THE INSTITUTE FOR PALLIATIVE MEDICINE
at San Diego Hospice
INTERNATIONAL PALLIATIVE CARE LEADERSHIP DEVELOPMENT INITIATIVE

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About Pain and Life

Motto: "Life is not what we want, but what we are given and beat". (Arnošt Lustig)

During my personal life and professional career I have come to recognize the importance of pain as part of the human experience. Often when we are in pain, we lose control. Conversely, if pain does not exist in our lives, we can be in danger of experiencing emptiness. Pain can teach us to feel the value of things, of others, and of ourselves. However, pain is not restricted to the physical dimension – it can be psychological, social, and spiritual, too. Very often all these dimensions are combined in a state of chronic pain.

Geriatrics

Geriatrics in Czech Republic (1997) was an expanding field thanks to the growing awareness of an ageing population. After the Medical Faculty of Masaryk University Brno I spent the next six years in the geriatric department at Faculty Hospital. Its multi-special patient spectrum offered me the opportunity of complex medical experiences, consultations with surgical, neurological and internal departments, opportunities for co-operation with families and a holistic model of care. Such interactive cooperation helped develop my respect for the purpose and importance of basic care, rather than seeing medicine as exclusively a high-tech field.

I began to understand our often-absurd efforts to treat what is incurable with routine examinations, basic care which is often depressing or dysfunctional, conflicting tensions with patients and families, sad lives of patients suffering from terminal, chronic diseases. All this co-existed in the age of computers, internet and mobile phones. Yet increasingly, multi-generational family units are rare so many young people have lost the opportunity to acquire wisdom from life lessons related to ageing, dealing with pain, and disease.

My First Hospice Experience

In 2003, I joined St. Joseph´s hospice and pain centre Rajhrad as a physician with 6 years of clinical experience. By that point, I had passed several courses in pain management and palliative care, and

spent more than a year there working night shifts three or four times per month. During the first months of my hospice position, what struck me most was how difficult it is to be a doctor and a man at the same time. In short, the challenges came from juggling the routines of Faculty Hospital, insufficient knowledge of symptomatic diagnostics, therapeutic processes and communication skills. In November 2003 I was facing the Salzburg course EPEC (Education for physicians on end-of-life care) and a few weeks later, my examinations for specialization in geriatrics.

In St. Joseph´s hospice Rajhrad, I have met several outstanding personalities who have been important influences on my professional life. Viola Svobodova was one, hired as head physician three months before I began working there. Reliable and friendly, her sense for the holistic nature of palliative care, expressive gift of empathy and her diligence helped model the way for me. She showed me how to balance the roles of physician, family member, husband and father. She demonstrated the relationship between physician and patient, physician and others, physician and God, and above all I learned this universal truth: **true love is unconditional**. Jan Zachoval was another influence, connecting his professional life with informatics early in his career. He successfully completed his postgraduate degree and when he turned 35 he found God, yoga and the hospital chaplaincy. He was ordained a priest at 62, and over time we became close friends. I regard him as my confessor. His feedback has strengthened me, saved me from imprudence, and instructed me when necessary.

Since beginning hospice work I have clearly seen the undisputed benefit of interdisciplinary team work. When I entered St. Joseph´s, I was disappointed to learn that the team was dissolved several months earlier.

There was nothing to do except begin building a new team, despite time and other challenges. The ward nurse was very helpful, but I still made errors and was conflicted with doubt. How could I communicate serious decisions regarding care or team organization and win my team's approval? The process was even more daunting in developing geriatric or non-cancer palliative care.

On reflection, I can see two key skills which were important for success – empathy and the communication. I also realized that effective feedback was extremely important and that I needed to accept feedback and learn lessons from that process. It is important to build and develop a network of people who can provide effective feedback.

Physician's Role – My Hospice Leadership Experience

The physician in hospice receives a unique opportunity to see the world of disease from the patient and family´s viewpoint. He must assume a professional responsibility to live a part of *life-with-disease* with the patient. Disease requires the physician to get under the patient's skin and places huge demands on the physician's personal, ethical and professional standards. The physician doesn't deal only with symptom treatment knowledge. There is much more. Palliative medicine permits the physician to be *a man in his own profession* in the widest sense of humanity. It is a long journey with each patient and it carries great responsibility.

I often hear how being *a man in my own profession* brings the risk of unprofessionalism. A certain detachment is necessary in the profession of medicine, and I understand the term 'certain detachment'. But we must accept that work in palliative care changes the living attitudes and behaviors of other physicians and staff. This is the challenge and we must work with it, looking for meaning, providing wisdom, guidance and sharing experience. Daily we ascend daily the Mont Blanc

of our emotional reservoir – to lose and gain at the same time. It is a never-ending story, requiring us to be attentive and to listen. And to be humble.

On top of personal changes, physicians experience a change of roles in the palliative medicine environment. They must share the decision-making process with other multidisciplinary team colleagues, and the proportion of shared decision-making changes from patient-to-patient. It is like a game of chess where you must continually sense when to hand over a part of a decision to a psychologist, family member, caring nurse or chaplain.

But there are still challenges for physicians. They can help the team understand priorities in a holistic model of care, and be supportive of the team. But they also work with the patient and family in the role of *physician–teacher*. Within the world of contemporary high-tech medicine, I believe this challenge is most difficult in palliative care, where it is important for physicians to provide palliative medicine with an appropriate degree of love.

Salzburg 2003 – EPEC (Education for Physicians in End-of-life Care)

I spent 6 years in geriatric medicine and understood it more from a clinical view. Then in Saltzburg in September 2003 I met Kathleen Foley, Frank Ferris, Charles von Gunten, and Mary Callaway at the Open Society Foundation seminar on palliative care. This seminar provided a major transformation in my attitude to the physician's role in palliative care.

During the course, despite my limitations with spoken English, it was easy for me to understand the context of presentations and discussions. It was fascinating. I could mark the didactic skills and strength, the precision used for building trust, attitudes and motivation. During the next years taking specialized courses in palliative medicine, I began to realize the importance of **leadership**. Most importantly, leadership was required to introduce palliative care within the wider context of public health care, the economy, social and personal values.

Of course on returning to work, the next steps were not easy. Great difficulties exist in the world of geriatric, internal or neurological non-cancer palliative care. In comparison with oncology, palliative care was on very thin ice and lacked the perception of being a basic medical specialty. That time helped me recognize one basic quality of good leadership: *it must be comprehensible*.

I realized that the best ideas will seem worthless without someone sufficiently skilful to introduce those ideas to others as being valuable. In the modern global world of internet, expressways and cell phones, the opportunity is larger than ever. We can do many things in many ways, but the toughest decision is to choose *what could be useful and how best to achieve it.* Leadership today is not restricted to 'great personalities'. It has become an essential part of daily life.

Princess Alice´s Hospice, Esher and St. Christopher´s Hospice, London

Professor Vorlicek gave me the next incredible opportunity at the beginning of 2003. With the financial support of two foundations and assistance from Professor Stark (a famous Czech paediatric surgeon working in England) I could spend five weeks in two English hospices. I sent many emails and received positive responses from Andrew Hoy (Princess Alice´s hospice) and St. Christopher´s hospice, London-Sydenham.

I left London in November 2004, having learned more than I had expected there. I could now say, “Yes, it works!"

- Holistic model of care, multidisciplinary *in a real medical life*
- Community care as a basic model of care
- Geriatric and other models of non-cancer palliative care

My time in London confirmed to me how important it was to implement palliative care as an integral part of the public health care system. Thanks to Professor Vorlicek and his unique skill to read in 'people preconditions', I was there at the right time and place. My thoughts quickly focused on how to implement palliative care within the existing public health care system in Czech Republic. It was the right route, although the more difficult one.

Specialization Curriculum for Physicians On Palliative Medicine

Since 1997 the Institute of Postgraduate Medical Education in Prague has been an educational centre in palliative medicine. Professor Vorlicek led the department of palliative medicine and in 2004 he invited me to become involved in preparing symptom seminars.

This opportunity made me realize I needed to develop my academic base, so I decided to start PhD studies in 2005. My topic of dissertation was an unexplored field in Czech medicine at the time: *Non-cancer diseases in palliative care.*

Professor Vitovec, well-known cardiologist and sub-dean of the Medical Faculty at Masaryk University in Brno, became the leader of my studies. I had known his department of cardiology and internal medicine at Faculty Hospital since my days at medical school. During those four years of study we realized how difficult it was to track down reports or surveys from the non-cancer palliative care field. Similarly, when I began working in my secondary physician role, it was equally difficult to build on geriatric and neurologic palliative care in our hospice.

My dissertation concentrated on the description of the contemporary physician's perception of the palliative care field, but also on the recommendations in organizational tasks and symptom care. The results and sources I used are found in chapters of “Palliative Medicine for Practise” (Slama, Kabelka, Vorlicek) which focused on non-cancer palliative care in the Czech Republic for the first time. This was historic. The hottest contemporary topics in the Czech palliative care platform are neurological and (above all) non-cancer geriatric palliative care.

In early 2005, Professor Vorlicek, Dr. Ondrej Slama and I again raised the older question: “Are there clear reasons to recognize Palliative medicine as a medical specialization in Czech Republic?” At that time we co-operated with algeziologists who asked our opinion about recognition of the medical specialization curriculum called “Palliative medicine and pain management”.

At that stage, we were not pleased because we had wanted to integrate palliative medicine within all relevant medical specialties. But I bowed to Professor Vorlicek's foresight and his two arguments: "How important should it be to recognize the specialty by the official process?" and "Not only the contents but also the mode of presentation will decide the issue of accessibility of palliative medicine in Czech Republic."

Of course, he was right.

The first cohort of exams started in late 2005. The co-operation with algeziologists brought improved pain treatment management and studies development to the field of palliative medicine, and disturbed the holistic understanding of palliative care. Hitherto, the question in Czech Republic had

been a confusion of, "What is holistic palliative care? Does it deal with symptoms, or is it strictly a matter of pain management?"

This was the main reason why we decided to form the Czech Society for Palliative Medicine (CSPM) and in 2010 our board started negotiations with algeziologists for the separation of both medical specialties: Palliative medicine and Algeziology.

Position of Head Physician in Hospice

"Who leads the other he must at first lead himself"*. The good leader is not faultless but he struggles to keep above the fray while he models the way for others.*

In early 2007 after four years of working in hospice, I was approached by hospice director Jaromir Bily enquiring whether I still had an interest in the position of head physician. I had a lot of ambitions and one was to develop the concept of hospice multidisciplinary care for patients with non-cancer diagnoses. St. Joseph´s hospice and pain centre Rajhrad gave me a unique opportunity and I did not hesitate[1].

I faced many immediate challenges. My age was the most difficult issue. I had to find a common language with physicians and colleagues who were a generation older than I. Then I had to explain new concepts to them: a family is part of the team, non-cancerous diseases can have very similar symptoms, patients need to know about the cancer, palliative care is not just an issue of quality pain management, communication is a main tool of good care, etc.

I felt I was balancing between social care and medical care, trying to ensure quality medical care while simultaneously encouraging a family environment. The pressure was permanent and continues even today.

I can confirm that multidisciplinary team sessions have proven to be key moments that illustrated, *The old rules have changed*. Right in front of the eyes of all team members we could use real clinical examples to explore compromises or discuss what did not work and why. We had to change a lot of our work with clinical nutrition, standard processes of patient admission to hospice care, and communication tools -- not only with patients and families, but also within the team. It was crucial to share clinical or other relevant pieces of information, to agree in next-care steps, and solve mistakes or interpersonal conflicts.

Three Pillars of Life with Palliative Medicine

In late January 2009, while establishing Czech Society for Palliative Medicine CMA JEP (Czech Medical Association of Jan Evangelista Purkyne), I was asked by my colleagues on the newly-elected board to assume the position of board president. Yes – again – it was an opportunity: to change something, to gain new experience and grow. It was a challenge but I accepted it with mixed feelings. At that point, new realities faced my wife and me -- we had a new baby and were still adjusting to new priorities and challenges. Sometimes it was difficult to find the balance in life.

When I reflect I cannot remember ever thinking: "Yes, now I am satisfied, everything is going well" -- or "Everything is done so now I can give my energy to family, friends or hobbies." From the time I began medical studies, life was crowded with activity. On top of work, my wife and parents helped me renovate our home over a four-year period. At the same time, I was working night shifts to supplement my income coaching volleyball four days a week training children in the Sokol

movement (traditional organization for physical, moral, and intellectual training) enjoying sports or alpine tourism. Occasionally my wife and I could share music or a rare evening of theatre.

The development of the Czech society for palliative medicine[2] and the St. Joseph´s hospice and pain centre[1] are two important pillars of my life. But the most important is the third pillar – my family life.

We can look at family life in the same way: a complex multidisciplinary team which is a tool of our personality that leads to change. And of course *running family life* is the core which allows us to do all the other things in our lives. It is the joy we savour when we are together, the growth and development of children, sharing common interests and so much more. We are not doing equally well in all aspects and of course there were more duties and responsibilities with the arrival of our third child in September 2011 -- fresh demands to my role as husband and father.

But fortunately I see this as part of life's journey, a gift where joy triumphs over anxiety. Of course, I need to refine my time-management skills and make priorities even more effectively than in the past. Also I must help my family understand my work is an important part of our common life: it is a very important **factor of balance**. Regardless, I never will be able to sufficiently express my appreciation to my wife, children, parents and friends in understanding this reality and helping me to the best of their ability.

Leadership Development Initiative (LDI)

The proposal for the LDI program at the Institute for Palliative Medicine at San Diego Hospice came in May 2009. It was not long after the foundation of CSPM, and it arrived at a time when I was busy and frustrated. My ideas were misunderstood and resisted, not only in my hospice team but also in my role as president of CSPM.

Two years have passed since then. If I can look at all of this in retrospect, I must say, “The proposal came to me at the very moment when I needed it.” LDI helps us see our challenges, supported by the understanding of professionals who have experienced similar troubles and mistakes. They can help us with their 'bird's-eye view' and their knowledge. The LDI program helped me to accept my role in life, while the financial resources covered some expenses connected with the position of CSPM president. Of course I had the opportunity to improve my presentation and communication skills and, most significantly, in English.

Once again, and with a deeper resolution, I was reminded of the main pillars of my life and the importance of keeping balance between them. There are two existing main tasks or projects that came out of the program:

1. Determination of priorities, time management and academic goals
2. In an English-speaking environment

Another visible outcome of my LDI journey is that I am president of the organizing committee for the next European palliative care congress, which will be held in Prague in 2013.

Palliative Care and My Future Life

I recognize that palliative medicine works well as the model of care for incurable patients. It provides not only pain management but also psycho-social support for patients and families. In fact, there is much larger philosophical issue at stake: *How the role of incurable disease can be important in human life.* In our role as physicians, we tend to concentrate more on physical pain.

Nine years earlier before entering the field of hospice care, dealing with physical pain involved ibuprofen, tramadol or pethidin. It is not difficult to see the world of disease only from the view of pharmaceutics medication. But direct contact with **the life review**, coming face-to-face with the dying process, showed me that physical pain is only *one part of the total pain.* This was described by Cicely Saunders.

Total pain is difficult to describe from the patient's point-of-view, and diagnostic scales are not always helpful. We often fear total pain because we suppose it to be untreatable. I now understand after ten years in the palliative care field how much I need **the wisdom of those whom I help make end-of-life tolerable.** It is not possible merely to take responsibility and be the partner of patients and families. It is **our duty and privilege** to do so.

From the point of view of leadership, I recognize that to lead somebody does not mean to control him/her. **Trust, conviction and respect** are much more valuable than unquestioning obedience.

I have several aims for the future. For one, I want to support the development of clinical non-cancer palliative care, principally in geriatrics, and broaden my academic horizons. But first of all, I feel the need to bring others on board who share my vision -- and not just in the Czech palliative care field. During recent months I have come to realize how difficult it is to keep a balance involving trust and skills, and a tension about the thrust of my professional life. I reconciled this tension as being a necessary part of my life, and I also accept with gratitude the role that palliative medicine plays in my life.