

# Anna Garchakova

Director, Belarusian Children's Hospice, Minsk, Belarus



**Anna Garchakova's work is a story of how a particular cause can trigger development of philanthropy in a country where NGOs and philanthropy had been treated with suspicion and distrust.**

Anna founded the Belarusian Children's Hospice (BCH) in 1994. The first children's hospice in the Former Soviet Union, BCH effectively introduced the concept of palliative care to FSU countries – a region where human life, let alone death, had very little value, and giving even to the most obvious causes was not part of the culture.

Belarus has been very suspicious of NGOs both at state and public level. BCH has proved that NGO projects can be truly charitable, open, professional and without a shadow of corruption. Thanks to Anna's work, public opinion about

philanthropy in Belarus has undergone a radical change and it has become popular to be 'socially useful'. It was BCH, which gains a lot of publicity, that gave rise to the development of volunteering and middle class giving.

Through her work Anna has helped gain public and state acceptance for the NGO sector. Her work has also led to improved conditions for social and medical NGOs in Belarus as a result of changes in legislation to support the activity of BCH. And BCH's work has in turn changed attitudes towards children with disabilities. Previously, parents of children with disabilities received no support and were frequently ostracized. In 2012, the government passed legislation recognizing the right to respite care for families with chronically and terminally ill children.

In addition to her work in Belarus, Anna Garchakova is training people in other FSU countries in palliative care and setting up charitable hospice services. She is also setting up a Children's Palliative Care Association in Eastern Europe to help other countries in the region to do the same.

I was a clinical psychologist working in the oncological unit of a children's hospital here and one day the head of the medical staff decided that we needed a way to care for terminally ill patients, so she sent me to the US to study their methods. That was the first time I came across the idea of hospices. I came back and wrote a report and my chief said, 'OK, do it'.

I think my biggest achievement is to create a very good palliative care team. If I leave the hospice, palliative care will continue. My greatest disappointment is that I was sure that when I showed people the difficulties handicapped and terminally ill children faced, they would say, 'we're ready to help,' but you have to work a very long time before people see this. It took 18 years for the government to pick up on it. For me it's so clear – we need to create a system for this kind of patient.

I have ambitious plans. First, I want to build a new building for the hospice

because the existing building is old and small. As well as providing medical facilities, it will be a research and education centre for Belarus and for all the former Soviet countries. I also want to develop a palliative care association for former Soviet countries which will publish a guide to developing a palliative care system, especially in rural areas, which is a big problem.

I want to mention two challenges. One is personal – it is the children's deaths. I've been doing this work for 20 years and you never get used to it. Second, our service is very good medically, but we need to create stronger organizations. If we improve our management we will provide better palliative care services.

As far as funding is concerned, we are trying to change people's outlook and things are very different from when we started. Our donors and volunteers understand that it's not just the

government that can change things; we as citizens can, too. We now get 78 per cent of our funding from Belarus and there are more small donations. It shows society is involved in this process. Also this year, we have been getting small amounts from people in prison. It's only \$5 a month, but for me it's a sign that the mentality is changing.

As well as changing the mentality, we need better regulations. Charitable organizations in our country are at a low level and there are no incentives to give. Donors pay tax twice, first on their income and then on donations. There's a lot of paperwork. We're used to it but it's complicated for donors.