The Facts
Each year more than 7.6 million people with cancer will die worldwide. Of these, 64% of cancer deaths occur in developing countries. For most cancer patients with advanced life-limiting illness, the prelude to death from cancer is a period of functional decline associated with progressive symptoms and an increasing burden of care. For most patients, day-to-day care is based in the community and provided by family and friends. Optimising symptom control and psychosocial support services benefits the patient and the caregiver.

The World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

Few countries around the world have national palliative care strategies; even fewer have implemented them.

UICC’s Response
The UICC Cancer Outcomes Statement, a set of action-oriented objectives, supports the delivery of the 11 targets of the World Cancer Declaration and calls for the following:

By 2018, all countries to develop and implement population-based palliative care strategies for cancer.

A Global Solution
The health of the population requires good palliative care, not simply for the benefit of the person dying, but also for caregivers while in the role and after the death, as well as providing substantial benefits for the health system.

For all populations and resource settings, palliative care should be part of national and jurisdictional health and social policies for all non-communicable diseases, including care delivery, education for the community and clinical staff, optimising models of service delivery, and research.

Supporting Evidence
At all levels of the health system, there are demonstrable benefits from very modest investments in palliative care, that improve the health outcomes of the community.

For patients: Symptom control reduces suffering and the horrendous impacts of incurable illness. For a terminally ill patient, access to specialised palliative care services means that their specific needs can be better met, for example, enabling a patient to die in the place of their choice, which for some will mean at home. Other demonstrable benefits for patients include improved satisfaction of care and comfort in the last weeks of life.

For caregivers: How well people make the transition from caring for a terminally ill patient back to other roles varies widely and often has long-term consequences. For caregivers, the benefits of palliative care services can include better adjustment after the death, and potentially greater ability to reintegrate back into society after the role of caregiver ends. Access to specialised palliative care services has numerous other benefits for the caregiver, including reducing anxiety, meaningful improvements in addressing the needs of caregivers, both in the short-term (“unmet needs”) and long-term (“moving on”), as well as affording a longer life for the caregiver having relinquished the role.

For the health system and health funders: The involvement of specialised palliative care services has a number of significant benefits including reducing the inpatient bed days as well as the number of hospital admissions. The involvement of palliative care is also associated with decreased costs when compared to conventional care.
Kerala: Demonstrating leadership in the delivery of pain relief and palliative care in India

Kerala, a small state on the southwest coast of India, has taken the lead role in the delivery of pain relief and palliative care in a resource-constrained setting. The state has a network of about 140 palliative care centres – more than all the centres in the rest of the country put together. This network first came to life in 1993 with the establishment of the Pain and Palliative Care Society (PPCS), a non-governmental organisation (NGO) based in Calicut, Kerala\(^\text{14}\). PPCS succeeded in developing a model of care adapted to the Indian situation, empowering care at home mostly delivered by relatives who are supported by an outpatient clinic. Home visits are offered to the bed-bound, and low cost oral morphine is made available for use by patients at home\(^\text{15}\). A study of 1723 patients over a 2-year period showed safe and effective use of oral morphine in the home setting without misuse\(^\text{16}\).

Collaborative efforts of the Pain and Policy Studies Group (PPSG) at Madison-Wisconsin with Indian palliative care workers resulted in the simplification of narcotic regulations in Kerala in 1999, with trained volunteers forming a major part of the workforce. The support spread with Neighbourhood Networks in Palliative Care (NNPC) facilitating increased active involvement of the community in the care process\(^\text{17}\). In 2008, acting on a proposal submitted by the NGO Pallium India (www.palliumindia.org), the Government of Kerala introduced a palliative care policy, integrating palliative care into general health care.

Many barriers still remain: Quality of services in some centres; lack of education of clinical staff; and capacity to deliver care in the absence of adequate medical and nursing support. Despite this, the achievement in Kerala is remarkable. Current priorities include an evaluation of the remaining barriers, and a plan of action to duplicate the model in the rest of India.

References


In 2009, UICC co-founded the NCD Alliance with the International Diabetes Federation and World Heart Federation. The International Union Against Tuberculosis and Lung Disease has since joined the Alliance, which now represents the four main NCDs and the interests of 880 member organisations in more than 170 countries.