



THERE IS NO OFFICIAL WORD FOR “HOSPICE” IN LITHUANIAN

**A REPORT ON VISIT TO LITHUANIA BY MIKE COWARD, CEO, ST LUKE’S HOSPICE (HARROW & BRENT), LONDON
31 JULY – 3 AUGUST 2012**

INTRODUCTION

There are few places to start a journey as depressing as Luton Airport at 05:00 on a cold, wet day. Fortunately, my destination, 1075 miles east-northeast, Vilnius, was basking in glorious sunshine and the reflected glory of an unexpected Olympic gold medal.

I first went to Lithuania in September 2004, when it had been suggested by a volunteer at St Luke’s that we could forge a link with palliative care providers in Lithuania. From this initial visit came our twinning link with *Kauno Slaugos Ligoninė* (KSL). For background, a copy of my report on that first visit is attached.

In subsequent visits I have attended and spoken at an international palliative care conference and delivered training to volunteers. My Medical Director has also lectured in Lithuania and we have been pleased to host visits to St Luke’s from KSL as well as from the Franciscan community in Kretinga and Klaipeda, the secretary to the Cardinal Archbishop of Lithuania, and we have been involved, via The Tiltas Trust (TTT) with palliative care in Northern Ireland, when there is a large Lithuanian Community. This, my fourth visit, was to see the progress that has been made in hospice and palliative care in Lithuania in preparation for a presentation to the British Lithuanian Society in September 2012.

PROGRAMME

The visit, which is the subject of this report, took place between 31 July and 3 August 2012. The itinerary was:

- 31 July : Fly to **Vilnius**
 Lunch with British Embassy representative
 Visit Central Polyclinic (Centro Poliklinika)
 Visit Hospice of Blessed Father Michael Sopocko
- 1 August: Drive to **Alytus**
 Visit *Teviskas Namai* Home Polyclinic care volunteer service
 Drive to **Kaunas**
 Visit KSL
 Drive to **Garliava**
 Visit GP practice with palliative care service.
- 2 August: Drive to **Klaipeda** (via Hill of Crosses)
 Visit St Francis planned Cancer Centre
 Visit Day Care Centre
- 3 August: Fly Home

THE TILTAS TRUST (TTT)

It was good to meet Mida Babliene, who is a Trustee of TTT, and who is also a senior staff member at the British Embassy in Vilnius. The Embassy has been very supportive of the British Lithuanian Society and through the Trust, of the development of palliative care in Lithuania. Indeed, the volunteer training to which I refer in my introduction was supported by the Embassy and the event was formally opened by HM Ambassador. TTT is, in effect, the charitable arm of the British Lithuanian Society, of which I am a member. It has funded the translation into Lithuanian of Macmillan literature on palliative care topics and has provided travel fellowships for members of the Lithuanian Palliative Care Association to visit the hospice movement in Northern Ireland, where there is also a large Lithuanian Community.

CENTRO POLIKLINIKA

The *Centro Poliklinika* is a public health non-profit institution that provides primary and secondary outpatient and inpatient care. Within the Lithuanian system care is provided at three levels:

Primary	-	GPs Gynaecology Surgeons Dentists Psychiatry Paediatricians
Secondary	-	Specialist medical care including cardiology, endocrinology, neurology District Hospitals
Thirdly	-	University Hospitals

The clinic also provides palliative care for children and adults as a primary level of healthcare.

Currently the polyclinic has a central diagnostic and administration centre with 5 branches in the city. For palliative care, the Head of Service has 17 nurses, of which 1 provides care for a home based palliative care patient 10 hours per day. There is 1 nurse assistant in this team, which also comprises 1 social worker and 1 palliative care physician (0.9 FTE). There are some 100 patients on the palliative care list. Referrals for palliative care are made by the family doctor. The team is licensed for palliative care. It is of note that palliative care can be provided in an institution, a day centre or in place of residence. The Lithuanian system uses the term outpatient when referring to home care.

Payment for palliative care services is on a tariff basis and below, for interest, are some examples of the tariff:

Palliative Care Doctor	1 x consultation per week 45 min	€9.3
Nurse	3 x 45 min consultation process	€6.9
Social Worker	1 x 45 min consultation per week	€4.7

The clinic receives €13,947 per month for its 100 palliative care patients. Of passing interest, a clinic doctor is paid about £950 per month gross and a nurse about £530 per month gross. (See Annexe A for information on number of palliative care institutions in Lithuania)

The Vilnius Polyclinic is planning an e-home nursing system so that results of tests at home are transmitted to the doctor's office and the analysis and results are fed-back wirelessly. There are also plans to convert one of the clinic branches to provide a hospice. The hospice is planned to be on the 3rd floor (4th floor in Lithuania!) from which patients would have a view of the city and access to a roof garden.

HOSPICE OF BLESSED FATHER MICHAEL SOPOCKO - VILNIUS

The new Vilnius Hospice, dedicated to the Blessed Father Michael Sopocko, was opened on 6 June 2012. It was built on the site of a ruined Vincentian convent, which has been donated by Cardinal Backis, the Archbishop of Vilnius to the Sisters of Divine Mercy. The project was entrusted to Sister Michaela Rak, a Polish nun who has had a great deal of experience, having managed the Hospice of St Camillus in Gorzon Wieklopolski in Poland.

The restoration work has produced a beautiful building. While the project was being developed, patients were cared for at home and in the community. The new building, in the shadow of a crumbling prison, is planned to take its first in-patients in September. It will accept both adults and children, predominantly, if not exclusively, focusing on those with a terminal cancer diagnosis. Building on the home care service, there will be 16 beds in multiple occupancy rooms with shared en-suites. There is no recreational space, nor any day care facilities. The Hospice will concentrate in the building on the final stage of life. Care will be free of charge, and will be delivered by professionals and members of the Church. Currently there are some 70 volunteers. Interestingly, admission to the Hospice would be on the basis of self-referral.

The focus of the care contrasts with that delivered in the UK. The emphasis in Lithuania appears to be on the needs of the dying and their preparation for death with dignity and love. In the UK, we focus on the quality of life and indeed St Luke's embraces "Enhancing the quality of life" as our strap-line. In this context, we have to consider the different cultures in the countries. Lithuania is a predominantly Catholic country and this Hospice has been developed and built by the Catholic Church. It is, therefore, not surprising that religion is central to their philosophy of the delivery of palliative care, albeit in a hospice setting.

What is to be celebrated is the opening of the first purpose-built hospice in Lithuania. I note elsewhere in this report that there are firm plans for 2 other hospices (as opposed to palliative care services) in the country: one in Klaipeda and a second hospice in Vilnius. There is also a fourth hospice being considered in the Alytus region but this is only at an investigatory stage.

ALTYUS

In Alytus I met Eimentas Balaika, a businessman whom I had previously met in Belfast during a fact finding visit to Northern Ireland hospices under the aegis of TTT. He has plans to build a hospice in the Alytus region through *Teviskas Namai*, an organisation of which he is Director, but, as I understand it, these plans, which I saw in Belfast, are still very much at the concept stage. He is providing volunteer visiting services to adult palliative care patients in the home, in hospital and in rehabilitation centres. There are some 100 expressions of interest from potential volunteers and about 20 who are active. He is working from a flat rented from the Red Cross. There has been a great deal of progress in having leaflets produced in Lithuanian, giving advice on a range of cancer topics. As elsewhere in my visit, I found the level of funding to be pitiful. However, the fact that there is now some state funding is a big step forward. Funding is also being provided by Rotary and Lions Clubs. He is also making use of the basic palliative care course (36 hours) devised by Professor Seskevicius.

KSL - KAUNAS

Perhaps because I am familiar with the building, the most dramatic evidence of progress has been the refurbishment of the *Kauno Slaugos Ligoninė*. The transformation of the wards is startling, with pastel colours giving a feeling of light and airiness to what were originally dark and unwelcoming corridors. It was good to see a new shower room that had been funded by a small amount of money raised by St Luke's

Hospice. The treatment rooms are much improved and the transformation and creation of office, training and meeting rooms on the top floor are equally impressive.

I had no doubt that the quality of care for the in-patients remains at an extraordinarily high level. Indeed, one lady came up to us during the tour to tell me how wonderful the care was being given to her mother. I was equally delighted to hear that the new tariff, although inadequate, did at least enable patients to stay on now, rather than having to face discharge when funding under the old system ran out. It is important to note that KSL is not a hospice per se, but takes and cares for terminally ill patients. Some of the patients I saw were in comas. The bedrooms remained somewhat cramped by UK standards, but this is an unfair comparison and the ethos of the hospital is one of achieving the highest possible standards of care.

They have adopted the St Luke's model of a multi-disciplinary team approach to patient care, with everyone now qualified on the new palliative care course, which I have already mentioned. At KSL, I also met staff from the Kaunas Palliative Practice Centre, the first to be granted a licence to practice. The team covers central Kaunas.

GARLIAVA

Dr. Asta Sileikiene who generously helped to co-host my visit, runs a GP practice in Garliava on the outskirts of Kaunas. I first met her in Belfast with Eimantas. Deeply passionate about palliative care, she and her team have attended the training course. Her practice, run from an old, converted local jail, has over 9000 patients and runs independently of the local polyclinic. It is threatened with losing the tenancy of the building for local political reasons, but manages to maintain an excellent staff and a warm, friendly and professional approach to its work. A consultant orthopaedic surgeon provides consultations on a pro bono basis. I was privileged to visit one of Asta's palliative care patients at home. To my untutored eye, the lady was extremely ill; nevertheless, it was clear from her attitude to her doctor and the way in which she was being helped that she was getting the best of care.

The clinic impressed me greatly. As part of the palliative care provision in Lithuania, it is certainly a beacon of innovation and determination to succeed against the odds.

KLAIPEDA

In the itinerary, I mention that the drive to Klaipeda (a round trip that day over nearly 700 miles!) went via the Hill of Crosses (Kryziu kalnas) http://sacredsites.com/europe/lithuania/hill_of_crosses.html This was not sightseeing, but a visit to a remarkable place in the Siauliai district. It is simply what it is called a small hill – a mound really - covered with thousands and thousands of crosses and crucifixes of all shapes and sizes. It is impossible to count the number, or even to estimate how many have been garlanded with rosaries. The crosses have been erected as votive offerings and the site has become a symbol of suffering, hope and undefeated faith. I include this in my report to underline the importance of the Catholic faith in Lithuania. We cannot, in my opinion understand the culture of the country in the context of end of life and palliative care unless we take careful note of the centrality of Catholicism in the national psyche.

In Klaipeda I was taken to see the site of a new cancer support centre development. Brother Benidiktas, of the Order of St Francis of Assisi, was the lynchpin of this development, which is involving the Franciscan order. On a site adjacent to the hospital, a stunningly simple yet amazingly beautiful church has been built. Beside it, a monastery is being constructed as well as the cancer centre. It was good to meet the Brother again as he and some of the other brothers had visited St Luke's a few years ago. The whole project is well advanced. Their plans include the development of a hospice adjacent to the cancer centre.

Also in Klaipeda, but in the town centre, I visited a small day care clinic run by a doctor and 2 nurses. It was in a small rented house. There was one room with 2 beds that were used for patient care, both morning and afternoon – 4 patients per day. There was also a small clinic room where patients were seen on an out-patient basis. There are plans to find a new building in due course to expand the size and scope of services

CONCLUSION

Throughout my visit, I was repeatedly told how much people involved with palliative care respected and appreciated the support of St Luke's Hospice. I was flattered that it was understood that my meetings in previous visits with Cardinal Backis had influenced him to grant the land for the Vilnius Hospice. While I was delighted that this was said, I cannot underplay the enormous amount of dedication and hard work of our Lithuanian colleagues. It was good to see the establishment and plans for the building of hospices and of the development of the basic training course, which I understand has trained several hundred students. The Lithuanians have certainly moved on a considerable way since 2004. The hospice may not reflect the UK model but, as I said in my paper of 2004, it is important for Lithuania to develop its own solutions for its own problems and challenges.

There are pockets of palliative care across the country. The focus is almost entirely on cancer and I suspect that this is unlikely to change until services have developed, maintained and funded to take a broader perspective on end of life care. Without trying to be nice in my definitions, I do not believe that culturally the country has come to terms with the difference between protecting and enhancing the quality of life for those who have a terminal prognosis and the care of the dying. I saw this most markedly at the Vilnius Hospice. I must emphasise that this is not a criticism, rather an observation of developing practice in a nation of a different culture to that which prevails in the UK.

I must also note that despite the introduction of national tariffs and the much reported development of a law for palliative care, there does not appear to be much co-ordination. The Lithuanian Palliative Care Association does much to keep people in touch with developments and there is good co-operation with other countries. However, with only 1 palliative care official in the Ministry of Health and an inheritance of soviet-style bureaucracy, it was hardly surprising that the opening of the new Vilnius Hospice did not seem to have been reported more widely than the church and the city itself. Indeed, my visit was the first time that Polyclinic staff, who had tagged along, had seen the new building

It was interesting to note that palliative care now has a body of law to support it. I was often told about how care had to be delivered in accordance with the law. As a democracy, still emerging from the baleful influence of Soviet occupation, which only ended 20 years ago, progress to establish and regulate new institutions and practice is clearly important to Lithuania – nearly as much as an Olympic Gold Medal. In some areas progress has overtaken the UK. There is a tariff (protected by law) and while the sums involved are clearly inadequate, the principle has been established. On my first visit to KSL, I was told how once funding was exhausted after a few months, patients had to leave the hospital if families could not afford to keep them. This is no longer the case. Progress indeed.

I am forced to consider how much better end of life care could be provided across the country with better co-ordination and exchange of information. I said in a previous report that end of life care needed a champion. This remains true today. Unfortunately, Professor Seskevicius, the President of the Lithuanian Palliative Care Association was not available during my visit. As the doyen of palliative care in Lithuania, he and his colleagues have made 7-league strides, but they need the support of the country as a whole and this is where a development of the ethos of end of life care will become increasingly important. The pressure must be kept on the Ministry of Health to allow, facilitate and fund the networks and associations

so that there can be a co-ordinated approach to provide that unique Lithuanian solution to a Lithuanian problem.

I must not lose sight of the fact that their concept of charity as we understand it in the UK, remains an uncertain concept outside of its religious context. My impression was that while the church plays an important part in the encouragement and organisation of care, for all practical purposes, it is the state which sets the tariff and which provides healthcare. Charitable bodies are beginning to emerge and there seems to be a nascent volunteer culture. That said, it will take time for this to grow and become an established part of society.

I was told on a number of occasions how initiative and enterprise was frustrated by bureaucracy and in some instances, by petty officialdom, conflicts of self-interest and corruption. I have no answer other than to applaud how, despite these problems, new services are being opened and developed.

Overall, I saw a different Lithuania to the one I saw in 2004. The streets seemed more vibrant and there was certainly more confidence about the future. Whether the opening of an M & S store on Gedimino Prospektas is progress is perhaps moot. I was left in no doubt that our contribution from St Luke's, The Tiltas Trust and other agencies was deeply and gratefully valued and that a hunger for learning and a thirst for knowledge would continue to drive the palliative care movement to become a hospice movement in the widest sense of the term.

AND FINALLY

I was completely unaware of the existence of the State Commission of the Lithuanian Language. The Commission is responsible to the SEIMAS (parliament) for language policy and for the regulation of the language. Unlike the Academie Française, whose recommendations carry no legal force, the decisions of the Commission are legally enforceable. While the word *hospisas* is currently used, adapted in the Lithuanian tradition, it has no official recognition as a Lithuanian word. Perhaps this sums up the progress made in Lithuania since 2004. The need for palliative care has been well established and the first hospice has been built with more planned. There is a long way to go to develop a full hospice movement and perhaps once hospice and end of life care is an integral part of Lithuanian life, clinical practice and culture, the Commission will gladly allow the official adoption of the word Hospice.

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Chief Executive Officer

St Luke's Hospice (Harrow and Brent)

15 August 2012

ANNEXE A

A DIGEST OF FACTS & FIGURES

- There are no volunteer hospice teams. Volunteering is very much as individuals within the health care system.
- Volunteers do not offer bereavement support.
- There is no hospital palliative care support teams
- There are 13 home palliative care teams for adults and 3 for children.
- In 2010, 37 healthcare facilities were licensed for palliative care. 13 provided full palliative care at home (doctors, nurses, social workers).
- 1 palliative care team provides multi-disciplinary teams in the home and hospital setting. (Vilnius Oncology Institute)
- 1 palliative care team in Tertiary Care Hospital (Kaunas University Hospital)
- No established inpatient hospices (Note: Vilnius Hospice opened in June 2012)
- Full palliative care services provided in 8 hospitals.
- Establishment of palliative care beds depends on availability of funding through to Patients' Fund.
- 8 palliative care services with 86 beds in non-Tertiary hospitals. 2 children's services with 1 bed.
- 1 Day-Care centre. In 2010 13 day-care centres were licensed for palliative care but services not provided.
- Palliative care services provided by professionals accredited on a 36 hour course. Course was recognised in 2007 and over 600 people have completed this course.
- Of the 9 medical schools, only Kaunas & Klaipeda University have provided mandatory training in palliative care.
- Klaipeda and Utena Colleges provide optional courses in palliative care for nurses.
- There is 1 professor and 2 assistant professors of palliative medicine in Lithuania – all at Kaunas University. There is 1 assistant professor of psychology.
- The Lithuanian Palliative Medicine Association was founded in 1995.
- There are no Lithuanian journals of palliative care.
- A number of professionals are actively involved in research at PhD & Masters Level.

- Twinning/Partnerships arrangements are with:
 - The Tiltas Trust
 - St Luke's Hospice UK
 - St Francis Cancer Support Centre Kretinga, Lithuania
 - Mustard Tree Cancer Support Centre Plymouth, UK
 - Garliava Family Clinic, Lithuania
 - Hassenburg Hospital, Germany
- Other collaborations:
 - Poznan University of Medical Sciences, Poland
 - St Christopher's Hospice, London, UK
 - Swialto Hospice, Poland
 - SW Lazanza Hospital, Poland
 - Caritas
- Lithuania ranked as a country where hospice – palliative care services are at a stage of preliminary integration with mainstream service provision.
- Palliative care was legitimised in 2007.
- There is no national palliative care strategy; however, there are plans at Ministry of Health level to improve provision.
- Palliative care services are free of charge since legislation of 2007.
- Oncology drugs are dispensed free of charge. Other drugs for palliative care patients are 80% funded.
- Palliative care in Lithuania is directed at cancer.

SOURCE

EAPC Atlas of Palliative Care in Europe 2010

My Impressions of Palliative Care in Lithuania – September 2004

My first contact with Lithuania came via a volunteer at my Hospice, St Luke's Hospice, (Harrow & Brent) who suggested that we might be able to forge a link with those interested in palliative care in Lithuania. From this very tentative beginning, came an invitation from Dr. Marija Rubaževičienė at the Department of Social Work at the University of Vilnius, and in early September, I found myself landing at Vilnius Airport, wondering what I would find. My programme including lecturing to the members of the Palliative Care Association, nurses and social workers in both Vilnius and Kaunas Universities. I also visited *Kauno Slaugos Ligoninė* and another palliative care hospital, as well as having discussions with a number of clinicians. I also attended a meeting between the Church, the University and Health Care Ministry, hosted by the Archbishop of Vilnius.

During my short visit, I was privileged to meet a large number of dedicated professionals who were committed to providing the best possible care in difficult circumstances. It is, perhaps a little unfair to make comparisons between our two countries; however, I have to say that the facilities and infrastructure I saw were urgently in need of considerable financial investment to bring them up to modern standards. I was also interested to find a different tradition of charity to that obtaining in the UK. We have a charity law going back to 1601 and some 188,000 registered charities in the country. From this tradition, we not only have a wealth of financial support for hospices through voluntary donations, we also find a huge number of people who are able to volunteer to work in the hospices, (and of course other charities). In my own Hospice, my 90 staff are supported by approximately 500 volunteers. These people carry out a very wide range of duties, from driving patients to and from the Hospice, to working in our shops, providing complementary therapies and maintaining our gardens. Of course, our social and cultural structures are different and what may and does work in the UK may not work in Lithuania. In the UK, care in hospices is entirely free of charge, regardless of ability to pay. I believe that this is something to aspire to in the longer term. In the immediate future, however, Lithuania will have to operate within the boundaries of your own society, law and traditions. I understand that for any form of hospice movement to get off the ground would entail funding by the Health Ministry and here there is considerable competition for available funds. To bring hospices and palliative care to the foreground will need lobbying and I have no doubt that if a prominent person could act as your champion or patron, then this will be of enormous benefit to any palliative care movement in Lithuania.

In the UK, most of the nurses coming in to palliative care do so from the National Health Service. Their basic training is undertaken within the Health Service and palliative care is one specialisation which people elect to follow post registration. Of course, there are a number of palliative care and hospice units within the Health Service as well as those, like mine, within the voluntary sector. If we are to attract nurses to leave the Health Service for the voluntary sector, we have to ensure that we are able to offer appropriate pay and conditions of service. There are a number of palliative care courses that nurses can follow; however, above all, nurses have to have a special interest in this type of work, as it is extremely demanding both professionally and emotionally. It does not suit everybody so that when recruiting nurses in particular, we are looking at a relatively small number of people. As part of our response at my Hospice we have established some development and training posts which we hope will go some way to re-dressing the shortage of specialised nurses in the UK.

I think that it will be of interest also to report the clinical practice in the UK within the hospice movement. We operate within multi-disciplinary teams comprising doctors, nurses, social workers and other clinical professionals. The care is patient-centred and each member of the team has an important part to play in determining the right care for the individual patient. Whilst, of course, each professional exercises his or

her own specialist knowledge, the vital concept is that the care is integrated and each professional has an equally important part to play.

I was asked why patients who are terminally ill should be cared for in hospices rather than hospitals. In the UK, the hospice movement grew out of the inability of the Health Service appropriately to care for patients in their last days and weeks of life. This is not to denigrate the care that is available, but rather to offer special and better care to these people. The key message in the hospice movement is those who are dying are still living and, therefore, they require and are entitled to the best possible care. I believe that the way in which we treat people in their last days is an important hallmark of our civilisation. Too often in the past, people have been marginalized in society as they are dying and for far too often the concept of death and dying has been a taboo subject. Hospices seek to acknowledge life and to celebrate it. The aim of the hospice is to ensure that each patient is as pain free as possible and also, within the boundaries of their physical capabilities, is able to enjoy the best quality of life up until the very end. What can be done for each patient is, of course, a totally individual thing. For some patients, the concept of symptom control may be extremely important. For others, we need to address their emotional, social or spiritual needs. Hospices are normally relatively small units – mine has 12 beds and 20 places for day-care patients – so that we are able to offer the most individual of care by having good staff to patient ratios. Too often in busy general hospitals, these ratios are simply not available, and therefore, we believe that we can provide highly personalised and intensive care. It is important to note that hospices are not hospitals, nor are they places simply where people go to die. They are integrated into the community, widely supported by the community and have had a growing acceptance for this role over the past 30 years or so. In the UK, a recent survey showed that some 56% of people would prefer to die at home and it is the part of the hospice mission to enable this to happen, if at all possible.

There is no doubt that hospice care as practised in the UK is extremely expensive. Not only do we have higher numbers of staff than would normally be established for hospitals, but because we do not make any charge for our services – accommodation, drugs, treatments, food are all free – this means that we have to look widely throughout the community for financial support. In the UK, the government, through the National Health Service, supports hospices by an average of approximately 30% of their expenditure. This means that the other 70% has to be found from voluntary contributions. We receive money from the public through general donations as well as receiving some money in memory of those who have died. We are active in seeking support from local businesses and companies and rely heavily on people remembering the hospice in their wills. I have a fundraising department within my organisation, which is responsible for generating this income. My understanding is, however, that this may not be entirely within the tradition in Lithuania, and consequently certainly in the early days, that you will have to rely heavily on government support. I believe there may well be organisations within the European Union who may be able to provide financial assistance and there are a number of charities who will wish to be involved. From my own point of view, we are trying to forge a link with the Kaunas Hospice so that we can exchange ideas and mutual support. I believe also that there are many of your countrymen living overseas who may well be able to provide support for a fledgling hospice movement in your country. In the meantime, I think it is important that as many people who are involved in palliative care band together to demonstrate that palliative care is not simply a nice thing to have, but it is a vital part of the care of people. Ultimately, a dying patient is a living patient, and it is important that those who are approaching death through disease are supported and looked after as professionally and with as much care as those who are recovering from a non-terminal illness.

I send everyone involved in palliative care in your country every good wish. MRC