

Love & Care
at the end of life

QUARTERLY REPORT

(October - December 2021)



PAST

CNVFILLM FF1

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23

CANVA STORIES

PRESENT

CNVFILLM FF1



23

CANVA STORIES

The Solace of Sparsh

Go gently, gently into the beyond
Don't go suffering at close of play.

Though terminal be your illness
Doctors shrugging and looking away
With little to offer by way of care
All's not lost and you need not despair
Sparsh Hospice stands by you all the way
Offering comfort and solace for free
Till you breathe your last, smiling,
With near and dear nearby.

Be it physical pain or mental forlornness
Be it any such other deuced symptom
Sparsh is equal to the task with its team -
Doctors, counselors, social workers et al.
We will create a heaven for you here
Before you go to the heaven beyond
Making you think that hell is fiction.
Just reach out to us from your helplessness
And we will ensure your deliverance from it
Be it lack of caregivers or financial distress
That hounds you in your terminal illness.

- Dr Samarender Reddy



FROM TRUSTEE'S DESK



JAGADISH RAMADUGU

- Treasurer & Long-Term Trustee
Rotary Club of Banjara Hills Charitable Trust

"The best way to find yourself is to lose yourself in the service of others."

- Mahatma Gandhi, Father of Nation

Founded 11 years back, Sparsh Hospice - Centre for Palliative Care, a project of Rotary Club of Banjara Hills Charitable Trust (RCBHCT), has grown leaps and bounds only because we are standing still while nurturing talent within, revisiting our processes and practices, continuous community engagement and has put us on a path of continuous improvement.

We believe that in every stride we proactively take, our approach to engage, educate and sustain the project and anchored in learning, action and hope. As last quarter Sparsh Hospice embarked on new journey by inaugurating the new state-of-art-facility at Khajaguda, Hyderabad, this quarter the Trust has pulled its effort to connect more partners, strategies its planning for coming years and strengthening the volunteering base.

This quarter was filled with new activities, onboarding new volunteers from different sectors such as students, family members, corporates and others. The feedback from them has instilled greater faith in the work we do - that our drivers of change, across the country, have imbibed volunteering as a habit - impacting the society at various levels.

Thank you for travelling with us to make this quarter yet another outstanding quarter for the RCBHCT & Sparsh Hospice. I would also like to extend my gratitude to all the Rotary members, Trust members who through their dedication and giving their time in making the project a success one. The Trust has been recognised nationally and internationally because of its project and the volunteers who are our main advocates.

'Friends of Sparsh' is getting stronger and going forward we want to onboard more volunteers to make our outreach and advocacy strong to serve the needy. Going forward, I encourage corporate, CSR institutions, individuals, loved ones of our beneficiaries and others to strengthen our volunteering programme 'Friends of Sparsh' and give their best to palliative care. Our passionate volunteers, employees, Trustees, Rotary members have strived to expand our outreach while continuously strengthening our programmes.

FROM CENTRE HEAD'S DESK



SHASHIDHAR K

- Centre Head , Sparsh Hospice,
a project of Rotary Club of Banjara Hills
Charitable Trust

As I write this note at the end of 2021, the world is no longer the same, it is coming to terms with COVID-19 pandemic and its enduring impact on all of us, especially the extremely vulnerable. While the pandemic has taught some tough lessons, it has also shone the spotlight on human resilience, renewed our sense of purpose and pushed us to stand united in its onslaught. The way forward into the new year is as a family, looking out for each other and for those in need.

We have completed a decade of services (2011 – 2021) and enter a new decade of service with renewed vigour. Post the inauguration of the new facility, Sparsh Hospice geared to scale up our operations, To meet the growing demand for our services, additional staff were added in the care and support teams.

I take this opportunity to thank SBI Card who supported us in this journey by way of meeting all operational expenses of the centre, without which we would have not reached this milestone. I also extend my gratitude to new donors such as Laurus Labs, Sri Ram Finance Ltd, Providence, Gupta Foundation and other individuals such as Ms. Meka Rajini, Mr Bagga & Family who supported us to reach more needy patients with serious health-related suffering.

Currently 32 inpatient beds are operational, including one day-care ward, four home-care vans delivering care and support to about 250 patients per day.

All of this was possible due to our dedicated staff working 24x7 to address issues of patients and family members, through our army of volunteers, patrons, and our dedicated peer community network. I appeal to corporates, CSR institutions, philanthropists and individuals to come together and partner with Sparsh Hospice to give back to community.

A big round of appreciation is to the Trustees of Rotary Club of Banjara Hills Charitable Trust who are extending their wholehearted support to Sparsh Hospice and the cause of palliative care.

I look forward to all of you joining hands with Sparsh Hospice to build a community where we respect and value each other and payback through service to the ones in need.

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Trustee

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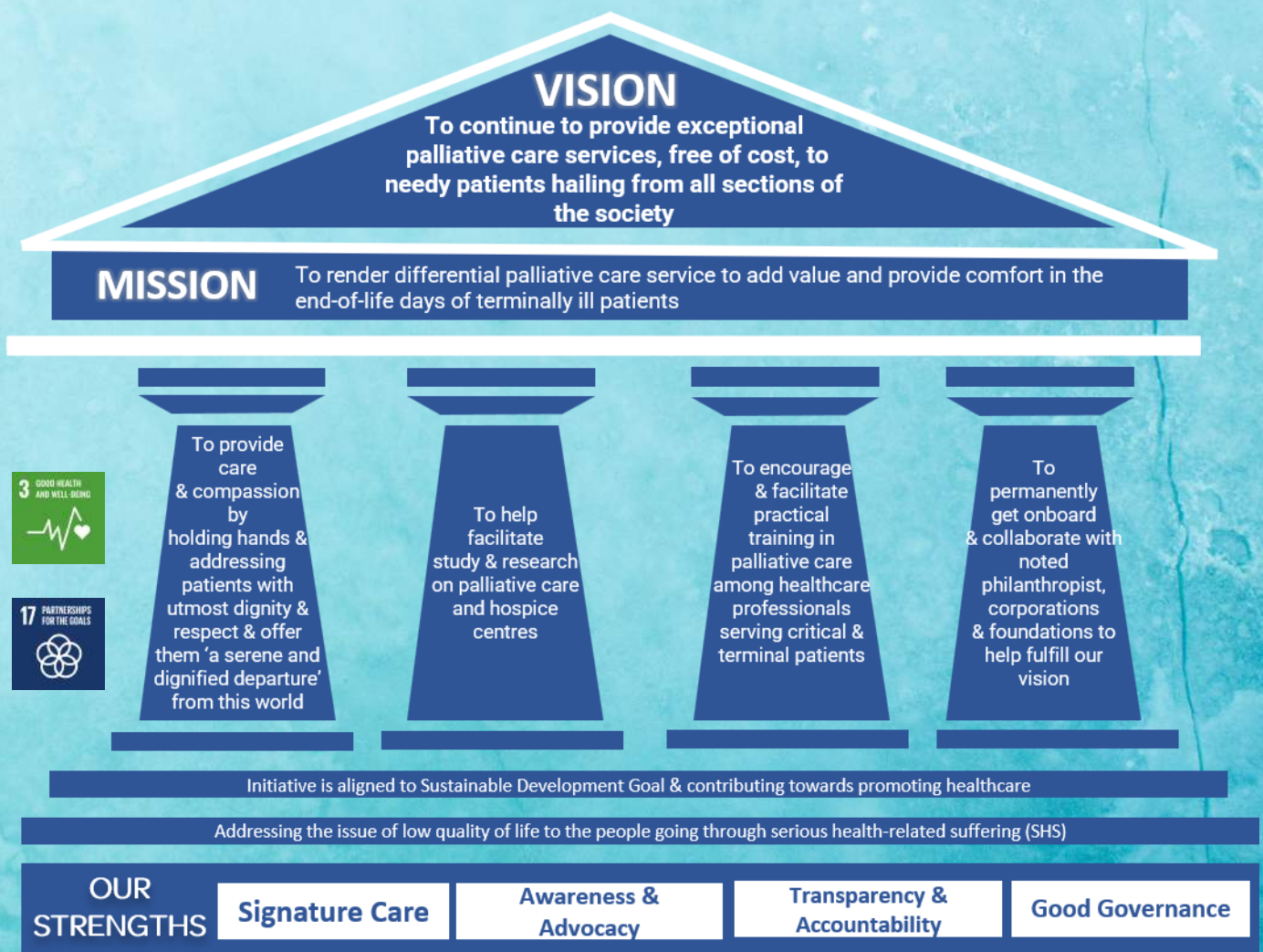
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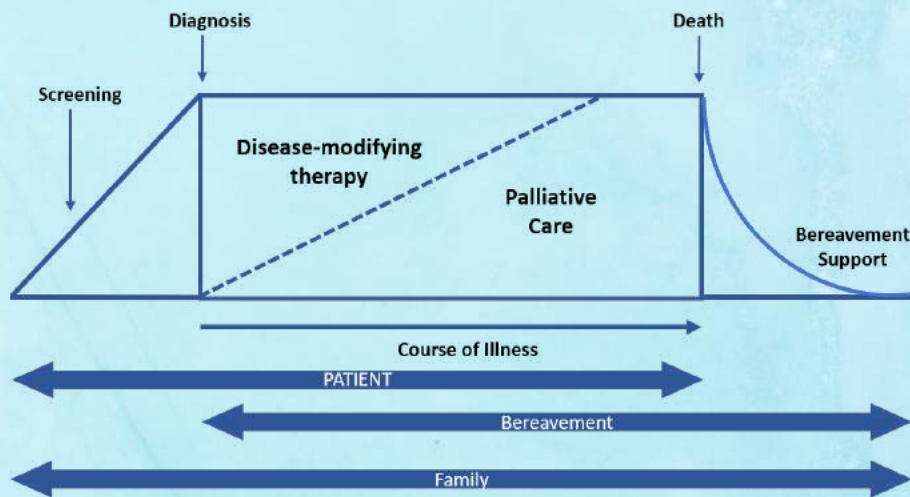
OVERVIEW

Sparsh Hospice established in 2011 is an initiative of Rotary Club of Banjara Hills (District RI 3150) under a separately constituted Trust named as **Rotary Club of Banjara Hills Charitable Trust**. It is a Centre for Palliative Care for patients with serious health-related suffering (SHS) such as cancer, Parkinson's, lung failure, strokes and others. When the 'treatment to cure' is no longer effective, patients opt for hospice care, where the curative care is of low importance, whereas making the remaining life of the patient better is the main agenda.

The thought of Sparsh Hospice took birth in this environment, where there was a total lack of support to the patient and their families in terms of medical, emotional, social, and spiritual care. Sparsh came into existence to strike a balance between the two extremes of deprivation; where the patient either has no access to remedial measures or on the other hand the comforting presence of their family. Our service is aligned to **Sustainable Development Goals (SDGs)** under **Goal 3 (Good health & well-being)** and **Goal 17 (Partnerships for the goals)**.



"Together we achieve more"



What is Palliative Care?

According to World Health Organisation, palliative care is a crucial part of integrated, people-centred health services. Relieving serious health-related suffering, be it physical, psychological, social, or spiritual, is a global ethical responsibility.

Figure 1: Stages of palliative care and relationship between disease-modifying therapy and palliative care in a patient with an incurable progressive condition. - Source: IPC 5 Introducing Palliative Care & Training Manual for Community Health Officer at Ayushman Bharat -Health & Wellness Centre

Why Palliative Care?

Western countries unlike India has a care system that takes care of people with life-threatening conditions, and provides physical, social, mental and spiritual support in the home setting. But India doesn't have much care facilities for such patients and therefore, Sparsh trying to fill that gap by its services of hospice centre and home-care services. India has a grim situation in terms of chronic or life-limiting condition as 1 in 5 suicides are committed by a person living with an advanced, chronic or life-limiting condition. Also in 2017, a Lancet Commission report recommended that palliative care should focus on all aspects of serious health-related suffering.

Current Scenario in India

2%

Less than 2% of India's 1.2 billion people have access to Palliative care.

Due to lack of basic social security the financial devastation of the family is far greater at the time of illness.



78%

of adults in need of palliative care live in low- and middle-income countries. India comes under low- and middle-income countries.

59th

India ranks 59th place in 2021 on quality of death and dying.



Sparsh Theory of Change

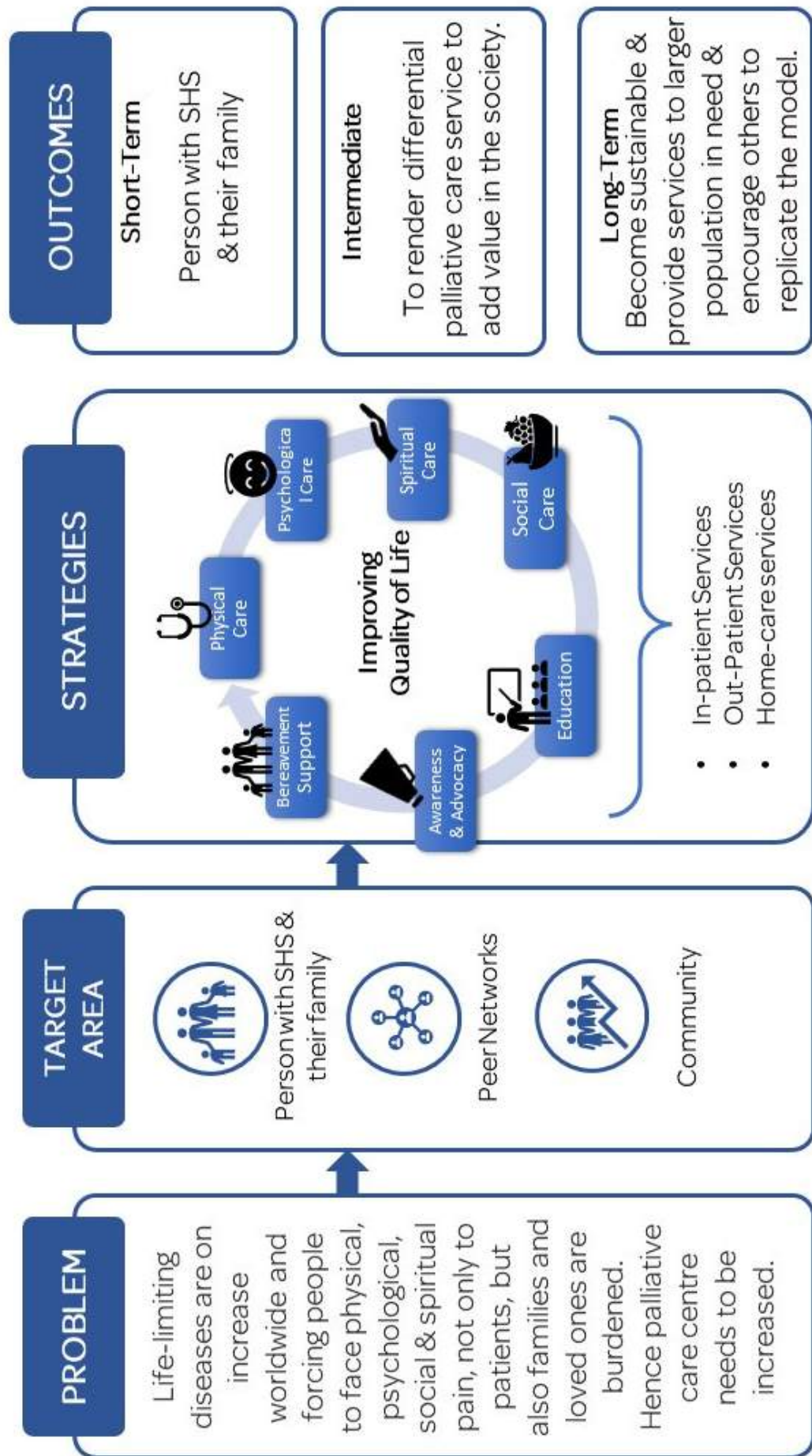


Figure2: Sparsh Hospice Theory of Change seeks to leave an impact in society while extending palliative care services.

STATISTICS

401
TOTAL NEW
PATIENTS
SERVED

We at Sparsh Hospice are firm believers of evidence-based service and transparency. Perhaps there is no better measure of our impact than our growing numbers. Our care team provides palliative care across three major areas, and they are:

- In-patient Services
- Out-patient Services
- Home-care Services

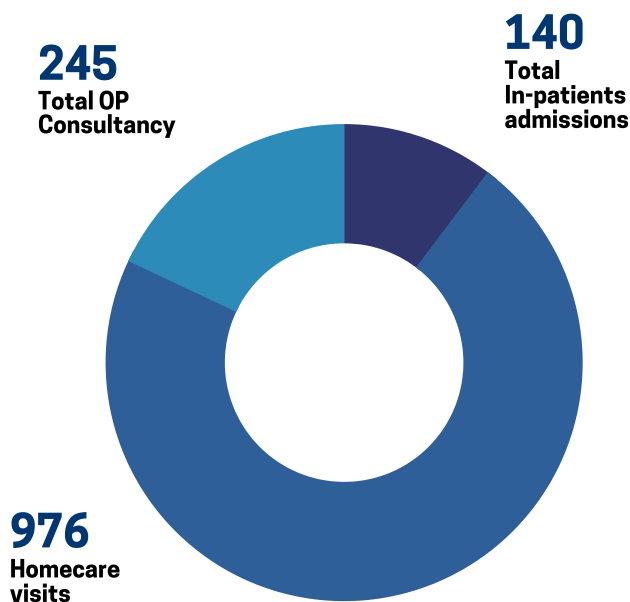


Figure 3: Graphical Representation of all patients served.

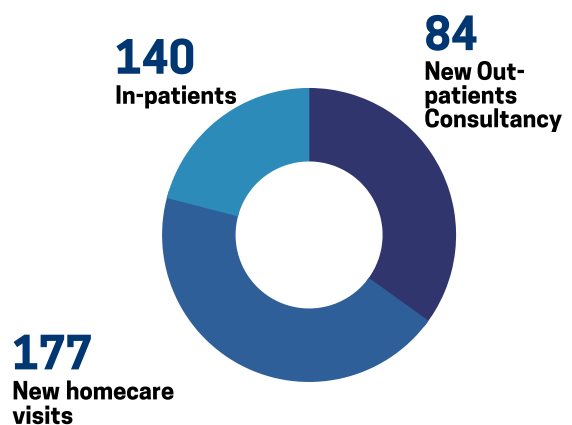


Figure 4: Graphical Representation of unique patients served.

Total New Patients Trend Quarter wise

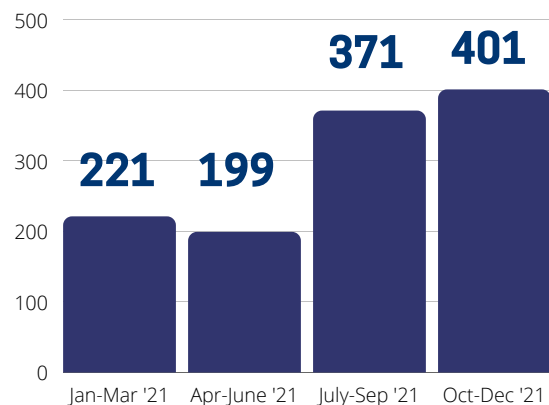
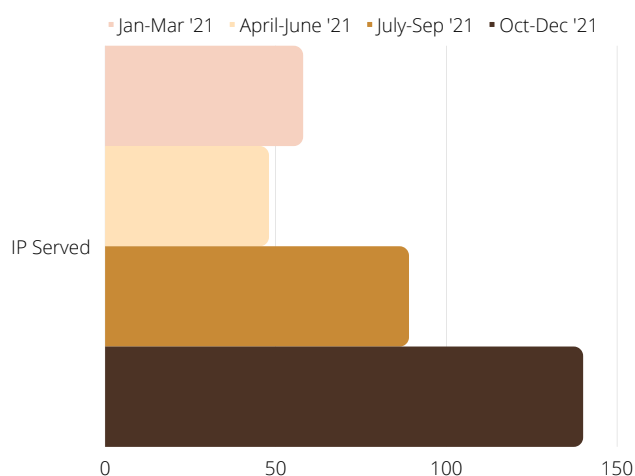


Figure 5: Graphical Representation unique patients served throughout the year.

IN-PATIENT SERVICES

Extending 'Signature Care'



Over a decade-long journey, we have consistently worked towards building a culture of 'signature care'. As palliative care workers catering to patients with serious health-related suffering, this means that we take holistic care of the person and their caregivers. Medical, psychological & spiritual counselling, pain & symptom management, caregiver/family sessions, conflict-resolution, and mobilizing social support for needy families, are some of the things we do.

	October	November	December	Total
New Admissions	45	55	40	140
Deaths	30	33	28	91
Discharges	16	20	13	49

Figure3: Statistics detail of new admissions, deaths and discharges in the in-patient services.

MAKING THE DAYS COUNT



*Seva Bharathi volunteer and others helping *Malleesh for shifting in ambulance to be brought to Sparsh.*

*Malleesh from nomads community in Telangana was already living on the brink when he got diagnosed from penile cancer. Until he and his family lived in Tanda (temporary settlement for living) 60 miles away from Hyderabad. The diagnosis meant that the little saving of the family was gone and her wife had to take care of their 3 sons.

Financially, emotionally the lone caregiver was drained. They came to know about Sparsh through our stakeholder, Seva Bharathi, a NGO. Due to the temporary settlement he was kept under tree all day and night since days. With Seva Bharathi help we brought *Malleesh & her wife for hospice care, where he and his wife is given proper stay, food, medicines free of cost. Sparsh team has helped inform the family about the palliative care and Malleesh believes he is being properly taken care here.

***Malleesh, the name has been changed due to privacy concern.**

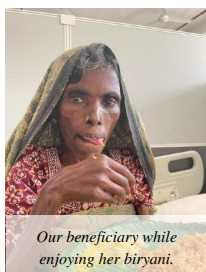
CELEBRATING TOGETHER



Ms Sudha Reddy, renowned philanthropist, organised a comedy show hosted by Mr Nitin Mirani on occasion of her birthday.



Celebration of our in-patient's birthday at Sparsh alongwith family members.



Our beneficiary while enjoying her biryani.



Our in-patient cutting a cake during Christmas celebration organised by Oakridge International School team.



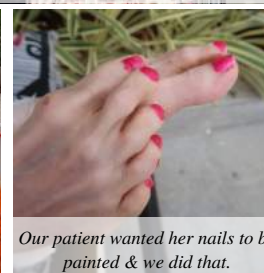
Our beloved patient singing a song during Diwali celebrations.



Our patient participating in an activity.



Sparsh beneficiary with doctor while festival celebration.



Our patient wanted her nails to be painted & we did that.

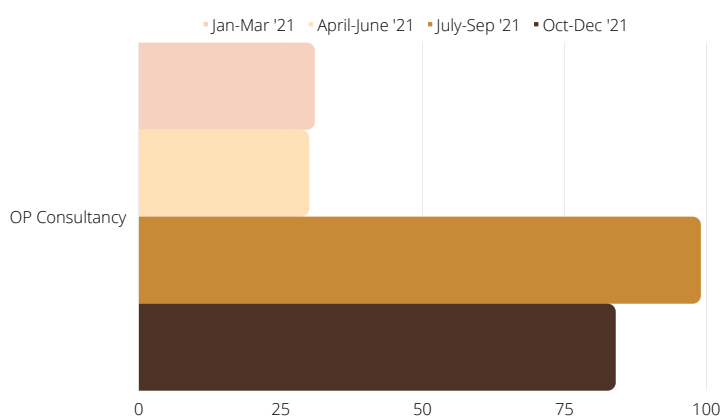


Group of women helping a patient for Bathukama dance.



OUT-PATIENT SERVICES

Connecting Dots



Outpatient consultations can often be a neglected area in palliative care. Sparsh Hospice is committed to providing high-quality care to our service-users who choose to come in occasionally for pain management, wound dressings, counselling, and a sense of community at the hospice.

	October	November	December	Total
New Outpatients	32	25	27	84
Re-outpatientinets	54	63	44	161

Figure4: Statistics detail of new outp-patients and re deaths and discharges in the in-patient services.

TAKING CHARGE OF HEALTH AND SOCIAL WELL-BEING



January 2021



March 2021



October 2021



December 2021

"The support has really helped me and my family in to fight from cancer struggles as I was the only earning member and now I am not able to do that." - Mahesh

Mahesh (name changed), native of Warangal, Telangana, has been fighting from bone cancer from more than a year. He and his wife has two children and he was the only breadwinner for the family. He came under Sparsh umbrella in January 2021 and since then we have been providing him free medicines, dry rations, patient personal care items and others on regular basis. As Warangal is 150 kms from Sparsh, our volunteer Ms Madhavi and her family came forward to make the deliveries possible. Every time they visit Warangal they collect the needed items and deliver to Mahesh.

CUSTOMISED CARING



Nurses while performing the wound dressing.



Sparsh Nurse while a conversation with out-patient family members.



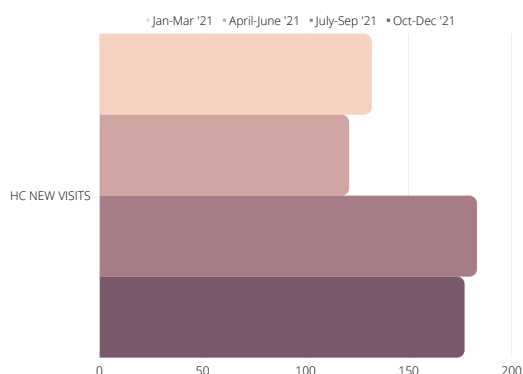
Family counselling session.



Out-patient while a visit at Sparsh.

HOME-CARE SERVICES

Care at comfort



Over a decade-long journey, we have consistently worked towards building a culture of "signature care". As palliative care workers catering to terminally ill patients, this means that we take holistic, or "total" care of the person and their caregivers. Medical, psychological and spiritual counselling, pain and symptom management, caregiver/family sessions, conflict-resolution, and mobilizing social support for needy families are some of the things we do as a part and parcel of "palliative care".

	October	November	December	Total
New Outpatients	32	25	27	84
Re-outpatinets	54	63	44	161

Figure4: Statistics detail of new out-patients and re deaths and discharges in the in-patient services.

PROVIDING DEATH WITH DIGNITY IN COMFORTABLE ENVIRONMENT

"I accept the fact that I am terminal and will not live more." - Bina

200 Chemos, unbearable pains, living in denial, what else can be more challenging for a patient and her family. Bina (name changed) was not ready to accept that her cancer is non curable and she was struggling from it since 2009. The infection reached to her skin when the family contacted Sparsh. Instead of several counselling visits the patient was in denial.

Our Hospice Administrator recalls the counseling session and shared that once she said that "You are not even a doctor how can you say that." And she replied " I am not saying anything Amma."

One fine day she said with relief that "Ok you can go now I know I accept the fact that I will not live more." And the same day she asked her family to make a video saying "Be brave" . Bina died the next day after her acceptance. She died in peace with accepting the fact and the end she was relieved by the burden of thinking that one day she will relieved from cancer.

MILES TO GO BEFORE WE SLEEP



Home-care team while family counselling.



Sparsh team while handing over gift to our beneficiary at their wedding anniversary.



Team member while file review meeting.



Home-care review meeting being conducted at regular basis alongwith all team members including doctor.



Extending social support.



Our home-care team beneficiary donating books for Sparsh library.



Education & Training in Palliative Care: Challenges & Strategies

-Dr. G. C. Robbie,
Palliative Care Physician

Palliative care applies to patients who have days, weeks to months or even years of life as the life limiting (Cancer or non Cancer) disease progresses and suffering is endless. These patients are quite delicate, physically, mentally and spiritually.

The focus of training is not to miss any aspect of suffering in a patient. Emphasis is placed on early identification of problems, impeccable assessment and management by all team members.

Providing holistic palliative care to patients is established primarily by enhancing intellect and knowledge of the entire team. We strongly believe that and have been educating the staff meticulously.

Training is challenging since it is all on-the-job learning, we have been evolving and modifying our teaching strategies and have customized it to reach out to the entire team at different times of the day, through classroom-based teaching, presentations, skits, practical demonstrations or one - on - one training in the wards, clinic, patient bed side during ward rounds and at home care.

See one, do one, teach one is an effective and efficient concept of learning is being implemented at Sparsh to enhance training. Group lessons on practical aspects along with hands-on training for the nurses, nursing aides are being conducted.

Discussions and presentations on topics related to mental, social, financial aspects of patient care and bereavement support are conducted by Social workers. Our pharmacist teaches and emphasizes medical staff on drug safety, control, proper dispensing and disposal of medicines.

Regular practical evaluations, theory quizzes, repeated reviews on ward maintenance, waste management, patient care, operating medical equipment, following aseptic precautions, regular patient follow ups and auditing medical records are emphasized.

We believe that Continuing Medical Education is crucial to maintain competency and confidence among the medical staff to give the best care to our patients at Sparsh Hospice. As a global citizen, I strongly believe that palliative care advocacy and education is much needed among the general public in India and around the world. So go on and spread the word.



Nursing Care in Elderly Population

- Rohith, Nurse, Sparsh

Comprehensive geriatric assessment along with enhanced communication and honest prognostication are important factors in identifying treatment priorities as part of effective clinical decision making. The principles of palliative care nurse in geriatric patients are as follows:

- Advanced planning
- Quality of life
- Bed bound care
- Passive exercises
- Mobility problems
- Personal hygiene
- Skin care
- Oral care
- Ambulating the patient
- Bowel and bladder care

The palliative care team has an expertise in the management of pain and other troublesome symptoms that may develop during the course of serious illness. The goals of symptoms management is to help the patient remain as comfortable, active and alert as possible. Good symptom control enables the patient to continue with favourite activities and enjoy the company of family and friends.

The patient care plan is individual and focuses on maximum comfort. Palliative care carefully monitors the symptoms of medications tailored to the needs of each patient.

Apart from giving them the medical care that they need, the elderly population with serious health issues expect empathy, compassion and constant assurance that care is at their disposal.

Geriatric population is very vulnerable emotionally and dependency does not sit well with them. We need to offer care to them keeping in view the family support, financial resources and social issues in addition to medical issues. Geriatric care has to be holistic in nature and it should be continuous.

Apart from giving them the medical care that they need, the elderly population with serious health issues expect empathy, compassion and constant assurance that care is at their disposal.

A day in the life of a nursing aide

- Nawaz, GDA, Sparsh



"Often as a nursing aid I inspire, but more often, I get inspired."

I remember a person admitted at Sparsh Hospice sharing her grief that she could not sleep for the past few days despite the sleeping medication. Working as a nursing aide for a palliative care centre, on the one hand, comes with the satisfaction of serving and, on the other hand, has its own set of challenges. According to my shift schedule, the first thing I do is take the progress report of all the assigned patients. So, my shift begins with me visiting patients and interacting with them and asking if they need anything at that moment.

And then continues with consulting the caregiver and patients and asking whether they have had a good night's sleep during a morning shift. Later, I ensure whether my assigned patients have been taken care of their dental hygiene, cleaned up, changed bedsheets and see if everything is tidy and have gotten ready to eat their breakfast as suggested by clinicians. After they are all cleaned and have completed their meal, I administer their medication and check whether any dressing or sessions are required for them. Later, I assist them by taking them around the hospice for a walk or spending time with them on the lawn. Then I have to document the medicines in a book and journal patients' progress. On the day of some celebration/festival/event, I have to ensure that interested people get access to it and make sure they are having a good time.

However, if it is an evening or night shift, I first make sure to collect the reports from the nurses assigned to the morning or evening shift and catch up on the current situation. I then go for rounds, check vitals, and make sure the patients have everything they need.

Before starting my shift, I prepare myself to work physically mentally and get through any challenges I might face. One of the biggest challenges that I face as a nursing aide is often keeping a brave face despite feeling extremely downhearted looking at the struggle's patients at Sparsh have and are going through.

Apart from the duties that any job is bound to have, my profession as a nursing aide has taught me something more than just fulfilling my responsibilities. It has taught me the power of humility and courage while reminding me of the power of a smile and the importance of touch.



Lessons from home-care visits

- Eshwaranna, Social Worker, Sparsh

"Compassion and tolerance are not the sign of weakness. They are the sign of strength."
- Dalai Lama

This message from Dalai Lama resonates with every social worker working in Palliative Care. In span of 5 years working as a social worker in palliative care has completely changed my perspective on life, judgements, values. I have visited hundreds of beneficiaries and family members from all walks of society. I have seen people with financially challenges, emotionally drained, have money but no one to care, people with no money to buy medicines. This all has taught me that whoever you are, care is not so easy we think.

Passing judgement is easy play but truly understanding is much harder.

Each day comes with new challenges such as distance, tiredness, trying to minimise social issues by being non-judgemental. Sometimes we spend hours and hours with a family while making them understand the patient situation and most difficult is breaking the news especially when the patient/family is in denial. It takes lot of energy and counselling days to make the last days count of patient a dignified one. No one should die in pain, it is a right to die in dignity.

I remember one patient family was really scared of us coming to their flat because everyone will come to know about the cancer and they myths related to the disease will set aside from the community. Realising the need and help our team took decision to visit them at night hours when there is very few people out and we helped in all the way we can. These are some of challenges we face everyday some wants us to meet at road to talk, some invites us for lunch and so on.

The visits have been an eye opener to me and taught me as a lot for my personal decisions too.



Advocacy through social media

Yutika Agarwal,
Sparsh Volunteer

The public awareness on palliative care in the world today remains insufficient for widespread effective and appropriate palliative care to be the norm. The general population, especially those without any previous related experiences, lack the awareness about the services and the help that palliative care centers provide. It is essential to increase awareness about palliative care to improve knowledge and access to the services in time of need, involve communities and to empower individuals.

To increase awareness on palliative care, one can leverage on the power of omnipresent social media to amplify voices, increase collaboration across diverse groups and to instantaneously spread information. Social media is a platform that has relatively innovative tools for spreading awareness and mobilizing communities in an advocacy effort. There are people who look at social media like Twitter/Facebook/Instagram etc. to get their daily updates and it gives one the ability to reach out to families, patients, and friends.

The online world is filled with discussions, comments, and anecdotes about the topics of death, hospitals and illness. In the recent past, the topic of death had been seen as a taboo. It is necessary for the society to be more prepared for death and increased awareness via social media can have a significant impact on the way terminally ill patients and their families approach the last leg of their lives. They can embrace palliative care and professional support to ease their journey in these difficult periods.

Social media can create a platform for sharing stories, narratives, and photos, providing facts and data in a consumable way, which engages an audience by helping them understand. It can create a platform that enables people to get the help that they need.



Training & Workshop

Our monthly schedule of meetings, review hours, and topic presentations continued as usual in this quarter, with the intent to facilitate continuous learning among the care team members. These delegated times provide an important space for discussion and reflection as a palliative care team, which ultimately reflects on the quality of care we provide to our patients and their families. The nursing team also conducted training programme for newly inducted nurses and the existing team members.

Sparsh doctor and nurses conducted regular on-job training, workshops, topic presentations for with aim of building capacity of the team. Social workers, pharmacist, volunteers and others also go on regular training, fellowship, webinars.

Key Highlights



15 sessions

of classroom training held for the team on several topics including quizzes, presentations

40 hours +

on-job training of nurses, nursing aids, aayahs/ward boys





Awareness & Advocacy

Public awareness of the concept of palliative care and of service availability remains insufficient for widespread effective and appropriate palliative care to be accepted as the norm. In particular, those without previous family-related experiences lack awareness. An increased awareness of palliative care is needed, in order to improve knowledge of and access to services when required, empower individuals, involve communities and ultimately to realise the objectives contained within international strategies for palliative and end-of-life care. Therefore, Sparsh Hospice regularly try to do community awareness in rural, urban and semi-urban areas to make people understand the need of palliative care. We also communicate with civil societies, local NGOs, online communities, stakeholders to keep in touch for making effective approach towards advocacy.

Key Highlights



54+

social media posts on platform such as FB, Instagram, Twitter, LinkedIn

90+

hours contributed towards awaring people about palliative care



Community participation

Social support through feeding under-privileged families



After Khushru Poacha's mother was diagnosed with cancer and was admitted to a hospital for surgery, he noticed that the relatives of other patients struggled in getting proper food to feed themselves. Since then through crowdfunding initiative Seva Kitchen he has helped thousands of families with food.

Similarly his initiative 'Neki Ka Pitara' is also installed at Sparsh Hospice, which provides nutritious food supplies to needy patients and family members.



There are other individuals, clubs, organisation who are sending social support for out beneficiaries such as **Inner Wheel Club of Banjara Hills, Lions Club of Hyderabad Jubilee Hills, Viswa Vatsalya Manch and others.**

We distribute groceries and other social support amongst our patient's families as a relief.



Helping with final rites of the patients as a bereavement support

Rohini Reganti, long-term Sparsh volunteer has been supporting the funeral rites of patients, who's family members are financially drained.

This quarter she supported under-privileged families with all the needed materials for funeral rites.

This initiative has helped Sparsh in supporting families emotionally and keeping the patient's last wish. These community participation is much needed for any non-profit organisation to sustain.



TESTIMONIALS

“

Services of Sparsh are very good. Highly recommended for terminally ill cancer patients. We are very Satisfied with services they are offering to my mother who is critically ill. Life would have been very difficult without Sparsh to be honest as she was going through so much pain due to Cancer. Sparsh doctors visit her every week At home and recommend medicines to ease her pain.

We are very thankful to Sparsh team for your great services !

- Lavanya Sudha Somayajula

“

Today, I happened to visit Sparsh Hospice, a great and noble driven voluntary organization. Incomparable service, it is.

May kind hearted people join hands to make this Organization sustain and carry forward this noble service " End of Life Care" concept. Thank you Sparsh for all the help.

- Rajasekhar Kandepu, Senior Director, KL University

“

Concept of Sparsh is best for the people suffering from cancer and service they are giving to patients is simply appreciable.

- Vinod Dhamsetty

“

Truly a "Blessing in Disguise".

- Amby Vemu

“

My grandfather was suffering with liver cancer. All private hospitals staff are very impolite including big branded hospitals. My entire family lost hope in people. Then we got to know about Sparsh, they took care of my grandfather very well and before admitting him to hospice they consulted him through video call as we were staying quite far from Hyderabad. Thank you so much for all the help you did to us and special thanks to Kalpana, Maheshwari and Sarada Ma'am.

- Vijay Rajalbandi

“

Great place... Great people.. they are serving mankind.. my mother admitted with Cancer last stage, and expired at there only.

They have served well.

Thank you all staff and doctors, and especially Sarada Ma'am.

- Madhusudhan Gogikar

SPARSH THROUGH PICTURES



THANK YOU FOR THE SUPPORT

Sparsh  Hospice

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NEFT to transfer Yes Bank

Name of Bank: Yes Bank

Account Title: Rotary Club of Banjara Hills Charitable Trust

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Account Number: 025094600000400

IFSC Code: YESB0000250



Sy No. 7/1/2, Next to Oakridge International School, Khajaguda, Hyderabad - 500008



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