

# Maharashtra Palliative Care Policy

Draft 2012

## **Palliative Care Policy in Maharashtra**

Life with an incurable and debilitating disease is often associated with a lot of suffering. In addition to physical problems, there are social, emotional, financial and spiritual issues caused by the illness. On the social domain, in the absence of any comprehensive social security system, families often get financially ruined.

Modern Principles of Palliative Care can take care of the suffering in patients with incurable diseases, considerably diminishing the anguish for the patient and the family.

It is aimed at '*Improving Quality of Life (QOL)*', by employing what is called "*Active Total Care*", treating pain and other symptoms, at the same time offering social, emotional and spiritual support.

In India it is estimated that the prevalence of patients who require Palliative Care are 10 million, 1 million with cancer and 7 million with other life limiting conditions.

This would work out to approximately 1 million patients for Maharashtra. Most of them reside in the rural areas where a basic Palliative Care along with Morphine availability would alleviate their suffering and allow them to die in the place of their choice with dignity.

**WHO guidelines developed by the National Consensus Project for Quality Palliative Care in 2004, suggest domains for the effective provision of Palliative Care at every Centre.**

<i>Sr. No</i>	<i>Aspects of Care</i>	<i>Approach</i>
1.	<b><i>Structure and Process of Care</i></b> Access and availability of qualitative and quantitative services	<ul style="list-style-type: none"> <li>• These Centres need to be developed for each state alongwith Govt. commitment</li> <li>• PHC's/ Rural Hospitals/ Tertiary Hospitals/ Urban Hospitals</li> </ul>
2.	<b><i>Physical</i></b> Pain Management	<ul style="list-style-type: none"> <li>• Pain assessment and management of other related symptoms.</li> <li>• Training of Doctors/ Nurses caring for patients to address the symptom burden effectively.</li> </ul>
3.	<b><i>Psychological and Psychiatric</i></b> Suffering of patients and their families is multi-factorial and care has to be individually provided	<ul style="list-style-type: none"> <li>• This needs adequate and trained Clinical Psychologists at every facility with the referral to a Psychiatrist where indicated</li> </ul>
4.	<b><i>Social</i></b> The burden of anti cancer treatment is enormous. Families have often been impoverished due to the therapy; some of which could have been an exercise in medical futility	<ul style="list-style-type: none"> <li>• Rehabilitation of Family</li> <li>• Bereavement support</li> <li>• Empowerment of the family to care for the patient</li> </ul>
5.	<b><i>Spiritual, Religious and Existential</i></b> Addressing Spiritual issues	<ul style="list-style-type: none"> <li>• It is important for health care providers to facilitate spiritual support if needed</li> </ul>
6.	<b><i>Cultural</i></b> Respecting Cultural differences	<ul style="list-style-type: none"> <li>• These need to be identified and harnessed to provide good bereavement support in a rich cultural heritage due to co-existence of many religions with their varied rituals surrounding a critical illness and death.</li> </ul>
7.	<b><i>Care of the Imminently Dying Patient</i></b> Place of Dying	<ul style="list-style-type: none"> <li>• Traditionally the hospital has become the 'safe' place of care especially for end-of-life care.</li> <li>• However, studies on preferred place of death have shown patient preference to be 70-80% achievable in 50% of patients in the developed world.</li> <li>• For countries with limited health resources, Home Care and a 'Good Death' at home are a means of saving limited hospital beds.</li> <li>• For this however, training of Community Health care workers has to be initiated on an urgent basis</li> </ul>
8.	<b><i>Ethical and Legal</i></b> These need to be developed to protect physicians acting in the best interests of patients at the end of life	<ul style="list-style-type: none"> <li>• Principles of Medical Ethics, especially around the issues of 'Medical Futility'</li> <li>• Clinical Guidelines for the safe and effective provision of Palliative Care along the disease trajectory</li> <li>• There are no laws in India regarding Withholding and Withdrawing futile treatments and the concept of Euthanasia</li> </ul>

Some domains relevant to India are as follows:

- 1. Use of Traditional Medicine:** With carefully conducted clinical trials into the role of Homeopathy and Ayurvedic medicines, the armamentarium of drugs available for symptom control can be enhanced.
- 2. Clinical Research:** Within the present era of ‘Good Clinical Practice’; clinical research into issues related to the suffering encountered by Indian families is very relevant.
- 3. Networking:** This is the most important concept in achieving the best possible care delivery. It is between the hospital based Palliative Care team, the GP providing out of hours care and the caregivers. The modality would depend on locally developed care pathways.
- 4. Role of NGO’s and Volunteers:** Where paid staff is inadequate, the help of trained NGO’s and volunteers make up a work force complementing the existing staff. The tremendous psycho-social burden of care is shared by these committed individuals; many of whom have experienced bereavement in their family.

World Health Organization observes that it is “the fundamental responsibility of the health profession, *to ease the suffering of patients*.”

This will not be fulfilled unless Palliative Care has priority status within public health and disease control programs; it is not an optional extra”. To ensure that palliative care is available and accessible to the majority of the needy, a major thrust should be on a primary health care approach.

***The State, under Article 21 of the Constitution of India, is duty bound to ensure the fundamental right to live with dignity.***

In Kerala, The Director of Health Services, Government of Kerala issued an order (No. PH 6/068463 dated 29th July, 2009) incorporating palliative care into the primary health care system in the state. Around 400 Gram Panchayats have established home care programs for bed ridden patients under the project. The project started in 2008 has been working on the implementation of the Palliative Care policy of Government of Kerala.

For Maharashtra a similar programme will be driven by the Maharashtra Chapter through CIPLA and Tata Memorial Centre can be created taking into consideration the needs of the patients in this state.

To this end, the Palliative Care Unit of the Tata Memorial Centre along with the Maharashtra chapter of the Indian Association of Palliative Care (IAPC), seek a develop a comprehensive policy to work with the State Government to create Palliative Care Centres all over the State.

This will involve:

1. Identification of key institutions where Palliative Care can be developed. This would involve 1 centre in each district
2. Identification of key personnel to run the programme
3. Funding for these or new recruitment to run the programme
4. Funding for medicines and other costs for patient care
5. Provision of Morphine at these sites. This involves license, storage and dispensation according to the NDPS act.
6. As the Centre is making efforts to make the above easier, involvement with the FDA to facilitate the same.
7. The National Rural Health Mission (N.R.H.M) has already taken the initiative to create and implement a rural centre for our state which will alleviate the suffering of patients from rural Maharashtra and allow them to die with dignity in the place of their choice. This will act as a model to create further such facilities.
8. Creating key facilities for training - Indian Association of Palliative Care (IAPC), Tata Memorial Centre and Cipla Foundation, Palliative Care training centre will take the lead in this area.

#### **Palliative Care Centers in Maharashtra**

<i>Palliative Care Centres</i>	<i>Location</i>
Tata Memorial Center	Parel, Mumbai
Cipla Foundation	Warje, Pune
Krishna Institute of Medical Sciences	Karad
Shanti Avedana Ashram	Bandra, Mumbai
Govt Medical College	Nagpur
Walawalkar Hospital	Derwan, Chiplun

#### **Gaps in the Services:**

- Lack of awareness about Palliative Care among Medical Professionals
- Limited access to appropriate Palliative Care Services for patients with life limiting conditions
- Reaching out to the patients in Remote areas
- Liaisoning with NGO's for Home Care Services in Taluka & District level

***Objectives of the Programme:***

Palliative Care is not the prerogative of cancer, though presently most facilities exist in cancer centers. To care for the larger population of non-cancer patients i.e. HIV/AIDS and children, facilities should be at a location where all patients have access. This would entail setting up of the service in urban and rural areas, with private-public partnership.

**Short Term Objectives: 5 Year plan**

1. Setting up of 5 more centers within the State. The decisions for choosing and setting up of the same, with allocation of budget, to be undertaken by DMER, DHS, NRHM with expert support from office bearers of the Maharashtra chapter of the IAPC.
2. Ensuring quality standards and recognition of Palliative care centers as per Audit tools by the Expert committee comprising Members of the Maharashtra chapter of IAPC and representative of the State Government.

**Long Term Objectives: 15 Year plan**

1. One Palliative Care Facility at each district in the State ( requirements below)  
Structure of proposed Centres including Training: 1 part time Palliative Care Unit for the cottage and rural hospitals. The staff could rotate during the week between 2-3 hospitals in the vicinity. There should be mobile Units to cover the villages in phases.
2. Health workers (ASHA) can be trained for identification of patients needing Palliative care. The patients would be brought to the cottage hospital for primary treatment. Follow up would be carried out by ASHA's. These activities could go hand in hand with early detection.
3. Essential medicines including Morphine to be made available at every centre.

Besides delivering patient care, these 3 centers will be responsible for -

- Providing the highest standards of Palliative care principles as practiced all over the world
- Development of evidence based guidelines for common clinical conditions in Palliative care
- Training and dissemination of knowledge
- Liaison with Central & State Govt. for propagation of Palliative Care
- Clinical Research for situations unique to Indian patients
- Advocacy and Networking

***Facilities:***

***Staff: Multi – Disciplinary Team***

- 3-5 Doctors
- 5 Nurses
- 2 Social Workers per Unit
- 1 Occupational Therapist
- 1 Clinical Psychologist
- Volunteers

**Education of Faculty:** Palliative care should be an integral part of cancer care beginning at presentation for patients with advanced disease cancer presenting to the hospital. This can be done through sustained education of medical Faculty at each centre.

**Funding:** There should be separate funding for Palliative care

**Morphine Availability:** Adequate training should be provided for dispensing of morphine.  
Modification of the NDPS Act 1985: To ensure easier availability of Morphine for Patients.

**Drug Availability:** Drugs required for effective Palliative care placed under essential drug list.

***Training and Capacity Building in Palliative Medicine:***

1. MD in Palliative Medicine at 1-2 centers
2. Diploma in Palliative Care Nursing
3. Training for all medical and Para Medical Professionals in Centre; to adopt Palliative Care Principles for all patients with advancing disease. This would ensure better '**Holistic Care**' and Symptom Management at presentation of the patient to the institution.
4. Train 100-150 doctors, nurses and social workers each year for work at the developing centers in their areas of drainage.
5. Training of volunteers and psychologists to care for the patient and families.
6. Training of MSW's to supervise the training and mentorship of ASHA's
7. Awareness for Palliative care at the Community level to take ownership for Palliative care programmes. This has been found to be effective in Kerala.

***At district hospitals through DMER & DHS:***

1. To set up Palliative care Units in each district. There are Medical colleges under Directorate of Medical Education and District hospitals under State Health Service.
2. For the District hospitals there should be funding through DMER/DHS.

***At PHC's through National Rural Health Mission (N.R.H.M):***

1. The existing doctor, nurse and social worker to be trained in Palliative Care.
2. Liaison with Cottage hospital through ASHA workers.
3. The Rural/cottage hospital would appoint a MSW who would supervise the work of the ASHA workers in doing surveys and finding out patients who would be taken to the cottage hospital. All doctors, nurses and social workers will be trained to take care of these patients and families. Funds for medicines including Morphine would come from NRHM.
4. Mobile Units should be set up where feasible for care at Home.
5. Community participation of village leaders should be encouraged
6. Morphine availability through FDA should be facilitated by Nodal Centres.

### ***Budget:***

There should be budgetary provision for palliative care under:

1. Directorate of Health Service- (To fund for training about 10 Doctors in one year- 6 lac/yr)
2. Directorate of Medical Education ( To fund nodal centers conducting the courses)
3. Local Self Government Institutions
4. National Health Programmes like NRHM, NUHM
5. Employees State Insurance Scheme

### ***Staff Cost:***

Each District hospital must have a Palliative Care Medical officer. This Medical Officer must have a minimum qualification MBBS, having completed a prescribed training in palliative care at any of the centers of excellence. The salary of the medical officer may be 35,000/- per month or as per the norms (whichever is lower).

Each Rural hospital must have a dedicated Medical Social Worker for Palliative Care at the centre. The MSW must receive a salary 12000/- per month or as per the norms (whichever is lower).

### ***Training Cost:***

These costs will include the cost of personnel training at Centres of excellence or the Nodal Centre and also development of training materials. The Government must be committed to supporting candidates to receive the 1 year training so as to staff each district hospital.

Cost for Medicines: There should be a provision to provide subsidized or free medicines.

### ***Private - Public Partnership:***

- The need for palliative care is being increasingly recognized in the private health care sector and some centers already exist.
- However as a large part of all healthcare in the state is provided by the private sector, many more centers must be developed as “Specialist Palliative care Units.”
- All private medical institutions must have a Policy for palliative care and End of life care.

### **Observations & Recommendations for improving Palliative care delivery in the Private Health Care Sector are:**

#### ***Capacity Building:***

1. **Physicians:** All physicians who care for patients with chronic life limiting conditions must have some basic training in palliative care. The MMC should recognize such training and trainees must receive appropriate credit points for the training.



All private Health Care Institutions must encourage 1- 2 individual physicians within their institution to take a lead in Palliative Care delivery and development.

2. **Nurses:** The Nursing Staff patients with chronic life limiting conditions in the inpatient or the outpatient care setting must be trained in Palliative care, so as to improve their response in dealing with the patient.
3. **Multi- Disciplinary Team-** Effective Palliative Care can be delivered by a multi-disciplinary team. Hence other staff members in the institution must also be involved in palliative care provision. For example, MSW in private hospital only deal with organizing the finances for the treatment, they should be equipped with palliative care approach.

### **Minimum Training:**

#### **Physicians & Nurses:**

Sensitization and awareness workshops, seminars to impart knowledge, skill and attitude for Health Professionals in Palliative Care

#### **Other Professionals:**

This would include Multi – Disciplinary professionals such as Physiotherapist/ Psychologist/ Psychiatrist/ Counselors

(A minimum 2 weeks observation post in a palliative care center before they are inducted to deal with cancer patients)

- Oncology/ ICU trained staff should also have 10 days placement in PCC before starting to deal with patients.
- Each Hospital dealing with cancer patient must have a palliative care team (min-1 palliative care Physician, 1 nurse, 1 MSW)

### **Services to be offered by Public Private Partnership:**

In order to improve Palliative Care Service delivery both Public and Private Health Care providers must be jointly involved in the following areas-

#### **1. Service:**

- Commitment to providing palliative care, including essential medications to poor patients either free of cost or at a minimal cost
- Staff members must be encouraged and supported to provide their expertise in patient care to institutions which may need them
- Support other institutions in developing palliative care services locally through training and guidance

## **2. Education:**

- The staff members working in palliative care must be committed to providing training other professionals

## **3. Advocacy:**

Joining hands in advocacy efforts aimed at the common public, policy makers and the health care fraternity

### **Access to Morphine and other Essential Medications:**

Any Private Institution with a specialist Palliative Care unit must ensure that those patients who need strong opioids for symptom control have uninterrupted access to the medication upon appropriate prescription. This can be ensured by:

- Having a dispensary which stores and dispenses the drugs
- Seamless access to a nearby facility which stores and dispenses the drugs
- Have each hospital with an oncology wing/ panel of oncologist & a palliative care team should have permission for storing or dispensing morphine for the convenience of the patient & their families.

### **Service Delivery:**

- Outpatient facilities
- Inpatient facilities
- Continuity of care and policy of non-abandonment
- Written guidelines for palliative care within the institution
- Documentation of care “Standard Patient Assessment Tool”
- Physicians who are practicing palliative care for more than 5/ 10 yrs., & those who have obtained degrees from foreign universities and continue to be in the field without break should be granted a validated degree. ( May be an entrance test to be conducted by the IAPC) Capacity building

**Research:** Minimum quality standards of the Palliative care service should be audited periodically using the Pallium India tool.

**GOVERNMENT COMMITMENT:** The inclusion of Palliative care in medical practice is impossible without the support of the Government.

The commitment of the Government of Maharashtra is sought in the following aspects-\

1. Service development, training professionals and funding allocation for the same
2. Inclusion in all medical and allied curricula
3. Advocacy and IEC for palliative care among the masses

## PAEDIATRIC PALLIATIVE CARE

### **Introduction:**

Cancer in children is curable at diagnosis in 60% as it is much more sensitive than in adults. There is a plethora of therapy available. Treatment is prolonged, often away from the child's home and using tremendous financial resources. This entire burden is acceptable as long as the aim is cure. Even for children presenting with relatively advanced disease; there is a chance for cure, which is taken both by the Oncologist and the parents. In India, most cancer centers can provide financial assistance for the treatment.

For some of these children, the disease progresses in spite of therapy or there may be a relapse. Though there is still some chance of cure and therapy for relapse will be initiated; this is the ideal time for the Palliative Care team to be part of the professional team caring for the family.

### **Incidence of Cancer in Children:**

In Western literature, the incidence of children needing Palliative care in Canada was 14.7 /10,000 children between 1984 and 1994. In Australia the crude average incidence is 13.8/10,000 under the age of 15. There are no accurate estimates for developing countries which include India, though it is lower as children die more from acute conditions and under nutrition. The most common cancers are leukemias 30%, brain tumours 20%, lymphomas 10% and other solid tumours form the rest. In India, there are no accurate figures.

### **The World Health Organization defines Palliative Care for children as follows:**

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

## **The Goals of Palliative Care for children are as follows:**

- Relief of physical symptoms
- Psychological support to the child
- Addressing spiritual issues
- Support to the family- parents, siblings
- Home care-Empowering the family to care for the child at home
- End of life care
- Liaising with local doctors, referral to hospice
- Liaising with volunteers, other organizations which can contribute to the holistic care for children with life limiting illnesses and their families.

## **Understanding the Scope of Pediatric Palliative Care:**

According to the WHO definition all children suffering from a chronic life limiting illness should be offered palliative care. The list of such life limiting conditions is exhaustive; in fact researchers in the UK have proposed a list of about 400 such conditions.

The ACT, UK has developed a classification of conditions where palliative care is applicable:

- 1. Life-threatening conditions** - curative treatment feasible but can fail (cancer, organ failures, HIV)
- 2. Premature death inevitable**-long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities (e.g. cystic fibrosis);
- 3. Progressive conditions without curative treatment** is exclusively palliative and may commonly extend over many years (e.g.mucopolysaccharidoses);
- 4. Irreversible but non-progressive conditions causing severe disability** leading to susceptibility to health complications and likelihood of premature death (e.g. cerebral palsy).

## **Aims and Objectives:**

### ***Aim:***

The aims of this section of the Palliative care policy are derived from the International children's palliative care network's charter of rights for life limited and life threatened children.

1. To ensure that children with life limiting illnesses have access to appropriate palliative care irrespective of the place where they are cared for.
2. To ensure that Palliative care for the child and family begins at the time of diagnosis and continues alongside any curative treatments throughout the child's illness, during death and in bereavement. The aim of palliative care should be to relieve suffering and promote quality of life.

3. Encouraging every child to participate in decisions affecting his or her care, according to age and understanding. A sensitive but honest approach should be the basis of all communication with the child and the child's family. They should be treated with dignity and given privacy irrespective of physical or intellectual capacity.
4. To attempt to ensure that every child or young person has access to education and wherever possible is provided with opportunities to play, access leisure opportunities, interact with siblings and friends and participate in normal childhood activities.
5. Ensuring that the child's home remains the centre of care whenever possible. Treatment outside of this home should be in a child-centred environment by staff and volunteers, trained in palliative care of children.
6. Every child and family member, including siblings, should receive culturally appropriate, clinical, emotional, psychosocial and spiritual support in order to meet their particular needs. Bereavement support for the child's family should be available for as long as it is required.

***Objectives:***

1. To empower children and their families to access palliative care.
2. To improve the access to pain treatments including opioids at all centres where care is delivered to children.
3. To sensitize all medical professionals about the need and the scope of pediatric palliative including emphasis on need for offering palliative care "when illness is diagnosed".
4. To train all medical professionals who may care for children in communication skills so that they can (i) engage in sensitive and honest communication with the child and her family, in an age- and culture- appropriate manner and (ii) encourage children to be involved in decisions about their care.
5. To train all doctors who may care for children with life limiting or life threatened conditions, in palliative care. This will be achieved by integrating Palliative care into medical curriculum.
6. To train other professionals like nurses, social workers, therapists etc. in pediatric palliative care.
7. To identify and engage key stakeholders and policy makers who can affect improving access to palliative care for children.

**Development of Services:**

Services which can provide pediatric palliative care can be divided into 3 categories:

1. Medical colleges and teaching hospitals
2. Medical centres within the State Government
3. Private health care sector.

### *Development of Pediatric Palliative care in Teaching Hospitals*

These institutions will play a major role in-

- Providing specialist Pediatric Palliative Care
- Developing faculty members who can disseminate the knowledge, skills and attitude to train other medical and paramedical professionals in pediatric palliative care

#### **Capacity Building:**

- **Pediatricians** - All physicians in the Department of Pediatrics should be trained in pediatric palliative care from centers which are already providing Specialist pediatric palliative care e.g. Tata Memorial Centre. A few pediatricians with special interest in pediatric palliative care should form a team who will deliver PPC to all pediatric patients in their institution.
- **Other physicians-** Specialists from other branches like Psychiatry, Anesthesiology, Social or Family medicine etc. should be identified and trained in PPC.
- **Nurses, Social workers, psychologists, therapists and other staff-** Palliative care is a team based care delivered in a well coordinated manner. Each one of the above health care professionals have an important role to play in providing effective PPC.

Physician	Pain and other symptoms Goals of care/advance care planning Communication Psychosocial spiritual needs Patient support system Assess discharge planning issues
Nurse	Pain and other symptoms Function Patient/family learning needs Psychological support
Social Worker	Patient/family perception of disease/illness Values of patient/family Patient/family feelings and stressors Spiritual issues Children's issues/concerns Financial issues/consideration Pain
Occupational/ Physiotherapist	Assisting mobilization Caring for a bed ridden patient Specific therapies for specific conditions like Cerebral palsy

Psychologist, Therapists	Play	Providing psychological support Counseling Diversion therapy Support groups for patients, families
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- **Involving volunteers and voluntary organizations:** These individuals and organizations often play an important role in PPC. They can be involved in supporting the patient and the family in their home, providing psychological support, counseling, providing social support wherever feasible, advocating for PPC etc.
- **Offering MD in Palliative Medicine-** MD in Palliative Medicine has been recognized by the MCI in 2011. The teaching hospitals may offer this course to enhance the availability of Palliative care specialists.
- **Staff posts as palliative care physicians-** The tertiary medical institutions can improve the access to palliative care of all patients by appointing palliative care specialists and by developing Departments wherever feasible.

### **Disease Trajectory:**

At diagnosis, there are very few children who would be referred for Palliative Care. If the general condition is good and the parents would like to initiate treatment, it is started. Hynson speculates that the spectre of death is ever present in the cancer disease trajectory, as a consequence of infection or any other complication. This is different than the situation in non malignant conditions where it is more prolonged, with much less chance of a sudden death. The presence of the Palliative Care physician from the inception of therapy has been referred to as ‘upstream palliative care’ where the seriousness of the situation is revisited at regular intervals. At the Tata Memorial Centre, the same presence in every Joint Clinic, ensures that where the toxicities of treatment outweigh the benefit; a discussion with the family members at the beginning can help them enter the Palliative Care pathway; while still initiating some form of Palliative chemotherapy. This helps the family come to terms with the situation and is a perfect example of slowly coming to terms with the ‘bad news’. Sometimes it needs the 2-3 courses of chemotherapy for acceptance to occur. It is very important for the Palliative Care team to be very supportive during the whole process.

### **Caring for the child and family:**

The transition for health to ill-health affects the child, parents and siblings in a variety of ways. This also depends on the age of the affected child. The reactions to relapse of the disease are similar to those which occur with bereavement. The grief reactions do not occur in any particular order. Families need time to adjust to every phase. Significant discrepancies between physicians and families acceptance of prognosis has been documented and understanding this should be a part of decision making.

### **Common symptoms and their management:**

Pain is the most common symptom. The management is as for all children. Here too, the emphasis is on oral medication. However, many of the children have a central line in the form of a Hickman or Peripherally Inserted Central line (PICC). If the life expectancy is short, ie. Acute Myeloid leukemia or a short relapse free interval in Acute Lymphatic Leukaemia or a solid tumour, the parents are encouraged to retain the line; which includes it's ongoing care. Some medication can then be administered without any trauma to the child ie Morphine for terminal breathlessness. In cancer, the role of Palliative radiotherapy or chemotherapy is very vital for symptom control as outlined below.

### **Use of anti cancer therapies for improving Quality of life:**

It is important to remember that cancer in children is responsive to therapy more than in adults. Where the tumour is causing symptoms, the judicious use of chemotherapy, radiation and even surgery can relieve distressing symptoms. The aim being symptom control, optimum tumour shrinkage is achieved with the minimum of toxicity. Chemotherapy regimes depend on the tumour pathology. Many regimes are standards of care for palliation, where benefits still outweigh toxicity. Wherever possible, oral chemotherapy is used so that children can take treatment at home.

### **Place of care:**

Even while Palliative therapy is continuing, the discussion with the family is necessary to ensure the best possible Quality of life for the child. In India, most of the families have been staying close to the cancer centre since diagnosis; disrupting family life especially for the siblings who are left at home in the care of grandparents, Uncles or even neighbors. It is an uphill task to help parents understand the importance of keeping the family together. They feel safe with the known circumstances and at 'home', often in the village, there is an absence of trained Pediatricians. The choice of oral chemotherapy and the presence of help lines help in the decision making. Since they can return at any time when there is need; this gives them the confidence to return home for some periods of time. Often, the circle of care is developed at home and they may never return. Contact is maintained with the help lines weekly.



**Terminal care in cancer:**

The same reasoning is followed for the terminal phase. Many families still return to the hospital as they do not have the confidence for a death at home. They are cared for in the ward by the team of Oncologists, nurses and Palliative Care team. Hospice deaths are rare as caring for the rest of the family is too difficult.

**Bereavement support:**

As with all families, the death of a child is very difficult. In cancer, this may be more so as sudden deaths are much more common. An engagement of the Palliative Care team early in the disease trajectory is helpful, as the teams dealing with active treatment may not have the necessary training to deal with the sudden death. With siblings also, the chance to say goodbye may not happen, with a sudden death from infection or haemorrhage. The parents and siblings need extensive bereavement support which may last for months. Abnormal grieving patterns must be carefully watched for. Here, the role of support groups are very important, to help newer bereaved families cope, along with the professional help.