

Issue 5, 1st July 2020

Can Cure is the Nag Foundation's quarterly newsletter that helps create awareness about various issues related to cancer and its treatment. It is an opportunity for our members, both doctors and patients, to share their insights and testimonies with you.



Srilata De, Nag Foundation

The New Normal?

The Covid-19 pandemic has unleashed changes that we could not have predicted a few months ago. The world came to a standstill with no travel, no retail, no entertainment, no sports and most of the world working from home. Our mindsets have started changing - perhaps a 'new normal' was born.

Covid-19 has often been called 'the great pause' - a time for reflection and introspection. We have learnt to consume less and realise the importance of good health and good immunity. We have been given this opportunity to slow down and cherish our times with our families and the need to prioritise. A lot of firsts have come up....virtual and digital have replaced the physical being. Adoption of AI and innovative technologies are the order of the day.

The pandemic has been a strain and has affected the primary healthcare system all over the world. The Oncology Department did not slow down because cancer does not stop. However, Foundations, NGOs and Trusts struggled to aid those in need as all donations were directed towards Covid-19. We hope this gets better with time and we can help the patients in need.

We humans are resilient, adaptable, and innovative. Our future remains bright and, working together, we will make it so!

In this newsletter, some of our foundation's members have penned their thoughts and experiences during these hard and challenging times.



Dr Almas Pathan, Palliative Care Specialist, Sahyadri Hospital

Home Chemotherapy – A Way Forward

On 21st March 2020, at the stroke of midnight, a total lockdown was announced by our government to curb the spread of Covid-19 which would have devastating effects on human life. The only movement allowed was for essential services. Everyone was asked to stay in their homes, life as it seemed stood still.

Treatment of cancer is a long process that stretches over a period of time. Many of our patients who were currently on treatment faced tough decisions. With unavailability of transport and a fear of the getting the disease, they had to make decisions regarding continuation of treatment. A question arose, 'Which was the greater evil, Covid-19 or cancer'?

The Oncology team at Sahyadri discussed this matter and decided that for some patients, home chemo would be a solution and for others who were unable to come to the hospital arrangements were made to organize transport to bring them to the hospital.

Home chemotherapy could be given only in certain treatment regimens like FOLFOX. The team consists of a trained chemo nurse and a doctor with ample experience in handling chemotherapy. Prior to starting the home chemo, all risks are explained to the patient and caregivers and consent is taken. All precautions are taken to avoid any emergencies.

The benefits of home chemotherapy are that it is done in a safe environment; it reduces travel time as well as minimizes exposure to infections. A doctor - patient connect increases patient compliance to treatment and this can be achieved in a home chemo situation.

Home chemo has been a learning experience, helping us to make treatment accessible and available to patients. The only disadvantage of home chemo is that insurance companies do not recognize it.

Mr. XYZ diagnosed with metastatic Stomach Cancer. He had a PICC line in place. chemo given was FOLFOX. We were able to address his fear and continue his treatment without interruption. Throughout his chemo he was constantly on his laptop working, something he would not have been able to do if he was in the day-care. He had a pleasant experience and appreciated the efforts of the team.

Mrs ABC diagnosed with metastatic Gall Bladder Cancer comes from a low socioeconomic background. She was on palliative chemo which gave her a better quality of life. However the fear of Covid-19 prevented her from coming to the hospital for her chemo. Home chemo was offered to her and although initially she was doubtful, her doubts were clarified and she agreed to take treatment. The entire treatment went as planned with no issues. Also, during a follow up visit, she reported fewer side effects than when she received chemo in the day-care. Being at home gave her a sense of control and security, a psychological booster.



Dr Sanjay MH, Radiation Oncologist, Sahyadri Hospital

Cancer and Covid-19 – How We Overcame It.

The Covid-19 pandemic from China has entered India like a storm. It ripped many individuals and also families. The first case was reported on 30th January 2020, and since then has steadily risen affecting many lives. As an Oncologist, I had the same fear like every other normal individual who feared infection from Covid-19. When the lockdown was announced in mid-March, I had plenty of apprehensions about whether to go to the hospital or not. I had to hold back my uneasiness and remember my professional responsibilities to my patients.

To avoid being infected, I took all possible precautions of wearing a mask and sanitising my hands as many times as possible. At home I would make sure the moment I came back, I would rush to take a bath, since I have an infant at home.

In the hospital it was a totally different atmosphere. Fear ran both ways, patients were afraid to come to the hospital and I was scared to talk to patients, since you never knew who is positive and who is not.

In my Department of Radiation, the working staff was cut down by 50%, to reduce overcrowding in the radiation console area. The basement parking area was converted into a large waiting area with adequate social distancing and comfortable seating arrangements were made. The biggest challenge was convincing patients to continue or start their radiation therapy. The problem with radiation sessions are that patients are required to come on a daily basis for 3-5 weeks depending upon the type of therapy and disease, unlike chemotherapy which is administered twice a week or three times a week. One-on-one counselling sessions helped them understand that incomplete cancer treatment was much more dangerous than Covid-19.

With great efforts and taking all necessary precautions we continued working and by God's grace none of our department staff were hit by Covid-19. I believe these days are not yet over, since we are now seeing a post-lockdown sudden surge in Covid-19 cases. In the coming days we only have to be more careful and cancer patients especially should consult their Oncologists before taking a call whether it's okay to withhold treatment or it's safe to go ahead with it.



Dr Rahul Kulkarni, Medical Oncologist, Sahyadri Hospital

Cancer Care During Covid-19

Currently the entire world is witnessing an unexpected turmoil of Covid-19. This has changed the global picture completely in the last 3 months and will continue to take a recovery phase in the months to come. Apart from all the sectors, the healthcare sector was the major sector affected in this pandemic.

The healthcare sector had to bear the brunt of playing the role of saviour as well as managing to sustain and continue to provide treatment to patients amidst the extreme challenges at all levels. The Covid-19 pandemic has created major dilemmas for providers in all areas of healthcare delivery, including cancer centres. Cancer being a dreaded disease in itself had to be managed with a perfect balance for risk and benefit during this period. Since this situation was unique to both patients and doctors, Oncologists all around the globe had to rapidly formulate guidelines while relying on inadequate and rapidly evolving information and on models of disease spread that are based on multiple assumptions. Several cancer centres drastically scaled back their services after preliminary reports from China showed that Covid-19 outcomes are significantly worse among patients with cancer. The resulting rationing of care left patients and Oncologists feeling frustrated and helpless. However there was no doubt that cancer care had to continue and soon almost all centres came up with their own guidelines and protocols so as to ensure cancer care.

Working as a Consultant Medical Oncologist at a tertiary care cancer centre and Multispecialty chain of hospitals in Pune, we initially went through the same phase of striking a balance between continuing cancer treatment and preventing the Covid-19 spread. The most important hindrance was the fear among patients and their relatives regarding acquiring Covid-19 as well as reaching the hospitals for chemotherapies during the lockdown. Understanding this obstacle, the immediate next step was to shift the patient communication to teleconsultation so as to ensure that our patients are not alone during this crisis. This ensured that there was an effective communication between us and we could clear myths and facts regarding the current situation and provide symptomatic treatment on tele/video consultation. This avoided the unnecessary patient visits to hospitals, thus preventing community transmission. Understanding the need of the hour, the organization came up with a completely segregated day care for chemotherapy patients and thus we could continue to provide cancer treatments in a safe and clean atmosphere which can be reassuring to patients. This helped us to convince our patients to continue treatment without fear.

In order to balance the risk of exposure and continuing the cancer treatment, we also modified our treatment protocols. For those who did not warrant aggressive

chemotherapies, switching to effective oral chemotherapies and hormonal therapies helped the patients to achieve cancer control while staying at home. Alternatively, for those requiring intravenous chemotherapies we altered the schedule making it such that they require visiting hospitals less frequently or reducing the dose intensity to make it less myelosuppresive so as to reduce the chances of immunosuppression.

Many of our patients initially faced issues during travelling to hospital for chemotherapy. It was also important that they followed all the government rules and regulations for preventing Covid-19 spread. Soon this problem was sorted out as we started providing request letters for allowing coming for necessary chemotherapies which facilitated patients to seek proper police permissions and continue timely chemotherapies. Some needy patients were also provided transport facilities arranged by the hospital so that they could continue treatment without interruption.

During the last three months, we witnessed a lot of changes in treatment and screening guidelines. One of the biggest challenges was not to incur unnecessary financial burden on our cancer patients. We could do this by rigorous screening of our patients before chemotherapy for any possible symptoms of Covid-19. With this we could avoid doing unnecessary Covid-19 testing before each chemotherapy unless the patient was symptomatic. This also ensured that patients are followed up closely with periodic teleconsultations so as to pick up early signs of any infection and test them for Covid-19 if required.

These last 3 months were a testing time for us. We saw some patients who stopped the treatment on their own just because of fear of Covid-19 and thus unfortunately had cancer progression. On the other hand we could also witness the courage and determination of our patients and their relatives to fight against cancer even in this adverse situation and those who went on to complete their treatment successfully. We salute their perseverance and courage.

I believe Covid-19 and lockdown has taught us many new things in the long run. It reopened the avenues of teleconsultation and in fact brought patients and doctors closer even from their homes and offices. It embarked on the importance of hygiene and cleanliness. It helped our cancer patients spend more time with their beloved families which I think is the most important part in cancer treatment. And above all it showed us that we always should be grateful to mother nature and the ultimate religious place is within you which can never be locked down.



Faith Pneumaka, Survivor

My Experience With Covid-19

"During the lockdown due to Covid-19, many people were feeling anxious.

Questions like - what next? How will I manage? What would happen if I get ill? Were constantly in our minds. If we were to weather the storm, we need to work together; we need to understand ourselves and each other. This was how at my society at Sunshree Crown coped during the lockdown and even there after

Vegetables and fruits were arranged inside the society and the younger folk saw that the senior citizens never wanted anything. A chemist's number was given to all and medicines were brought home. People's movement were restricted. Every possible precaution taken. Our society residents at Sunshree Crown have got closer. It's been a new experience and a beautiful feeling of togetherness. The most important part is hearing praises from different houses all getting closer to God".



Rebecca D'Souza, Nag Foundation, Psycho-Oncologist,

Of all the things that we dreamed of, we never dreamed that we would experience a pandemic. The last time the world witnessed a pandemic was in 1918, the Spanish flu. Even though we did see another pandemic in 2009, the H1N1 flu strain, it was easily contained and treatable.

As a part of containment, the government called for a lockdown, and seeing and hearing the trauma of the virus, we heard and changed our life and lifestyle. As the lockdown extended, it affected all of us one way or the other. Stress, familial disturbances, anxiety, worry, depression and fear were some of the mental health issues we faced. To face what was happening and what would happen we need to be physically healthy but more importantly mentally fit.

There are things that we can do to keep ourselves mentally fit.

- Use information the right way: it's important to be updated about what's happening around us, but to put that information in the right perspective and be objective about it is also very important.
- ✓ Keep a routine: With so much changing, keeping a routine is a way of maintaining control.
 - Maintain a wake up and sleep schedule
 - Exercise as much as possible
 - Eat healthy
 - Balance work and family
 - Learn new skills
 - Keep a check on screen time

- ✓ Make time for yourself: Doing things for yourself to boost up your inner strength helps deal with anxiety and fear.
 - Begin your day with a short meditation
 - Laugh the blues away
 - Develop a hobby
 - Connect with people
 - Express your thoughts and feelings (journaling, art, movement, mood board etc)
- Bond with family: A strong family can help members adjust to the different and difficult situations and emotions. Opening the communication gates to share and listen to each other helps in building strong bonds among family members.
- Covid-19 has taught us many lessons from resilience to gratitude, from being alone to connecting with others, from understanding oneself to reaching out to others with issues, from creative expression to spiritual growth.

AN APPEAL

(Photos retracted to respect privacy)

Anant Jadhav	Sahil Sagar Bibave
A 15 year old bright, hardworking, enthusiastic young boy studying in Std X in a government school in Tujlapur.	A 14 year old cheerful, full of life boy, studying in Std. VIII at Uttkarsh Primary and Secondary School, Ambegaon Budruk, Pune.
He comes from an agricultural family in a small village. His parents take pride in him and want to give him an opportunity to achieve his dreams. Diagnosed with Non-Hodgkin lymphoma he requires chemotherapy	Diagnosed with Ewing's Sarcoma, which is a type of cancer that forms in bone or soft tissue. Sahil has a good prognosis and will be able to
as well as surgery.	have a complete cure, provided he has the right treatment.
Let us give Anant an opportunity to reach his full potential. He will require extensive chemotherapy for a period of over a year followed by surgery. Total cost of the treatment is ₹ 3 lakhs .	Total cost of treatment ₹ 7 lakhs. Let us give Sahil all the help he needs to make a complete recovery.

We were busy with some activities before the lockdown-





A talk on Palliative Care by Dr Frank Ferris (Executive Director of Palliative Medicine, Research and Education at OhioHealth in Columbus, Ohio, USA)



8th March 2020 - International Women's Day



Our activities reflect our vision and mission of Cancer – Care to Cure. Our dedicated team of doctors, professionals and survivor volunteers reach out into the community to destigmatise Cancer and to educate and inform women and men about the curative aspects of Cancer. The survivorship programmes for patients and caregivers help them navigate life after Cancer.

Total No. of patients supported	10
Total No. of Herceptin vials given	08
Total No. of patients helped for radiation	09
Awareness Camps / Medical Camps	12
Support Group Meetings	04
Continuing Medical Education Programmes For Professionals	01

The First Quarter: 01 January-2020 to 31 March-2020

During the lockdown we have had a few digital support group meetings. We had several webinars and podcasts as well as our continuing medical educational programmes.



If the Nag Foundation has made a difference in the lives of our patients and enabled individuals to reconsider health priorities, it is because of the empathy and the generosity of our patrons and donors. We would like to thank –

Prakash Ramchandra Gogte Mary V, Helsabeck Shohaib Manzoor Kazi Ambarish Raghuvanshi Rooma Dubay Amit Rajesh Pand Mangala Mahadik K. K. Nag Pvt Ltd.

A special thank you to all our donors who wish to remain anonymous

All donations are eligible under the 80 G Income tax exemption.

We are registered by the FCRA.

Website: <u>www.nagfoundation.org</u> Email: <u>sde@nagfoundation.org</u> Contact: +91 9326060014

For Private Circulation Only