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STRATEGY FOR PALLIATIVE CARE

1. Current Status and Need:

- In the year 2004, over 20 lakhs Indians had cancer.
- More than 80% (16 lakhs) of them were incurable at the time of diagnosis, and needed palliative care.
- By year 2015, it is projected that the total prevalence of cancer in the country would be 25 lakhs.
- By 2015, even if the mortality rate were to come down to the international standard of 50%, 12.5 lakh Indians would still need palliative care.
- All patients need supportive care during treatment.
- Palliative care is mentioned as pain relief and terminal care in NCCP; but not practiced as an integral part of cancer care in most RCCs and oncology wings.
- Oral morphine, the most important medication for relief of cancer pain, is not available to more than 99% of patients.
- There are very few doctors and nurses in the country with any palliative care education.

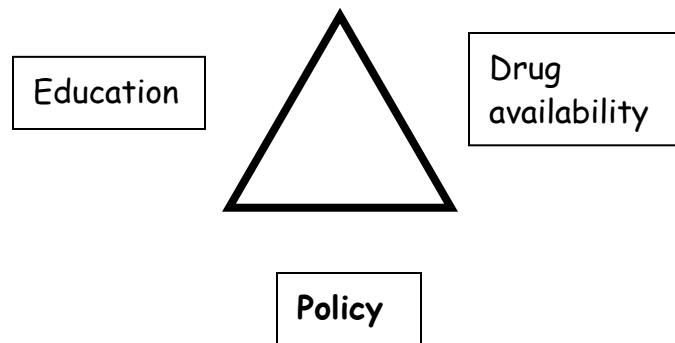
2. What is palliative care, and what is supportive care?

Palliative care attempts to improve quality of life of patients and families through assessment and management of factors reducing quality of life, like pain and other symptoms, as well as psycho-socio-spiritual problems. Most of those undergoing curative treatment need supportive care – application of principles of palliative care – reducing suffering and improving compliance to treatment.

3. Common barriers to access to palliative care that have been identified are:

- 3.1. Lack of palliative care services in most of the country.
- 3.2. Lack of awareness among professionals, administrators and the public.
- 3.3. Lack of facilities for palliative care education in the country.
- 3.4. Unrealistic narcotic regulations preventing access to opioids for those in pain.
- 3.5. Lack of clear guidelines for those wishing to provide palliative care services.

4. WHO recommendation for palliative care development: The World Health Organization (WHO) recommends that, to be effective, any palliative care policy has to address all three sides of the following triangle with the State Policy at the base, their broad objective being to improve access to palliative care to all those who need it.



5. **Broad objectives:** To develop
- A. Strategy for formulation of Palliative Care Policy, including involvement of non-governmental organizations
 - B. Strategy for development of Palliative Care Delivery services including manpower
 - C. Strategy for improved, safe, availability of opioids for pain relief
 - D. Strategy for Palliative Care Education and Training of professionals and others including volunteers.
 - E. Strategy for Advocacy, Awareness Building and Community Participation

6. **POLICY:**

6.1. **Objective:**

- 6.1.1. Declaration by NCCP that palliative and supportive care should be essential parts of cancer care.
- 6.1.2. Declaration by all states & UTs that palliative and supportive care should be essential parts of cancer care.

6.2. **Strategy**

- 6.2.1. Include 'provision of palliative and supportive care with community participation' as a separate objective of the revised NCCP
- 6.2.2. Inclusion of a palliative care provision in the Health Policy of State Governments

6.3. **Coverage:** Health policy of centre and 50% of states/UTs

6.4. **Timeline:**

- 6.4.1. Inclusion in NCCP before 11th FYP
- 6.4.2. Inclusion in State Policy – over first 2 years of FYP

6.5. **Budgetary requirement:** Nil

7. DEVELOPMENT OF PALLIATIVE CARE SERVICES:

7.1. Objective:

7.1.1. Integrate Palliative Care into cancer care in all RCCs and 100 other cancer treatment facilities in the country

7.1.2. Strategy:

7.1.2.1. **RCC Scheme:** Starting palliative care service in all Regional cancer centers

7.1.2.2. **Out-of-RCC Scheme:** Starting palliative care services in 100 other institutions (DCCP/Oncology Wings of Medical Colleges/NGOs)

7.1.2.3. **Coverage:** 25 RCCs and 100 other institutions in the country.

7.1.2.4. Timeline:

7.1.2.4.1. Year 1: 5 RCCs and 10 other Cancer treatment centres

7.1.2.4.2. Year 2: 5 RCCs and 25 other Cancer treatment centres

7.1.2.4.3. Year 3: 5 RCCs and 25 other Cancer treatment centres

7.1.2.4.4. Year 4: 5 RCCs and 25 other Cancer treatment centres

7.1.2.4.5. Year 5: 5 RCCs and 15 other Cancer treatment centres

7.1.2.5. Budget:

7.1.2.5.1. RCC Scheme: Rs 8.625 crores and

7.1.2.5.2. Out of RCC Scheme: Rs 32.828 crores

7.1.2.5.3.

8. OPIOID AVAILABILITY

8.1. Objective:

8.1.1. Ensuring simplified narcotic regulations in all states and union territories of India with realistic standard operating procedures.

8.1.2. Ensuring uninterrupted availability of oral morphine in all regional cancer centers and in all hospitals where palliative care facilities have been started.

8.2. Strategy:

8.2.1. Opioid Availability Workshops: Up to 3 workshops in 5 years by each RCC involving palliative care professionals, NGOs and officials from concerned Departments in the State, and of the adjoining State/UT where there is no RCC.

8.3. **Coverage:** All States and Union Territories

8.4. **Timeline:** 3 workshops each year for every year of FYP in every RCC.

8.5. **Budget:** Rs 0.75 crores

9. PALLIATIVE CARE EDUCATION AND TRAINING:

9.1. Objectives:

9.1.1. Develop training modules for

9.1.1.1. Doctors

9.1.1.2. Nurses

9.1.1.3. Social workers/counselors

9.1.1.4. Volunteers

9.1.2. Provide palliative care education to professionals and volunteers.

9.1.3. Ensure effective training in palliative care at least in all oncology post graduate programs including practical exposure and inclusion in the examination process.

9.1.4. Develop tools and methods for Qualitative Assessment of Palliative care Services

9.1.5. Development of at least one nodal palliative care training center in five geographical regional zones – North, Northeast, West, East and South of India.

9.2. Strategy:

9.2.1. Training For palliative care doctors and nurses of 25 RCCs and 100 Out-of-RCC Centres (budget provided in RCC and Out of RCC Scheme in item 7)

9.2.2. Sensitisation in Palliative Care for rest of the staff of 25 RCCs and 100 Out-of-RCC Centres (budget provided in RCC and Out of RCC Scheme in item 7)

9.2.3. 12 Working Group Meetings, each with 6 faculty members for development of training modules for Palliative Care for Professionals and Undergraduates, and for training for Social Workers/Counsellors (to be done over 3 years)

9.2.4. 6 Working Group Meetings for developing tools and methods for Qualitative Assessment of Palliative Care Services rendered to be done over 3 years

9.2.5. One month rotation in palliative care for oncology postgraduate residents in RCCs/Palliative Care Centres/Regional Training Centres.

9.2.6. Upgradation of one each palliative care centre in five geographical zones in India to Regional Training Centres

9.3. Coverage:

9.3.1. All States and UTs, 25 RCCs and 100 Cancer Treatment Centres

9.4. Timeline: As given in spreadsheet attached.

9.5. Budget:

9.5.1. Training and Sensitization provided in RCC and Out of RCC Schemes

9.5.2. Development of teaching modules: Rs. 0.12 crores

9.5.3. Development of Quality Assessment Tools: Rs 0.06crores

9.5.4. Development of Regional Training Centres: Rs 2.8 crores

10. PATIENT ADVOCACY & AWARENESS BY NGOS/INSTITUTIONS

10.1. Objective:

10.1.1. Development of Peer Support Groups for cancer Patients and Families

10.1.2. Promotion of public awareness and promotion of community and NGO participation in palliative care

- 10.2. **Strategy:**
- 10.2.1. Hold 4 Peer Support Meetings per year in all 125 Palliative Care Centres
 - 10.2.2. 600 Palliative Care Awareness Programs by NGOs/Institutions
- 10.3. **Coverage:** All States and UTs,
- 10.4. **Timeline:** Over 5 years
- 10.5. **Budget:**
- 10.5.1. For Peer Support Meetings: provided in RCC and Out of RCC Scheme in item 7.
 - 10.5.2. Budget for 600 Awareness Programs Rs 0.48 crores

Note:

- More specific timelines and outcome measures are attached in spreadsheet
- More detailed strategy for each of the above schemes follows.

SCHEME 1: RCC SCHEME

Starting fully functional palliative care service in all Regional cancer centers (or strengthening them where they exist), which should have the following:

- Full-time personnel: One doctor, one nurse and one social worker
- Essential drugs including morphine available free for poor patients (appendix 1)
- Inpatient facilities available for palliative care
- Palliative care training available in the form of two days sensitization course as a CME – every six months to majority of doctors, nurses, social workers and volunteers (appendix 2,3,4 &5)
- All oncology residents rotated through the palliative care program for one month and nursing students for at least one week each
- Involvement of at least one NGO for palliative care delivery
- One functional home visit program

Coverage: All 25 RCCs in FYP

Timeline: 5 RCCs each year over 5 years of FYP

Budget:

Scheme 1	RCC Scheme	per month	per annum	FYP in Rs	FYP in Cr
1.a	Staff				
	1 full time doctor+nurse + social worker	50000	600000		
1.b	Drugs(as per Essential Drug List) for poor patients		200000		
1c	Training				
	For Staff in Palliative care		100000		
	For sensitisation for rest of the staff		50000		
	Total Training		150000		
1d	Homecare(RCCs Contribution to Homecare Service, bal from NGO)		200000		
	Total Per RCC		1150000		
Scheme 1	Total For 25 RCCs over FYP			86250000	8.625

OUTCOME MEASURES

- Number of patients seen in palliative care unit
- Number of personnel being trained including percentage of RCC staff

- Amount of morphine consumed
- Number of NGOs involved
- Quality Assurance measures incorporated (as developed by Working Group by end Year 3 of FYP)

SCHEME 2: OUT OF RCC SCHEME

Starting palliative care programs in oncology departments in Medical Colleges/other hospitals or by non government agencies, with community participation: (institutions willing to take this up are to be asked to apply for support under this scheme; 100 centers are to be selected; 1-5 per state and one per union territory)

Full time or part-time personnel: One doctor, one nurse and one social worker

Essential drugs including morphine available free for poor patients (appendix 1)

Inpatient facilities available for palliative care

Palliative care training available in the form of two days sensitization course as a CME – every six months - to majority of doctors, nurses, social workers and volunteers (appendix 2,3,4 &5)

All residents, nurses and trainees rotated through the palliative care program, where applicable

Involvement of at least one NGO for palliative care delivery

One functional home visit program

Quality assurance measures incorporated

Coverage: 100 Cancer Treatment Centres in the Country

Timeline: 10 Centres in Year 1, 25 each in Years 2, 3 and 4, and 15 in Year 5 = Total 100

Budget:

Scheme 2	100 Other Palliative Care Centres -PCCs (DCCP/Oncology Wings of Medical Colleges/NGOs)	per month	per annum	FYP in Rs	FYP in Cr
2a	Staff				
	1 part time doctor +nurse+social worker	50000	600000		
2.b	Drugs(as per Essential Drug List)		200000		
2c	Training Courses for Drs and Nurses in Centre		100000		
2d	Peer Support Meetings 4 per year@8000		32000		
2e	Homecare(PCCs Contribution to Homecare Service, bal from NGO)		200000		
	Total Per Palliative Care Centre		1132000		
Scheme 2	Total For 100 Centres in Country			328280000	32.828

OUTCOME MEASURES

- Number of patients seen in palliative care unit
- Number of personnel being trained including percentage of RCC staff
- Amount of morphine consumed
- Number of home visits
- Number of NGOs involved
- Number of volunteers involved in palliative care
- Quality assurance measures incorporated Services (as developed by Working Group by end Year 3 of FYP)

Scheme 3: OPIOID AVAILABILITY WORKSHOPS

All palliative care centers must have morphine. An updated document on procurement of oral morphine will be developed with assistance from NGOs and provided to all palliative care centers. This is to help hospitals and centers to procure oral morphine in a more effective way. Guidelines will be made for states with and without the amended rules.

To ensure availability of morphine in all palliative care centres, only those units which have a licence for oral morphine, will be provided for funds to set up a palliative care service (as described above).

RCCs should facilitate the procurement of licences for morphine by other palliative care centers. This can be done by organising morphine availability workshop in all states and Union territories conducted by each RCC.

Opioid Availability Workshops : Up to 3 workshops over the 5 year period organised by each RCC involving palliative care professionals and NGOs, with all concerned Departments at State and District levels in the State, and of the adjoining State/Union Territory where there is no RCC.

Coverage: All States and Union Territories
 Timeline: 3 workshops each year for every year of FYP in every RCC
 Budget: Rs 0.75 crores

Scheme3	Opioid Availability Workshops	per Workshop	per annum	FYP in Rs	FYP in Cr
	Maximum of 3 workshops in 5 years @ Rs 1 lakh per workshop for 25 RCCs	100000		7500000	0.75
Scheme 3	Total			7500000	0.75

Outcome Measures:

- Number of States and UTs with Simplified Narcotics Rules and simple standard operating procedures for their implementation
- Annual consumption of morphine
- A system of proper documentation of morphine stocks and dispensing

SCHEMES 4 AND 5: EDUCATION, CURRICULUM DEVELOPMENT AND REGIONAL TRAINING CENTRES

Development of Regional Palliative care Training Centres:

Capacity development of five palliative care centers in five geographical regions in the country to empower them to develop as nodal training centers which can take on education and training of personnel in the region

The role of Regional Training Centres:

To train personnel in palliative care by conducting “hands-on” training courses of four to six weeks, which will be conducted for doctors, nurses and social workers by these regional centers.

Selection of Regional Training Centres:

To set up the Regional centers, applications will be invited from institutions interested in taking up this program and selection will be done in collaboration with RCCs in the region. A teaching module for the training programs will be developed in collaboration with NGOs in the field like Indian Association of Palliative Care (IAPC).

The task force will request NGOs in the field like Indian Association of Palliative Care (IAPC) to set standards for training in all regional centres - by a committee that will oversee and discuss with the Regional training centres, ensure uniformity, help with resource persons, evaluation and monitoring and development of a module.

Coverage: All States and UTs, 25 RCCs and 100 Cancer Treatment Centres

Timeline: Given individually in attached spreadsheet.

Budget: Training and Sensitization provided in RCC and Out of RCC Schemes (Item 7)

Scheme4	Education & Curriculum Devpt	Per meeting	Total in lakhs	Total in crores
	12 Working Group Meetings, each with 6 faculty for development of teaching modules/Curricula for Palliative Care Professionals and Undergraduates to be done over 3 years	1,50,000	1800000	0.18
	6 Standard Setting Group Meetings for developing tools and methods for Qualitative Assessment of Palliative Care Services rendered to be finished in 3 years	1,50,000	900000	0.09
Scheme 4	Total		2700000	0.27

Scheme 5	5 Regional Training Centres	per month	per annum	FYP in RS As per time-line	FYP in Crores
	Staff				
	1 full time doctor+nurse+Secretary	50000	600000		
	Office		100000		
	Course Material		200000		
	AV Aids			200000	
	Library			100000	
	Visiting Faculty Expense 4 courses*2 faculty		200000		
	Total per Centre p.a.		1100000		
Scheme 5	Total for 5 Centres over 5 years per timeline			29400000	2.94

OUTCOME MEASURES

Teaching modules/Curriculum for Courses in Palliative

Tools and methods for Qualitative Assessment of Palliative Care Services

List and Number of courses run

Number of Doctors, Nurses, social workers and volunteers trained

Number of Training centres accredited every year

PATIENT ADVOCACY & AWARENESS BY NGOS/INSTITUTIONS

Awareness programs: Aimed at improved awareness among public about the possibilities of pain relief and palliative care to decrease suffering in the community and to improve participation of the community in palliative care.

Peer Support Meetings 4 each year provided

For all 25 RCCs in the Reintegration and Rehabilitation Program

For all 100 Palliative Care Centres in the Out of RCC Scheme

Palliative Care Awareness Programs

Scheme 6	Patient Advocacy & Awareness by NGOs/Institutions	Per Awareness Program	per annum	FYP in Rs	FYP in Cr
	600 Palliative Care Awareness Programs ~120 p.a. (Publicity Rs 1000+ Handouts/posters 6000+Venue/AV 600+Honorarium for faculty Rs 400)	8000	960000	4800000	0.48
Scheme 6	Total			4800000	0.48

Outcome Measures:

Number of Programs conducted

Number of Participants

EXECUTIVE SUMMARY

1. Current Status and Need:

- In the year 2004, over 20 lakhs Indians had cancer.
- By year 2015, it is projected that the total prevalence of cancer in the country would be 25 lakhs.
- Those who get cured need help to be rehabilitated and re-integrated to society.
- When the breadwinner of the family has the disease, or dies, the family needs to be rehabilitated.
- Reintegration/rehabilitation measures in the country are seldom practiced as an integral part of cancer care in the majority of RCCs and oncology wings.

2. What is rehabilitation / reintegration?

Reintegration and rehabilitation aim at restoring meaning to life even as a person copes with cancer, its treatment and side effects, physical disability and/or impairment and its fall-out on one's life and the life of the family, during and after treatment. In cases where the patient succumbs to the disease, this extends to reintegration of the family members helping them to cope with their loss, and in cases where the patient was the breadwinner, providing means to a livelihood. It is essential that families receive support both during and post-treatment to help them re-integrate into society. This means support in education and employment, and support when a patient lives through cancer. There should be no discrimination against families or patients in later life because of the illness and its effects. Those who have suffered the loss of a family member to cancer should have ongoing access to professional and peer group support.

3. Common barriers to access to rehabilitation/reintegration that have been identified are:

- 3.1. Lack of rehabilitation / reintegration services in most of the country.
- 3.2. Lack of awareness among professionals, administrators and the public.
- 3.3. Lack of guidelines on the subject

4. Broad objectives: To develop

- A. Five model rehabilitation/reintegration programs attached to five regional cancer centers in the country distributed between the five geographical zones of the country.
- B. Basic rehabilitation/reintegration services in all the other regional cancer centers.
- C. Basic rehabilitation/reintegration programs services in 50 other cancer treatment facilities in the country (DCCPs, oncology wings of Medical Colleges or NGOs).
- D. Guidelines for psycho-social support to patients
- E. Educational programs for professionals
- F. Peer support groups with regular meetings.

5. POLICY:

5.1. Strategy

- 5.1.1. Include development of rehabilitation/reintegration services as a separate objective of the revised NCCP
- 5.1.2. Inclusion of provision for rehabilitation/reintegration in the Health Policy of State Governments

5.2. Coverage: Health policy of centre and 50% of states/UTs

5.3. Timeline:

- 5.3.1. Inclusion in NCCP before 11th FYP
- 5.3.2. Inclusion in State Policy – over first 2 years of FYP

5.4. Budgetary requirement: Nil

6. DEVELOPMENT OF REHABILITATION/REINTEGRATION SERVICES:

6.1. Objective:

- 6.1.1. Integrate rehabilitation/reintegration into cancer care in all RCCs and 50 other cancer treatment facilities in the country

6.1.2. Strategy:

- 6.1.2.1. **Model rehabilitation/reintegration Center Scheme:** Starting

model rehabilitation/reintegration service in 5 Regional cancer centers in 5 geographical zones of the country, which can also act as training centers.

6.1.2.2. Basic rehabilitation/reintegration Service Scheme: Starting rehabilitation /reintegration services in the remaining 20 RCCs and in 50 other institutions (DCCP/Oncology Wings of Medical Colleges/NGOs)

6.1.2.3. Coverage: 25 RCCs and 50 other institutions in the country.

6.1.2.4. Timeline: Given in spreadsheet

6.1.2.5. Budget:

6.1.2.5.1. 5 Model centers : Rs 6.368 crores and

6.1.2.5.2. 75 Basic services : Rs 12.6 crores

7. REHABILITATION/REINTEGRATION EDUCATION AND TRAINING:

7.1. Objectives:

7.1.1. Develop training modules for professionals

7.1.2. Provide rehabilitation/reintegration education to professionals and volunteers.

7.1.3. Develop and conduct peer support groups and carer support groups

7.2. Strategy:

7.2.1. Develop psycho-oncology training modules for professionals

7.2.2. Regional training workshop for professionals twice a year

7.2.3. Regional training workshop for rehabilitation/reintegration teams twice a year

7.2.4. Sensitisation in psychosocial support and communication skills for rest of the staff of 25 RCCs and 50 Out-of-RCC Centres.

7.2.5. Peer support and carer support programs for patients and families in 25 RCCs and 50 Out-of-RCC Centres.

7.3. Coverage:

7.3.1. 25 RCCs and 50 other Cancer Treatment Centres

7.4. Timeline: As given in spreadsheet attached.

7.5. Budget:

7.5.1.	Development of psycho-oncology guidelines	0.1 crore
7.5.2.	Regional training workshop for psychooncology	0.3 crores
7.5.3.	Regional training in rehabilitation/reintegration	0.3 crores
7.5.4.	Sensitisation programs in psycho-oncology	0.9 crores
7.5.5.	Peer support / carer-support groups	0.9 crores
Total budgetary requirement during the five year plan:		21.468 crores

Note:

- More specific timelines and outcome measures are attached in spreadsheet
- More detailed strategy for each of the above schemes follows.

SCHEME 1: MODEL REHABILITATION/REINTEGRATION CENTER SCHEME

Starting five model rehabilitation/reintegration centers in five Regional cancer centers (or strengthening them where they exist). They will serve also as training centers. They should have the following

Staff:

- 1 Physiotherapist
- 1 Occupational therapist
- 1 Speech therapist
- Clinical Psychologist/Counsellor
- 1 Nurse

Equipment including consumables

Home-away-from home; run in collaboration with NGOs

Vocational/activity center

- Essential drugs including morphine available free for poor patients (appendix 1)
- Inpatient facilities available for palliative care

- Palliative care training available in the form of two days sensitization course as a CME – every six months to majority of doctors, nurses, social workers and volunteers (appendix 2,3,4 &5)
- All oncology residents rotated through the palliative care program for one month and nursing students for at least one week each
- Involvement of at least one NGO for palliative care delivery
- One functional home visit program

Coverage: 5 RCCs in five geographical regions in the country.

Timeline: Given in spreadsheet

Budget: 6.368 crores as given in spreadsheet

OUTCOME MEASURES

- Number of patients seen
- Number of personnel trained
- Number of NGOs involved

SCHEME 2 & 3: BASIC REHAB/REINTEGRATION SERVICE

Starting palliative care programs in the remaining 20 RCCS and in 50 other oncology departments in Medical Colleges/other hospitals or by non government agencies, with community participation: (institutions willing to take this up are to be asked to apply for support under this scheme; 50 centers are to be selected; 1-2 per state and one per union territory)

Full time personnel:

- One physiotherapist,
- One clinical psychologist/counselor,
- One nurse

Coverage: 70 Cancer Treatment Centres in the Country

Timeline: given in spreadsheet

Budget: 12.6 crores (details in spreadsheet)

OUTCOME MEASURES

- Number of patients seen
- Number of personnel trained
- Number of NGOs involved
- Number of volunteers involved

SCHEME 4: REHABILITATION/REINTEGRATION EDUCATION AND TRAINING:

Objectives:

- i. Develop training modules for professionals on psycho-oncology.
- ii. Provide rehabilitation/reintegration education to professionals and volunteers.
- iii. Develop and conduct peer support groups and carer support groups

b. Strategy:

- i. Develop psycho-oncology training modules for professionals by a working group including NGOs working in the field.
- ii. Regional training workshops are to be held in different parts of the country to train professionals to address psycho-social needs of patients and families. A total of 10 workshops are contemplated under this scheme.
- iii. Regional training workshop for rehabilitation/reintegration teams twice a year in different geographical regions of the country to train professionals.
- iv. Sensitisation in psychosocial support and communication skills for rest of the staff of 25 RCCs and 50 Out-of-RCC Centres.
- v. Peer support and carer support programs for patients and families in 25 RCCs and 50 Out-of-RCC Centres. These are to be developed in collaboration with NGOs, primarily run by them, with a facilitator from the center.

c. Coverage:

- i. 25 RCCs and 50 other Cancer Treatment Centres

d. Timeline: As given in spreadsheet attached.

e. Budget:

- i. Development of psycho-oncology guidelines 0.1 crore

ii. Regional training workshop for psychooncology	0.3 crores
iii. Regional training in rehabilitation/reintegration	0.3 crores
iv. Sensitisation programs in psycho-oncology	0.9 crores
v. Peer support / carer-support groups	0.9 crores
Total	2.5 crores

Annexures:

- i. Information on Rehabilitation/Reintegration
- ii. List of organizations involved

Descriptive write-up on REINTEGRATION AND REHABILITATION (From Cankids...Kidscan)

A. Reintegration and Rehabilitation aims at restoring meaning to life even as a person copes with their cancer, its treatment and side effects, physical disability and/or impairment and its fall-out on one's life and the life of the family, during and after treatment. In cases where the patient succumbs to the disease, this extends to Reintegration of the family members helping them to cope with their loss, and in cases where the patient was the breadwinner, providing means to a livelihood.

It is essential that families receive support both during and post-treatment to help them re-integrate into society. This means support in education and employment, and support when a patient lives through cancer. There should be no discrimination against families or patients in later life because of the illness and its effects. Those who have suffered the loss of a family member to cancer should have ongoing access to professional and peer group support.

During the past 20 years, the treatment of cancer has evolved. Current surgical procedures are often less extensive than those used previously, and are frequently combined with adjuvant chemotherapy and radiation treatment. Indeed, the use of multiple cytotoxic treatments has become commonplace in the treatment of many cancers. This more prevalent use of multiple cytotoxic management strategies has prolonged the primary treatment period and increased the toxic effects of treatment. Ultimately, these advances in treatment along with improved detection and diagnosis have been a boon for cancer patients. As we move into the 21st century, individuals diagnosed with cancer are living longer than ever before. Approximately 60% of patients newly diagnosed with cancer are expected to survive more than 5 years. Proximally, however, the effects of cancer itself, along with longer, more toxic treatment, can adversely affect all areas of function (physical, cognitive, social, vocational and economic).

The physical and psychosocial impairments encountered by cancer patients are numerous. Physically, impairments of the nervous system, musculoskeletal system and internal organs are common consequences of cancer and its management. Psychosocially, depression and anxiety are frequently encountered. Asthenia, a chronic, pathological fatigue, is the most common problem reported by cancer patients. These impairments, either singly or collectively, may diminish function and quality of life (QOL). Despite the prevalence of functional impairment in cancer patients, rehabilitation is not a common component of cancer treatment throughout most of the world.

With increasing survival rates, quality of survival assumes a vital significance in the field of cancer. It is estimated that in India every year, 5,00,000 new cases of cancer are being

diagnosed and that at any given time, there would be approximately 2 million Indians suffering from the disease. More than 50 percent of them need rehabilitation services.

In view of the poor economy, absence of social security legislation, different patterns and standards of living and a fatalistic oriental philosophy towards life, the rehabilitation techniques and methods in a developing country like India have to be simpler, economical and well adapted to the social milieu. Furthermore, a **comprehensive system of rehabilitation services** should be organised within a shorter period, so as to keep pace with the standards already existing in the developed countries.

In India many of the cancer patients are illiterate and are unable to continue working at heavy manual jobs. They, therefore, have no jobs to return to, nor other sources of income to fall back upon. Thus even when the physical ailment is under control the socio-economic consequences remain unsolved and are most distressing. In many cases, where the only earning member or the head of the family is stricken by cancer, whole families are disintegrated. **Family rehabilitation** is a critical need.

Rehabilitation for Rural Cancer Patients: A vast majority of cancer patients in India are from the rural areas. Most of them are unable to continue working in heavy farming jobs on returning home. They also need some form of employment and means of livelihood, while they are getting their treatment at the cancer facility, away from their home and village. Training sections in several rural and cottage based industries such as grocery, poultry-farming, leather work, horticulture, dairy farming etc. need to be set up. On completion of training, patients can be suitably placed or self-employed in their own rural areas, after obtaining the necessary financial assistance for them from the nationalised banks.

B. Areas to focus on:

1. Employment
2. Back to School:
3. Physical Restoration and Rehabilitation Services
4. Psycho-Social and Community Adjustment Services: Emotional Support, Counselling, Survivor Networks, Information Networks and Resources, Rewards and Recognitions.
5. Rehabilitation Research

1. Employment:

One of the main goals of reintegration is a return to meaningful employment. There need to be resources in the community for

- a. information,
- b. individualized training and education programs to help prepare the patient to return to full employment,
- c. Opportunities for employment during and after treatment both for the patient and the family
- d. Legislation to retain employment and job during cancer treatment, or to get salary compensation during absence. Need to consider Leave for Caregivers as well.

2. Back to School:

Today, children with cancer receive much of their treatment in the outpatient setting. This allows them to continue to participate in school programs and to grow intellectually and socially. However, treatment often involves frequent clinic visits, radiation, surgery, or hospitalization, causing most children to miss some school. For many, returning to school can be a frightening and emotional experience.

In the Indian context, specially for underprivileged children, going to Government schools, more often than not the doctors advise the children not be sent to school on account of high infection risks, during treatment, due to low cell counts. Going back to school becomes difficult, as many parents are financially exhausted by the treatment, and schools more often than not will not keep the seat vacant and readmission becomes very difficult.

Equally important the children need to be kept learning during the treatment phase.

The back to school program must cover:

Educational Assistance

School Liaison

Ongoing Learning during treatment

Scholarship

3. Physical Restoration and Rehabilitation Services

This involves the use of prostheses, exercises, and physical therapy.

4. Psycho-Social and Community Adjustment Services: Emotional Support, Counselling, Survivor Networks, Information Networks and Resources, Rewards and Recognitions.

5. Rehabilitation Research

Non-government organizations in India involved with Rehabilitation/Reintegration work in Cancer

Sl No	Name of organisation	Representatives
1	Can Support, Kanak Durga Basti Vikas Kendra Sector-12, R K Puram, New Delhi-110022. Tele:011-26102851/26102869 Fax: 011-26102859 Email:cansup_india@hotmail.com Website: www.cansupport-india.org	Ms Harmala Gupta Tel :011-26145515 (R).
2	Cancer Sahyog, Q5A, Jangpura Extn. New Delhi-110014. Tele:011-24319572/4907 Email:incansoc@nda.vsnl.net.in	Shri P K Ghosh T-011-26899707 (R).
3	Jodharam Memorial Cancer Society, C/O Hind Electronics Industries, 69/6, Najafgarh Road, Motinagar, (Opposite Indian Oxygen), New Delhi-110015. Tele:011-25933682,M-9811372845.	Shri Saran Dewan, T-011-55482811 (R). Mob. 9810222008
4	Laryngectomee Club of India, F-11A (G-8 Area), Near Harinagar Clock Tower, New Delhi-110064. Tele:011-25127049	Shri S P Goel T-011-25127049 (R).
5	Mastectomees Association, Sahi Hospital, Jangpura, New Delhi-110014. Tele:011-24319802/4086.	Ms Kanta Gopal T-011-26145993 (R).
6	Sahayta Charitable Welfare Society, 1220, Sector-18C, Chandigarh -160022. Tele:0172-2660168. Email:sahayta@satyam.net.in	Ms Neelu Tuli Mob:9316120808
7	Cankids...Kidscan D7/7 (Basement) Vasant Vihar, New Delhi 110057, INDIA Ph : (91) 11 51663671/2; Email:poonambagai@cankidsindia.com	Ms Poonam Bagai (91) 9811525745

8	Cancer Concern Society, Flat-608, Maheswari Complex, Road No.1, Mansab Tank, Hyderabad-500028. Andhra Pradesh. Email:noblem@sancharnet.in	Mr.Noble Massey Tel: 040-23312351(R). M-9849084965 Email:amarnoble@yahoo.co.in
9	Can Stop, Dr. Rangarajan Memorial Hospital, Shanthi Colony, 4 th Avenue Annanagar, West, Chennai-600040. Tel:044-26268844. Email:vijaya_raghu@hotmail.com	Dr. V B Rangarajan T-044-28157758(R) M-9841099363 Email: canstop@smfhospital.org
10	Coimbatore Cancer Foundation G.K.N Memorial Hospital, Post Box.6327 Post Box.6327, P.N Palayam, Coimbatore-641037, Tamil Nadu	Shri L Vincent Sundararaj Administrative Officer. T No.-0422-2216211
11	Friends of Curie, Curie Centre of Oncology, St.John's Medical College Hospital Campus, P.O-Koramangala, Bangalore-560034. Tele: 080-25538194/0724, Extn-293. Email:drbrindha@yahoo.com	Dr Brindha Sitaram Resi: 'Krithika' 178, 36 th 'A' Cross, 7 th Block, Jayanagar, Bangalore -80 T-080-26630209 (R).
12	Jeevodaya, New No.1/272, (Old No.1/86) Kamraj Road, Mathur, Manali P.O Chennai – 600068. Tele: 044 – 25555565/ 25559671. Email:jeevodaya@vsnl.com	S Hermas, FCC, Chairman Dr.R.Nanjuda Rao, President Sr.Ancina, FCC, Ex. Dir. Sr.Lalitha Teresa, FCC, Secy
13	Lakshmi Pain And Palliative Care Clinic 136, Poonamallee High Road, Chennai -600084, Tele:044-26411597 Email:m-tiruvandanan@hotmail.com	Dr.Mallika Tiruvandanan T- 044-26411336 Fax:044-26411879
14	Palliative Care Patients'Benefit Trust Pain and Palliative Care Clinic, Medical College PO, Calicut 673008, Kerala Email: pain@vsnl.com	Dr Anil Kumar Paleri 9447853340
15	Pallium India (Trust) G-1, Express Towers, Kasim Lane Judges' avenue, Kochi 682017, Kerala	Dr K.S.Lal 9446925946
16	Can Care, Sacred Heart Convent, Jamshedpur-831001. C/O, IMS Learning Resources, 2/7, H.S.Tower, L Road, Bistupur, Jamshedpur-831001, Tele:0657-2421351/3091269.	Sr. Felicia Fernandez AC Tele:0657-2431898. Email:shconventjsr@sify.com Ms Gurpreet Kaur Bhatia, Tele: 0657-2306447 (R). Email:gurpreetjsr@yahoo.com
17	Hitaishini, CD-54, Salt Lake, Sector -1,	Ms Vijaya Mukherjee T-033-23375817 (R).

	Kolkata-700064. Email: hitaishini_india@yahoo.com	M-9830009928 Ms Nupur Chakraborty, T-033-24304800 (R).
18	Laryngectomee Club, CCWH&RI, Mahatma Gandhi Road, Thakurpukur, Kolkata-700063. T:033-24678001/03/, 24532781-3.	Shri Bibhuti Chakraverty T-033-24610068(R) M-9831818088
19	Mahavir Cancer Sansthan, Phulwari Sharif, Patna-801505, Tele:0612-2250127, 2253956. Fax:0612-2253957. Email:mahavircancer@rediffmail.com	Dr J K Singh T-0612-2354666 (R). M-9835035466/9431021001 Dr Varsha Singh, T-0612-2275824
20	Prerak, 32, Metcalf Street, 2 nd Floor, Kolkata-700013, Tele:033-22827127 Mob:981016033. Email:prerak13@rediffmail.com	Dr Rati Vajpeyi T-033-24481952 (R). Email:vajpyi@cal.vsnl.net.in/ rati54@yahoo.com
21	Sankalp, 47, Nehru Nagar, Bhilai-490020, Chattisgarh. T-0788-2440490 Email:designersdream@rediffmail.com	Ms Kanika Jain T-0788-2391180 (R). M-9826122584 Ms Sangeeta Verma, T-0788-2210495(R), M-9826122393
22	Dream Foundation, 107, Municipal Industrial Estate, Gandhinagar, Worli, Mumbai-400018. Fax:022-24973413. Email:dreamfound2000@yahoo.com	Shri K M Aarif Tele:022-24973412 (R)
23	Indian Cancer Society Rehabilitation Centre, 74, Jerbai Wadia Road, Parel, Mumbai - 400 012. Tel: (91-22) 2415 6651. Tel: (91-22) 2413 9445 / 9451 / 9452 (office)	Dr. (Ms.) Usha Bhat
24	Karuna Kare Foundation, 21, Manas Complex, Satellite Road, Ahmedabad-380015. Email:karunakare@hotmail.com	Shri Ushakant Shah Tele:079-55129955.
25	V Care, 132, Maker Tower 'A', Cuffe Parade, Mumbai-400005, Fax:022-22184457. Email:vcare24@hotmail.com Email:vgupta@powersurfer.net vcare24@hotmail.com	Ms Vandana Gupta Tele:022-22188828 (R) M 9821058678 Ms Vibha Hemrajani, M 9821058668
26	Cancer patients' Aid Association King George Memorial, Dr. E. Moses Road Mahalaxmi, Mumbai Helplines: 022-4975462, 022-4924000	Ms Manju Gupta
27	Tata Memorial Hospital Rehabilitation Services Parel, Mumbai, 400012	