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EXECUTIVE SUMMARY

Even though more than 85% of deaths occur after a period of prolonged illness, debilitation and suffering, only less than 2% of India’s population has access to pain management and palliative care. It is estimated that 5.4 million people a year in India stand to benefit from access to holistic care that is patient-centred and not disease-focused. Yet obstacles in its growth are too many and not only include factors like population density, poverty and workforce development at base level, but also limited national policies and lack of institutional interest in palliative care.

Sanjeevan aims to provide community-based home care for the incurably and terminally ill, chronically bedridden and elderly, by taking care of their physical, psychological, social, emotional and spiritual needs. The idea is to empower the neighbourhood to look after patients at home, supported by home care teams and trained health care professionals. It involves sensitisation of the community and giving training in palliative care to all stakeholders including local people, volunteers, social workers, police personnel, doctors, nurses and health care workers at the primary care level. Links with existing medical institutions facilitate establishment of home care programs for patients.

Empowerment of community to address its own health issues creates an inclusive, independent and sustainable model, which has proved to work even for a socioeconomically and educationally backward society like rural Puducherry. The scalable and replicable nature of this model is important in setting a precedent for the rest of India.

Over the last four years, Sanjeevan has generated exceptionally good results in Puducherry, with 150 villages covered and looking after 1,560 patients with the support of 1,800 trained volunteers. In the next five years, we hope to cover entire Puducherry, mainstreaming the activity to general health care along with financial sustainability.

This document presents details of the Sanjeevan initiative, with the achievements made so far along with its plans and projected financials for the next five years.

The total estimated budget for Sanjeevan across the next five years (2019-2024) is Rs. 60,011, 865 (Rupees Six Crores Eleven Thousand Eight Hundred and Sixty-five).
ABOUT US

Sri Aurobindo Society, an international not-for-profit organization, head-quartered in Puducherry, has been working on its mission of social transformation through individual perfection since its inception in 1960. The foundation of its approach is in bringing a change of consciousness in the individuals towards higher ideals, awakening an aspiration in them to find their true potential and purpose, and then enabling them to realize these in life. When, in a community or a group, individuals thus evolve in self-leadership, its positive influence gradually helps in the transformation of the entire society.

The Society’s aim is to bring positive change, empowerment, deeper values and excellence in various aspects of social development with the following objectives:

- To establish scalable, sustainable and replicable models of inclusive development of society
- To find solutions based on deeper spiritual values for social transformation
- To empower and assist the community to identify issues of development and work towards resolution through ownership and responsibility
- To extend its actions to every activity of life.

Its wide range of activities includes the following:

- Education
- Rural Development
- Sustainable Development and Renewable Energy
- Health
- Youth
- Women
- Leadership and Management
- Indian Heritage and Culture
- Special Initiatives like Community-based Palliative Home Care, Education and Rehabilitation for Special Children, Prisoner Reformation etc.

The Society has been recognized by the Government of India as a Charitable Organisation, as a Research Institute, and an Institution of Importance across the nation, with operations over 300 centres and branches across India.

It runs various successful programmes under its umbrella, many of which have received national and international recognition. Some of the important initiatives are:

- Rupantar - A Multi-Dimensional Program for Transforming Education and Inspiring Action
  - 13 lakh teachers oriented to innovation in education in 22 states of India
  - Zero-Investment Innovation in Education Initiative (ZIIIEI) - 1.5 lakh teachers implemented innovations in classrooms
  - Mental Health Program - 55,000 RMSA teachers oriented
  - 12,000 teachers trained to support children with hidden disabilities
SARVAM - Integral Village Development Program
- Spans across 18 villages while benefitting 20,000 people
- Sustainable Rural Health and Nutrition with JIPMER, Ashoka Innovators for the Public and Arvind Eye Care
- **English Access Micro Scholarship Program with US Embassy** - 2 village children have been awarded a free trip to the US
- **Community Radio Station** - an audience of 50,000 across 30 villages
- Sanitation with DRDA and HDFC, Livelihood with L&T, Digital Literacy with TCS

Sharanam - National Centre of Excellence for Rural & Sustainable Development
- **Recognized by United Nations Environment Programme** for vernacular

Education Innovation Fund for India - National Program for Innovation in Education
- **US$1M to 18 outstanding education innovators** from across the country
ABOUT PALLIATIVE CARE

Death comes to all of us. More than 50 million people in the world die every year, but only less than 15% of these people die suddenly or unexpectedly. Others usually die after a period of prolonged illness and debilitation. Many of the people with incurable or terminal illness spend their last days, months or even years in misery. This time is often associated with a lot of suffering. Pain; symptoms like breathlessness, nausea and vomiting; paralysis of limbs; and foul smelling ulcers can make life unbearable not only for that person, but also for the family. In addition to physical problems, they usually suffer from social, emotional, financial and spiritual issues caused by their condition.

However, suffering at the end of life can be effectively reduced through sensitive care with effective control of physical symptoms, and good psycho-social, emotional and spiritual support. The system of care aiming to improve quality of life of the incurably ill, dying and bedridden people is called Palliative Care.

Palliative care relieves suffering and improves the quality of life of the elderly, the terminally ill, of people living and dying with chronic and incurable illnesses like cancer, and people with HIV/AIDS. Palliative care responds to physical, psychological, social and spiritual needs, and extends the care, if necessary, to provide support in bereavement. It is patient centred, and not disease-focused.

According to the definition given by the World Health Organisation, palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and addressing of psychological, social and spiritual problems is paramount. The goal of palliative care is to provide the best possible quality of life for patients and their families. Many aspects of palliative care can also be applied earlier during the course of the illness, in conjunction with treatment. Palliative care:

- Affirms life and regards dying as a natural process of life
- Neither hastens nor postpones death
- Provides relief from pain and other distressing symptoms
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient’s illness and in their bereavement
NEED ASSESSMENT

The need for Palliative Care has never been greater and is increasing at a rapid pace, due to the world’s ageing population and increase in cancer and other non-communicable diseases. Despite this need, Palliative Care is still not sufficiently developed in most of the world. Since the early 1980s, the need for Palliative Care for cancer patients has been progressively acknowledged worldwide. More recently, there is increased awareness of the need for Palliative Care for other chronic diseases or conditions such as HIV/AIDS, congestive heart failure, cerebrovascular disease, neurodegenerative disorders, chronic respiratory diseases, drug resistant tuberculosis, and diseases of older people. However, there remains a huge unmet need for Palliative Care for these chronic life limiting health problems in most parts of the world. Globally, in 2011, over 29 million people died from diseases requiring Palliative Care. The estimated number of people in need of Palliative Care at the end of life is 20.4 million. The highest proportion, 94%, corresponds to adults of which 69% are over 60 years old and 25% are 15 to 59 years old. 6% of all people in need of Palliative Care are children. The great majority, 78%, of adults in need of Palliative Care at the end of life, belong to low and middle-income countries.

It is estimated that 0.3 percentage of the population (or 60% of all those who die) at a given point of time would require Palliative Care in some form or the other. With a death rate of 7.48/1000 and a population of 1.21 billion, more than nine million Indians die every year. The total number of people in need of Palliative Care in India can thus be estimated to be 5.4 million people a year. In addition, there are a significant number of patients living with advanced non-communicable diseases in need of Palliative Care in the country. India is estimated to have more than 2 million patients with cancer at any point of time. There are an equal number of patients with other mostly incurable diseases like AIDS, progressive neurological, cardiac, respiratory and other diseases. With the rapid ageing of the Indian population, the highest number of patients needing Palliative Care will, in the future come from the elderly terminally ill. Most of the elderly and those with advanced chronic diseases can get relief from suffering if Palliative Care is available.

A study on ‘quality of death’ carried out by Economist Intelligence Unit of ‘The Economist’ in 2010 covering 40 countries, ranks India the last, below Mexico, Brazil and Uganda, among others. The estimated average coverage of Palliative Care services in the whole country is less than 2%. Patients in need of Palliative Care are people with chronic life threatening diseases. By the time the disease is pronounced to be incurable, most of the patients would have already spent a huge amount of money on treatment. In the absence of an accessible Palliative Care system to guide and treat the patients, most of them get drawn to inappropriate, futile and expensive treatments leading to further harm including financial liabilities. Lack of Palliative Care facilities lead to improper use of scarce resources meant for curative therapy and also blockage of hospital beds.

PROPOSED SOLUTION

The word Sanjeevan linked to ‘giving life’ and ‘immortality’ reflects the aim of bringing quality and meaning to life of the ill person and to the carer, because there is the search of ‘timeless life’ in all of us.
We believe that suffering at the end of life can be reduced only by an integral approach addressing the entire being - the body, surroundings, emotions and mind with an attempt to establish harmony with the inner most self. Palliative Care, to be truly effective, has to be based on complete understanding life and death. Such an approach can enrich the philosophy and practice of Palliative Care as well as the patient and the care giver. Involvement in end of life care are opportunities to support individuals facing the final crisis in their life. This can be a transforming experience and make life worth living both for the cared and for the carer. The only way to achieve it is to involve the entire community and bring it together with the force of compassion.

Social experiments in Kerala have shown that it is possible to involve people from different walks of life to make a difference in end of life care. This can be India’s major contribution to end of life care, and the number of people who can benefit from such a system can be very large.

Sri Aurobindo Society (SAS) in partnership and collaboration with the Institute of Palliative Medicine, has initiated Sanjeevan for the development of a comprehensive system of community based care for the incurably ill, chronically bed ridden, elderly and dying people, based on deeper values and the long search in India for the meaning of life. The other collaborating partners are Helpage India, JIPMER, AV Medical College, Puducherry Police and Tamil Nadu Institute of Palliative Medicine.

OBJECTIVES

The aim is to establish a community based model for Palliative Care across the entire state of Puducherry, which is sustainable, scalable and replicable. The process involves sensitisation of the community and giving training in Palliative Care to all those interested, training doctors, nurses and health care workers at the primary care level, linking up with existing medical institutions, establishing home care programs to care for patients at home. This contains

1. Capacity building in the community aiming to equip various sections of the society to play their role in the care of the elderly, chronically bed ridden and dying patients. The target geographical area of about 300 sq. km consists of Puducherry town (42 wards) and the neighbouring villages (Ariyankuppam, Villianur, Mannadipet, Bahour and Nettapakkam). The target population is around 1 million. The actual number of patients in need of palliative care is not available. But a projection based on World Health Organization estimates the minimum of 3,000 patients in need of palliative care.

2. Establishment of outpatient outlet/day care centre supported by practitioners of both allopathic and alternate systems as well as practitioners of yoga/artists/trainers.

3. Establishment of home care units led by nurses trained in Palliative Care and supervised by doctors trained in Palliative Care.

4. Linking with existing agencies including those in Government sector.

5. Setting up a Centre of Excellence for Palliative Care for dissemination of information and training community volunteers.
SCOPE

The project is a capacity building and demonstration project - a facilitator in nature. The interest, knowledge and skills generated in the community by the project is expected to facilitate the development of Palliative Care services. The clinical and community leads developed by the project are expected to continue the sensitization and training process even after the project period. SAS will continue to establish and run the project for 5 next years. All the sensitization and training programs will continue independently thereafter.

In addition to establishment of Palliative Care services for the needy in Puducherry, the demonstration project is also expected to serve as a model for development of similar projects in other regions in India and abroad.

During the next five years, Sanjeevan proposes to transition towards a more holistic and independent model by empowering the communities to be self-sustaining and building a multi-facility centre with in-patient care units, out-patient clinic and a training centre.

METHODOLOGY

The strategy for capacity building and integration of the program to the mainstream involves the following activities in an interactive matrix.

- Sensitization Programs

Sanjeevan is committed to generate awareness among individuals, families, communities, community based organizations and elected representatives on the need for community based care and support especially for people with chronically/terminally ill and bedridden patients. This contributes to the foundation of sustainable value creation among the community. Various basic awareness programs are being conducted in the panchayats, colleges, and community, in the form of discussions, meetings, interactive talks and street plays. The idea is to sensitize the public regarding the need and scope of community based palliative care service.

Sensitization programs have reached out to police personnel, level health care workers, social workers, nurses, doctors and students. By sensitizing level health and social workers such as Anganvadi and Asha workers, grass root level outreach can be done by connecting with primary health care workers at every village.

While infusing the palliative care approaches to the nurses, nursing students and doctors we ensure that a group of professional medical practitioners committed to compassionate care is available in future for sustained activities in palliative care.
in the region. This helps the doctors and medical officers to have bird view on Palliative care, need and scope among the patients.

- **Training Programs**

  A range of training programs are conducted with the aim to enhance the ability and competence of the local people to address the psychosocial needs of the patients and families and to facilitate the development of locally sustainable home care programs in the background of a network of nurses and doctors with expertise in palliative care to support these initiatives.

  Groups of trained volunteers are linked to palliative care professionals and health care facilities in their communities. Community Volunteers are responsible for setting up palliative care units in the network. The following training programs are being conducted under the project.

  **For Community Volunteers:** Three hour training programs are offered to community volunteers who are willing to spend at least two hours per week to look after bed-ridden or dying patients in their neighbourhood. This is the basic training in which a new volunteer will get know about palliative care, terminal/chronically ill patient and their problems, and the role of the community.

  **Train the trainer program (TOT):** Community volunteers interested to train others are offered ‘Train the Trainer’ programs. (TOT). This program aims at creating a pool of trainers to act as a resource person for the local volunteers training program so that sustainability of the project is ensured. These are intensive 16-hour palliative care training programmes.

  **For Health Workers and Social Workers:** It is a 2-day intensive training program for community health workers and social workers who are interested to volunteer their services in palliative care. They are oriented on the home based care, nursing
issues and basic communication skills.

**For Community Nurses:** Community nurse plays a vital role in home based care service by managing the symptoms and addressing the nursing issues during the home care visits. The community nurse training program is part of the 3-month Basic Certificate Course in Palliative Auxiliary Nursing (BCCPAN) for supporting the local home care groups. Additionally, WHO approved Basic Certificate Course in Palliative Nursing (BCCPN) is also available for B.Sc Nursing students.

**For Doctors:** Basic Certificate Course in Palliative Medicine of 6-week duration at IPM, Calicut is suitable for doctors with an interest in palliative care. The course provides hands-on training in symptom management and communication skills.

**PROGRESS TO DATE**

Introducing the concept of palliative care and community participation in a socio-economically backward community, sensitizing people, generating interest and capacity building of different strata of people to develop and sustain the initiative is a complex but rewarding work. In all the villages where we have patients now, we have been able to develop a strong network of supporting people and to link them up with trained professionals and health care institutions. We have also managed to get the Public Health machinery at various levels interested and involved. The message has been “Palliative Care is everybody’s business.” We have been able to show that even a socio economically and educationally backward society like rural Puducherry can be empowered to address its own health issues.

As a result of these efforts, Sanjeevan now looks after 1,560 incurably ill, elderly, bed ridden and dying patients in Puducherry. More than 500 people had died with dignity at home under our care. All patients in need of palliative care in 147 out the 400 villages in the area are covered.
Proposal for Sanjeevan, Palliative Care

The coverage in the villages we work is total and comprehensive. The aim is not just to provide medicines, but to make sure that the patient lives and die with dignity. This means building a supportive psycho social environment in addition to offering medical and nursing care.

Patients we look after are provided with:

- Medical and nursing services by our home care teams
- Free medicines and nursing consumables
- Physiotherapy for the needy
- Food for those patients and families who cannot afford to procure food
- Companionship by trained volunteers
- Involvement in creative activities through music therapy and painting session
- Referral and transport to collaborating institutions whenever necessary

Fig 1: Outcomes of Sanjeevan

150 Villages
1,560 patients
500 patients died with dignity

500 patients died with dignity
1,560 patients
150 Villages

Proposal for Sanjeevan, Palliative Care
Under the sensitization schemes, 637 programs were conducted in the community covering more than 8,000 people. It includes:

- 160 police personnel from Puducherry Police
- 640 Anganwadi teachers from different villages trained with the support of the Department of Social Welfare
- 3-hour sensitization programs for 126 staff nurses and 163 nursing students
- Enrolment of 200 students from schools and colleges trained in palliative care
- 60 doctors who completed the Basic Certificate Course in Palliative Medicine at IPM

Training programs have been equally successful and reached all the stakeholders in the initiative. It involved:

- A total of 82 training programs were conducted with 1,450 community volunteers
- 8 master training programs were organized in which 183 trainers were involved
- 15 government doctors, 45 government staff nurses and 22 government community nurses were trained as volunteers under this scheme
23 community nurses have been trained for home care visits through BCCPAN
17 staff nurses have been trained through BCCPN
24 doctors have successfully completed the WHO approved BCCPM course

In partnership with Indian Institute of Palliative Medicine, Sanjeevan has compiled and published a training manual called ‘A Workbook for Carers’. The Lal Bahadur Shastri National Academy of Administrators, Mussourie, has taken the initiative to translate the workbook in Hindi to extend its outreach.

The Sanjeevan model of palliative care is poised to cross boundaries of the country with its published training material and manuals being translated in Ceylonese, Bangla and Thai to be used in palliative units in Sri Lanka, Bangladesh and Thailand respectively.

HAPPIER ENDS

We have seen that the Sanjeevan transforms lives. One example is that of Vishal (name changed for the sake of confidentiality). Towards the end of June 2017, an Anganwadi teacher from the Sanjeevan network referred a patient (a resident of Irulansandai, Puducherry) for palliative care—a 9-year-old child who is suffering of third-stage brain cancer. He was both in mental turmoil and physical pain. The Sanjeevan team immediately started working on his case history as well as counselling his parents. They put his case up for a referral of morphine to ease his pain and revised his medicines to ensure that his short life is as pain and symptom-free as possible. The interventions helped him to come back to near normal life in spite of the progressing disease.

During one of the conversations with the team, Vishnu (who had to drop out of school due to cancer treatment) wished that he could celebrate at least one birthday, which he has never done before. On July 11, 2017, the Sanjeevan team organized a birthday party for him where all his school and
neighbourhood friends were invited. They had a great day together, one of the best days in his life though the number of days he is expected to live is limited.

CURRENT FOCUS: FOR NEXT 5 YEARS

- **Consolidate the gains of the project**: The project presents a unique model for development of palliative care at the primary health care level in low- and middle-income countries. The model needs to be consolidated, documented and presented to the rest of the World, which is one of the prime agendas over next 5 Years.

- **Incorporate the project into mainstream health and social welfare system starting with Puducherry**: The work is in progress towards this direction. It entails training and collaborating with health care professionals and social welfare teams. More systemic action that involves a draft of a policy for the Government to adopt, is also ready. The key aim of the initiative is to make palliative care mainstream by mainstream health and social welfare systems including government and private institutions which will determine the logical conclusion of the efforts.

- **Program Expansion to cover the whole state of Puducherry**: The immediate challenge before the project is to reach out to a total of marginalized 3000 patients in need of care and support, across the state. This is due to the absence of systemic support currently.

- **Project Sustainability**: Developing local systems to ensure that the project is both delivering positive results as well as is sustainable until either integrated into mainstream or supported by Government is the prime focus of the initiative. The process of organizing trained volunteers into village level committees and handing over administrative responsibilities need to be started, towards which the project Sanjeevan needs to anchor the process and then ‘hand-hold’ the committees till they are stable.

- **Sanjeevan Centre**: One of the important milestones that Sanjeevan proposes to achieve within the next 5 years is to establish the Sanjeevan centre which will provide care to inpatients using a synthesis of allopathy and alternate systems. This will also have an outpatient unit. It will also serve as a research centre for palliative care and a training centre mostly for medical practitioners and nurses.

EXPECTED OUTCOMES

The key outcomes of next five years are expected to be

- Coverage of all of 400 villages and urban areas in Puducherry with an estimated number of 3,000 patients by continuation of the sensitization and training activities for various stakeholders of the society

- Establishment of Sanjeevan Centre with a 15-bed capacity and an outpatient unit along with research and training facility

- A state-level Palliative Care policy for the people drafted and adopted by the Government of Puducherry with our support

- Involvement of more local medical colleges and hospitals to increase the professional support and network so that home care of the patients is managed effectively

- Training modules for nurses and doctors that can be integrated in their respective courses
• At least **70% self-sustainability** through a local network of supporters who can finance the program on the ground

• **Proper documentation of the methodology** which can be used to set up similar models of Palliative Care across the world

The aim of the project “Sanjeevan” is not just to make basic home care services accessible to thousands of needy patients who are towards the end their journey of lives, but also to help them live and die with dignity. The goal of the initiative is to showcase to the world, a working compassionate community model of palliative care for low- and middle-income countries. This is the urgent need of the hour also, as we observe and experience that the problems of the elderly and people with advanced non-communicable diseases have become the major challenge before health and social welfare systems all over the world.

**FINANCIALS**

Financials presented below does not include the cost to set up the Sanjeevan Centre. The proposed layout of the centre is attached as **Appendix 2**.

The total proposed budget for extending the current Sanjeevan program for the next 5 years is **Rs. 60,011, 865 (Rupees Six Crores Eleven Thousand Eight Hundred and Sixty-five)**.

The summarized budget is provided below while the details are given in the attached **Appendix 1**.
# Budget Summary

<table>
<thead>
<tr>
<th>Description</th>
<th>Year 1 Cost (INR)</th>
<th>Year 2 Cost (INR)</th>
<th>Year 3 Cost (INR)</th>
<th>Year 4 Cost (INR)</th>
<th>Year 5 Cost (INR)</th>
<th>Total Across 5 years (INR)</th>
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<td>Remunerations</td>
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<tr>
<td>Salary of Community nurses</td>
<td>372,000</td>
<td>1,040,000</td>
<td>1,160,000</td>
<td>1,550,000</td>
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<td>Salary of Staff nurse</td>
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<td>363,000</td>
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<td>439,230</td>
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<td>Salary of Medical officer -</td>
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<td>880,000</td>
<td>968,000</td>
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<td>1,171,280</td>
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<td>822,800</td>
<td>905,080</td>
<td>995,588</td>
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<td>Salary of Part time Director</td>
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<td>440,000</td>
<td>484,000</td>
<td>532,400</td>
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<td>Salary of Drivers</td>
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<td>861,000</td>
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<td>350,000</td>
<td>375,000</td>
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<th>Reviews/ Dissemination</th>
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<td>Workshops/ Seminars</td>
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<td>1,250,000</td>
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<th>Administrative and Incidentals</th>
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<td>Stationery/ Case Sheets</td>
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<td>Conveyance and Communication for team</td>
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| Total Administrative and Incidentals | 185,000 | 210,000 | 230,000 | 245,000 | 270,000 | 300,000 |

Proposal for Sanjeevan, Palliative Care
### Proposal for Sanjeevan, Palliative Care

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<th>Category</th>
<th>Year 1</th>
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<th>Year 4</th>
<th>Year 5</th>
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<td>800,000</td>
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<td><strong>Total Administrative Expenses</strong></td>
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<tr>
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<td>2,375,000</td>
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<td><strong>Total Operational Cost (B)</strong></td>
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<tr>
<td></td>
<td>8,504,500</td>
<td>9,858,000</td>
<td>11,458,900</td>
<td>13,675,650</td>
<td>14,814,815</td>
<td>58,311,865</td>
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<tr>
<td><strong>Home Care Units (Capital)</strong></td>
<td>3 (current)</td>
<td>4 (add one)</td>
<td>4</td>
<td>5 (add one)</td>
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<tr>
<td></td>
<td>-</td>
<td>800,000</td>
<td>-</td>
<td>900,000</td>
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<tr>
<td><strong>Total Capital Expense (C)</strong></td>
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<tr>
<td></td>
<td>-</td>
<td>800,000</td>
<td>-</td>
<td>900,000</td>
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<tr>
<td><strong>Grand Total (D = B+C)</strong></td>
<td>8,504,500</td>
<td>10,658,000</td>
<td>11,458,900</td>
<td>14,575,650</td>
<td>14,814,815</td>
<td>60,011,865</td>
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</tbody>
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APPENDIX 2

LAYOUT OF THE PROPOSED SANJEEVAN CENTRE