Alpha Palliative Care Bylaws

1. Preamble

Alpha Palliative Care expanded the scope of palliative care to include victims of all life limiting diseases from the very inception in the year 2005 when the home care services were started. Over a period of time Alpha Palliative Care expanded further to cover people suffering from restricted mobility such as stroke survivors, accident survivors, spinal cord injury like paraplegia and quadriplegia, people with various other neurological disorders, age-related frailty and people with chronic kidney disease needing dialysis.

Over the years Alpha Palliative Care has developed many examples of good practice in palliative care and there are increasingly strong networks of community-owned palliative care providers helping to spread good practice, which has rendered Alpha Model Palliative Care unique!

Alpha Palliative Care has been spreading the message that it is the duty of the community to take care of its members who are suffering due to pain and distress- not as a charity but as a duty and has been successful in motivating communities to set up palliative care centers in their respective areas.

The palliative care centers thus set up were regulated as one in one Block Panchayath (population about 300,000) in such a way that the palliative care home delivery is possible during the hour of the patient's need; not when convenient for the provider!

This approach brings together existing guidance regarding Alpha Hospices and Link Centers, promotes good practice and makes recommendations on development of services rendered.

The aim is to provide a strategic framework, which will provide a basis for consistently high-quality palliative care services that are available uniformly across India. This strategy has been formed after learning from Neighborhood Network in Palliative Care (NNPC) which our parent organization Alpha Charitable Trust co-founded in the year 2001. Alpha Palliative Care further developed the concept into Community Ownership.

Alpha Palliative Care value the initial support received from The Institute of Palliative Medicine formed by its parent organization Pain and Palliative Care Society, Kozhikode under the leadership of Dr. Suresh Kumar.

2. Research Survey

Alpha Palliative Care would like to recognize and thank all the volunteers and staff members who took time to conduct a survey in the year 2008 covering 1000 people who received palliative care from what was then known as Alpha Pain Clinic to find out what were the problems faced by the patients in agrarian and resource-poor countries like Kerala in India. The survey revealed that physical problem suffered was the most severe. However, once the physical issue is brought under control, then the most severe problem identified was financial which find no mention in the WHO definition of Palliative Care!

The survey results published in 2009 included the following slide:

Research Survey Result 2009		
	Problems	(Mean Score)
1.	Physical	71
2.	Financial	66
3.	Social	45
4.	Emotional	51
5.	Spiritual	1.5

The survey identified that when the debt caused by the burden of huge expense involved in the treatment of the disease goes beyond the ability of the patient, his/her immediate family and friends, the patient and their family face social isolation. This revelation helped Alpha to understand the problems faced by the patients and their families better and could come up with various programs to address these issues more efficiently.

3. Background

It was in a get together of 490 families who were the recipients of regular monthly pension from Alpha Charitable Trust in Edamuttam on August 15th, 2004 that the seed for Alpha Palliative Care was sown. The gathering that day was kick started with the hoisting of the national flag by Comrade Raman at 9 am and continued till 5 pm. Everyone dined together and interacted freely giving their points of views, all of which were given a patient hearing, and important aspects from the discussion were scribbled down. On the basis of the past association with Pain and Palliative Care Society, Calicut since 1995 and the knowledge gained from the regular visits to the 'pain clinic' functioned from one of the buildings of Calicut Medical College, it was understood that what was required

for most of them was Palliative Care! Following this, volunteer sensitization programs followed by volunteers training classes and nurses training conducted. On 3rd May 2005 Alpha Home Care commenced under the leadership of Dr. Krishna Kumar by providing Palliative Care to Bhuvaneshwari Amma, a neighbor who was suffering from cancer. Back then, Palliative Care was deemed as treatment provided to terminally ill cancer patients. However right from its inception, nearly half of the patients under Alpha's care were non-cancer patients, which made Alpha unique and distinct among Palliative Care providers. Alpha recognized and adopted a policy to deliver palliative care for all terminally ill patients irrespective of the nature of disease from its very beginning.

4. Brief Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illnesses. It is achieved through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems, physical, psychological, social and spiritual.

5. Alpha Palliative Care Policy

We, in Alpha Palliative Care, undertake to care the patients and their families and respect them as individual human beings who have their needs as perceived by them.

Undertakes to deliver appropriate care at the door step of the patient while preserving their option to visit Alpha Hospices and Link Centers for symptom control so that they have a choice to receive their treatment and care, at home or at out patient's clinic or in hospice. Provide the treatment and care without discrimination irrespective of race, religion, caste, creed, gender, political affiliation and socio-economic status.

Provide the services in an atmosphere of mutual love and human respect, where no prayers will be conducted other than those of the individual's choice.

Provide a platform for all those in the community to take part in this service to the humanity as transparent as possible.

Provide correct and timely information about health conditions and treatment plan to the patient and the family and accept patient's choices as far as possible.

Provide a homely and welcoming atmosphere where patient and the family will feel free to talk and express their opinion and aspirations.

We undertake to provide as best end of life care as possible which neither hastens nor postpones death.

We undertake to support the family through-out the course of treatment and care and continue family support even after the death of the patient, taking the aspirations of the patient into consideration.

We undertake to raise financial resources from as many individuals and organizations as possible but reject financial support if conditions are attached.

We value and respect the self-less work of the volunteers and students who collectively own this humanitarian initiative.

We value and respect the high quality and dedicated work of the doctors, nurses, physiotherapists, drivers, paramedics, housekeepers, hospitality and other staff members and undertake to implement measures to ensure their welfare.

We undertake to offer opportunities to the students to serve the community and bring the youth to the leadership of Palliative care and Social service in India

We further undertake to conduct training and research and share knowledge and information with those working in the rest of the world and collaborate with all, for continuous improvement in the services rendered.

Every person with life-limiting conditions, irrespective of age, should be able to receive palliative care, appropriate for their assessed clinical, cultural, social and psychological needs.

Every health care professional should incorporate basic palliative care in their approach to clinical practice, knowing when to call in specialist palliative care colleagues to improve the quality of life of patients.

6. Mission

Alpha Palliative Care has a mission to enhance the quality of life of human beings in pain and distress due to life limiting illnesses without discrimination on grounds such as race, religion, caste, creed, gender, political affiliation or socio-economic condition and by delivering palliative care at the hour of need, at the place of need, free of any cost to the receiver driven by our duty of care towards the community.

7. Vision

People should be able to enjoy good quality life before death as a human right and have a good death, when that eventuality finally occurs. Helping one another is a duty; not a charity.

8. Hub and Spoke Method

Alpha Palliative Care has devised a 'hub and spokes' method where the hub is the Hospice and the spokes are Link Centers. The Link centers work under the Hospice for medical service, training and palliative medicines.

9. Alpha Hospice

Unlike in the Western Countries, Alpha Hospices are essentially designed for symptom control, not for long term stay. Alpha Hospice is a home with basic hospital facility open 7 x 24 hours where people suffering from pain, nausea, vomiting, breathlessness and various other difficulties could be admitted for symptom control for a few hours or few days and return home to live with whatever they call as the family or move to a care home in the absence of a family. Hospices play a major role in ensuring acceptable quality of end of life care.

Alpha Hospices provide training in palliative medicine for doctors, nurses and community volunteers and will distribute palliative drugs to various link centers operating under the hospice.

Alpha Link Centers operate under the guidance of Alpha Hospice to provide home care, daycare, Punarjani (Neuro rehabilitation) care and training.

10. Support Groups

Support Groups will be formed from people desirous of promoting the quality of life of human beings in pain and distress caused either by life limiting diseases, accident or by age-related frailty. Support Groups will be formed separately for:

- Punarjani Care
- Rehabilitation
- Dialysis Care

All these areas are generally neglected by palliative care and social organizations; it may be possible for Alpha Palliative Care to find new volunteers interested to work for these causes. The new volunteers could be those attracted towards one or two of the causes listed above, they may not necessarily have interest in other activities of Alpha Palliative Care.

10.1. Alpha Punarjani

Alpha Punarjani Care Centre is equipped with modern physiotherapy equipment, constituting an integral part of Alpha Link Centre where people with restricted mobility are brought from their homes in vans having side doors and those having own mode of transport receiving palliative physiotherapy by trained physiotherapists at least once in a week, every week. The beneficiaries are classified into four (4) groups and offered memberships in clubs such as:

- Udayam (patients with spinal cord injury like Paraplegia and quadriplegia)
- Pulari (stroke survivors),
- Asakiran (neurological disorders like parkinsonism, multiple sclerosis)
- Rainbow (children with cerebral palsy like disorders)

Members of each club suffer from psycho-social and spiritual pain in addition to their physical challenges. The Support Group should be able to solve those pains tailored to individual need while physiotherapist and physiotherapy assistants work to improve upon their mobility.

10.2. Dialysis Support Group

It is estimated that kidney function of about 65 million people in India slows down gradually leading to Chronic Kidney Disease (CKD). Diabetics are the reason for 30% occasions whereas Hypertension could be causing CKD in 20% of the cases. A variety of reasons lead to CKD in the rest of the cases.

Kerala Population being 3% of all Indians, 1.8 million people could be having CKD is Kerala, of whom 10% may require dialysis three (3) times every week. However, due to scarcity of the dialysis centers and unaffordable cost involved, most patients needing dialysis are unable to access the service.

Alpha Palliative Care would like to address this huge problem by setting up one center with 16 dialysis machines initially, at their Hospice at Edamuttam in Thrissur District of Kerala. The capacity will be increased gradually and leading to implementing similar centers attached to all Alpha Palliative Care Hospices and Link Centers. The Dialysis Support Groups could shoulder this responsibility to a large extent.

Dialysis clubs are to be formed giving memberships to the patients and the care-givers which could study the problems faced, in addition to giving psychological boost and togetherness, to find their economic, psycho-social and spiritual issues and to work out solutions individually and collectively.

10.3. Rehabilitation Support Group

Rehabilitation support is required for the two groups referred above as well as the people coming to the Hospice for symptom control. It has been noticed that by the time the cancer patients and patients suffering from other chronic disease register in Alpha Palliative care, they have reportedly lost all their assets after pledging or selling them for the treatment. On many occasions the family sells even their house in their desperate bid to save the life of the relative. Sometimes the relative dies, the family becomes homeless!

Similar is the case of Punarjani patients as well as that undergoing dialysis. Though they suffer from psychosocial and spiritual pain in addition to their physical issues, financial pain remains the utmost.

Though it may not be possible to support all the patients financially, soliciting sponsorship of house repair, skill development etc. Could be practical steps. Many of the Punarjani patients need skill development once they achieve improvement in the mobility and start loving life. This matter deserves serious study before implementation.

Sponsoring education and training of their children and help to arrange weddings of their daughters are some other needs.

10.4. Eligibility to Join Support Groups

Ideally the people with a mass base interested to work for one particular cause is eligible to join Support Groups. These should be the people having grass-root level contacts and ability to conduct Social Engineering. Let us invite doctors. nurses. paramedics. engineers. engineering tradesmen, teachers, students affiliated to palliative clubs of Students Association of Palliative Care (SAPC) volunteers, Parents & Teachers Association (PTA) members, business men such as those connected to chambers of commerce, management associations, merchants association, government employees, members of residents associations, people employed in private sector, Pravasi Malayali Associations, and people from all walks of life to join the support groups.

10.5. Dis-eligibility

Let us NOT invite religious leaders, caste organization leaders and political leaders though Alpha has great respects to all of them, except those who have proven their love for human beings in pain and distress without any vested interest and agenda, able to work beyond the interests of their respective organizations. Let us NOT invite people with criminal intents, people with unacceptable character and people who do not believe in gender and social equality.

People who are already involved with Alpha Link Centers should not be made members at any level in the support groups since they are already working for the cause. Similarly, people who are working with other palliative care centers should first terminate their relationship with them before associating with the support groups even if they were volunteers of Alpha palliative Care in the past!

10.6. Governing Body of Support Group

Each Support Group ideally should have about 200 members, each contributing minimum Rs100 (Rupees One Hundred) each month by way of ECS. Each Support Group will have 25% of its members from student/ teacher community and the remaining members of the group should be decided in such a way that no one gender (male or female) exceeds 66% of the total strength of the Group. Each Support Group will have the following office bearers:

- One (1) General Convener (male/ female)
- Two (2) Joint Conveners (female/ female)
- One (1) Joint Convener (Student/ youth)
- One (1) Joint Convener (faculty)

The five members together will constitute the Governing Body of the Support Group.

The term of office of Governing Body shall be 1 year.

11. Executive Council of Alpha Hospice

- 11.1. The office bearers of the three (3) Support Groups together will form the Executive Council of Alpha Hospice with 15 members. However, the fourth activity of the hospice, which is to provide short-term inpatient care for patients referred from the link centers, essentially for symptom control and end of life care. In the current structure there is no provision for the support group for those availing symptom control and the Executive Council of the hospice will directly manage the operation of this activity.
- **11.2.** The Hospice shall maintain at its registered office a register of its Executive Council members with following particulars.
- i) The name and the address of the members.
- ii) The date of which the member was admitted.
- iii) The date on which a member ceased to such membership.
- **11.3**. A person ceases to be a member when he/she cease to be an office bearer of the Support Group or death or resignation or found of immorality, theft, mischief, gambling or convicted in any criminal cases by the Government.
- **11.4**. Every member shall have an equal right to vote at the Executive Council meeting.
- **11.5**. The Executive Council shall have full powers to run the Hospice. The Hospice shall be run & operated according to the rules and regulations and principles set down in this bylaw. The day to day operation of the

Hospice shall be administered by the Governing Body of the Executive Council.

- **11.6**. The Executive Council will have the following Office Bearers who will form the Governing Body of the Hospice.
 - President
 - Secretary
 - Treasurer

The Bank account operation of the Hospice shall be delegated to the Governing Body of the Executive Council with minimum 2 signatures. (Signing cheques beforehand will be construed as a misuse of the authority, which will invite cancellation of delegation of authority to sign the cheques)

All the three should not belong to any one gender.

11.6.1. PRESIDENT

President will be the head of the Executive Council and will preside over the General body and Governing body meeting of the Hospice conveyed by the General secretary for the purpose of carrying out the various activities of the

Link Center. Term of the President shall be 1 year and shall be elected by the Executive Council every year.

11.6.2. SECRETARY:

- a. To sign on behalf of the Hospice all correspondents and to maintain the
- records of the proceedings of the meeting of governing body.
- b. To summon and attend the meeting of governing body.
- c. To call the meeting if desired.
- d. He shall also represent the Hospice at various quorum functions.
- e. To bring forward new ideas and ventures and implement them after a discussion with an objective to make them successful.

f. He shall maintain the day to day reports of functioning of the Hospice.

Term of the Secretary shall be 1 year and shall be elected by the Executive Council every year.

11.6.3. TREASURER

He shall keep and maintain all vouchers and books of accounts of all receipts and payments of the society and to furnish all necessary information to the Finance Department of the Head Office of Alpha Palliative Care. Term of the Treasurer shall be 1 year and shall be elected by the Executive Council every year.

12. Alpha Link Centre

Alpha Link Centers are community-owned palliative care centers where the community finds own resources – financial, human and material- necessary for implementing, maintaining and managing the centre without any support either from government or from any large corporate entities. The community volunteers who derive pleasure serving other human beings without discrimination on grounds such as race, religion, caste, creed and political affiliation work together with self-motivation.

Though scarce of resources, all the services are provided free of any cost to the beneficiaries while doctors, nurses and other staff members are paid as per the industry standards.

Palliative Home care is the major service offered by the link center. Palliative-trained doctors and nurses visit the patients in their home to relieve pain and other symptoms while palliative-trained community volunteers try to find out the non-physical pain suffered. The volunteers get together to address those problems.

Alpha Link Centers are palliative care delivery centers working 9am to 5pm, Monday thru Saturday, equipped to provide home care, day care, outpatient care to people suffering from life limiting diseases such as cancer, parkinsonism, dementia, renal disease, chronic mental disease, organ failures etc., owned and governed by the local community at no cost to the beneficiaries. Alpha Link have Punariani facilities where regular Centers physiotherapy is provided to improve the quality of life of the people facing restricted mobility such as accident survivors, stroke survivors, people with neurological and congenital diseases.

Alpha Link Centers follow a multidisciplinary team approach, by including the services of nurses, doctors, physiotherapists and community volunteers to provide care. Speech therapists, occupational therapists and psychologists are outsourced.

Link centers are implemented on Development Block basis. Each block has a Block panchayat, with a population of about 300,000 inhabitants. Each Block is expected to have about 150 to 200 people needing dialysis. Alpha Palliative Care would eventually like to set up dialysis care centers attached to every link center.

12.1. Alpha Chapters

Alpha Palliative Care Link Centers will organize Alpha Chapters at panchayat level in rural areas and divisionwise in municipalities and corporations.

12.2. Organization Structure and Governing Body of Alpha Chapter

Each Chapter ideally will have 100 to 200 members, each contributing minimum Rs100 (Rupees One Hundred) each month by way of ECS. Each Chapter will have 25% of its members from student community and the remaining members of the Chapter should be decided in such a way that no one gender (male or female) exceeds 66% of the total strength of the Body.

Each Chapter will have the following office bearers:

- One (1) General Convener (male/ female)
- Two (2) Joint Conveners (female/ female)
- One (1) Joint Convener (Student/ youth)
- One (1) Joint Convener (faculty)

The five members together will constitute the Governing Body of the Chapter.

13. Executive Council of Alpha Link Centers

- **13.1.** The office bearers of Alpha Chapters together will form the Executive Council of Alpha Link Centre with 5 members from each Panchayat level Alpha chapter. For Example, if there are 7 Alpha chapters formed, the executive Council of that Link center will have 35 members.
- **13.2.** The Link Center shall maintain at its registered office a register of its Executive Council members with following particulars.
- i) The name and the address of the members.
- ii) The date of which the member was admitted.

- iii) The date on which a member ceased to such membership.
- **13.3**. A person ceases to be a member when he/she cease to be an office bearer of the Support Group or death or resignation or found of immorality, theft, mischief, gambling or convicted in any criminal cases by the Government
- **13.4**. Every member shall have an equal right to vote at the Executive Council meeting.
- **13.5**. The Executive Council shall have full powers to run the Link Center. The Link Center shall be run & operated according to the rules and regulations and principles set down in this bylaw. The day to day operation of the Link Center shall be administered by the Governing Body of the Executive Council.

The Executive Council will have the following Office Bearers who will form the Governing Body of the Hospice.

- President
- Secretary
- Treasurer

The Bank account operation of the Link Center shall be delegated to the Governing Body of the Executive Council with minimum 2 signatures.

All the three should not belong to any one gender.

13.5.1. PRESIDENT

President will be the head of the Executive Council and will preside over the General body and Governing body meeting of the Link Center conveyed by the General

secretary for the purpose of carrying out the various activities of the Link Center. Term of the President shall be 1 year and shall be elected by the Executive Council every year.

13.5.2. **SECRETARY**:

- a. To sign on behalf of the Link Center all correspondents and to maintain the records of the proceedings of the meeting of governing body.
- b. To summon and attend the meeting of governing body.
- c. To call the meeting it desired.
- d. He shall also represent the Link Center at various quorum functions.
- e. To bring forward new ideas and ventures and implement them as successful.
- f. He shall maintain the day to day reports of functioning of the Link Center.

Term of the Secretary shall be 1 year and shall be elected by the Executive Council every year.

13.5.3 TREASURER

He shall keep and maintain all vouchers and books of accounts of all receipts and payments of the society and to furnish all necessary information to Finance Department of the Head Office of Alpha Palliative Care.

Term of the Treasurer shall be 1 year and shall be elected by the Executive Council every year.

All the three should not belong to any one gender or religion.

14. Central Council (CC)

The concept of Central Council is proposed by the Trustees of Alpha Charitable Trust to include the

representatives of the community-owned link centers and hospices to be a part of the decision-making process.

The Executive Committees running each Link Centre and Hospice will elect one representative each to the Central Council (CC).

- **14.1**. Central Council representatives elected from each hospice and link Centre together with the Chairman of Alpha Charitable Trust, heads of Medical department, Community department and Accounts Department- all the CC members collectively shall be known as Central Council.
- **14.2**. The Chairman, Alpha Charitable Trust, will be the chairman of the CC. The Community Director and Medical Director of Alpha Palliative Care, Chief Physiotherapist, Alpha Palliative Care and Accounts Manager of Alpha charitable Trust will be ex-officio members of the Central Council without voting rights. And any changes in their employment contract and job description will require consent and approval of the Board of Trustees.
- **14.3**. The number of CC members shall correspond to the number of Alpha Link Centers and Hospices that existed at any point of time plus Chairman of the Trust, the heads of the Medical, Community, Punarjani and Accounts Department.
- **14.4**. The Central Council will have female / male members with minimum 33% representation to male/female. Trans-genders are welcome to be members.
- 15. Central Council Member (Elected)- Duties and Rights

- **15.1**. A member elected by the Executive Council, any one among them shall be their representative to the Central Council.
- **15.2**. The Executive Council electing a representative to the Central Council will have the authority to call back the representative and elect another person to be at CC any time by following the procedure to call such meetings.
- **15.3**. The CC member individually will not have any right to interfere in the functioning of the Link centers except in cases where inappropriate matters are found to be happening there. Even in such instances, the CC member's responsibility is to report the matter to the Governing Council to take corrective action.
- **15.4**. The CC members shall read the minutes of the Central Council meeting in the Executive Council of the respective Link Center/Hospice. The CC Members must record the opinion expressed by the volunteers and inform them immediately to the Governing Council and if remained unaddressed, shall report to the Board of Trustees, depending on the merit of such opinion.
- 15.5. Central council (CC) members or their appointed bodies shall be entitled to determine at their absolute discretion the person or persons entitled to receive help from Alpha Palliative Care funds and to what extend and what shape and the CC members shall utilize the income for the charitable objectives in such shares and proportions and in such discretion they think fit.
- **15.6.**The CC members shall be at liberty at their absolute discretion to accept contributions, collections or donations to Alpha Palliative Care from associations, trusts or from any person or persons, firm or company, subject to the

condition that the contributors or subscribers shall not be entitled to participate in or have any say or control of the management or administration of Alpha Palliative Care of these presents or the application of such contributions, collections or donations and the CC members shall hold the same upon Alpha Palliative Care and subject to same powers, provisions, covenants and conditions as are herein contained.

- **15.7**. Any CC member may retire at any time without assigning any reason and without being responsible for any costs occasioned by such retirement.
- **15.8**. The surviving or continuing CC members may act as CC Members, PROVIDED HOWEVER that if the number of CC members fall below 50%, the minimum fixed by these presents, the CC members shall not, except for the purpose of filling any vacancy, act so long as the number is below the said minimum.
- 15.9.ID Cards will be issued to all

16. Eligibility and Code of conduct of the Central Council Member

- **16.1**. The CC member thus elected should be unbiased irrespective of race, religion, caste, creed, gender, political affiliation and socio-economic issues.
- **16.2.**The CC member should be able to identify himself / herself with the interest of the patient and the families and will stand by them in all humanitarian issues.
- **16.3.**A CC member will uphold moral high ground in all aspects and will believe in gender equality.

- 16.4.A CC member will not be a convicted criminal and will not be involved in unlicensed money lending, illicit liquor trading, women trafficking, drug pedaling or any other illegal and immoral activities.
- 16.5.A CC member could be a member of a political party or a member of a Caste / religious organization but should possess the ability to see all the patients and the families as human beings and take decisions accordingly in an unbiased humanitarian way.
- **16.6.**A CC member should have sufficient knowledge about the 'Strategic Directions' of Alpha Palliative Care and other initiatives of Alpha Charitable Trust and should sign a declaration to abide by the policy and principles of Alpha Palliative Care.
- **16.7.**A CC member should identify self with the interests of people at the bottom of the socio-economic pyramid and should stand by them in all socio-economic conflicts.

17. Resignation / Exit of Central Council Member

A CC member may submit resignation giving or without giving any reason, with 30 days' notice. Any such resignation / disqualification should be recorded and acknowledged.

17.1. A CC member shall also cease to be a member of the central council in any of the following events:

If he/she dies or become insane.

If he/she becomes bankrupt, or

If he/she becomes insane or otherwise become incapable to act, or

If he/she fails to attend the CC meeting on three (3) consecutive meetings. In such instance, the Governing Council will ask the concerned Link Centre to elect a new CC member or

If he/she is removed from the Central Council by the Board of Trustees of Alpha Charitable Trust.

The Board of Trustees is empowered to remove any CC member found to violate the eligibility and code of conduct listed above and working against the fundamental objectives of Alpha Palliative Care

- Working inconsistent with the objectives
- · Practicing discrimination of any nature
- Found to nurse ulterior motives
- Found to have criminal intend or unkind behavior.
- Influenced by vested interests financial, religious, and political or gender based inappropriate behavior

18. Advisory Councils

The CC is entrusted to form Advisory Councils such as those dealing with subjects such as, but not limited to:

- Education and Skills Training
- Quality Evaluation and Continuous Improvement,
- Dialysis Services
- Punarjani Care

- Rehabilitation
- Volunteers Training Courses.
- Implementation and administration of Palliative Clubs in various educational and training institutions within the geographical area of each Link Centers.
- Propagation of the principles of Alpha model palliative care and end of life care, living will etc.
- Social media and newsletters
- Staff welfare

Members of the Advisory Councils could be outsourced but the conveners are desired to be a Central Council Member, except in cases where such a talent is not available in the Central Council.

19. Authority of the Central Council

The Central council will discuss and decide all policy matters and all matters of serious nature and consequences with regard to Alpha Palliative Care.

- 19.1. CC is authorized to take all the important decisions including issuing guidelines on how to run all Link Centers and Hospices working under Alpha Palliative care such as Hospice care, Punarjani care, Dialysis care and Rehabilitation Support and similar initiatives established under Alpha Palliative care at present and those going to be established in future.
- **19.2.** Approve Budget of Alpha Palliative Care every year.

- **19.3.**To issue guidelines to Governing Council on the day to day administration of Alpha Palliative Care in order to work with in the budget approved for the year.
- **19.4.**Propose and plan programs from time to time for raising funds for the organization.
- **19.5.**Propose employee welfare schemes and implement / administer such schemes.
- **19.6.**Propose schemes for the safety of the staff and volunteers
- 19.7.Propose measurable scales to assess the efficiency of the staff and volunteers, and implement the schemes with incentives and disincentives to motivate efficiency including Awards for the best performing link centre/ department/ staff / volunteer
- **19.8**. Central Council (CC) or their appointed bodies shall be entitled to accept donations in cash or kind and to raise funds by various ways deemed appropriate such as arranging charity shows, by accepting fees, subscriptions and other methods.
- 19.9. The Central Council with the power vested upon it can from time to time alter, substitute or delete any clause or clauses of this bylaw and new clause or clauses may be added to this bylaw by way of resolution with 75% concurrence of the total members, passed in the meeting of Central Council and duly entered in the minutes of the CC and it shall form part of this bylaw after the approval of the Board of Trustees.

20. Duties & Responsibilities of "Central Council"

20.1.Complete Responsibility to run "Alpha Palliative Care" comprising of Hospices and all Link Centers, including finding ways and means to run according to the budget approved for each year shall be with the Central Council.

20.2. Other responsibilities of the Central Council shall be:

- a. To evaluate the functioning of the hospices, link centers, dialysis centers, Punarjani and rehabilitation programs periodically and work out plans for continuous improvement in all aspects
- b. To evaluate the budget prepared by the Hospices and Link Centers and allocate from the Tharavad (Head Quarters) budget, depends on the funds required by them from time to time.
- c. To evaluate the effectiveness of each and every department and propose measures for corrective and preventive actions as an on-going process
- d. To evaluate various projects under Alpha Palliative Care and prepare critical / appreciating notes, advice the Board of Trustees accordingly

- e. Study training needs of the staff and the volunteers and to recommend appropriate training and education
- f. Prepare advocacy programs with regard to end of life care and propose policy guidelines to statutory bodies, social organizations, hospitals both private and government.
- g. Propose training courses for doctors, nurses, physiotherapists, physio assistants and the volunteers –both adults as well as youth.
- h. Study various curriculum available, propose curriculum appropriate for the youth and adult volunteers.
- i. To arrange training to volunteers sensitization, community volunteer training, Trainers Training (Training to take Volunteers Training classes) etc. The training should include elements:
 - Managing Community Owned Palliative Care system –Alpha Model.
 - To make them capable of communicating with patients and families
 - To help the people at the hour of their need by finding out the problems faced by the patient and the families.
 - To promote teamwork and team building skills
- j. To work with Disaster Management Projects proposed by the local / state/ central government
- k. Commemorate anniversaries of those living and death anniversaries of the patients who were in the care of Alpha Palliative care, appropriately.
- I. Observe special days such as Gandhi Jayanthi, World Hospice & Palliative care day, Earth Day,

Alpha Anniversary etc. individually in each center and collectively participating the members of the public.

- m. Formation of Compassionate Communities by identifying and acting on Compassionate Needs. The CC will identify people who need intervention by the community to help them lead a dignified life. These could be people suffering from one or more of the following problems:
- People living alone who are to be repatriated in times of humanitarian crises, people living with physical weakness / mobility issues / old age problems etc.
- People unable to support the family or even unable to support themselves financially due to incurable conditions of any diseases so that the volunteers could gather list of their relatives, friends, colleagues and neighbors who are interested to support the family.
- n. The CC to help the compassionate community to work out Action Plan, review action taken reports periodically until such a time the person / family reaches a position that the affairs could be managed without the support of the compassionate community.
- o. People needing End of Life Care due to any reason other than medical so that the volunteers could visit the person, understand the care needs. Register them for Palliative Care /health care so that members of the Community could live with dignity in all aspects. If a time comes that death become inevitable, a good quality of death is to be assured.
- p. The Central Council would spearhead research in areas of specific issues concerning palliative care

which are different from those in developed countries.

21. Other Terms and Conditions

- **21.1**. The Central Council will uphold the larger interests of Alpha Palliative Care and the initiatives of the parent organization.
- **21.2**. The registered office of the Central Council shall be at Alpha Palliative Care Hospice, Nr: /ward. Valapad Panchayath, PO EdamuttamThrissur District, Pin 680568 Kerala State.
- **21.3**. The Board of Trustees of Alpha Charitable Trust shall have power to change the Registered Office to any other place in Kerala by adopting a resolution. The area of operation of the Trust shall be confined to India.
- **21.4**. No part of the corpus, income, receipts and Funds of Alpha Palliative Care and accretion and addition thereto shall be spent, utilized, or applied by the CC members on any expenditure outside the territories of India, and as such the area of operation of the trust shall be within India only.
- **21.5.** It shall be lawful for the CC to call meetings / get together of those who would donate monthly / annually to raise the working capital to run the hospice / hospices/ care homes / orphanages functioning under Alpha Palliative Care.

22. Central Council Meeting

- 22.1. The Quorum for the meeting of the Central council shall be one half of the number of members in the CC at any given time. In case the quorum is not available within half an hour from the time appointed for holding a meeting, the meeting shall be adjourned to the same day next week at the same time and place or to such other day, time and place as the CC may determine. If at the adjourned meeting also (i.e. meeting held after the initial adjournment) a quorum is not available within half an hour of the appointed time, the members present shall be the quorum. The decisions thus made will be binding on all members present or absent. However, if any CC member is unable to attend the meeting he/she can send a proxy on his behalf any other member of the executive council he represent.
- **22.2**. Notice of the meeting of the Central Council and all communications may be sent to the members by email at their addresses registered for the time being in the records of the CC and should be sent at least 10 days prior to the date of the proposed meeting. This shall be done by the Administration manager on the advice of Governing Council.
- **22.3**. The agenda of the meeting shall be prepared by the Governing Council.
- **22.4**. Central Council shall meet at least once in a quarter of the year. Governing Council shall initiate to call for the CC meeting at such place and time it decides. Chairman of Alpha Charitable Trust shall have the power to call a CC meeting at any point of the time he feels fit.

The frequency of the CC meetings could be once in every one or two months as long as the notice sent at least 10 days in advance to all members of the CC, with the agenda

- **22.5**. In case of difference of opinion arising among the CC members and the votes are equally divided, the Chairman shall have a casting vote.
- **22.6.** A minutes book of the proceedings of the CC meetings shall be kept which needs to be circulated among all CC members from time to time. Any resolution passed during such meeting shall be valid, only on the signature of majority of members.
- **22.7**. There will not be any option for a proxy to attend a CC meeting.
- **22.8**. The CC meetings in no way will replace the monthly meetings of the Executive Councils of the Hospices and Link Centers taking place under the community department to evaluate their functioning.

23. Term of Central Council

- **23.1**. The term of each CC member will be 3 years from the start of a financial year, extended by a similar period if elected by the Executive Council of the Link center / Hospice and approved by the Board of Trustees.
- **23.2.** After two consecutive terms the member concerned should stay out of the CC for two terms minimum, to make room for others to become members
- 23.3. The Central Council will report to the Board of Trustees of Alpha Charitable Trust represented by its

chairman or a Trustee mandated by the Board of Trustees.

24. Resignation / Exit of CC Member

- **24.1.** A CC member may submit resignation giving or without giving any reason, with 30 days' notice. Any such resignation / disqualification should be recorded and acknowledged.
- **24.2**. The Board of Trustees is empowered to remove any CC member found to violate the eligibility and code of conduct listed above and working against the fundamental objectives of Alpha Palliative Care
 - Working inconsistent with the objectives
 - Practicing discrimination of any nature
 - Found to nurse ulterior motives
 - Found to have criminal intend or unkind behavior.
 - Influenced by vested interests financial, religious, and political or gender based inappropriate behavior

25. Governing Council (GC)

Three (3) members will be nominated by the Board of Trustees from the elected members of Alpha Palliative Care Central Council (CC) to form "Governing Council". Additionally, 2 members will join them in order to support and advise the Council and make the decision process easy. The Medical Director and the Community Director of Alpha Palliative Care will join as the Advisory members of the Governing Council who work in tandem with the elected GC members, so the total members of the Governing Council will become 5.

26. Duties and Responsibilities of Governing Council

- **26.1.** The day to day management of the Head Office of Alpha Palliative Care is the responsibility of Governing Council. The decision-making power rest with the 3 elected members of the GC and is considered to be in perpetual sitting at Tharavad where a record will be kept on all decisions made. The consultation with other GC members could be by word, phone call, WhatsApp, e-mail or other means of communication as long as it is recorded in the register. All such decisions shall be made only after taking advise of the 2 Advisory members of the Council.
- **26.2**. Governing Council, apart from the day to day management of Alpha, each GC member nominated by the Board will be assigned with specific area of responsibility such as but not limited to:
 - Ensure sufficiency of funding for Link Centers, Hospice, Punarjani, Dialysis and other projects identified by the Central Council.
 - Ensure the co-ordination between all the Link Centers and all other divisions with the HO. Ensure that the whole of Alpha work as one unit and progress as envisaged to be a large organization.
 - To propose to the Central Council for approval, of setting up new Link Centers with a feasibility study.
 - Interacting with various ministries of Government of Kerala, Government of India such as Ministry of ministry of social justice and empowerment, Ministry of Women, Family and Community Development, Ministry of Skill Development And Entrepreneurship, Ministry of health and family welfare etc. to get government support to the patients, families to improve their quality of life

- Appointment and Administration of Advisory Councils including appointment, conducting meetings, taking reports, submitting them to the CC
- Central Council Affairs such as receiving complaints and suggestions, organizing meetings, preparing minutes, communicating with Alpha Charitable Trust etc.
- **26.3**. GC will initiate and organize CC meetings minimum once in a quarter year with notice sent at least 10 days in advance to all members of the CC. Agenda of the meeting is to be a part of the notice. The conveners of the Advisory Councils could be called to submit reports if such reports have relevance to the agenda.

The frequency of the CC meetings could be once in every one or two months as long as the notice sent at least 10 days in advance to all members of the CC, with the agenda

27. Term of office of GC

The Term of GC members nominated from the Central Council will be one financial year but with eligibility for renomination for three consecutive terms. The re-nomination will of course depend up on their individual performance.

28. Reporting of GC

The GC members will report to the Central Council.

The CC is empowered to accept or reverse any decision taken by the GC.

29. The Board of Trustees shall delegate the power to operate the bank accounts of the Tharavad of the Alpha Palliative Care to the Governing Council as soon as the Board is convinced about the suitability and competence.

30. Removal of GC Members

The Board of Trustees only and is empowered to remove any Governing Council Member if found to violate the code of conduct listed below: -

- Working inconsistent with the objectives set out in this bylaw
- Practicing discrimination of any nature
- Found to nurse ulterior motives
- Found to have criminal intend or unkind behavior.
- Influenced by vested interests financial, religious, and political or gender based inappropriate behavior

31. Community Department Meeting

Monthly meetings of the Executive Councils of the Hospices and Link Centers shall take place under the Community Department Director to evaluate their functioning.

32. Accounts

The Accounts Manager shall keep proper books of accounts and shall be audited by a Chartered Accountant as at the close of 31st March of every year. The Audited Financial Statement shall be presented and approved in the Central Council meeting within 6 months from the end of the financial year.

33. Conclusion

The community would organize themselves to support all fellow human beings suffering from pain and distress caused due either to life limiting diseases or accidents without discrimination irrespective of race, religion, caste, creed, gender and political affiliation. People will be compassionate to each other while supporting others. No one would suffer unnecessarily. People would live in dignity with reasonably good health, irrespective of their income level. A good death will be an option for all.

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