

Creating a palliative care system for children

In Latvia, EQUAL is funding an initiative that is unique amongst all the Development Partnerships (DPs) in this Community Initiative. Led by an NGO, the Society of the Children's Palliative Care (SCPC), the project is developing and implementing the concept of palliative care for children¹ throughout the country. The idea is to create a psychosocial, medical and spiritual support system for terminally ill children and their families. "We help people to overcome the loss and to balance their family life, without losing their ties with society. We help family members to overcome the crisis and we provide the necessary help to enable their reintegration into society and the labour market," says Anda Jansone, the Project Director.



A child with a terminal illness requires uninterrupted care, in some cases for many years. This entails at least one of the family members, usually the mother, taking childcare leave for a considerable period of time and frequently it can result in the loss of employment. After the death of a child, such parents find it difficult to reintegrate into the labour market and often slip into that group of people who are at most risk of social exclusion. In fact, after a long period of emotional tension caused by caring for a terminally ill child and later by the child's death, comprehensive assistance is needed to limit the detrimental psychological, social and career effects that are the result of these devastating experiences. Even if the burden of caring for a terminally ill child has been placed on its mother, individual counselling is provided for the father, the mother and the whole family. Those consultations before, and after, the death of a child help the father and mother to develop a more fulfilling relationship and to offer strength and support to each other, during this extremely difficult period in their lives.

Clearly, a centre where terminally ill children could receive professional care, would allow the parents to work on the improvement of their vocational skills, to continue with, or to seek, employment and to reintegrate more smoothly into society and the labour market.

The project intends to make these types of services available across Latvia. A first, but important, step has been made in that direction thanks to EQUAL. Mobile teams of professionals are being established that will help families in all parts of the

A holistic, multidisciplinary approach

The focus of the DP's endeavour is the establishment of a Palliative Care Centre for Children that will allow them to receive multidisciplinary and co-ordinated care. In fact, palliative care is carried out by a multidisciplinary working group, which includes physicians, nurses, a social worker, a chaplain and a psychologist. Where necessary, a physiotherapist, a dietician or other specialists can also become involved in the care programme. The family of the ill child plays a major part in planning this programme and in taking the associated decisions.

¹ Excerpt from DP's information booklet: Palliative care is an active, full-scale care of children (and members of their families) suffering from progressive chronic diseases – those for who treatment potentialities are exhausted. This care combines alleviation of pain and other symptoms, solution of psychological, social and spiritual problems to provide the maximum comfort to the patient. It assists the child in using his physical abilities, so that it would feel as well as possible, that its wishes would be fulfilled, that people it loves would surround it. Groups of diseases, which come across more often, belong to oncological, haematological diseases, AIDS, hereditary genetic diseases and multiple system diseases, heart, nephrotic, liver, lung diseases, illnesses of nervous system in the final stage, and these of immune system.

country and to expand this provision, the DP is placing a special emphasis on training specialists to work in the palliative care of children.

The fact that there are no specialised bereavement centres of any sort in Latvia highlights the innovative character of the project. The eight years of experience of the Society of the Children's Palliative Care clearly indicates the need for services that can offer professional care to bereaved individuals that will support and comfort them in their grief. Getting life back to as near normal as possible is important for everyone who has lost a close relative and it also can help bereaved parents to begin to consider the possibilities of having other children in the future.

Joining forces to help parents and children

SCPC has built a close cooperative relationship with the Riga City Council Welfare Department's Health Care Division, which is the national partner in the project. Three strategic partners are located in the regions of Latvia and these are the Livani Hospital, the Children's Social Care Centre "Veģi" and the social care center "Spēkavots" in Ventspils.

Three strands of interlinked activities

The project started at the beginning of 2005 and the major strands of its activities are well underway. During this first year of its existence, it has worked intensively with the target audience. A survey was carried out to assess the needs of the target groups (parents and children), before exploring a possible sample of families to benefit from the new service. Families were then selected, on their needs and in relation to the different groups of children's diseases. A palliative care service is meanwhile being provided to ten families with incurably ill children. In addition, five families are currently receiving psychological and spiritual support during the bereavement period. All these activities are carefully monitored and evaluated. Twice each month, team supervision is offered to the professionals working within the project. A psychotherapist also measures the psycho-emotional condition of the team members in their long-term work with incurably ill children and their families.

At the same time, the project has targeted family doctors with the aim of informing them about the need for children's palliative care in Latvia. Prior to launching the mobile palliative

care teams in the different regions, three seminars were held for interested professionals to inform about the specific features of palliative care services and the benefits to families and society. Meanwhile, future care specialists for the regional teams have been selected and will shortly commence their training.

Reaching out to policy makers, professionals and the public-at-large

The DP makes every effort to ensure that those political decision makers and public authorities that will have to decide on the sustainability and transfer of the new model into the mainstream health care system after EQUAL, are kept informed about the progress of all of its activities. Also booklets in three languages and a brochure have been produced to inform the public-at-large about the project. A website provides more information about the DP's aims, method and activities and these activities have also been covered in the main Latvian newspapers and on national radio.

Cooperation and exchange with the international community of professionals in this specific field are seen to be crucial important. Reports of the project's approach and findings have featured in medical journals and its representatives are always willing to share their experience at relevant European and International events.

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