2004 - A NEW HOSPICE SERVICE IS BORN - ARZAMAS, RUSSIA

Summary

This article gives a brief account of a short course in palliative care run in Arzamas, near Nizhny Novgorod, in Russia. It finishes with an indication of the developments in the city after the course.

The background

In September 2003, an e-mail arrived on the screen of a computer on the Essex-Suffolk border. It sought help in establishing palliative care in the Nizhny Novgorod region of Russia and proved to be the first of many, starting a correspondence between Dr. Elena Vvedenskaya, the President of the Nizhny Novgorod Association for Palliative Care and Wendy Jones, one of the Trustees of the Victor Zorza Hospice Trust, and, soon, several others who joined the project.

The e-mail made another 'first' for the Victor Zorza Trust, too, giving opportunity for the Trust to adopt a different approach to its work. Hitherto, the Trust had responded, and still does, to requests for funds to assist in the development of palliative care in Russia and the other states of the former Soviet Union. This time, the Trust responded in a different way: rather than simply putting its collective hand into its collective pocket for approved projects, the Trust itself initiated the response.

Dr. Vvedenskaya, who had been passionate about palliative care for a considerable time and was desperately seeking to establish the concept in Nizhny Novgorod, had booked to attend the multi-professional course to be run at St. Christopher's Hospice in May 2004. After discussion, trustees of the Victor Zorza Hospice Trust agreed that the best way to help would be to provide basic education in palliative care for some of the staff who would form the core of a team with whom Dr. Vvedenskaya would work on her return from London. Accordingly, Wendy Jones was charged with the responsibility of organising a short course on behalf of the Trust.

Preparations

Dr. Anthony Smith, Consultant in Palliative Care, Jo Carby, Nurse Specialist in Palliative Care, Dr. Kate Hanwell, G.P. trainee registrar in Hospice, and Wendy Jones, former Lecturer in Palliative Care, formed the team that began its teaching preparations during the summer of 2004. Simultaneously, in Nizhny Novgorod, Dr. Vvedenskaya, and in Arzamas, a city about 110 km to the south, Dr. Alexander Tsopov and his wife Dr. Lyudmila Tsopova, co-operated with several colleagues both in the hospital and health administration to ensure that basic necessities such as living and classroom accommodation, meals, transport and interpreters were all provided when the team arrived. The wonders of modern electronic communication allowed us all to share progress with each other and to ensure that, where possible, the teaching was shared with our Russian colleagues. This had many advantages: the course would be seen as a shared venture by the students; the Russian doctors who were in a position to carry some of the teaching load would be validated both in the eyes of the students and in the view of senior colleagues and Administrators; the risk of imposing western values on an Eastern European culture would hopefully be minimised; and our Russian colleagues would be able to test out some teaching methods which were new to them and gather experience in so doing.

Statistics

Nizhny Novgorod has a population of 3.6 million, of whom 20,000 die each year from advanced cancer. Of these, 17,000 are in pain, 9,000 have breathing problems, and 1,000 suffer gastro-intestinal symptoms during the last year of life. In addition, there are 50,000 patients with non-malignant diseases, of whom 33,000 are in pain in the final year of life. 20,400 suffer from breathing difficulties, and 13,600 have gastro-intestinal problems. There is, therefore, a total of 70,000 people who die in distress every year. It is to assist these patients and their families that the Nizhny Novgorod and Arzamas team hope to develop good palliative care services.

Implementation

The venue in the city of Arzamas was planned by our Russian hosts, as there were facilities available there, the majority of the participants were based there, suitable accommodation for the visiting team could be found there, and Arzamas was likely to provide the location for the first hospice service.

The venue was comfortable, though cold at times! It was not always possible to have a computer available for PowerPoint presentations, and an overhead projector was only intermittently available and working. Nevertheless, these minor difficulties did not seriously affect the delivery of teaching sessions, as all the members of the team were well able to function in spite of them.

Interpreters

Whenever an educational course is planned in a country where English is not the first language, it is essential that sufficient interpreters are available. Translation is extremely tiring for the translators and changes in interpreters are vital either at natural break-points in each session or at its end. It is also essential, particularly in the teaching of palliative care, that the translators are seen as part of the team. They are often, as was the case in Arzamas, largely young people whose life experiences do not yet extend to the topics which form much of the substance of a palliative care course. Similarly, they need to be prepared for any ward or home visits, which form the clinical component of such courses, and their wishes or hesitancy respected.

In Arzamas, we were fortunate to have the help of a team of excellent young people who were in the final year of their English language course, together with two of their tutors. They all threw themselves into the work with enormous enthusiasm and skill, and, as typifies good palliative care, anyone with a command of both languages helped at difficult moments. At times, the laughter provoked by amusing misunderstandings acted as lubricant oiling the wheels of warm mutual relationships.

Course participants

Twenty participants were officially registered for the course, but on several occasions there were more than this number, while at other times there were fewer attendees. Participants were drawn from several disciplines and different areas of health care delivery. As is often the case, many of the doctors, nurses, social workers and others who formed the group had to fit the care of their patients around the teaching, and so had to miss some sessions.

In spite of this, a feature that characterised the whole group was their great enthusiasm, readiness to learn and keenness to put new learning into practice.

Course programme

"The best-laid plans of mice and men gang oft awry……." wrote Robert Burns, a Scottish poet favoured by the Russian people, and our course plan was no exception. Quite often, different priorities arose which took precedence over the plans for the day, but in every case the overall objective – the promotion of a favourable environment for the growth of palliative care in the region – was met, while minimising the disruption to the educational input of the course.

The visiting teaching team was able to meet with the press and with senior officials of the City Administration and the Health Administration, as well as many senior staff of the local hospitals. These meetings gave the opportunity to emphasise the significance of palliative care and its potential impact on health delivery within the city and region, as well as giving a public platform for raising awareness within the local community.

Clinical teaching

No palliative care course can be complete without an attempt to utilise the best teachers we have: the patients. In Arzamas, this was achieved by splitting the participants into smaller groups to attend wards or homes where patients with far-advanced, but not necessarily malignant, disease, were being cared for. Each time this occurred, groups were accompanied either by a doctor-nurse team drawn from the UK visitors, or on one occasion by a doctor-doctor or nurse-nurse team. The participants were thus able to watch multi-disciplinary working to some extent, and to observe the relationships between the medical and nursing professions in the western practice of palliative care. At the times when two doctors or two nurses were working together, the focus of the teaching centred on concerns specific to those professions and accordingly the students were separated by disciplines to reflect this. Following all clinical visits we held plenary sessions so that groups were able to share their experiences with those who had not visited.

Putting theory into practice

It was gratifying to learn that, following one of the clinical visits to a particularly ill, distressed patient, the ward medical and nursing staff implemented as much as was possible of the regime that had been suggested. A little later the same week, we heard that the gentleman had died peacefully and free of all distress.

A building for the hospice?

The day before we left Nizhny Novgorod, we were shown a building that might be offered by the Arzamas city authorities for conversion to a hospice unit. Currently in use as a military hospital and standing in the campus of the district general hospital, it is well-located on the outskirts of the city. There is much work to be done – it has no heating, and no running water – but there is the will to succeed.

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