation in 1993, the Hungarian healthcare system today is principally a comprehensive, compulsory, employment-based national health insurance scheme that provides near universal coverage both in terms of treatment and in terms of population, with nearly all citizens receiving care whether or not they contribute. The management and supervision was delegated to a self-governed committee. The compensation of the providers falls within the responsibility of the National Fund and is mainly contribution orientated.<sup>153</sup>

In 2003, the total per capita expenditure on health care<sup>154</sup> was Intl \$1,269 (8.4% of GDP).<sup>155</sup> Among the countries of Central and Eastern Europe, this figure falls within a spending range of Intl \$ 327 in Bosnia-Herzegovina (9.5 % of GDP) and Intl \$1,669 in Slovenia (8.8% of GDP). At 5.3% the smallest spending as a percentage of GDP is in Estonia (Tables 5 and 6).

The WHO overall health system performance score places Hungary 43/191 countries. This composite measure of overall health system attainment<sup>156</sup> is based on a country's goals relating to health, responsiveness, and fairness in financing. The measure varies widely across countries and is highly correlated with general levels of human development as captured in the human development index.

<b>Table 5 : Health expenditure (Intl \$) per capita: Central and Eastern Europe 2003</b>		<b>Table 6: Health expenditure (Intl \$) as a percentage of GDP: Central and Eastern Europe 2003</b>	
Country	Per capita	Country	% GDP
Albania	366	Albania	6.5
Bosnia- Herzegovina	327	Bosnia- Herzegovina	9.5
Bulgaria	573	Bulgaria	7.5
Croatia	838	Croatia	7.8
Czech Republic	1,302	Czech Republic	7.5
Estonia	682	Estonia	5.3
Hungary	1,269	Hungary	8.4
Latvia	678	Latvia	6.4
Lithuania	754	Lithuania	6.6
Macedonia	389	Macedonia	7.1
Poland	745	Poland	6.5
Romania	540	Romania	6.1
Serbia	373	Serbia	9.6
Slovakia	777	Slovakia	5.9
Slovenia	1,669	Slovenia	8.8

*Source: WHO World Health Report 2006*

### Political economy

In 1948 Hungary lost its sovereignty when the communist party took exclusive power, backed by the USSR. In 1968 the command economy was partially liberalised, distinguishing Hungary from neighbouring communist countries. A peaceful transition to multi-party democracy was achieved in 1989 when the communist party agreed to give up its power. Free elections were held in March 1990, the year that Hungary became a member of the Council of Europe. Although earlier liberalisation in Hungary allowed a more gradual approach to economic reform, the transition still proved challenging. In 1991, GDP fell by around 12% and did not regain growth until 1994; inflation peaked at 35%. Real wages in 1997 were 76% of the 1989 level. With the increase in foreign investment, however, and a programme of stabilisation, GDP began to grow. By 1998 unemployment had fallen, inflation had reduced and real wages had increased.<sup>157</sup>

In Hungary, GDP per capita is Intl \$ 15,826. This falls within the range of \$3,845 (Bosnia-Herzegovina) and \$20,326 (Slovenia) in the countries of Central and Eastern Europe (see Table 7).<sup>158</sup>

**Table 7: GDP per capita (Intl \$): countries of Central and Eastern Europe, 2004**

Country	GDP per capita (Int \$)
Albania	6,158
Bosnia- Herzegovina	3,845

Bulgaria	8,269
Croatia	11,406
Czech Republic	18,598
Estonia	14,102
Hungary	15,826
Latvia	11,802
Lithuania	12,572
Macedonia	5,892
Poland	12,647
Romania	9,884
Serbia	4,272
Slovakia	14,310
Slovenia	20,326

Source: WHO World Health Report 2006

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<sup>18</sup> <http://www.hospicehaz.hu/eng/>

<sup>19</sup> PaCE project interview with Dr Katalin Muszbek: Central European University, Budapest – 25<sup>th</sup> February 2002.

<sup>20</sup> IOELC interview: Dr Katalin Muszbek, Budapest – 12<sup>th</sup> March 2007.

<sup>21</sup> This is part of an article written by Kate Dobo included in the hospice house promotional literature entitled: *To die with dignity – it is the right of us all.*

<sup>22</sup> IOELC interview: Dr Katalin Muszbek, Budapest – 24<sup>th</sup> April 2004.

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- <sup>131</sup> IOELC interview: Dr Agnes Ruzsa Budapest – 17<sup>th</sup> October 2003.
- <sup>132</sup> IOELC interview: Dr Katalin Hegedus – 12<sup>th</sup> March 2007.
- <sup>133</sup> Clark, D., and Wright, M. 2003. *Transitions in End of Life Care: Hospice and Related Developments in Eastern Europe and Central Asia*. Buckingham: Open University Press, Hungary, pp. 59-68.

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<sup>134</sup> Population Division of the Department of Economic and Social Affairs of the United Nations Secretariat. *World Population Prospects: The 2002 Revision and World Urbanization Prospects: The 2001 Revision*. Official homepage of the United Nations: <http://esa.un.org/unpp>. Accessed May 14th 2007.

<sup>135</sup> Clark, D., and Wright, M. 2003. *Transitions in End of Life Care: Hospice and Related Developments in Eastern Europe and Central Asia*. Buckingham: Open University Press, Hungary, pp. 59-68.

<sup>136</sup> <https://www.cia.gov/cia/publications/factbook/geos/hu.html>

<sup>137</sup> Clark, D., and Wright, M. 2003. *Transitions in End of Life Care: Hospice and Related Developments in Eastern Europe and Central Asia*. Buckingham: Open University Press, Hungary, pp. 59-68.

<sup>138</sup> EAPC Palliative Care Facts in Europe Questionnaire, 2005

<sup>139</sup> Katalin Hegedus: Hospice in Hungary 2006. Hungarian Hospice Palliative Association, 2007. [http://www.hospice.hu/docu/Hospice\\_in\\_Hungary\\_2006.pdf](http://www.hospice.hu/docu/Hospice_in_Hungary_2006.pdf) (English)

<sup>140</sup> IOELC interview: Dr Katalin Muszbek, Budapest – 12<sup>th</sup> March 2007.

<sup>141</sup> *Health Care Systems in Transition: Hungary* (2000) Copenhagen: The European Observatory on Health Care Systems: 1

<sup>142</sup> Globisch, M. 2004. Hungary. In: R. Gronemeyer, M. Fink, M. Globisch, and F. Schumann, *Helping People at the End of their Lives: Hospice and Palliative Care in Europe*. Giessen, Germany: University of Giessen.

<sup>143</sup> <http://www.who.int/countries/hun/en/>

<sup>144</sup> Population Division of the Department of Economic and Social Affairs of the United Nations Secretariat. *World Population Prospects: The 2002 Revision and World Urbanization Prospects: The 2001 Revision*. Official homepage of the United Nations: <http://esa.un.org/unpp>. Accessed May 14th 2007.

<sup>145</sup> Clark, D., and Wright, M. 2003. *Transitions in End of Life Care: Hospice and Related Developments in Eastern Europe and Central Asia*. Buckingham: Open University Press, Hungary, pp. 59-68.

<sup>146</sup> Rodler, I., and Zajikas, G. 2002. Hungarian Cancer Mortality and Food Availability Data in the Last Four Decades of the 20th Century. *Annals of Nutrition and Metabolism*, vol. 46(2): 49-56. Cited in Globisch, M. 2004. Hungary. In: R. Gronemeyer, M. Fink, M. Globisch, and F. Schumann, *Helping People at the End of their Lives: Hospice and Palliative Care in Europe*. Giessen, Germany: University of Giessen, p. 173.

<sup>147</sup> This refers to adult mortality risk, which is defined as the probability of dying between 15 and 59 years.

<sup>148</sup> <http://www.who.int/countries/hun/en/>

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149 <http://www.unaids.org/en/>

150 [http://www.unaids.org/en/Regions\\_Countries/Countries/hungary.asp](http://www.unaids.org/en/Regions_Countries/Countries/hungary.asp)

151 EAPC Palliative Care Facts in Europe Questionnaire, 2005

152 IOELC interview: Dr Katalin Muszbek, Budapest – 12<sup>th</sup> March 2007.

153 Globisch, M. 2004. Hungary. *In: R. Gronemeyer, M. Fink, M. Globisch, and F. Schumann, Helping People at the End of their Lives: Hospice and Palliative Care in Europe.* Giessen, Germany: University of Giessen.

154 Total health expenditure per capita is the per capita amount of the sum of Public Health Expenditure (PHE) and Private Expenditure on Health (PvtHE). The international dollar is a common currency unit that takes into account differences in the relative purchasing power of various currencies. Figures expressed in international dollars are calculated using purchasing power parities (PPP), which are rates of currency conversion constructed to account for differences in price level between countries.

<http://www3.who.int/whosis/country/compare.cfm?country=s&indicator=strPcTotEOHInIntD2000&language=english>

155 <http://www.who.int/countries/hun/en/>

156 Tandon, A., Murray, C. L. J, Lauer, J. A, and Evans, D. B. *Measuring overall health system performance for 191 Countries.* GPE Discussion Paper Series: No 30; WHO

157 Hungary country profile: United States Agency for International Development, website [www.usaid.gov/regions/europe\\_eurasia/countries/hu/index.html](http://www.usaid.gov/regions/europe_eurasia/countries/hu/index.html)

158 <http://www.who.int/countries/hun/en/>