

ANNUAL REPORT



OUR PATIENTS AND THEIR FAMILIES – OUR INSPIRATION

THE
JIMMY S BILIMORIA
• FOUNDATION •



We cannot change the outcome,
but we can affect the journey

Ann Richardson

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We are The Jimmy S Bilimoria Foundation, established 7 years ago, to provide PALCARE – a multidisciplinary, home-based, palliative care service for Greater Mumbai and its surrounding areas, that is delivered in the comfort of the patient's home, to those living with serious, debilitating conditions and in particular those patients living with cancer. Our service is focused on enhancing the quality of life for both the patient and caregiver and promoting dignity in death.

“WHAT OUR PATIENTS' FAMILIES HAVE TO SAY”

In my mom's last days PALCARE was very closely helping me with taking care of my mom. I would have been completely lost without the doctor's and sister's help. I never knew there was a system of palliative care, but I am so thankful I got to know.

PALCARE patient's daughter - 07th April 2021

Palcare has been associated with my family since February 2021. They have guided us through every step, right from our smallest concerns to ensuring my grandmother's death was a peaceful one. I will forever be indebted -to them.

PALCARE patient's grand daughter - 03rd May 2021

Our family will always remain obliged to you and your team for the care and support provided to us while my father was fighting with cancer. Your support ensured that his journey was painless and peaceful.

PALCARE patient's children – 01st July 2021

(Your team) has guided us to an extent where taking care of the patient had become very seamless. From medicines to techniques they have guided us on everything. Grateful and thankful that I discovered them.

PALCARE patient's daughter-in-law – 21st July 2021





Sir this team is wonderful! I was there for 3 hours myself, and witnessed their approach and care. I don't know how to thank you enough for all this that you arranged! I am truly blessed to have you all to guide.

PALCARE patient's relative – 26th August 2021

We only depended on the PALCARE team, for medicines, pain management, and also emotionally ..They guided us at every moment and were always just a phone call away. They would home visit us even though it would be raining. We also appreciate the psychologist, who also came to meet mom.

PALCARE patient's daughter – 12th September 2021



The day i was referred to PALCARE, it was a big sigh of relief for me as i had been a lone caretaker for my father. I had the required support whenever required. I would like to express my Heartfelt Gratitude to the entire team of PALCARE for such excellent support to us in our critical time.

PALCARE patient's son – 31st October 2021

Knowing that you guys were just a phone call away was very comforting in this time when I as his caregiver was unsure and afraid of so many things. You all educated and prepared me as well and gave us both tremendous support in his last days.

PALCARE patient's daughter – 5th March 2022

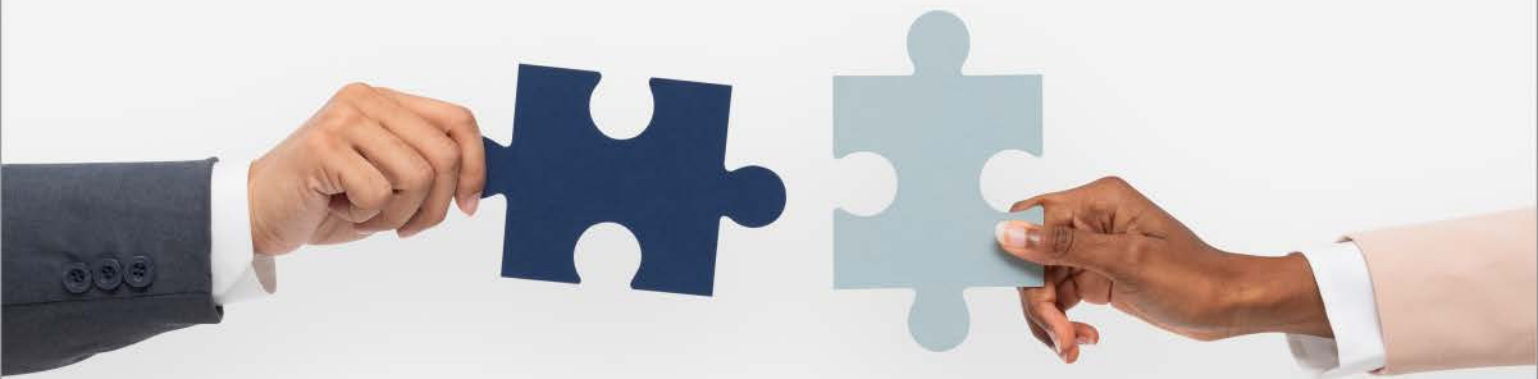
OUR PATIENTS - OUR DRIVING FORCE



LOW TECH. HIGH TOUCH.

It's a lot about compassion and empathy.
A loving smile, holding hands, sitting quietly
by their side. Just letting them know
that we are there for them.





OUR TEAMS - THE HEARTBEAT OF THE ORGANISATION



OUR DOCTORS



OUR COUNSELLORS



OUR NURSES



OUR ADMIN

THE YEAR THAT WENT BY

Dear Friends and Well-wishers, who are our extended family at PALCARE,

I am happy to present our foundation's report for the financial year 2021-22. Our journey over the past twelve months has been one of pride and joy as we continue to be blessed with the love and gratitude of our patients and their families.

Through this period, we have remained focused on our vision to deliver pain and symptom management, coupled with a very vital psychosocial counselling, to primarily those with advanced stage cancer, in Greater Mumbai, and its neighbouring areas, always in the comfort of their homes.

At PALCARE, every step we take is guided by our mission to ensure that both patient and caregiver should have a better quality of life, through the compassionate care of a well-qualified and interdisciplinary medical team of doctors, nurses, psychologists and social workers.

Our values originate in the belief that every individual, irrespective of income, social status, gender, religion, caste or creed, has the right to have a dignified existence – not only in health, but in sickness as well; and most importantly, has the right to die in dignity.

While palliative care in India is definitely gaining greater recognition each year, unfortunately, it is still a long way from being accepted widely enough to reach its full potential. Palliative care should be respected as a natural corollary to



curative treatments, and more particularly for those for whom cure is no longer an option. It is, therefore, indeed sad that oncologists, specialists and general physicians do not refer patients to palliative care early enough in the trajectory of their patient's condition, so that these patients may receive the benefits that palliative care provides.

Despite this tardy response to palliative care from the medical fraternity, and even though the pandemic continued to affect the city and the lockdowns continued sporadically as a result, PALCARE looked after as many as 627 patients in 2021-22. In this period, the team delivered the service through both

face-to-face visits and telemedicine, unlike in the previous year when almost all visits were on the phone and through video communications.

One could say a positive consequence of the COVID pandemic has been that patient care has morphed into a hybrid of in-person home visits, coupled with virtual visits conducted over video calls. The incorporation of telemedicine into our clinical framework of operation has led to greater efficiency in time management and enhanced frequency of communication with patients.

An important milestone in this period was on 22 March 2022 when PALCARE enrolled its 2000TH patient - a 74-year-old lady from Goregaon, West Mumbai, who came to us with Hepatocellular Carcinoma that had spread to the lung and bone.

Presently, PALCARE is privileged to look after over 170-190 patients at any given point in time. But, we cannot underscore enough, that even while our volume of patients grows, our

efforts are continuously focused on improving the quality of the service, by expanding our knowledge and skills in palliative care – both through hands on experience and learning from experts.



In 2021-22, PALCARE expanded the number of teams so as to be able to reach the many new patients that have come our way, mostly through referrals from Tata Memorial Hospital. We have recruited two more physicians, five nurses and three counsellors. Today the 6 geographical zones are covered by 8 teams, each comprising one doctor, two nurses and one counsellor. This is because some zones have expanded so rapidly they require more than one team to

manage the zone.

With the rapid expansion of teams, a primary challenge is to be able to ensure that new staff, no matter how experienced they be in a hospital set up or in a private clinic, are quickly, but effectively, trained in the principles of palliative care and are inculcated into the PALCARE culture and ethos, so that the organisation uniformly delivers a high-quality service across each zone.

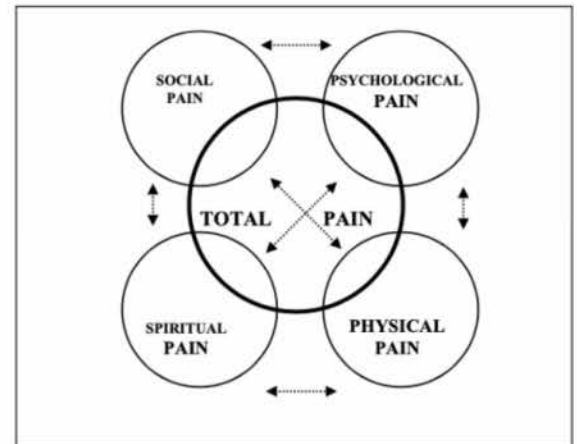
PALCARE has, therefore, had to ensure that new staff are made thoroughly familiar with PALCARE's Clinical Guidelines, so meticulously developed by an expert team of palliative care veterans such as Dr. R. Akhileswaran from Singapore, Dr. Jeremy Johnson from the UK, Dr.



Jenifer Jeba from Christian Medical College, Vellore and Dr. P Jayarajan, who was at that time, the Chief Medical Officer of PALCARE.

Today, less experienced members of the team are mentored by older, more experienced PALCARE hands who have first-hand knowledge in providing palliative care and are well versed in its dignity-promoting values and philosophies. This requires patience and diligent training of old and new staff alike.

Similarly, as the demand for palliative care becomes more evident in India, even though at not quite the pace we would like, this in turn leads to an increasing need for well-trained counsellors in the field, especially as one of the three main pillars of palliative care is psychosocial counselling.



But trained counsellors do not exist in adequate numbers in this country. Deeply aware of this lacuna in training modules for psychosocial counsellors in Mumbai and other parts of the country; in December 2021, PALCARE developed an on-line course for mental health professionals to teach the principles of palliative care counselling. Topics of the course include 'Introduction & Basics of Palliative Care', 'Counselling Skills', 'Breaking Bad News', 'Managing Denial and Collusion', 'Depression in patients with life-limiting illnesses', 'Psychosocial and Spiritual Pain' and 'Self-care for Mental Health Professionals'.

The inaugural course, ran from 16 to 28 December 2021, and was highly commended by the participants. In the words of one participant: ***"It was one of the most enriching and rewarding experiences to be a part of this training. Simply loved it!! Thank you so much"***.

In the coming year, we wish to continue our effort sin disseminating our knowledge through various forums, engaging staff in regular training so as to enhance their knowledge and skills and of course, serving patients in need across the city.

In parting I want to add that when a person is faced with a serious life limiting condition, one which will ultimately lead to death, that person and his/her family are often in a traumatic state of shock. How the person dies will remain in the memories of the loved ones left behind. Palliative care,

therefore, plays such a significant role in helping such patients and their families to come to terms with their situation, while simultaneously helping them attain a decent quality of life, for the remainder of their time, and preparing them for a peaceful death.

This is what PALCARE aims to achieve:
Quality in life. Dignity in death.

With my very best wishes to all our patients, their caregivers and families, donors and grantors, well-wishers and our dedicated and committed staff.

Pheroza Bilimoria
Founder Trustee



IN MEMORY OF



Jimmy Bilimoria

When Jimmy Bilimoria passed away in May 2013, from a two-year battle with cancer, his family came to realize that patients with serious and life limiting conditions, such as advance-stage cancer, have a gamut of symptoms to deal with, including pain and emotional distress. But there were no facilities at that time in Mumbai that could help them deal with their emotional turmoil or reduce Jimmy's physical pain and discomfort from a host of symptoms. And that is when they decided that it was about time that Mumbai should have a home based palliative care facility. This is the genesis of PALCARE.

THE BOARD OF TRUSTEES

The Board of Trustees is highly involved with the functioning of the Foundation and constantly provides guidance and advice to the management.



Homi R. Khusrokhhan

Erstwhile Managing Director, Glaxo Group, Tata Tea Ltd., Tata Chemicals and Senior Advisor, Private Equity, Tata Capital, he has been President of the Willingdon Club and is highly regarded in business circles.



Akbar Khan

CEO India at Rain Instant Pay, with more than 25 years' experience spanning investment banking, corporate finance, SME lending and financial technology, including in varied leadership.



Pheroza Bilimoria

Founder Trustee, PALCARE. She is the first woman President of the Advertising Club Mumbai, the Advertising Standards Council of India and the India Chapter of the International Advertising Association.



Rishaad Bilimoria

Partner at the Tata Opportunities Fund, a USD 600 million Private Equity Fund at Tata Capital. Rishaad holds a Bachelor's degree from Harvard University, Cambridge, USA in Economics and an MBA from the London Business School, UK.



Leila Bilimoria

Founder of LBS Consulting LLP, a boutique marketing firm based in Mumbai. With over 17 years of experience in the PR industry, Leila was previously an Associate Vice President, at GolinOpinion, the PR division of Mullen Lowe Lintas Group.

QUALITY & CLINICAL ADVISORY BOARD

PALCARE's Clinical Advisory Board comprises a group of distinguished experts in palliative care, who guide the foundation on medical issues thereby helping to ensure that the highest quality of clinical standards are upheld. They are truly leading lights in the field. Members of this Board include:

Dr. R. Akhileswaran

Palliative Care Specialist doctor in Singapore, with international exposure and deep ties to India.



Ms. Harmala Gupta

Founder of CanSupport, and pioneer in setting up home-based palliative care in Delhi and North India.



Dr. Mary Ann Muckaden

Palliative Care Specialist doctor in India and till recently, head of the palliative care department at Tata Memorial Hospital - hence wide exposure to patients at the lower end of the socio-economic spectrum.



Dr. Jeremy Johnson

Emeritus Consultant in Palliative Medicine from the UK - with an MBE for his palliative care work, well known and Chief Mentor, Karunashraya, Bangalore



Dr. Naveen Salins

Professor and Head, Department of Palliative Medicine, Kasturba Medical College, Manipal, and member of the executive group, Medical Council of India



Dr. Jenifer Jeba

Professor and Head of the Palliative Care Unit, Christian Medical College and Hospital, Vellore and Honorary Tutor at School of Medicine, Cardiff University, UK

Dr. Seema Rao

Department of Palliative Medicine, Kasturba Medical College, Manipal, and faculty + consultant palliative training programme for cancer treatment centres in India



The Q&CAB, which was setup in December 2020, meets six times a year. At each meeting, a particular PALCARE zonal team (on rotational basis) presents a case study. Under the Chairmanship of Dr. Akhileswaran, the board reviews the presentation, which is pre-circulated to the members of the Committee prior to the meeting, with each member then providing his/her perspective, clinical pearls and advice on what was handled well and what could have been handled differently.



The Quality and Clinical Advisory Board in session via Zoom

PATIENT DATA

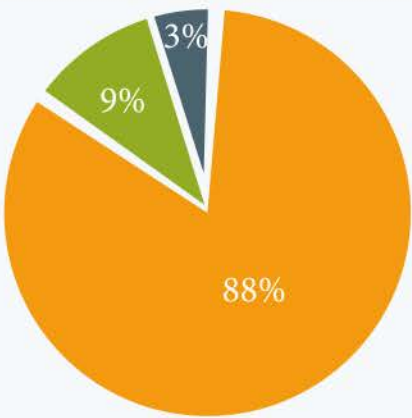
Each month PALCARE monitors the number of patients enrolled by the organization. Here are a few of the charts.

PALCARE - Comparison of New Enrolments and Unique Patients Year upon Year																
New Enrolments	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Total	Carried over from previous year	Total in our care- Unique Patients	
2021-22	21	30	36	27	46	36	59	50	53	32	53	60	503	124	627	
2020-21 (pandemic year)	7	10	9	16	12	18	46	22	11	26	41	41	259	118	377	
2019-20	31	27	29	39	40	32	44	34	42	38	29	32	417	100	517	
2018-19	19	35	37	38	34	38	37	28	30	30	22	24	372	91	463	
2017-18	14	6	13	24	15	15	17	25	24	31	32	36	252	41	293	
2016-17	19	25	23	13	13	2	14	11	9	10	9	12	160	33	193	
2015-16									15	21	9	16	61		61	

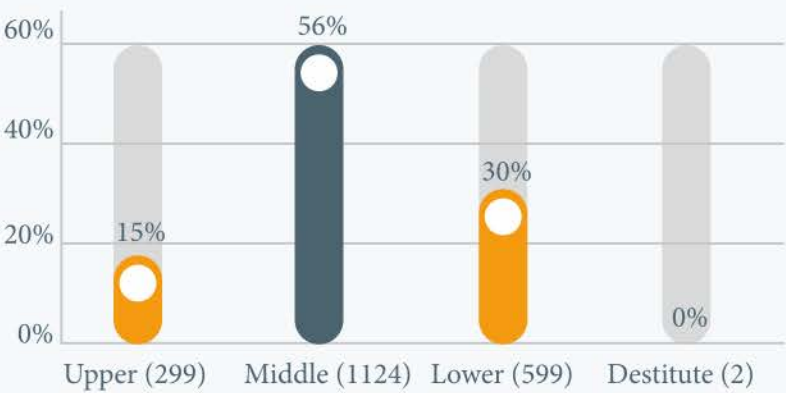
Data for 76 months from the start of the service to 31 March 2022

TOTAL NUMBER OF PATIENTS-2024

- Demises (1775)
- In Our Care (179)
- Discharged (70)

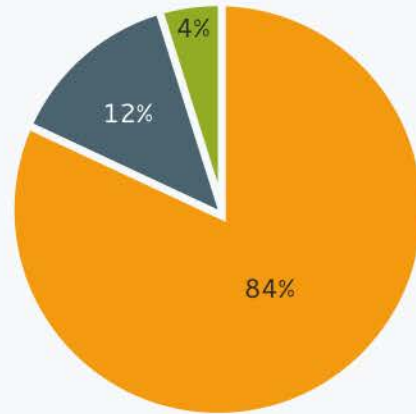


BY ECONOMIC STATUS 2024 PATIENTS



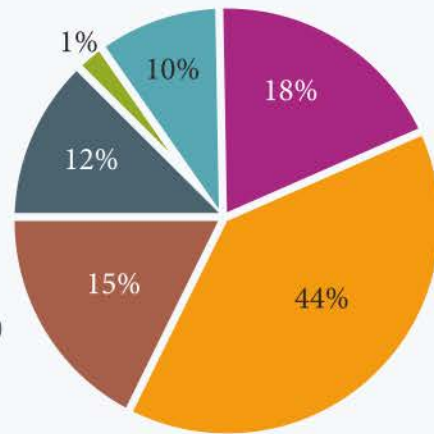
PLACE OF DEATH PATIENTS - 1775

- Home (1488)
- Hospital (216)
- Hospice (71)

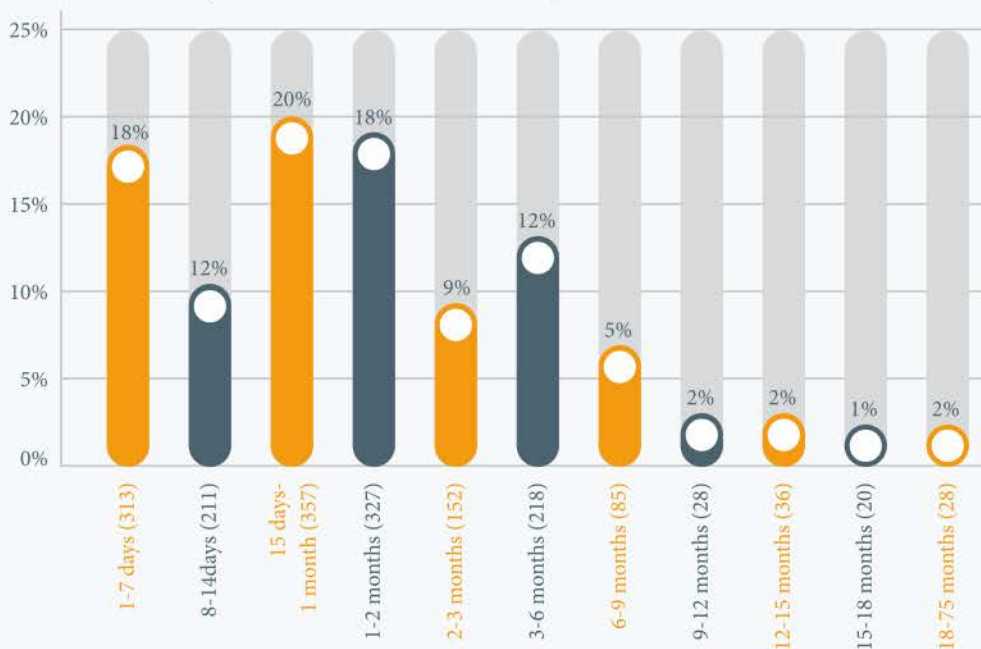


PATIENTS BY REFERRALS 2024 PATIENTS

- DOCTORS (367)
- TMH (899)
- HOSPITALS (299)
- PATIENTS/PATIENT FAMILIES (235)
- ALL OTHERS (198)
- SOCIAL MEDIA (26)



NUMBER OF DAYS WITH PALCARE (DEMISED PATIENTS) - 1775 PATIENTS



FINANCIALS

SUMMARY INCOME			
<i>fig.in INR</i>			
Particulars	Audited	Audited 2020-21	Audited 2021-22
	2019-20		
Donations received	109,98,115	98,58,222	68,51,812
Grants received	64,78,970	34,64,618	60,62,001
Interest earned on Investments	45,77,459	48,46,535	46,65,979
Total	220,54,544	181,69,375	175,79,793

SUMMARY EXPENDITURE			
<i>fig.in INR</i>			
Particulars	Audited	Audited 2020-21	Audited 2021-22
	2019-20		
Salaries- Medical Team	106,93,836	115,20,747	149,58,802
Salaries - Admin/Accounts	30,21,256	29,40,302	31,45,071
Total Salaries	137,15,092	144,61,049	181,03,873
% of total costs	76%	82%	81%
Digital Software-Palcare	45,500	-	10,00,000
Computers and printers	-	81,509	71,996
Furniture & Fixtures	77,237	-	-
Total Capital Costs	1,22,737	81,509	10,71,996
	1%	0.50%	5%
Kit for Doctors and Nurses	30,332	58,715	38,511
Medicines for Patients	1,02,211	59,447	34,010
Training	36,518	8,000	2,950
Specialised courses, guest lecturers and attendance at seminars	2,04,625	54,636	16,450
Conveyance Medical Team	4,67,954	55,899	3,28,156
Communications Medical Team	24,546	16,399	26,116
Advisory Board meetings	1,13,323	-	-
Marketing expenses	2,38,629	3,36,505	1,18,040
Caregiver programme	60,480	-	-
Destress Programs	81,105	-	21,033
Digitization & Allied exps.	1,45,422	29,655	1,37,925
Medical Kit Maintenance	12,000	1,000	-
Medical Library	12,374	2,349	16,660
Total Program Cost	15,29,519	6,22,604	7,39,851
	9%	4%	3%

FINANCIALS

Particulars	Audited	Audited 2020-21	Audited 2021-22
	2019-20		
Recruitment costs	73,269	2,407	70,800
Office rent	12,80,400	13,44,432	13,61,235
Audit fees	1,71,740	2,20,630	77,880
Admin expenses	10,61,444	9,32,858	10,25,603
Total Admin Cost	25,86,853	25,00,327	25,35,518
	14%	14%	11%
Grand Total Costs	179,54,201	176,65,490	224,51,239

SUMMARY - Cost Per Patient			
Particulars	Audited	Audited 2020-21	Audited 2021-22
	2019-20		
Number of Home teams	4.5	4.5	6.5
Number of Patient visits	4,513	6,564	8,765
Average visits per patient	9	17	14
Cost per patient (INR)	34,728	46,858	35,807
Cost per team (INR)	39,89,822	39,25,664	34,54,037
Cost per visit (INR)	3,978	2,691	2,561

CREATING AWARENESS FOR PALLIATIVE CARE

With a view to spread awareness on palliative care, PALCARE engaged in the following activities:

Lumiere Torchbearer Thursday - 22nd April 2021



Our Founder Trustee, Pheroza Bilimoria was invited to be the guest speaker at Lumiere's Torchbearer Thursday event (held online because of COVID) at which she spoke to a lay audience on the principles of palliative care, its importance as the third arm of medicine, and the benefits to patient and family.

World Palliative Care Day 2021 – 9th October 2021

On the occasion of World Hospice and Palliative Care Day 2021 in October, PALCARE's senior psychologist, Devaunshi Mehta, delivered a virtual talk on the psychosocial aspects of palliative care to a large online platform of doctors. The theme in 2021 was on accelerating access of palliative care across all income groups, particularly the more financially challenged. The talk was very well received by the medical community.

As a part of the activities organized by the Mumbai Palliative Care Network, of which PALCARE is a member, PALCARE's patient Ms. Tannaz Birdy, was interviewed on Radio 1 by Hrishikesh Kannan. She praised the PALCARE service and explained how it helped her.

Activities in 2021-22

PALCARE initiated and participated in a host of activities in 2021-22. These include awareness programmes as all activities serve to boost knowledge and hone skills.

SaathSaath Helpline.

This is an initiative of CIPLA Foundation to make palliative care more easily accessible. Callers seeking guidance on how palliative care can help their loved ones, and where to find palliative care organizations across India, can call 1-800 -202-7777. For the launch of the helpline, on 7th October 2021, PALCARE's patient's caregiver, Mr. Sunil Shah provided a video clip on his and his wife's very rewarding experience with PALCARE.



PROFESSIONAL DEVELOPMENT

- As always, clinical staff continued to broaden their palliative care knowledge by participating in internal training sessions (led by senior physicians and senior nurses) and by attending external training webinars as well as conferences.
- Each zonal team held a meeting every Monday morning to prioritize active patients as low, medium or high and draw up a home visit schedule for the week.
- Team meetings continued to be held once a week for all teams via ZOOM and provided a space for the discussion of high priority cases and challenges faced so that there is a pooling of knowledge arising from individual teams' experiences.

• **GUEST SPEAKER**

10th March 2022 – Dr. Reena Sharma from CanSupport, Delhi spoke about the use of injectable Fentanyl in a palliative home setting.



• EXTERNAL CONFERENCES

5th April 2021:

PALCARE'S accountants and medical coordinator attended the Cipla Foundation's Workshop on CSR Amended Rules and Registrations led by Noshir Dadrawala from the Centre for Advancement of Philanthropy (CAP).

8th – 29th May 2021:

"Basics in Palliative Care Nursing", an online intensive three-week training course held by Tata Memorial Hospital was attended by PALCARE's newly hired nurse, Sr. Priti Jadhav.

6th August 2021–6th May 2022:

Two of PALCARE's physicians, three counsellors and our social worker participated in Pallium India's "Foundation Course in Palliative Care" that commenced in August 2021, and ran through the spring of 2022.



Foundation Course in Palliative Care

To familiarise healthcare providers with the psychosocial aspects of providing care in palliative care settings.

Eligibility: Any recognized undergraduate degree/ diploma with interest to work in the healthcare sector.

Classes Scheduled: 30 Sessions
1 session per week
Fridays

Starts on: 6 August 2021 (Friday)
Ends on: 6 May 2022 (Friday)
Class Timing: 3:00 PM - 4:30 PM

Last date to register: 23 July 2021

For more information please visit:
<https://palliumindia.org/events>
tipsecho@palliumindia.org

PALLIUM INDIA **ECHO**

24th July– 28th August 2021:

Dr. Kalpesh Jain, Dr. Santona Pal, Sr. Pratibha Sawalkar and Sr. Seema Patil participated in the "Pediatric Palliative Care Program" held by Tata Memorial Hospital. The course was designed to prepare doctors and nurses to meet the increasing demand of Pediatric Palliative Care within various health care settings.

6th August 2021:

PALCARE'S Founder Trustee, Accountant and Medical Coordinator attended a workshop organized by the NGO, Caregiver Saathi, entitled "How can family caregivers use crowd funding to raise funds for the care/treatment of their loved ones?". During the talk, Rohit Chinchani from Ketto, a popular crowd funding platform, spoke about its partnership with more than two hundred hospitals in India (including Tata Memorial Hospital) and described how organic and inorganic campaigns work to raise funds for under privileged patients.

7th, 8th, 14th, 15th, 21st & 22nd August 2021:

As part of their palliative care training, PALCARE's two newly-hired nurses completed the "Cipla's Foundation Course for Nurses in Palliative Care."

11th– 13th February 2022:

Eight PALCARE staff participated in the online 29th International Conference of the Indian Association of Palliative Care (IAPCON) 2022.



A team from PALCARE attended the Saath-Saath event bringing together patients, families and volunteers at the Annual Day at the CIPLA Palliative Care and Training Center, Warje, Pune on 29th March 2022

• INTERNAL TRAINING

A total of 38 Internal training sessions were held during the year, and these were conducted by PALCARE's senior physicians, senior psychologists and senior nurses via ZOOM.

They covered a gamut of subjects including, but not limited to, Standard Operating Procedures for the PALCARE Medical Team, Counselling Skills, Communication for Healthcare Workers, Breaking Bad News, Anti-cancer Medications, Fatigue & Asthenia, Nausea & Vomiting, Neuropathic Pain and Opioids, and so on.



PATIENT STORIES

What She Wanted To Hear

(Patient from Mainland Zone)

The reason why palliative care is so different from other medical interventions is that its care carries on well after the patient's death.

This is a story of Nalini, a young woman of 35. She lived in a one room flat in a Mumbai suburb. With her lived her children- a girl who is 20, a boy who is 5, and her mother. Her husband, who was a journalist, was abusive and an alcoholic. According to her mother, they used to have constant arguments, and one day he left Nalini and the children, and went to his native place. He got into trouble with some people, and was murdered during a scuffle sometime in 2018. Upon receiving the news of her husband's death, Nalini and the children refused to go see his body and attend his funeral, and with that the husband's family cut all ties with her.

Nalini had to raise her children and take care of the house without any help from anyone except her mother. She started to work as a house help. Soon after, she was diagnosed with an advanced stage cancer of the buccal mucosa. PALCARE enrolled her on the 2nd of March, 2022.

At the time of enrolment, Nalini was already bed bound, and was deteriorating at a substantial pace. There was a fungating wound on her right foot, a wound on her neck, second degree bedsores on her buttocks, loss of power and sensation on both her lower limbs, and immense pain. "She had a pleasant smile, and that was the

only way she managed to talk properly", recalls PALCARE's psychologist.

Nalini, and her family, except the little boy, were aware of her diagnosis and prognosis. Through all this suffering and pain, Nalini's primary concern was the education and the wellbeing of her children. She was open about it with the PALCARE team. Palliative care is team work - doctor, nurse, counsellors, and the caregivers. The team got to work, and did their best to address and manage her symptoms. They visited her frequently. Her pain was brought to substantial control although her wounds didn't heal at the time of her death, as they required more time to heal.



Diseases such as cancer are life-limiting. More often than not, the majority of the patients who come into palliative care have very limited time left. Within a week of her enrolment, Nalini started to deteriorate. It was just a matter of days now.

Meanwhile, like most of PALCARE's patients, her case was presented at PALCARE's weekly team meeting. Apart from all medical and nursing matters, the wellbeing and the education of her children were discussed too. One of our senior doctors wrote a post on the Mumbai Palliative Care Network's WhatsApp chat. In a day, a member of the network, a doctor, pledged to sponsor the education of both children. Kindness and generosity are almost rare to find in today's times, but in the line of our work, we often find these rare people. As her daughter told PALCARE, that her children's education would be taken care of, was something that Nalini very much wanted to hear before she died.

Nalini died on the 11th of March, 2022 at her home. She leaves behind her two children. With all her suffering, we are happy she could leave this world with an assurance that her children's schooling would be taken care of.



*Names have been changed for purpose of confidentiality

Beyond Cancer

(Patient from East Zone)

Dementia is an intense and difficult disease to live with. Not just for the ones suffering from it, but also for the family and caregivers.

While around 98% of patients that PALCARE enrolls have cancer, less than 2% are patients with other life limiting and serious conditions, and we are very careful of who we take into our care, not because we don't want to, but because it is

extremely important that we understand and are equipped to manage the disease and its presenting symptoms.

On the 18th of February, 2022, PALCARE enrolled Kusum, a 79 year old woman. For the last four years, Kusum has been suffering from Dementia, Alzheimer's, and Parkinson's disease. She was bed bound and her general condition was poor. She also presented symptoms of irrelevant talking, failure to recognize people,

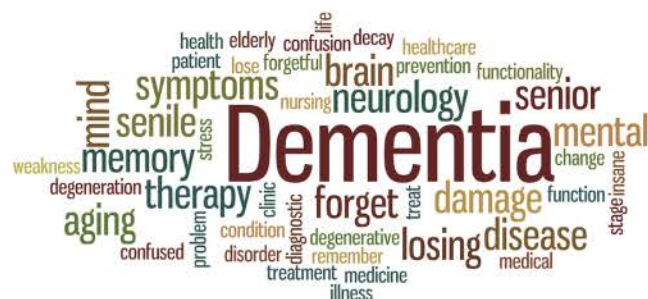
and difficulty in communication and

comprehension. But what bothered her most were the Ryle's tube and catheter, which hampered her sense of independence. Although the family wanted to keep Kusum comfortable, their idea of care clashed with her own wishes.

The PALCARE team recognised this conflict in goals of care, and immediately addressed Kusum's agitation and discomfort with the family. In their long and comprehensive sessions, they discussed Kusum's desire for independence, her wish of how she wants to live her life, and emphasized that quality of life matters more than the attempt to prolong life. With much effort, the family was convinced. Eventually, the Kusum's tube and the catheter were removed. Medications were regulated and brought down to the ones that were absolutely necessary. UTI and Urosepsis were treated with antibiotics.

What the team saw in the following visit after the enrolment was nothing less than amazing. Kusum walked herself to the living room in her bright orange night gown, and when she conversed with the team she looked cheerful. There was a spectacular change in her mood. She was happy. The family also mentioned that she

had been taking proper meals orally. Her aggression was in control and she slept well. Her overall condition was surely better. In fact, she planned to visit her village for ten days!



There is a sense of joy and contentment when we see such positive change in a patient's life. Palliative care is tough and intense, and we may not get the desired result every time with every patient due to several factors. But the one thing we know for sure is, it works, and it is necessary, for Kusum, and for thousands like her. It is this truth that keeps us motivated, to do what we do every day, which is to bring comfort to the lives of terminally ill people, so that there is dignity even in death.

*Names have been changed for purpose of confidentiality





PALCARE

There's no place like home

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