

OFFICIAL JOURNAL OF HEART CARE FOUNDATION

January-March 2023 Vol 09 Issue No: 03



**CARING**

# HEARTS

World  
Heart Day  
2022

**CARE GIVERS**

What you should know?



**WORLD  
HEART  
DAY**  
29 SEPTEMBER



**HEART CARE  
FOUNDATION**

A heart to heart affair

**LISIE**   
**HEART  
INSTITUTE**

# **HRUDAYA SANGAMAM 2022**



## **WORLD HEART DAY CELEBRATIONS**

**A Heart to Heart Affair**

**Title Sponcer**



**Society for  
Heart Failure  
and Transplantation**



**Sunday, September 25, 2022**  
**IMA House, Near JLN Stadium, Kaloor**





**Padma Shri Awardee  
Dr. Jose Chacko Periapuram  
Chairman, Heart Care Foundation**

# Chairman's MESSAGE

*Dear Friend of Heart Care Foundation,*

**A**s we welcomed the new year 2023, I also welcome all of you to the activities of the Foundation for the year 2023. After a very successful 'Heartathon' over the last world heart day, active participation in the Spice coast Marathon, multiple awareness classes and so on, the Foundation enters a new horizon of activities in 2023. These massive projects are aimed at saving lives as well as improving the life quality through education and awareness programs. Kerala is the health hub of India and at the same time the capital of health issues also.

This may be partly related to the increase's longevity, affordability and availability of health-related data.

Common non-communicable diseases causing great threat to a healthy life are diabetes, hypertension, cardio vascular diseases, cancer and lung diseases. Unless interventions are made to prevent and control non-communicable diseases, their burden is likely to increase substantially in future, due to ageing population and changes in life style.

Considering the high cost of medicines and longer duration of treatment, this constitutes a greater financial burden to low income groups. Rampant modernisation and urbanisation, drastic lifestyle changes, heavy dependency on alcohol and tobacco, affinity for white collar jobs, unhealthy eating patterns, low priority for physical exertion, high levels of stress in all strata of population are some of the reasons contributing to the prevalence of non-communicable diseases in the state.

In India, it is estimated that 42 percent of total death are due to NCDs. In Kerala, the situation is more serious as more than 52 percent of the total death between the productive age group of 30 and 59 is due to NCD. Hypertension, diabetes mellitus, cardio vascular diseases, stroke and cancer are the major non communicable diseases seen in Kerala. Sudden cardiac death also in on the ascend.

We need to focus on such factors when we design the health care reforms in future. That's where the Foundation can play a major role and is doing so currently. I urge all the friends and members of the Foundation to support the activities in the coming years too.

Thanking you

Yours sincerely

A handwritten signature in black ink, appearing to be 'JCP'.

**Dr. Jose Chacko Periapuram**  
Chairman, Heart Care Foundation



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- 03** Chairman's Message
- 05** Editor's Page
- 06** COO's Page
- 07** From the patient's point of view
- 09** Changing Demographics and care giving
- 10** Care Givers... What you should know?
- 12** World Heart Day 2022
- 14** Marathon 2022
- 16** CPR Programmes
- 18** What does end-of-life care mean for people who have Cancer?
- 22** Advise to patients with heart failure regarding SELF-CARE
- 24** 15 Things Caregivers should know after a loved one has had a stroke
- 25** CPR Awareness Session
- 26** Overcoming the Overwhelming: Understanding and Coping with Caregiver Stress
- 30** Caretakers and their Care!
- 32** We need your help...
- 35** HCF Trustees



## CARING HEARTS

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**Mr. Krishna Kumar P.**  
Chief Editor

# Editor'sPAGE

*G*iving Care or Needing Care at some stage in one's life is as certain as death itself. Some adapt to it willingly and sometimes it is forced on you. Earlier, during the days of joint families, care giving was never such an issue. Nor were those needing care so isolated and haplessly lonely. Someone, a relative, a friend, a neighbour, always does the rounds, almost daily and this human interaction is such an essential element in the wellness of any human being, especially bedridden. A few soothing or encouraging words, a genuine smile or a light caress will do wonders and make an invalid feel wanted and give them a sense of belonging.

*Today, the scenario is so cruelly different. One should feel lucky if their loved ones are living with them or near them. Even those that live together are busy in their own worlds, having so little time to care for others, even their own family and children. Can't really blame them too, the corporate work culture lives so little time for themselves or their families. What is the most common option? A home nurse from an agency wherein they take care of just the basic needs of the invalid. The so called "Nurse" is just a woman (mostly) or a man just trying to make her/his own ends meet. Added to that is the burden the family takes on to bear the demands of the "nurse".*

*I can go on and on about this because my father fell to a stroke and stayed bedridden for a long few years and we had a parade of "nurses" giving him "care" till he moved on. Were their service good, the way nursing was intended to be? Were they able to address any basic, simple health issues? Were they at least able to give a dose of insulin? Not at all! They were more of a help, just an assistance to us, a person willing to share the tedium and believe me, it was a tedious job and we were thankful for any help that was available. However loving you are, the sheer drudgery of the relentless job wears you down. When he moved on, there was profound sadness but there also was a sense of relief. Almost five years of care giving suddenly came to a thankful end!*

*Was our feeling of relief lack of love? Never! But the long suffering of a bedridden person affects the entire family who take care, wears them down and sometimes even upsets their normal rhythm of life.*

*What could be an alternative? What if a professionally managed institution with trained personals with different health care skills in attendance 24/7 is available? Will we be able to overcome the taboo of "neglecting" our loved old ones, in order to give them a better quality of care and life, without them feeling neglected? No easy answers!*

*In this edition of caring hearts, we present articles relating to care and care givers. Read on and please try to find out more about the health care industry in Kerala. Understand more about the facilities and options so that you may be able to give your elderly loved ones a relatively better health care and with the camaraderie of their contemporaries, make them feel a bit more alive and less lonely.*

**KRISHNAKUMAR**



**Mrs. Limi Rose Tom**  
People Solutionist  
& Entrepreneur

# COO'sPAGE

*"There are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need a caregiver." — Rosalyn Carter*

Human life is designed inherently for interdependence from the very first moment to the last breath. A nurse must have received most of us, as we entered this world and at the end also many have a caregiver as they leave. Care givers nurture, help us survive and thrive. It's a critical piece of puzzle sans which human life and medical care becomes impossible.

We have dedicated this issue to share thoughts and perspectives for caregivers, of caregivers and by caregivers. Caregivers might be highly trained professional like nurses or paramedical staff or semi trained caregivers who live in with a receiver if need or ordinary people who take up the role when a need arises in the family. We have all been a caregiver at least once, to our children parents or siblings, for sure. Care-giving is primarily a science and more importantly an emotional art too. Nothing needs to be elicited on caregivers' professional and functional knowledge, without which a receiver doesn't bounce back. But the emotional support they give and how they enable and empower is equally critical.

India has an estimated 10% above 60 years which is expected to grow to nearly 30% in another decade. There are other sections of the society who needs ongoing care because of medical conditions. Care giver availability, quality and support eco system has huge gaps to cover in the next one decade. States like Kerala also records of youth choosing to spend prime years abroad, which again reduces caregivers within family units also. India also has 2.2% of the population with one or the other form of disability.

Caregiver burden is the strain borne by one who looks after the needs of someone who is chronically ill or disabled. This stress can take many forms – psychological, emotional, and financial to name a few. Studies have found significant incidence of anxiety and depression in caregivers of those with disorders such as dementia. Apart from mental and emotional burden of caregiving, there are also physical health complications that can develop, like sleeping issues and high blood pressure. This is to be recognised by caregivers, receivers and institutions and supported. There are support ecosystems and groups of caregivers like that in the case of neurodivergence. Other segments may also follow suit.

At the national level government is focussing on some specific initiatives. India is home to 17.5% of the world's population and yet accounts for only 4% of the world's health expenditure. Budget proposing of setting up 157 new nursing colleges is a positive step in increasing the number of caregivers .

Heart Care Foundation, has been giving awareness to individuals who have undergone surgical procedures of the heart along with their primary caregivers. The sessions form an opportunity to engage and share stories which may help each other.

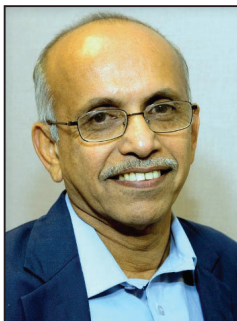
With joint efforts by government, medical institutes, care giver groups, may we have a better way to address the availability, quality, access and well being in caregiving.

*"It is not how much you do, but how much love you put in the doing." — Mother Teresa*

**LIMI ROSE TOM**



# From the patient's point of view



**Padma Shri Dr. M.R Rajagopal**  
Founder Chairman of Pallium India  
Pioneer in Palliative  
Medicine in India

A long time back...  
At my MD examination In anaesthesiology, the examiner asked me,  
“Tell me the one contraindication for morphine?”  
“Dyspnoea,” I replied.  
“Good,” said the examiner.  
That was the correct answer at that point of time.  
45 years later...  
I treated one of my medical teachers

with advanced cancer. When I saw him first, his cancer had spread to his lungs and he was on oxygen 24/7. And yet, he was significantly uncomfortable. He could not sleep for more than an hour or so at a stretch. He had discussed it with the family and elicited a promise from them that he would not be taken to hospital again. And that he would be allowed to live and die at home. His loving son, a doctor working abroad, agreed.

By the way, when facing the prospect of an incurable illness, home is where most people would like to be in if they could get medical support at home.

A doctor and nurse from Pallium India started giving him home visits and started him on tiny doses of morphine - 2.5 mgs four times a day along with other medicines. Morphine, that 45 years back, my examiner and I knew to be the one medicine to be avoided in his condition.

What had changed in the meantime was our understanding of the way morphine works and the right way of administering it. It is true that morphine can cause depression of breathing in a much higher dose at which it can be lethal like almost every other medicine.

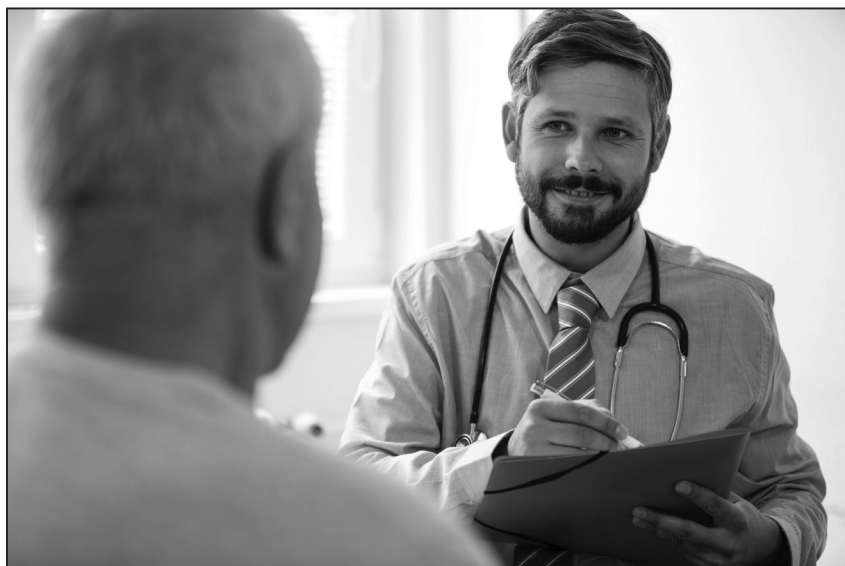
Certainly morphine has a respiratory depressant effect - it tends to work on a certain part of the brain to depress the respiration. If you give it in a much higher dose than is required, it can decrease the rate of breathing from about 12 to 18 per minute to

much lower levels. At a certain level, it becomes inadequate. Even then, remember, the patient may be rousable. If you wake the person up and ask what is wrong, the person may wake up and say ‘nothing’ and drop back to sleep. But that person could die in half an hour because the breathing gradually becomes inadequate.

But that is the effect of an overdose. In the right dose, the effect on the breathing centre in the brain is to decrease the sensation of breathlessness. It decreases the urge to breathe deeper and deeper. When you breathe very deep and hard, your breathing becomes inefficient. A person with lung disease should be taught to take slow, easy breaths – as easy as possible. Such a slower, easier breathing is precisely what a low dose morphine would achieve. I’m not going here into the physical principles of why hard breathing becomes inefficient and slow deep breathing becomes more efficient.

In the case of my medical professor, this was the effect - his breathing dropped from about 32 times to a much healthier 20 per minute. Mechanically, the breathing became more efficient. With the same effort of muscles, now, he could take in more air and thus he could get more oxygen. In two days he was off oxygen. He was not breathing as hard as he used to. And he could sleep a lot better. He did not require oxygen inhalation again for the couple of months that he lived till the very last day.

Of course, giving morphine was not the only thing that we did for him at home. He had significant body ache, the usual consequence of prolonged bed bound state. Gentle physiotherapy might have helped a little bit. But in this case, he did not tolerate it; it



made him breathless. He was also put on round the clock paracetamol at a dose of approximately 12 mg/kg, four times a day. This was important. This is such a common medication and is taken so lightly that it is seldom given at the right dose at the right time. Around 12 mg/kg is usually what is required. And if we do not exceed 15 mg/kg, it does not cause toxicity even when used for prolonged periods of time. But it is not enough to take this common medicine twice or thrice a day. When the person has a continuous ache or pain, it is required four times a day. This also improved the patient’s quality of sleep and therefore quality of life.

We also explored his emotional status when he found himself well enough to answer questions. For example, the following was a typical conversation.

“Your eyebrows are furrowed. Is something worrying you a lot?”

He did not respond. We waited. This is important. Sometimes people have to organize their thoughts. And respond when they are ready to.

“Do you think you are in depression?” I asked again.

“No,” he responded.

“Is it anxiety?”

He nodded, slowly. And after a few seconds said emphatically, “Yes. Anxious.”

“Would you like to tell us what the anxiety is about?”

“I don’t want to be taken to hospital.”

We assured him that, as his son had already promised he will be taken care of in his own home.

“Certainly no intensive care unit”, he persisted. “Will you guarantee that?”

We gave him an emphatic affirmative. We know how commonly intensive care units cause suffering at the end of life with the isolation from the family, with the constant noises and beeps, no difference between night and day, fluorescent lights being on all 24 hours.

“Is there something else that you are worried about?”

He thought for a moment and then said, “No, if you promise me that you will not take me to hospital, I can stay here at peace.”

Much later on one day he asked for Holy Communion. We facilitated this at home. Eventually he died in reasonable comfort.

There are two major points that I want



to make here.

1. That for every medicine [including morphine], there is a dose that is useful for a particular problem and a dose that can be lethal. In the case of morphine, unlike most other drugs, the dose may vary widely. With a person in respiratory distress, small doses given 4 to 5 times a day would be comforting. For someone in pain, the dose may vary very much depending on the degree of pain.

2. Someone with incurable terminal illness, very often [though not necessarily], would like to stay in a place where they feel connected, usually one's own home. It is true that this may not be always possible; but whenever possible, we should facilitate it. Such people, when they are disconnected from familiar environment where they feel connected, much too often get delirious and sometimes agitated. That would be a very sad ending.

There is growing perception of the value of palliative care integrated into healthcare in any clinical situation associated with serious health related suffering. In India, a growing body of pulmonologists, neurologists and oncologists have undergone training in palliative care with the intention of integrating it into their routine pulmonology practice. Dr. RajamIyer, a senior pulmonologist in Hinduja Hospital says, "I wish I had been exposed to palliative care earlier in my career. I now realize that though I was helping patients early in their illness, inadvertently, I was actually doing harm to many towards the end of life. Nowthat I include palliative care in my pulmonology practice, my work is satisfying even when I am unable to sustain their lives."

Such integration of palliative care, which was recommended by the World Health Assembly [decision-making body of World Health Organization] in 2014, is slowly but steadily growing in India. None of the pulmonologists, neurologists or oncologists is leaving their specialty to practice palliative care. Instead, they integrate principles of palliative care including scientific symptom control as well as emotional, social and spiritual support into their practice. Now they realize that healthcare should be more than treatment of diseases and as the World Health Organization defines it, health is physical, social and mental well-being and not merely absence of disease or infirmity.



# Changing Demographics and Care giving



**Mr. Joseph Alex**  
Managing Trustee  
Signature Aged Care

Changing demographics and aspirations of younger generation is creating newer challenges in caregiving. Caring Hearts spoke with Mr. Joseph Alex, a pioneer in this field.

*Q: Can you share about the status of geriatric care ecosystems currently?*

*A: During the days we started, existing "old age" homes and retirement homes were*

for individuals who could manage their own lives and go about with some support. These institutions just did not have the infrastructure or ecosystem to take care of a bedbound individual or someone needing a bit more of nursing assistances. Then an additional home nurse would be requested and attached to the individual. We started with professional medical care services. Now the old age and retirement homes have also begun providing basic medical care/support.

*Q: In your opinion, what is the need of the hour so far as old age homes are concerned?*

## Coverstory

We all need a perspective shift in our outlook to old age homes. There are multiple phases of a post-retirement life. One phase maybe active and independent/partially dependent. The later phase may need deeper support. We all need a shift in perspective about this phase. We all love continuing to keep our loved ones somehow in our homes and any change from the comfort zone, especially when you are already dependent, is not easy. But the fact that quality talent and support systems may not be possible in homes is a reality we must be open to accept. A "domestic support" or a "home nurse" may not be qualified to take care of all needs, and even frequent hospital visits may come into picture. But a hospice with medical support, ensure quality care, reduces hospital visits and is more practical. With Kerala slowly becoming sorta "old age hub", this is a pragmatic perspective forward.

**Q : It is estimated more than 10% of India is above 60 yrs. How good are we?**

A: Studies project that by 2031, we may have nearly 30% of India's population as senior citizens. We also find almost entire youth planning their future abroad. Most of them want to do even graduation abroad and even after that looks for employment and settling down somewhere abroad or at the max in a metro city in India. This exodus will add to a scenario and in less than ten years, every fourth person we meet would be a senior citizen.

**Q : Kerala as a state has a lot of NRK and their ageing parents back home. With outflow increasing, how do you see things shaping here?**

A : With the exodus of youth, the aged population will find it a bit tough. A generation change occurs every 15-20 years. The current generation who is ageing, values independence highly. They are a set of individuals who has travelled, has experiences, left a legacy at work places, and even has their nest eggs/ pension to fall back on. All these makes them want to be independent sans relying on their children. But at a point most of them needs some kind of an institutional support.

**Q: How do you see the future of care giving as a career opportunity, especially in Kerala?**

A : The cream of caregivers – qualified and competent ones are finding jobs abroad. Middle East, Europe etc are markets who are attractive caregivers with lucrative returns. It's a global supply led phenomenon. Shortage of caregivers is already pronounced in most of the developed geographies. People with less than 6 months of experience, but qualified have been able to land impressive jobs in care home abroad. In Kerala, all indicators tell us caregivers will be a shortage. We may never be able to match offers from abroad. Our only available pool might be those who has a relocation/ mobility constraint.

**Q: How updated are care givers about assistive technology, assistive devices, dietary and rehab systems?**

A : We have a lot of assistive elements opening up focussed at making caregiving easier. Individual home-based facilitation maybe a challenge. An institutional facilitation is pragmatic. Societies like US, Europe etc have seen all these through cycles and matured. Instructions can make this leg of life easier, all needs available and functional.

Care givers in Indian context are people who are close to the patient, who love them and put their efforts to the maximum possible for the care of the patient. They are mainly relatives of the patient who may be ignorant about the duties and responsibilities and the effects of caregiving. Caregiving is usually rewarding and only less than 25% of caregivers have negative effect of it. Several studies show that the burden of care giving is reduced overtime. Therefore the consequences of care giving need to be taught to caregivers and adequate support and encouragement can help the caregivers to provide the optimum care to the patient. Caregivers 'stress is a term defined from the psychological problems related to the negative consequences of care giving but now a broader term like care givers' burden is used to define this problem.

### Risk factors

Being a female itself is identified as one of the factors that increases the stress as they are mostly emotional in doing so. Low education, social isolation, those having depression or anxiety, those with financial difficulties and duration of the care taking are the other risk factors for the negative effect of the care givers, especially in people who are lacking coping skills. Moreover if there are any health issues in the care giver, the stress will further deteriorate the health of the care givers. Caring of the loved ones are stressful even for the most resilient people .

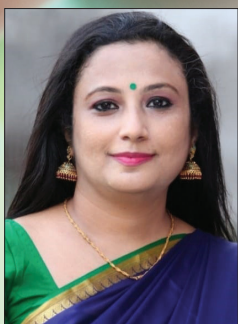
### Consequences of caregivers' burden

It can affect both care giver and the



# CARE GIVERS...

## WHAT YOU SHOULD KNOW?



**Dr Elsie Oommen,**  
Consultant Psychiatrist,  
Medical Trust Hospital, Kochi

care recipient. Most negative effects are reduced levels and provisions of care giving, decrease in quality of life and physical and psychological health deterioration.

### How to cope?

Coping mechanisms to reduce the stress have to be advised to the long term care givers. Most of them may need a financial assistance which should be taken care by the society and the government. Conflict between the carer and care giving responsibilities and family needs places higher levels of burden on the care giver. So managing care givers 'burden is self, institutional and societal. Heart foundation is actually meant for this purpose as an institutional interven-

tion. It gives support to the caregivers and tips for the proper care giving.

### Here are some of the tips to manage stress of the caregivers

First of all accept all sort of helps that is possible to improve the efficacy of caregiving. Enlist the ways others can help you. Friends and relatives can support you by relieving a day or two, shop for you, cook for you, or can give financial aids etc. Government should understand and act benevolently to the caregivers of chronically ill patients. Social organisation can also help in a similar fashion. Panchayats can identify the needy and support them.

Get connected. Although you are stuck at hospital or home with caregiving, you should be well connected with the society and family through phone and visual medias. You can also seek help with various apps for shopping medicines, food delivery, house keeping etc.

Join a support group of similar people which can be a great help with the encouragement and practical tips. Ex-

perience sharing with understanding people can solve multiple problems.

Set realistic goals and focus on what you are able to provide. Large task can be broken into smallest steps, prioritise the task and learn to say "No" to the requests that are draining you.

Do your best and don't feel guilty.

Set up personal health goals like sleeping, exercises, food habits etc. Do not postpone your appointment with your doctors or medicines.

Have a break, if someone is there to take care of your loved ones for getting yourself recharged.

Don't hesitate to take professional help. If you feel anxious or depressed which cannot be relieved by self techniques.

Taking care of your loved ones is the best thing you can give back to them. But that doesn't mean that you should burn out. There is always a balance which you should find out by yourself according to the situation and be ready to seek help from others whenever necessary. ■■

# World Heart Day 2022

World Heart Day 2022 was observed with a host of meaningful campaigns this year by Heart Care Foundation.

The week long campaign was kicked off on 23 September 2022 with an All Kerala Bicycle Ride in partnership with Muziris Cycle Club. The Ride, led by Dr. Jo Joseph, Trustee HCF, was done in two legs, one starting from North and second South. The group of cyclists covered \$\$ hospitals and did sessions on CPR and heart health. One of the teams had a unique opportunity to do CPR on one person and save his life. The cyclists reached

IMA House on 25 September 2023 and was received by Shri. Jayasurya, who spoke on the relevance and impact of such an initiative.

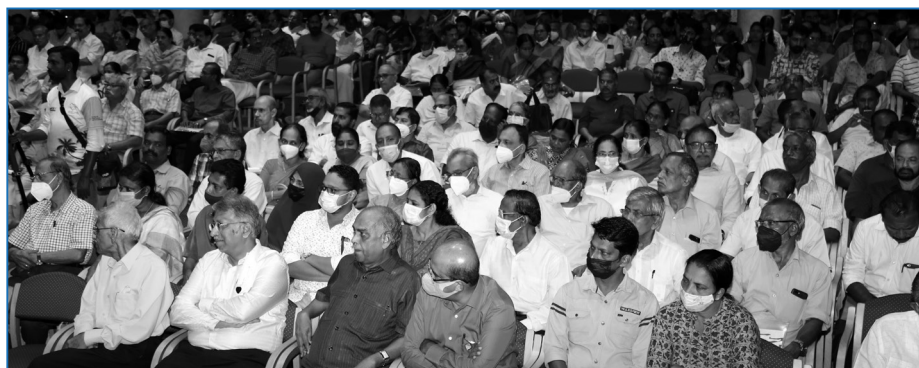
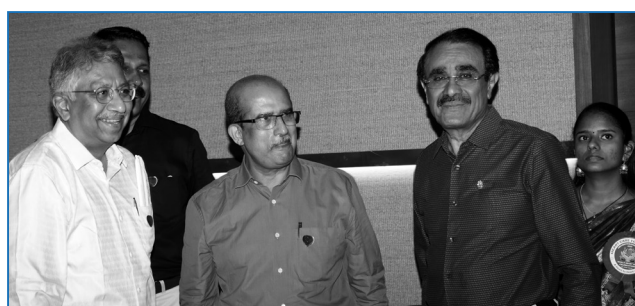
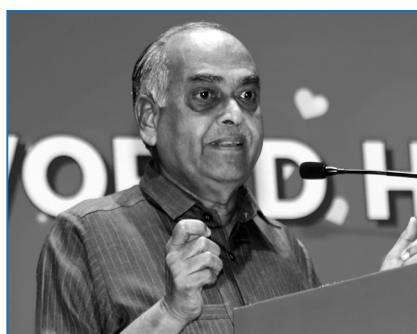
The technical event started with a session on Heart Health which was attended by individuals who have undergone some surgical procedures, along with their family. This was followed by a talk on healthy diet.

The formal finale was inaugurated by Honorable Mr. Justice Cyriac Joseph, Lokayukta Kerala, presided by Dr. Jose C Periappuram, Chairman HCF, joined by Mr. Bindu Madhav, Chairman Bhima Jewels, the Princi-

pal Sponsor of Heartathon, Dr. Jacob Abraham - Trustee HCF & Chief Cardiac Anesthetist, Lisie Heart Institute, Dr. Rony Mathew Kadavil, HOD, Cardiology, Lisie Hospital and Mr. Raju Kannampuzha - Secretary HCF.

The formal event was followed by a panel discussion comprising of Cardiologists, a Surgeon, a Physio and a Dietician, which answered questions from attendees.

On the World Heart day, 29 September, HCF organized a CPR hands on training at Vytila Mobility Hub, which saw 200 plus travelers, staff and bus drivers taking hands on CPR lessons.











# Marathon 2022

Heart Care Foundation volunteers pledged to run the Spice Coast Marathon 2022, on 4 December at Kochi, championing the cause of Organ Donation. The 198 strong HCF team won the Corporate Challenge for the biggest group, in the 5 KM fun run event. The star attraction was Dinoy, who ran successfully with a recipient heart! The Marathon was flagged off by none other than Master Blaster Sachin Tendulkar. At the valedictory event HCF leaders along with Dinoy was felicitated. Sachin autographed Dinoy's jersey and posted in his FB page about the same. This is a big testimony and a happy occasion for all volunteers who supported this run and its cause. Sachin remarked on how inspiring Dinoy's run was. We are planning to take up this thought to create awareness that after being a transplant recipient, one need not limit life! Dinoy's also gearing to go further and be a beacon of that message in the year to come..









# CPR PROGRAMMES

April 2<sup>nd</sup> Saturday 2022 at Lulu Mall – Kochi

In connection with World Health Day – 2022, The Heart Care Foundation in association with Basic Responders and lulu Mall, Kochi conducted a session on Cardio Pulmonary Resuscitation programme. The session conducted at 4 pm Saturday 2nd April 2022, at the main atrium of the lulu shopping mall Kochi.

The proceedings of the first session began with the Welcome/Introduction address by Dr. Jose Chacko Periappuram Chairman, Heart Care Foundation. And was followed by Mr Shibu Philip Lulu mall Business Head, welcomed

the audience and spoke about the CPR facilities at Lulu shopping mall.

Then Dr Jacob Abraham Trustee, Heart Care Foundation detailed presentation about CPR, what is CPR? And how to do it? After his session this was followed by the presentation by Dr Jo Joseph. In his presentation he touched upon the functions of heart, the diseases affecting the heart, and the methods to prevent the disease.

Then Mr. Kiran N M Director of Basic Responder trained all participants during the occasion. Around

300 more than participants attend the training programme. Mr. Linu and his band entertained the crowd at lulu with some hit numbers. After the music session the floor was open for a quiz programme.

The programme was conducted by Mr. Krishna Kumar, Chief Editor Heart Care Foundation. In that time Mr. Stephan Pascal Programme Co-ordinator distribute brochure and membership form who attended the programme. The event ended at 7 pm and Ms. Limi thanked everyone who attended.





## October 29, 2022 at North Railway Station Ernakulum

The Awareness class and about Basic Life Support-CPR conducted for the staff and a porter of North Railway Station Ernakulum was led by Dr. Jo Joseph (Trustee HCF). Dr. Jo Joseph gave a brief on Heart Care Foundation and its projects before making a detailed presentation on CPR. The session was well attended by over 80 participants. During the



class Doctor narrated real life incidents on the use of CPR and thereby conveyed the need of knowing these skills to the participants.

Doctor took time to answer all

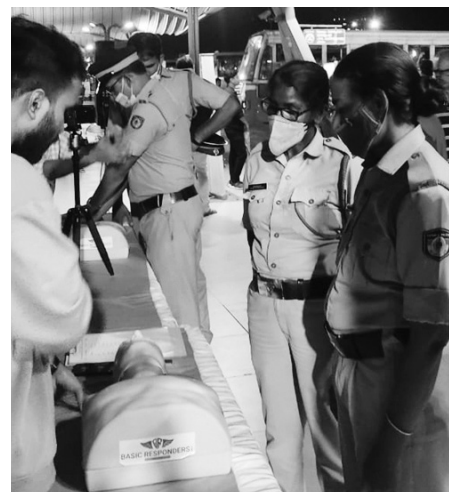
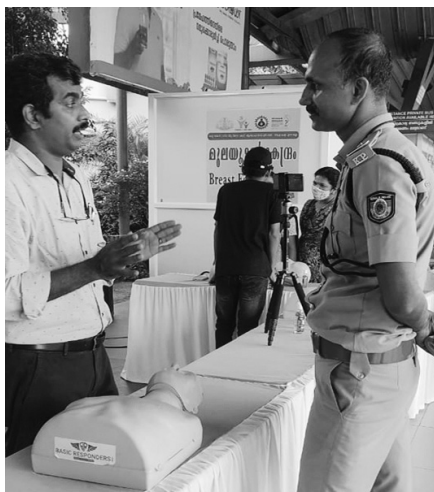


the queries of the participants and allowed some participants to have a feel of the real time operation by using the mannequins for demonstra-

tion. The session was very lively with participants actively asking questions on various aspects of CPR.

## September 29, 2022 at Vytilla Mobility-Hub

In connection with World Heart Day –September 29, 2022, The Heart Care Foundation in association with Basic Responders conducted a session on Cardio Pulmonary Resuscitation programme. The session started at 2 pm. The proceedings of the first session began with the Welcome/Introduction address by Ms. Limi Rose Tom COO Heart Care Foundation. Dr. Jo Joseph. In his presentation he touched upon the functions of heart, the diseases affecting the heart, and the methods to prevent the disease. Then Mr. Kiran N M Director of Basic Responder trained all participants during the occasion. Around 250 more than participants attend the training programme.



# What does end-of-life care mean for people who have Cancer?



**W**hen a person's health care team determines that the cancer can no longer be controlled, medical testing and cancer treatment often stop. But the person's care continues, with an emphasis on improving their quality of life and that of their loved ones, and making them comfortable for the following weeks or months.

Medicines and treatments people receive at the end of life can control pain and other symptoms, such as constipation, nausea, and shortness of breath. Some people remain at home while receiving these treatments, whereas others enter a hospital or other facility. Either way, services are available to help patients and their families with the medical, psychological, social, and spiritual issues around dying. Hospice programs are the most comprehensive and coordinated providers of these services.

The period at the end of life is dif-

ferent for each person. The signs and symptoms people have may vary as their illness continues, and each person has unique needs for information and support. Questions and concerns that family members have about the end of life should be discussed with each other, as well as with the health care team, as they arise.

Communication about end-of-life care and decision-making during the final months of a person's life are very important. Research has shown that if a person who has advanced cancer discusses their options for care with a doctor early on, that person's level of stress decreases and their ability to cope with illness increases. Studies also show that patients prefer an open and honest conversation with their doctor about choices for end-of-life care early in the course of their disease and are more satisfied when they have this talk.

Experts strongly encourage patients

to complete advance directives, which are documents stating a person's wishes for care. They also designate who the patient chooses as the decision-maker for their care when they are unable to decide. It's important for people with cancer to have these decisions made before they become too sick to make them. However, if a person does become too sick before they have completed an advance directive, it's helpful for family caregivers to know what type of care their loved one would want to receive. More information about advance directives can be found below in the Related Resources section of this fact sheet.

## How do doctors know how long a person will continue to live?

Patients and their family members often want to know how long a person who has cancer will continue to live. It's normal to want to be prepared for the future. But predicting how long someone will continue to live is a hard question to answer. A number of factors, including the type of cancer, its location, and whether the patient has other illnesses, can affect what will happen.

Although doctors may be able to estimate the amount of time someone will continue to live based on what they know about that person, they might be hesitant to do so. They may be concerned about over- or underestimating the person's remaining life span. They also might be fearful of giving false hope or destroying a person's will to live.

## When should someone call for professional help if they're caring for a person with cancer at home?

People caring for patients at home should ask them if they're comfortable, if they feel any pain, and if

they're having any other physical problems.

There may be times when the caregiver needs assistance from the patient's health care team. A caregiver can contact the patient's doctor or nurse for help in any of the following situations:

- The patient is in pain that is not relieved by the prescribed dose of pain medication.
- The patient is experiencing onset of new symptoms, such as nausea, vomiting, increasing confusion, anxiety, or restlessness.
- The patient is experiencing symptoms that were previously well controlled.
- The patient shows discomfort, such as by grimacing or moaning.
- The patient is having trouble breathing and seems upset.
- The patient is unable to urinate or empty the bowels.
- The patient has fallen.
- The patient is very depressed or talking about suicide.
- The caregiver has difficulty giving medicines to the patient.
- The caregiver is overwhelmed by caring for the patient, is too sad, or is afraid to be with the patient.
- The caregiver doesn't know how to handle a certain situation.

Keep in mind that palliative care experts can be called upon by the patient's physician at any point in the person's illness to help with these

issues. They are increasingly available not only in the hospital, but also in the outpatient setting.

### **When is the right time to use hospice care?**

Many people believe that hospice care is only appropriate in the last days or weeks of life.

Research has shown that patients and families who use hospice services report a higher quality of life than those who don't. Hospice care offers many helpful services, including medical care, counseling, and respite care. People usually qualify for hospice when their doctor signs a statement saying that patients with their type and stage of disease, on average, aren't likely to survive beyond 6 months. More information about hospice can be found below in the Related Resources section of this fact sheet.

### **What are some ways to provide emotional support to a person who is living with and dying of cancer?**

Everyone has different needs, but some worries are common to most dying patients. Two of these concerns are fear of abandonment and fear of being a burden. People who are dying also have concerns about loss of dignity and loss of control. Some ways caregivers can provide comfort to a person with these worries are listed below:

- Keep the person company. Talk,

watch movies, read, or just be with them.

- Allow the person to express fears and concerns about dying, such as leaving family and friends behind. Be prepared to listen.
- Be willing to reminisce about the person's life.
- Avoid withholding difficult information. Most patients prefer to be included in discussions about issues that concern them.
- Reassure the patient that you will honor advance directives, such as living wills.
- Ask if there is anything you can do.
- Respect the person's need for privacy.
- Support the person's spirituality. Let them talk about what has meaning for them, pray with them if they'd like, and arrange visits by spiritual leaders and church members, if appropriate. Keep objects that are meaningful to the person close at hand.

### **What other issues should caregivers be aware of?**

It's just as important for caregivers to take care of their own health at this time. Family and caregivers are affected by their loved one's health more than they realize. Taking care of a sick person often causes physical and emotional fatigue, stress, depression, and anxiety. Because of this, it's important for caregivers to take care of their own body, mind, and spirit. Helping themselves will give them more energy, help them cope with stress, and cause them to be better caregivers as a result.

It's also helpful if caregivers ask for support from friends and family members. Such help is important to help lessen the many tasks involved in taking care of a loved one who is sick or dying.

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## What are some topics patients and family members can talk about?

For many people, it's hard to know what to say to someone at the end of life. It's normal to want to be upbeat and positive, rather than talk about death. And yet, it's important to be realistic about how sick the person may be. Caregivers can encourage their loved one without giving false hope. Although it can be a time for grieving and accepting loss, the end of life can also be a time for looking for meaning and rethinking what's important.

During this period, many people tend to look back and reflect on life, legacies created, and loved ones who will be left behind. Some questions to explore with a patient at the end of life are the following:

- What are the happiest and saddest times we have shared together?
- What are the defining or most important moments of our life together?
- What are we most proud of?
- What have we taught each other?

Patients with serious, life-threatening illness have stated that being positive or adding humor remains an important outlet for them. Even at this challenging moment, laughter may still be the best medicine.

## How should caregivers talk to children about a family member's advanced cancer?

Children deserve to be told the truth

about a family member's prognosis so they can be prepared if their loved one dies. It's important to answer all of their questions gently and honestly so they don't imagine things that are worse than reality. They need to be reassured that they will be taken care of no matter what happens.

Caregivers need to be prepared to answer tough questions. To do this, they should know what their own feelings and thoughts are about the situation. They need to be able to show children how to hope for the best while preparing for and accepting that their loved one may die.

## How does cancer cause death?

Every patient is different, and the way cancer causes death varies. The process can depend on the type of cancer, where it is in the body, and how fast it's growing.

For some people, the cancer can't be controlled anymore and spreads to healthy tissues and organs. Cancer cells take up the needed space and nutrients that the healthy organs would use. As a result, the healthy organs can no longer function. For other people, complications from treatment can cause death.

During the final stages of cancer, problems may occur in several parts of the body.

- Digestive system: If cancer is in the digestive system (e.g., stomach, pancreas, or colon), food or waste

may not be able to pass through, causing bloating, nausea, or vomiting. If the cancer prevents food from being digested or absorbed, patients can also become malnourished.

- Lungs: If too little healthy lung tissue is left, or if cancer blocks off part of the lung, the person may have trouble breathing and getting enough oxygen. Or, if the lung collapses, it may become infected, which may be too hard for someone with advanced cancer to fight.

- Bones: If cancer is in the bones, too much calcium may go into the bloodstream, which can cause unconsciousness and death. Bones with tumors may also break and not heal.

- Liver: The liver removes toxins from the blood, helps digest food, and converts food into substances needed to live. If there isn't enough healthy liver tissue, the body's chemical balance is upset. The person may eventually go into a coma.

- Bone marrow: When cancer is in the bone marrow, the body can't make enough healthy blood cells. A low red blood cell count will cause anemia, and the body won't have enough oxygen in the blood. A low white blood cell count will make it hard to fight infection. And a drop in platelets will prevent the blood from clotting, making it hard to control abnormal bleeding.

- Brain: A large tumor in the brain may cause memory problems, balance problems, bleeding in the brain, or loss of function in another body part, which may eventually lead to a coma. In some cases, the exact cause can't be pinpointed and patients simply decline slowly, becoming weaker and weaker until they succumb to the cancer.

Again, every patient is different and all processes have different stages

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and rates in which they advance. And some conditions have treatments that can help slow the process or make the patient more comfortable. It's very important to keep having conversations with the patient's health care team.

### **What are the signs that death is approaching, and what can the caregiver do to make the person comfortable during this time?**

Certain signs and symptoms can help a caregiver anticipate when death is near. They are described below, along with suggestions for managing them. However, each person's experience at the end of life is different. What may happen to one person may not happen for another. Also, the presence of one or more of these symptoms doesn't necessarily mean that the patient is close to death. A member of the health care team can give family members and caregivers more information about what to expect.

#### **Withdrawal from friends and family:**

- People often focus inward during the last weeks of life. This doesn't necessarily mean that patients are angry or depressed or that they don't love their caregivers. It could be caused by decreased oxygen to the brain, decreased blood flow, or mental preparation for dying.
- They may lose interest in things they used to enjoy, such as favorite TV shows, friends, or pets.
- Caregivers can let the patient know they are there for support. The person may be aware and able to hear, even if they are unable to respond. Experts advise that giving them permission to "let go" may be helpful. If they do feel like talking, they may want to reminisce about joys and sorrows, or tie up loose ends.



#### **Sleep changes:**

- People may have drowsiness, increased sleep, intermittent sleep, or confusion when they first wake up.
- Worries or concerns may keep patients up at night. Caregivers can ask them if they would like to sit in the room with them while they fall asleep.
- Patients may sleep more and more as time passes. Caregivers should continue to talk to them, even if they're unconscious, for the patient may still hear them.

#### **Hard-to-control pain:**

- It may become harder to control pain as the cancer gets worse. It's important to provide pain medication regularly. Caregivers should ask to see a palliative care doctor or a pain specialist for advice on the correct medicines and doses. It may be helpful to explore other pain control methods such as massage and relaxation techniques.

#### **Increasing weakness:**

- Weakness and fatigue will increase over time. The patient may have good days and bad days, so they may need more help with daily personal care and getting around.
- Caregivers can help patients save energy for the things that are most important to them.

#### **Appetite changes:**

- As the body naturally shuts down, the person with cancer will often

need and want less food. The loss of appetite is caused by the body's need to conserve energy and its decreasing ability to use food and fluids properly.

- Patients should be allowed to choose whether and when to eat or drink. Caregivers can offer small amounts of the foods the patient enjoys. Since chewing takes energy, they may prefer milkshakes, ice cream, or pudding. If the patient doesn't have trouble with swallowing, offer sips of fluids and use a flexible straw if they can't sit up. If a person can no longer swallow, offer ice chips. Keep their lips moist with lip balm and their mouth clean with a soft, damp cloth.

#### **Awareness:**

- Near the end of life, people often have episodes of confusion or waking dreams. They may get confused about time, place, and the identity of loved ones. Caregivers can gently remind patients where they are and who is with them. They should be calm and reassuring. But if the patient is agitated, they should not attempt to restrain them. Let the health care providers know if significant agitation occurs, as there are treatments available to help control or reverse it.
- Sometimes patients report seeing or speaking with loved ones who have died. They may talk about going on a trip, seeing lights, butterflies, or other symbols of reality we can't see. As

## Coverstory

long as these things aren't disturbing to the patient, caregivers can ask them to say more. They can let them share their visions and dreams, not trying to talk them out of what they believe they see.

The dying process:

- There may be a loss of bladder or bowel control due to the muscles relaxing in the pelvis. Caregivers should continue to provide clean, dry bedding and gentle personal care. They can place disposable pads on the bed under the patient and remove them when soiled. Also, due to a slowing of kidney function or decreased fluid intake, there may be a decrease in the amount of urine. It may be dark and smell strong.

- Breathing patterns may become slower or faster, in cycles. The patient may not notice, but caregivers should let the doctor know if they are worried about the changes. There may be rattling or gurgling sounds that are caused by saliva and fluids collecting in the throat and upper airways. Although this can be very disturbing for caregivers, at this stage the patient is generally not experiencing any distress. Breathing may be easier if a person's body is turned to the side and pillows are placed behind the back and beneath the head. Caregivers can also ask the health care team about using a humidifier or external source of oxygen to make it easier for the patient to breathe, if the patient is short of breath.

- Skin may become bluish in color and feel cool as blood flow slows down. This is not painful or uncomfortable for the patient. Caregivers should avoid warming the patient with electric blankets or heating pads, which can cause burns. However, they may keep the patient covered with a

light blanket.

### What are the signs that the person has died?

- The person is no longer breathing and doesn't have a pulse.
- Their eyes don't move or blink, and the pupils are dilated (enlarged). The eyelids may be slightly open.
- The jaw is relaxed and the mouth is slightly open.
- The body releases the bowel and bladder contents.
- The person doesn't respond to being touched or spoken to.
- The person's skin is very pale and cool to the touch.

### What needs to be done after the person has died?

After the person has died, there is no need to hurry with arrangements. Family members and caregivers may wish to sit with the body, to talk, or to pray. When the family is ready, the following steps can be taken.

- Place the body on its back with one pillow under the head. If necessary, caregivers or family members may wish to put the person's dentures or other artificial parts in place.
- If the person is in a hospice program, follow the guidelines provided by the program. A caregiver or family member can request a hospice nurse to verify the death.
- Contact the appropriate authorities in accordance with local regulations. Contact the person's doctor and funeral home.
- When the patient's family members are ready, call other family members, friends, and clergy.

Provide or obtain emotional support for family members and friends to cope with their loss.



**Dr. Jo Joseph**  
Consultant Cardiologist  
Lisie Hospitals

## Maintain optimal nutritional status

If you have a body mass index >35 kg/m<sup>2</sup> consider weight reduction since this might improve your functional capacity and quality of life. Please consult a dietician if possible. The general recommendation is to promote healthy lifestyle and weight loss, preferring plant-based food (fruit, vegetable, seeds, nut, legumes, whole grain cereals) over animal-based, processed foods and added sugar. Among animal-based aliments, fish and fermented dairy should be preferred over meat, minimizing the intake of red meat.

Unintentional weight loss may be a sign of deteriorating heart failure and impending cachexia and should be brought to your health care providers' attention.

Avoid excess of salt intake, that is keep <5 g a day (just under a teaspoon). This can be done by not adding salt during the preparation of food; not having a saltshaker on the table; limiting the consumption of salty snacks and choosing products with lower sodium content.

Avoid large amounts of fluid intake. Adapt fluid intake in times of high heat and humidity, nausea/vomiting.

Limit alcohol intake to two units of



alcohol per day if you are a man and one unit if you are a woman, or no intake if alcohol has caused or contributed to your heart failure.

In case of nutrient or vitamin deficiencies, supplementation may be considered, but there is no clear role for routine micronutrient supplementation. Some 'natural' or herbal supplements may interact with medication or might be high in potassium. Seek advice from the heart failure team before considering their use.

If you have recurrent hyperkalaemia (high potassium level), the amount of potassium-containing foods and supplements should be limited.

### **Optimize exercise tolerance**

Undertake daily and regular exercise and be physically active, such as walking, cycling, swimming, jogging, rowing or light weight exercise

Ask your heart failure team for advice if you have questions regarding whether it is safe to exercise, and which exercises suit you best.

Adapt physical activity to your symptoms and personal preferences.

If possible, undertake regular exercise at a level sufficient to provoke mild or moderate breathlessness. Extreme athleticism should be avoided.

### **Sexual activity**

If your heart failure is stable, be reassured about engaging in sex, provided sexual activity does not provoke undue symptoms. If erectile dysfunction is a problem, ask for advice on possible treatment.

### **Medication taking**

Try to engage in the management of your medication, understand the rationale, benefits and potential adverse effects of medical therapy.

# Advise to patients with heart failure regarding

## SELF-CARE

If preferred, encourage a family member to join you when your medicines are discussed.

Discuss with your health care provider(s) anything that is hindering you from taking your medicines.

Consider use of tools/aids to help remind you to take your tablets, such as a dosette box, electronic reminders, phone cues, etc.

When starting heart failure medication, you may temporarily feel fatigue or tiredness; this is common, and is usually resolved after a few weeks.

Because several heart failure medicines can cause dizziness, spacing individual drugs out at different times throughout the day may help. In case of dizziness, it can help to elevate your legs or stand up slowly.

To limit disturbance of daily life caused by diuretics consider taking diuretics in the morning or up to lunchtime.

Let your health care provider know if you think you are having a side effect.

### **Optimize psychological status**

Try to recognize concerns and worries

and try to ask for help.

Consider attending support groups to where patients can exchange views and understandings.

Consider talking to family and friends, or a health care provider about your concerns/worries.

Try to be physically active, even when you feel down.

### **Optimize sleep**

Be aware that good sleep promotes health.

Insomnia is common and if it occurs, begin with 'sleep hygiene' activities such as avoiding caffeine late in the day.

Consider doing relaxing activities before sleep. Yoga and mindfulness in the evening can improve sleep, as can a short walk outside. Consider avoiding TV, mobile phone, or computer use in the last hour before sleep.

Consult your health care provider if you need to use more pillows at night due to shortness of breath (orthopnoea), suffer from recurrent awakening during the night (paroxysmal nocturnal dyspnoea), or experience sleep apnoea.



# 15 Things Caregivers should know after a loved one has had a stroke

These 15 tips can help you identify and handle common issues as you care for your loved one with stroke.

1. It's better to find out than miss out. Be aware of your loved one's medications and their side effects. Find out if your home should be modified to meet the needs of the stroke survivor. Ask a doctor, nurse or therapist to answer your questions about what to expect.
2. Reduce risks, or stroke may strike again. Survivors are at high

risk of having another stroke.

Make sure your loved one eats a healthy diet, exercises, takes medications as prescribed and visits their healthcare provider regularly.

3. Many factors influence recovery: where in the brain the stroke occurred; how much of the brain was affected, the survivor's motivation; caregiver support; the quantity and quality of rehabilitation; and the survivor's health before the stroke.
4. Gains can happen quickly or over time. The most rapid recovery usually occurs during the first three to four months after a stroke, but some survivors continue to recover well into the first and second year after their stroke.
5. Some signs point to physical

therapy. Caregivers should consider assistance from a physical or occupational therapist if their loved one has: dizziness; imbalance that results in falls; difficulty walking or moving around daily; inability to walk six minutes without stopping to rest; inability to participate in or complete daily activities.

6. Don't ignore falls. Falls after stroke are common. If a fall is serious and results in severe pain, bruising or bleeding, take your loved one to the emergency room. If your loved one has minor falls more than two times within six months, see your physician or physical therapist for treatment.
7. Measuring progress matters. How much acute rehabilitation therapy your loved one receives depends

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partly on the rate of improvement. Survivors in acute rehabilitation are expected to make measurable functional gains every week based on the Functional Independence Measure Score (FIMS). Functional improvements include daily, mobility and communication skills. The typical rehabilitation expectation is improving 1-2 FIMS points per day.

8. Monitor changes in attitude and behavior. Evaluate whether your loved one is having a hard time controlling emotions. Consult a healthcare provider to develop a plan of action.
9. Stop depression before it hinders recovery. Post-stroke depression is common, with as many as 30-50 percent of stroke survivors depressed in the early or later phases of post-stroke. Post-stroke depression can significantly affect your loved one's recovery and

rehabilitation. Consult a health-care provider to develop a plan of action.

10. Seek support. Community resources, such as stroke survivor and caregiver support groups, are available for you and your loved one.
11. Learn the ins and outs of insurance coverage. Consult with your loved one's healthcare provider, case manager, social worker or insurance company to find out how much and how long insurance (private or government supported) will cover medical and rehabilitation services in and out of the hospital and to determine out-of-pocket expenses. This can vary substantially from one case to another.
12. Know when to enlist help. If rehabilitation services are denied due to lack of "medical necessity," ask your loved one's health-

care provider to provide records to the insurance carrier and, if necessary, call the insurance company.

13. Know your rights. You have access to your loved one's medical and rehabilitation records, including written notes and brain imaging films.
14. Take care of you. Take a break from caregiving by asking another family member, friend or neighbor to help while you take time for yourself. Eat healthy, exercise and get adequate rest.
15. Believe in a higher recovery As a bonus tip, know that a higher recovery is always possible. It doesn't matter how many years have passed since stroke – the brain is constantly changing throughout life. Don't give up if you think you've hit the end of the road, because you probably haven't.

## CPR Awareness Session on Heart Care Foundation for Lisie Hospital Nurses





# Overcoming the Overwhelming: Understanding and Coping with Caregiver Stress



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**“Understanding and Managing Caregiver Stress: Tips and Strategies for Coping with the Challenges of Caregiving”**

“There are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need a caregiver.” — Rosalyn Carter

A caregiver may be motivated to provide care for many reasons, by feelings of duty and responsibility as well as of guilt. Doty (1986) identified three factors underlying family caregiving motivations: love and affection, desire to reciprocate past help and societal norms. If you know the selfless, rewarding life of caring for another person, then you also know how heavy things can get. That's true whether you're a family caregiver or a caregiver working with a patient. Sometimes, just a kind word of support can help us rise above caregiver

burnout.

## **Caregiver stress: Tips for taking care of yourself**

Caring for a loved one strains even the most resilient people. If you're a caregiver, take steps to preserve your own health and well-being.

As the population ages, more caregiving is being provided by people who aren't healthcare professionals. About 1 in 3 adults in India provides care to other adults as informal caregivers.

A caregiver is anyone who provides help to another person in need, such as an ill spouse or partner, a disabled child, or an aging relative. However, family members who are actively caring for an older adult often don't self-identify as a “caregiver.” Recognizing this role can help caregivers receive the support they need.

**Caregiving is rewarding but stressful**

Caregiving can have many rewards. For most caregivers, being there when a loved one needs you is a core value and something you wish to provide.

But a shift in roles and emotions is almost certain. It is natural to feel angry, frustrated, exhausted, alone, or sad. Caregiver stress — the emotional and physical stress of caregiving — is common.

People who experience caregiver stress can be vulnerable to changes in their own health. Risk factors for caregiver stress include:

- Being female
- Having fewer years of formal education
- Living with the person you are caring for
- Social isolation
- Having depression
- Financial difficulties
- Higher number of hours spent caregiving
- Lack of coping skills and difficulty solving problems
- Lack of choice in being a caregiver

### Signs of caregiver stress

As a caregiver, you may be so focused on the loved one that you don't realize that your own health and well-being are suffering. Watch for these signs of caregiver stress:

- Feeling overwhelmed or constantly worried
- Feeling tired often
- Getting too much sleep or not enough sleep
- Gaining or losing weight
- Becoming easily irritated or angry
- Losing interest in activities you used to enjoy
- Feeling sad
- Having frequent headaches, bodily

pain or other physical problems

- Abusing alcohol or drugs, including prescription medications

Too much stress, especially over a long time, can harm your health. As a caregiver, you're more likely to experience symptoms of depression or anxiety. In addition, you may not get enough sleep or physical activity, or eat a balanced diet — which increases your risk of medical problems, such as heart disease and diabetes.

### Strategies for dealing with caregiver stress

The emotional and physical demands involved with caregiving can strain even the most resilient person. That's why it's so important to take advantage of the many resources and tools available to help you provide care for your loved one. Remember, if you don't take care of yourself, you won't be able to care for anyone else.

**Focus on what you are able to provide.** It's normal to feel guilty sometimes, but understand that no one is a "perfect" caregiver. Believe that you are doing the best you can and making the best decisions you can at any given time.

**Set realistic goals.** Break large tasks into smaller steps that you can do one at a time. Prioritize, make lists, and establish a daily routine. Begin to say no to requests that are draining, such as hosting holiday meals.

**Get connected.** Find out about caregiving resources in your community. Many communities have classes specifically about the disease your loved one is facing. Caregiving services such as transportation, meal delivery, or housekeeping may be available.

**Join a support group.** A support group can provide validation and encouragement, as well as problem-solving strategies for difficult

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### To help manage caregiver stress:

**Accept help.** Be prepared with a list of ways that others can help you, and let the helper choose what he or she would like to do. For instance, a friend may offer to take the person you care for on a walk a couple of times a week. Or a friend or family member may be able to run an errand, pick up your groceries or cook for you.

situations. People in support groups understand what you may be going through. A support group can also be a good place to create meaningful friendships.

**Seek social support.** Make an effort to stay well-connected with family and friends who can offer non-judgmental emotional support. Set aside time each week for connecting, even if it's just a walk with a friend.

**Set personal health goals.** For example, set goals to establish a good sleep routine, find time to be physically active on most days of the week, eat a healthy diet, and drink plenty of water.

**Many caregivers have issues with sleeping.** Not getting quality sleep over a long period of time can cause health issues. If you have trouble getting a good night's sleep, talk to your doctor.

**See your doctor.** Get recommended vaccinations and screenings. Make sure to tell your doctor that you're a caregiver. Don't hesitate to mention any concerns or symptoms you have.

### **Respite care**

It may be hard to imagine leaving your loved one in someone else's care, but taking a break can be one of the best things you do for yourself — as well as the person you're caring for. Most communities have some type of respite care available, such as:

**In-home respite.** Healthcare aides come to your home to provide companionship, nursing services, or both.

**Adult care centers and programs.** Some centers provide care for both older adults and young children, and the two groups may spend time together.

**Short-term nursing homes.** Some assisted living homes, memory care homes and nursing homes accept people needing care for short stays while caregivers are away.

### **The caregiver who works outside the home**

Nearly 60% of caregivers work outside of the home. If you work outside the home and you're a caregiver, you may begin to feel overwhelmed. If you do, think about taking leave from your job for a period of time.

### **You aren't alone**

If you're like many caregivers, you have a hard time asking for help. Unfortunately, this attitude can lead to feeling isolated, frustrated and even depressed.

### **Things to be done for Self-care**

#### **Taking Care of Your Physical Health**

"Family caregivers spend an average of over 24 hours a week providing care — that's more than an entire day you don't have for yourself," says Kotler-Klein.

This may lead to frequent fast-food trips, skipped workouts and less sleep. And even though it may be challenging to prioritize your own physical health, it's critical to do so to avoid problems down the road, such as heart disease and bone loss.

#### **Taking care of your physical health as a caregiver includes:**

- Eating healthy. You may want to plan meals ahead of time, cook nutritious meals for both you and your loved one, or keep some quick but healthy snacks on hand.
- Avoiding stress eating. Even if it's been a particularly hard day, resist

the urge to try to feel better by eating junk food.

- Staying active. Try taking mini exercise breaks throughout the day instead of all at once. If possible, find ways to be active with the person you're caring for.
- Getting enough sleep. Aim for at least seven to eight hours each night.
- Try to go outside every day for at least 10 minutes in the morning or mid-afternoon. Sunlight and the outdoors are powerful tools in fighting depression.
- Make time for the things you enjoy. Ask for help so that you can go to a movie, meet a friend or go shopping.

#### **Taking Care of Your Mental Health**

Caregivers often prioritize their loved ones, which can leave less time to do the things they enjoy. In fact, caregivers report that positive activities in their lives are reduced by nearly 30 percent as a result of their care-giving responsibilities.

"These responsibilities can leave you feeling overwhelmed, unhappy and isolated," adds Kotler-Klein.

Fortunately, there are ways to lessen





these negative effects of caregiving. Taking care of your mental health as a caregiver includes:

- Finding time for yourself. Set aside time for yourself every day — even if it's just 30 minutes — to read, exercise or talk with a friend.
- Asking for help from family, friends and neighbors. Ask someone you trust to stop in while you take a walk or go to the gym.
- Managing stressful moments. If you're feeling frustrated, take a few deep breaths and know when to take a couple of minutes to yourself.
- Getting support from others, such as family, friends and healthcare providers. Don't let your negative feelings fester — address them right away to keep them from getting worse.
- Learn to set boundaries.
- Say no to non-essential demands on your time.
- Find ways to make time for activities and people that are important to you. Get professional help if caregiving seems overwhelming.
- Consider joining a support group for caregivers, as well. Other caregivers' experiences may be similar to yours, and they may be able to provide you with some tips and support as you face some of the same challenges.

### **Find Ways to Help Your Loved One and Yourself**

“Being a caregiver means you have extra responsibilities on your plate, but there are ways to make them more manageable,” explains Kotler-Klein. “For example, staying organized with a daily routine or to-do list can help you prioritize what needs to be done now and what can wait.”



**Caregiving is an essential role that requires a great deal of time, energy, and emotional investment. While caregiving can be challenging and stressful, it can also be deeply rewarding and fulfilling**

don't hesitate to ask for help, either. Talk to your loved one's healthcare provider to learn ways to better and more efficient care for their needs. And if you're feeling particularly overwhelmed, ask another family member or friend to help out every once in a while.

Also, if you're financially able to, consider taking a break from your job. The Family and Medical Leave Act (FMLA) requires most employers to allow up to 12 weeks of unpaid leave each year for eligible employees to care for a relative. Check with your insurance company and the patient's insurance company to see if there are resources for caregiving, respite care or mental health services.

The person you are caring for deserves the best version of yourself — well-rested, renewed, and refreshed.

They wouldn't want you to ignore your own needs and end up physically or mentally exhausted. By noticing the signs of caregiver stress, you can stay happy and healthy while providing the care your loved one needs.

Caregiving is an essential role that requires a great deal of time, energy, and emotional investment. While caregiving can be challenging and stressful, it can also be deeply rewarding and fulfilling. It is important for caregivers to receive support to help them manage the demands of their role and maintain their own health and well-being. As a society, we must recognize and value the vital role that caregivers play and provide them with the support they need to continue providing care and support for their loved ones ■■



# Caretakers and their Care!



**Ms. Reney. M. Sebastian**  
Manager-Resident Relations  
Bless Retirement Living

For time immemorial we have always expected families as a unit to provide support to assist their older parents, grandparents, and other family members when they can no longer function independently. However, with evolving roles and

changing scenarios, the dynamics of care have changed drastically so have the roles of the caregivers. As the world progressed, specially in India; we witnessed the shift from joint family units to nuclear family system. To add further, brain drain became the new norm and all of a sudden, the foundation of care dwindled! This was never a serious concern up until recently. We witnessed many new Genz concerns of empty nest syndrome, growing numbers of anxiety, loneliness, depression and an inverted growth pyramid. Even this was negotiable, but the ultimate distress was that we do not have alternate solution for care.

In the yesteryear; care, empathy and love were words associated with womanhood. While the men found means to function, women kept the balance at home. But with changing situations, society finds it difficult to accept a working woman or an empathetic man! Even the level of care needed for elders are highly questionable. With drastic increase in the percentage of elders in the society, our system is yet to catch up with a fool proof system that could cater to their needs. Just like a new born, they have to be guided well through their golden age or the second innings.

While, the concept of old age home is

still considered a taboo or a nightmare for many, the acceptance of care homes or retirement facilities have picked up momentum. The initial aversion could be due to lack of education or awareness, or the poor service conditions of these facilities. We Indians love copying the West, and this is even reflected on the concept of care too! As we progressed, with many being educated, well enough to see the world, the idea has swept in well. Many wanted to experience life, while for some it is an escape from the thoughts of being a burden to their children. In a population where the elders have become increasingly impaired over time, such as with increasing frailty, dementia, Parkinson's disease, or advanced cancer, the caregiving role or the necessity of these facility have expanded exceptionally.

The main question when choosing a facility is always about their services offered. The relief on the faces when they know that there is 24 hours nursing support is unparalleled. The contemporary concept of hiring a home nurse is diminishing as they have lost the trust in the quality and continuity of the service. However, the transition from the comfort zone of their homes to retirement facility is not simple.

Adapting to new systems and people, locality and even food can take time. Even when the shift happens the expectation on care is as equivalent to the care they demand. This is the very reason why there is a diminishing line between professionalism and care.

Even though there are many common experience when it comes to the role of the caregivers; the trajectories can never be predetermined. Often this relationship involves numerous back and forth interaction with different stakeholders. The most daunting

**One who bears the crown, wears the crown; likewise, the person who takes up the responsibility should be committed to the individual as long as it is needed. From being a household status, caregivers are promoted to the status of a professional career**



concern of a caregiver in a facility is how to provide effective services to the residents. The complexity of this situation worsens when there is a miscommunication or a disagreement with the type of care given or the way it should have been provided. For a resident with a life threatening health condition, the constant anxiety of death indirectly puts pressure on the caregivers. These transitions along with the health status of the resident affect the social, physical, and emotional health of the caregiver over time.

One who bears the crown, wears the crown; likewise, the person who takes up the responsibility should be committed to the individual as long as it is needed. From being a household status, caregivers are promoted to the status of a professional career. Covid-19 was the biggest learning ground for many, from an undignified job pattern, caregiving just took a whole new avatar. With improved systems to cater to the elderly and their needs, the demand for the profession has doubled. Many countries even recruit their caregivers to support their

facilities. Even with many automation happening across the globe, mankind has understood that, we cannot replace care with anything else. The different verticals that they cover is the testimonial to their irreplaceable stature!

With recruiters looking into the professional qualifications of these caregivers, it is important that they undergo continuous training. As an emerging industry, availability of jobs will be become rampant. In a world that seeks white collar jobs, this emerging profession has started making rounds among people from all walks of life. The advantage of this job is that anybody can apply, but what makes you stand out is your qualifications. Though we have few academic courses that offer such certification, there is no practical exposure that they could offer. With limited number of facilities in the vicinity, it is high time the academic as well as policy makers look into options of stimulation lab or other advanced technologies to develop their skills to prepare them for a better tomorrow.





# *We need your help... Let us help those in need together...*



**D**ear Friend, since you are reading this I presume that you either are a Heart Care Foundation member or a member friend has given this to you. Either way, you are very important to this humble movement called Heart Care Foundation and we all are thankful for whatever help your valuable association can bring to the Foundation.

Let me briefly explain to you the activities of the Foundation. Founded on the World Heart Day, September 29, 2005 and inaugurated by the then Governor Sri. R.L Bhatia, HCF was able to successfully complete several projects related to heart care in Kerala. Our first project **'Save 1000 hearts, 1000 lives, 1000 families'** provided financial assistance to over 1500 needy patients from all over the state, without any discrimination in cast or creed. The next program **'Save a Life, Save a Lifetime'** launched in 2007 has been a big hit among the corporate houses, schools and colleges and we have conducted over 200 training sessions on Basic Life Support-CPR and was instrumental in the installation of AED's (Automated External Defibrillator) at many prominent public centers.

Every World Heart Day is celebrated as the inception day of Heart Care Foundation and during the very elegant official function each year, an eminent doctor,

selected by an expert panel, is awarded the Heart Care Foundation's **Lifetime Achievement Award**. Another very important activity,

**'Hrudayasangamam'** happens twice a year and its primary objective is the rehabilitation of patients who underwent heart surgery during the period. Through general Q&A with senior doctors, physiotherapists and dietitians, the patients are encouraged back in to normal life stream. Family members of the patients form an integral part of this get-together and the experience sharing as well as the general Q&A with the experts helps them realize that their loved one is no longer an invalid. Adding charm to this social gathering is our **'Social Excellence Award'** constituted in memory of our founder member Mr. C V Shanmugam. Selected by another expert panel, the awardee is an eminent personality that excelled in their respective field of activity.

Yet another project is ongoing and is unique as well as ambitious and will help a much larger populace, hopefully covering the entire state. Recently launched by Sri P.Sreeramakrishnan, Honorable Speaker, Kerala Legislative Assembly, **'Hridayapoorvam'**, is aimed at making the general public **'Heart care literate'**, panchayath by



**HEART CARE  
FOUNDATION**

panchayath. In a three phased program, people of age group 30 to 60 will be given tests at the local labs and the results will be fed in to a software program developed under the guidance of the HCF. The program will analyze the cardiac risk factor of each result and an awareness session conducted by an eminent cardiologist will make sure that everyone understands their cardiac health. Those with risks will be advised to consult their local physician and others will be given general tips to keep up a healthy, heart friendly life style. We have selected **Alangad Grama Panchayath** as the first locality for the project and response from the people as well as the government agencies has been very heartening. Hopefully, entire Kerala will soon be **Heart Care literate** in a short while.

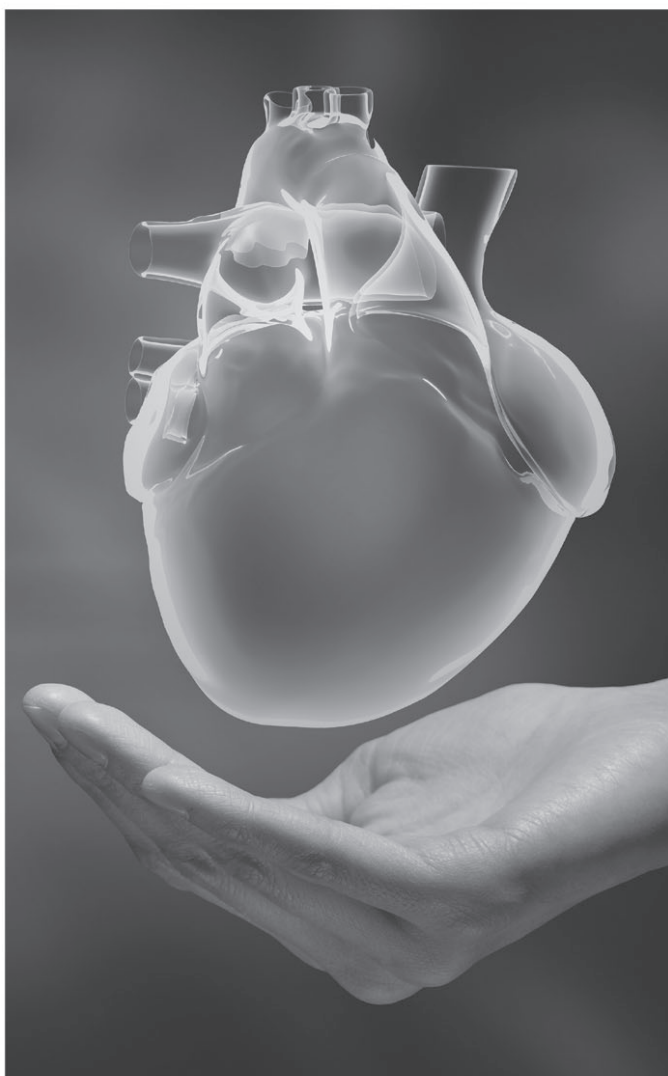
There are many ways to actively associate with Heart Care Foundation. Being a member is the first step. Please get in touch with any member or directly with the HCF office and they will guide you.

We need your help. Let us help those in need together.

Looking forward to your association,

**Dr. Jose Chacko Periappuram**  
Chairman, Heart Care Foundation

*There are many ways to actively associate with Heart Care Foundation. Being a member is the first step. Please get in touch with any member or directly with the HCF office and they will guide you*







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Our  
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