

Introducing Hospice Care in Central Slovakia

Home Care Enables Terminally Ill Patients in Banska Bystrica to Live Out Their Final Days with Comfort and Dignity

Nestled in a region rich with natural beauty and resources, the central Slovakian city of Banska Bystrica is home to some 90,000 people, many of whom live in the small, bucolic villages that surround the town proper. Centuries ago, Banska Bystrica grew wealthy thanks to mining interests—primarily gold and copper. Like many other communities around the world that once flourished because of mining, economic prospects waned as the earth's bounty was depleted. As more and more young people moved away in search of work, the average age of the city's population crept higher and higher. At the same time, the past 30 years have witnessed rising rates of chronic conditions resulting from unhealthy lifestyle choices.



Hospice nurse Anna Babelova cares for cancer patient Zuzana Kapustova at her home in the village of Malachov a few miles outside of Banska Bystrica. (Photo: Kathryn Utan)

"Roughly 20 percent of our citizens are in their post-productive years and diseases such as cancer, hypertension, obesity, and cardiovascular ailments have resulted in a marked increase in mortality and morbidity rates," explains Dr. Michal Mikula, director of the Diocesan Charities of Banska Bystrica. "Nearly a decade ago, it became clear that care and treatment for terminally ill patients was a critical priority, not just in Banska Bystrica but in all of Slovakia. But it was also clear that the existing system of medical and social care could not meet the needs of these patients. So, we began searching for an optimum model that would help people to die with peace and dignity," he says.

In a region where upwards of 80 percent of all deaths occur in hospitals crippled by severe funding deficits and inadequate staffing, this means that far too many people suffer through their final days in pain and fear cut off from their homes and the people they love. Similarly, social support for the families of terminally ill patients—as well as counseling and assistance for those who have lost a loved one—is virtually nonexistent, according to Mikula.

For a caring individual, being forced to watch someone suffer a long, lonely, and agonizing death from an incurable disease is a bitter pill to swallow. This is especially true for healthcare

providers and allied care professionals who know that there is a kinder, gentler way for people to make it through their final days. In many countries, however, the concepts of palliative care and hospice are virtually in their infancy. Such is the case in Slovakia, where the term "hospice" first appeared in legislative documents in April 2000 and standards for the provision of palliative care followed suit more than two years later in August 2002.

Before those laws ever hit the books, an AIHA healthy communities partnership linking the neighboring cities of Martin and Banska Bystrica with Cleveland, Ohio, set the wheels in motion to provide compassionate care for those with chronic or terminal illnesses. "Soon after our partnership was launched in 1997, we conducted a SWOT (strengths, weaknesses, opportunities, and threats) analysis to determine the most pressing needs of our community. Care for the elderly and terminally ill was found to be sorely lacking," recounts Maria Filipova, manager of health and social services at the Banska Bystrica Municipal Authority.

Through AIHA's healthy communities partnerships, various community stakeholders work together to find effective, sustainable solutions to health and quality-of-life issues. Municipal governments, healthcare providers, schools, churches, businesses, and civic organizations all have a hand in effecting positive change. In Banska Bystrica, a coalition was established to help ensure that these constituent organizations have a voice in the process of developing effective programs. With regard to the hospice project, the Diocesan Charities soon emerged as a leading force.

"Because we lacked both the funds and the legal framework for creating a traditional in-patient hospice, we decided to focus on providing home care that would offer terminal patients the possibility of living their final days at home in a comforting and familiar atmosphere," Mikula says. "We work in cooperation with patients and their families to meet four key goals: ensuring that pain and other unpleasant symptoms are managed as effectively as possible; that the home environment creates a warm and loving circle of care; that the psychological, spiritual, and social needs of the patients and their families are met; and that the emotional needs of survivors are met after the patient has passed," he explains.

Still, this is no easy task. At first, many doctors had no idea what hospice care entailed and they were resistant to the new concept. Some even refused to sign the necessary authorization forms that would allow patients to return home under the care of the hospice team. Another major stumbling block was purely financial—because Slovakia had no legislation authorizing hospice or palliative care, state insurance companies did not reimburse for these services. This

put a tremendous strain on institutions and individual care providers alike and many care providers ended up volunteering their time to the cause.

It was this dedication—coupled with the support of their partners in Cleveland—that empowered the hospice team in Banska Bystrica and kept them forging ahead with the project. Describing her first visit to hospice centers in the United States, Babelova says she was struck first and foremost by the intimacy of the setting. "The rooms were so homey and the patients could have their families and friends with them. Really, it didn't seem like an institutional setting at all. I was also amazed to see what an important role volunteers play in the provision of care and support. That's something I'd never experienced before because there is no history of voluntarism in Slovakia or most other countries in the region. I think public education can help change this, but we've found it to be difficult," she acknowledges. "I also did everything I could to inform all the primary care physicians and hospitals in the area about our services, visiting them all and distributing informational packets that explained the concept."

For prospective hospice patients, the first step is touching base with the hospice team to discuss their situation and schedule an appointment for an in-home evaluation, according to Babelova. "That way, we can determine the actual needs of the family and how we can help. If the family requires nursing care, then I'll go to the patient's doctor to discuss what I can do to assist with pain management and other forms of care. Sometimes the physical care is the easiest part, though," she says, explaining, "The most difficult part for some people is the loneliness they feel. They come to view me as a friend and I develop a fondness for them. It's very demanding work from a psychological perspective, to be sure."

As demanding as the work is, it is also incredibly important—especially for the patients who would otherwise spend their final days in the institutional chill of a lonely hospital ward. For 80-year-old Zuzana Kapustova and others like her, hospice care offers a different kind of death. A death they can control.

"I know that I have cancer and that I will die, but I want to die here in my own home surrounded not by pain but by God's love and my flowers," she says pointing to the pictures of bright blossoms that adorn the walls of her bedroom.



Thanks to hospice care, Zuzana Kapustova receives the care she needs in her own home. Hospice nurse Anna Babelova taught Kapustova's daughter Hana (center) and granddaughter Jarmilla (right) how to take care of her in between the nurse's visits. (Photo: Kathryn Utan)

Smiling at her nurse, Kapustova continues, "Anna helps me to bear the pain, she gives me medicine, and brings clean bandages. She taught my daughter Hana and granddaughter Jarmilla how to care for me, too. I've lived in this village all my life, and now that I am home from the hospital I have many visits from family and old friends. At night, I hear the familiar sounds of my home and read my books ... it makes being so sick almost bearable and I feel so happy to be in this place." Surveying the room slowly and deliberately, she nods her head just once. "Yes," she says softly, "this is how I want it to be."