

Merimna

The Society for the Care of Children and Families Facing Illness and Death



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This article, in our occasional 'Centres of Excellence' series, describes a unique non-profit organisation that is pioneering bereavement and end-of-life care and support to children, young people and families in Greece. Merimna is the only source of community-based support for bereaved and seriously ill children and their families in Greece and is supported entirely through private donations and fundraising, which makes its existence still more unique.

Merimna (which means 'care' in Greek) is a non-profit organisation based in Athens for the care of children and families facing illness and death. It was founded in 1995 by an interdisciplinary team of nine health care providers and university professors with long clinical experience in the care of children, adolescents and families. Our motive, at the time of Merimna's inception, was to develop home care services for terminally ill children, in response to the findings of a study on the support needs of bereaved parents. With no available home and palliative care services, families had to cope on their own with the challenges of end-of-life care if they wanted their child to die at home. The government had refused the request to develop what it considered 'useless' home care services for children at the end of life, and regarded this as the responsibility of volunteers, not of professionals. They, the government argued, should remain hospital-based.

We quickly realised that, in a country where death was largely a taboo topic, consistently avoided in discussions with seriously ill and bereaved children, thereby systematically disenfranchising their grief, we needed first to create a fertile ground in which palliative care and bereavement services would be accepted and used. With this in mind Merimna's board decided to begin by focusing the work of the organisation on two main goals:

- raising the awareness of the Greek public on issues related to serious illness, death, dying and bereavement, and

- training health care providers and educators in how to recognise children's needs and how to provide appropriate support when death, dying and bereavement affect their personal, family and school life.

Awareness-raising

The response was beyond all expectations. The need to openly address and discuss these issues was reflected in the public's response as well as that of the community of professionals who fervently attended our conferences, seminars, lectures and training programmes. Our goal was to disseminate evidence-based knowledge that reflected our clinical experience, was free of psychological jargon, and useful to those supporting children through illness and death. Information aimed to normalise grief, depathologise bereavement, and empower the community to foster open communication, assume a supportive role and enhance belonging for the bereaved and/or seriously ill child or adolescent.

To this day, more than 250 lectures and seminars have been offered by Merimna all over the country, in response to invitations from local communities and schools. In addition, four conferences have attracted more than 1000 participants each, with presentations from Greek and international experts such as Cicely Saunders, Jeanne Quint Benoliel, Robert Neimeyer, Barbara Sourkes, Barbara Monroe, Mooli Lahad, Stephen Fleming, Julie Stokes, Robert Stevenson, Frances Dominica-Ritchie, Myra Bluebond-Langner and others. The conferences focused on the following topics:

- Mourning in our life (1996)
- When illness and death affect school life (1998)
- Losses in children's lives (2003), and
- Paediatric palliative care: challenges and opportunities (2009).



The labyrinth was created by Merimna with the community of Farkadona to mark the passage from trauma to growth three years after the death of seven of its young people in the Maliakos school bus crash

Training

In parallel to the awareness-raising process, Merimna offers training programmes (ranging from 100 to 200 hours each) for professionals from a range of different educational backgrounds, postgraduate studies and/or clinical experience. Each training programme has a theme (ie. Childhood bereavement counselling and family support, Psychosocial interventions in disaster situations, Paediatric palliative care). Learning is not limited to the simple acquisition of the knowledge and skills necessary to assist children and families in illness and death situations, but extends to an in-depth exploration of both self and team dynamics in the face of death. A key objective is to help participants develop an understanding of how they affect and are being affected by their encounters with children, families, co-workers and colleagues who are involved in the grieving process. Methods of teaching are both didactic and experiential, and supervised clinical practice is central to the learning process.

To this day, more than 200 psychologists, social workers, educators, nurses and paediatricians have been systematically trained and act as key figures in their work setting and co-ordinators of interventions when death affects children, families, schools or communities. They belong to a panhellenic network of trained

professionals, and volunteer their services when Merimna organises a large scale psychosocial intervention after a disaster event.

Merimna services

Today Merimna provides, free of charge, three types of services:

- counselling
- crisis and disaster interventions
- paediatric palliative care.

Counselling services

A Counselling Center was founded ten years ago and is staffed by trained psychologists who offer individual, family and group support to children and adolescents who are grieving the loss of a significant person, or who are themselves seriously ill or have a family member who is suffering from a life-threatening illness.

We offer preventative counselling and support to all children and families who seek our services – those who are experiencing a normal grieving process as well as to those whom we identify as being 'at risk'. Such prevention aims at facilitating the normal grieving process, at enhancing open communication and mutual support

among family members, and at minimising the likelihood of grief complications and adjustment difficulties. In addition, we offer long-term support to a selected number of children, adolescents and parents who are experiencing psychological problems as a result of a particularly traumatic death in the family.

Special attention is given to the unique developmental needs of pre-school and school-aged children, adolescents and young adults, who have different ways of understanding and experiencing death and of expressing their grief and coping with their loss. Parental support is perceived as integral to the support of children, while services are often extended to other individuals who play a key role in a child's or adolescent's life (teachers, peers etc).

Our trained psychologists conduct a thorough assessment with every child and family that comes to our centre. This assessment aims to identify pre-loss, loss-related, and post-loss factors that affect the child's and parent's coping with illness or death, their psychological well-being, and their current support needs. This enables the clinicians to create an action plan for individual, family or group counselling, which is presented to and agreed with the family. The psychological well-being of children and parents is re-assessed at the end of our work and the effectiveness of our interventions is evaluated.

The theoretical background that guides our interventions is based on Bowlby's attachment theory and a systemic approach that recognises the impact of serious illness and death on families, school communities and other groups to which children and adolescents belong. Sometimes, cognitive-behavioural techniques are integrated in trauma interventions that aim to equip children and adolescents with the skills to manage their traumatic responses to loss. The main focus of our interventions is on relationships that are severed by death or threatened by a serious illness, and on relationships that are redefined in the face of loss. This relationship-centered approach also pays particular attention to how each staff member affects and is affected by encounters with bereaved and seriously ill children and families. Regular supervision sessions, staff meetings and ongoing training provide opportunities for increased self awareness and mutual support among team members.

Over the past few years Merimna's helpline, which provides information and guidance over the phone, has been overwhelmed by requests for support from parents, educators and psychologists living in other parts of Greece, outside Athens. This renders imperative the development of a second counselling centre in northern Greece. To achieve this goal, in 2010 Merimna is providing in-depth training in childhood bereavement care for professionals living in Thessaloniki. At the same time it is mobilising the local community to generate financial support for bereavement services that are in high demand in that area.

Interventions in crisis and disaster situations

Merimna has to date provided psychosocial support to elementary and high school students following three major disasters, in response to requests from the Ministry of Education and/or the Ministry of Health and Social Solidarity. These were the earthquake in Attica (1999), the Maliakos road traffic accident in central Greece that

caused the death of seven teenagers (2004), and the wildfires in the Peloponnese (2007), in which 67 people died, many others were injured and some 815 houses and 1.8 million hectares of forest and cultivated fields were destroyed. All interventions went beyond the management of the initial crisis and involved a close and long-term collaboration with several school communities.

Our community-based psychosocial approach addresses both individual and collective trauma and grief. The focus is initially on creating a holding environment in which community members can freely express their feelings, thoughts and needs, and develop a partnership with professionals. Emphasis is then placed on identifying risk factors that render children, adolescents, families and school communities vulnerable to short and long-term psychological problems, as well as protective factors that contribute to their resilience. We adopt a systemic approach that empowers students, teachers, families and local leaders to understand the impact of the disaster, identify their needs, and mobilise or expand their resources. Interventions are co-created with them, rather than being imposed, and address concerns and needs in ways that are meaningful and appropriate at different points in time through the process of community adjustment.

Our approach in disasters differs from the psychiatric model of intervention that focuses exclusively on the prevention and treatment of psychopathology and victimises children and adolescents by regarding them as highly vulnerable and damaged by traumatic events. We perceive the community as able to cope with the challenges it encounters by building on its own resources and drawing on the information, guidance, support or therapeutic interventions we can offer for children and adolescents who are in greater need for long-term help.

It is worth mentioning the importance of preventing the stigmatisation and marginalisation of a seriously traumatised community and the enhancement of communication with the wider society. In that respect, following the Peloponnese wildfire disaster, Merimna developed the Green Ribbon Project. This is a creative activity that invites children aged from five to 17 years from all over the country to write stories and draw or create a tree (with material provided by our organisation) onto which they project feelings, anxieties, hopes and desires associated with their life experiences. The activity is completed individually or with an entire classroom, following specific guidelines that we provide to school staff. Twinning schools from the wildfire areas with schools from other parts of Greece enabled students to exchange their artwork and share experiences through a website (www.prasiniklostidemeni.gr) or by visiting each other.

Paediatric palliative care services

Merimna has recently developed an innovative programme to provide (for the first time in Greece) palliative home care services to terminally ill children and their families. The project is based on Merimna's collaboration with one of the two largest paediatric hospitals in Athens. The close collaboration between a public hospital and our non-profit organisation was deemed necessary to ensure continuity of care between hospital, home and Merimna's counselling



Merimna developed the Green Ribbon Project following the 2007 Peloponnese wildfire disaster. The national initiative aimed to provide a means for all children and young people across Greece to talk about their hopes and fears and life experiences

centre, which runs support groups for bereaved parents and siblings. Each step in the development of this new service is being evaluated to ascertain that the needs of children, adolescents, families and professionals are being met in appropriate ways.

Dissemination of knowledge

One of Merimna's practices has been the continuous dissemination of knowledge and accumulated experience to other professionals and lay people. This is being achieved in at least four ways:

- open teamwork with community services, including close collaboration with paediatric and adult hospitals, mental health services and rehabilitation centres for parents with co-dependence problems
- publications – Merimna's books, leaflets, conference proceedings and children's stories
- educational DVDs – the latest, entitled *Pathways through Loss*, depicts the experiences of adolescents and teachers following the Maliakos road traffic accident. It describes their trajectory from trauma to growth and the help they received from Merimna during their three-year collaboration. Together with a leaflet on coping with trauma and loss, this DVD will hopefully become available to schools throughout Greece

- research, including the following topics that have been or are still being explored: a) educators' attitudes towards seriously ill and bereaved children; b) short and long-term psychological effects of disasters on children and adolescents; c) the evaluation of a relational learning approach in paediatric palliative care education; d) the development of a protocol for an in-depth psychological assessment of children's trauma and grief, and e) the effectiveness of individual vs group interventions with bereaved children and their parents.

Conclusion

Merimna's uniqueness lies in this systematic and parallel development of comprehensive clinical, educational and community services that are highly regarded in a country where modern palliative and bereavement care is minimal or non-existent. With its pioneering work, this organisation sets a high standard for paediatric palliative care and childhood bereavement services and creates new opportunities for professionals to specialise in this important field of work.

Merimna's funding resources come solely from private donations from individuals, companies and foundations, and the invaluable and faithful support of the Friends of Merimna, a non-profit organisation founded in 2002 that raises funds to support our goals and activities.