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Life in the times of COVID-19

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# Mex NEWSLETTER

The COVID-19 Pandemic has affected more than 3 million people worldwide and caused over 200,000 deaths. This outbreak has resulted in a global crisis - medically, economically as well as emotionally, due to the challenges faced from this deadly virus. India currently has more than 20,000 active cases and 886 fatalities - (as on 27th April 2020 - track the impact of COVID-19 here) leading to a nationwide lockdown affecting thousands of migrants, daily wage earners and patients - especially those suffering from chronic illnesses. Given these circumstances, like most organizations, The Max Foundation team in India and Friends of Max decided to work from home to ensure the safety of our team as well as our

As always, our motto: "Together We Share and Learn" stands firm and in keeping with that, our approach towards the COVID-19 outbreak helps each other show courage

and hope in the face of this disease. The Max Foundation team in India and our City Chapter Leaders began working together to communicate with our patients, their caregivers and treating physicians all across the country by sharing credible information regarding the situation and providing emotional support in addition to resolving the logistical challenges arising due to the lockdown. Our team created posters – based on the information given out by WHO, published them on our social media platforms and shared them internally through Whatsapp groups. Amma sent out messages updating patients and Friends of Max members at regular intervals regarding the ongoing situation and assuring them that our team is doing the best we can to serve those in need. We realized that our patients are now, more than ever, in need of support,

keeping in mind the obstacles faced due to the lockdown as well as their life-long cancer diagnosis. We have decided to stand by them in these times by proceeding with our Chai for Cancer 2020 campaign – which will be launching in May, to cater to the needs of our patients.

We strongly believe that together we will fight the Big C's – COVID-19 and Cancer.

- Rachel Simons, Communications Manager, Friends of Max

# **Amma Speaks**

patients.

These are very strange times and our worst nightmare doesn't seem so bad when we look at what this COVID-19 Outbreak is doing to us and the world around us. But then again, we did not take into account the strength of the human spirit and how all over the world everyone is channelizing all the love and positive energies possible to combat this threat to our life as we know it. For all of us, our patients come first and while working with them and assuaging their fears on all fronts, we are learning so much about them. These are cancer patients already dealing with the burden of their diagnosis and most of them are on lifelong treatment. And now that burden just got heavier given how much more vulnerable they are. Add to that the possibility that they may not be able to collect their supply as their hospitals are closed. Throughout these difficult weeks we have been aware of how helpless the patients are feeling. There have been too many factors contributing to the hopelessness of the situation. The only way out was to look

at the situation squarely in the face and look within for inner reserves saved especially for times like these.

We began working with our physicians first - pleading with and cajoling them. Don't ask me where our Program Officers got the courage to stand up to them and make them understand no prescription meant no dispensation. One by one they capitulated and themselves began seeing how they could send us individual prescriptions. We know they had to struggle to find time and resources - both scarce, but they did it.

We had known quite early enough when the lockdown was enforced and all public transport withdrawn from the roads that our hands were tied. There was going to be no way we were going to be able to send anyone their supply. We realised the patients also had to put in their efforts and be proactive. Our first thought was to not make them feel helpless but encourage them to be inventive and see what they could do to help themselves- and their loved ones to see how far they could go to meet those who were putting themselves out

for them.

And lo and behold, we began hearing of what they were doing - Nagerkoil is a little town in the state of Tamil Nadu. We heard how the husband of a patient cycled 76 kilometres to Trivandrum in Kerala to go pick up his wife's prescription. We heard how in the time of lockdown, Fire Station and Police Station personnel in Kerala were helping patients who approached them for getting to the dispensing outlets.We heard of patients asking family and friends in cities and towns where it was possible to move around a little to go collect their supply for them. We heard of Friends of Max City Chapter Leaders going to collect for those of their brethren who could not travel.We heard of patients begging for place in ambulances from villages to get to their dispensing outlet. We saw patients sharing their experiences and giving advice to each other over the city WhatsApp groups we created for them. We felt their camaraderie for each other. We felt their love for each other. Indeed and literally, love always finds ways - helped by courage.

- Viji Venkatesh



The World Health Organization (WHO) published the following information regarding the COVID-19 Virus:

#### Overview:

Coronavirus disease (COVID-19) is an infectious disease caused by a newly discovered coronavirus. Most people infected with the COVID-19 virus will experience mild to moderate respiratory illness and recover without requiring special treatment. Older people, and those with underlying medical problems like cardiovascular disease, diabetes, chronic respiratory disease, and cancer are more likely to develop serious illness. The best way to prevent and slow down transmission is be well informed about the COVID-19 virus, the disease it causes and how it spreads. Protect yourself and others from infection by washing your hands or using an alcohol based rub frequently and not touching your face. The COVID-19 virus spreads primarily through droplets of saliva or discharge from the nose when an infected person coughs or sneezes, so it's important that you also practice respiratory etiquette (for example, by coughing into a flexed elbow). At this time, there are no specific vaccines or treatments for COVID-19. However, there are many ongoing clinical trials evaluating potential treatments. WHO will continue to provide updated information as soon as clinical findings become available.

#### Symptoms:

The COVID-19 virus affects different people in different ways. COVID-19 is a respiratory disease and most infected people will develop mild to moderate symptoms and recover without requiring special treatment. People who have underlying medical conditions and those over 60 years old have a higher risk of developing severe disease and death.

#### Common symptoms include:

- fever
- tiredness
- dry cough

#### Other symptoms include:

- shortness of breath
- aches and pains

#### sore throat

- and very few people will report diarrhoea, nausea or a runny nose
- People with mild symptoms who are otherwise healthy should self-isolate and contact their medical provider or a COVID-19 information line for advice on testing and referral.
- People with fever, cough or difficulty breathing should call their doctor and seek medical attention.

#### Prevention:

To prevent infection and to slow transmission of COVID-19, do the following:

- Wash your hands regularly with soap and water, or clean them with alcohol-based hand rub.
- Maintain at least 1 metre distance between you and people coughing or sneezing.
- Avoid touching your face.
- Cover your mouth and nose when coughing or sneezing.
- Stay home if you feel unwell.
- Refrain from smoking and other activities that weaken the lungs.
- Practice physical distancing by avoiding unnecessary travel and staying away from large groups of people.

Source: World Health Organization - https://www.who.int



The CML Advocates Network - For Chronic Myeloid Leukemia Patient Group Advocates published an article titled "Corona Virus Disease and CML patients" sharing information about the virus and addressing questions that patients might find useful.

#### **Diagnosis of COVID-19**

Positive diagnosis of COVID-19 requires detection of the virus by nasopharyngeal swab in symptomatic patients. In most countries, tests are restricted to persons highly suspected of COVID-19 or who had been in close contact (directly or less than 2 meters from) with infected individuals.

#### **Treatment of COVID-19**

Treatment is essentially supportive, either at home or in hospital. There are currently no specific antiviral medications to kill the new coronavirus. Severe forms of infection require transfer in hospital and eventually in an intensive care unit.

#### Risk factors for severe or fatal COVID-19

Older adults, people with some coexisting chronic illnesses (like chronic lung diseases as an example) and those contracting secondary infections seem to be at higher risk of severe COVID-19 but more precise risk factors are not clear yet. As a general rule, immunosuppressed individuals should be considered at high risk. Children are rarely affected.

#### Are CML patients at higher risk for severe or fatal COVID-19?

There are no available specific data on the new coronavirus infection or COVID-19 in CML patients treated with tyrosine kinase inhibitors (TKI).

At the moment in a normal situation, neither chronic phase CML per se nor tyrosine kinase inhibitors against CML appear to induce a state of clinically significant immune suppression. However, we really do not know if protection from COVID-19 requires a level of immune control that non optimallycontrolled CML or TKI therapy may in part impair. Therefore, we recommend CML patients under TKI therapy to be extremely cautious and to strictly follow the restrictive measures suggested by health authorities of their respective countries, in order to avoid the risk of contamination and to prevent the spread of infection.

Don't forget that you may be at higher risk of severe infection due to non CMLrelated causes (like older age, other diseases, immune suppressive treatment for another disease).

### What to do if you have CML and you contract coronavirus or COVID-19

- 1. If you have symptoms compatible with COVID-19 or have been in close contact with a coronavirus infected person, follow your country-specific procedure (usually a dedicated call centre).
- 2. Inform your hematologist/oncologist by phone or email or fax (don't come to hospital on your own as you may contaminate health care providers or other fragile patients).
- 3. Don't stop your treatment with TKIs unless your hematologist or oncologist asks you to do so, but ask your hematologist to contact the team taking care of you in case of confirmed COVID-19 as adjustment may be needed.

Source: CML Advocates Network

https://www.cmladvocates.net/home/110news/969-coronavirus-disease-and-cmlpatients

# COVID-19 and cancer: practical considerations - By Dr Bhawna Sirohi for cancer patients and their doctors



In these exceptional times every cancer patient is stressed and anxious and has one question on their minds – will my treatment be compromised by COVID-19? The sad reality is that COVID-19 is already impacting cancer diagnostics and treatment.

As doctors, we have to balance risks versus benefits on a daily basis. Right now, for many of our patients, given the risks associated with the infection in the

MBBS, FRCP, Director, Medical Oncology, Max Healthcare, National Capital Region, India

> immune-compromised, those with comorbidities and with advanced age, it would be sensible in the short-term to delay any treatments that will compromise the immune system further.

For cancer patients undergoing active treatment there are numerous issues that need to be addressed individually with a shared decision-making model between the patient, family and the oncologist.

## Suggested measures for patients

- 1. Have a detailed discussion on the phone with your oncologist about the risks versus the benefits of ongoing treatment as this has to be tailored for every patient.
- 2. Transmission occurs typically if there is sustained exposure to the virus and there is lack of personal protection/ hand hygiene. Hand hygiene must be followed rigorously by you and your caregiver. Hand washing should be done for 20 seconds. Gloves or sanitiser are NOT a substitute for hand washing. If using a sanitiser, use one with at least 60% alcohol.
- 3. Can any hospital visits be deferred; can any procedures be carried out at home?
- 4. If you have to go to the hospital, do not take more than one caregiver with you.
- **5.** Fever, dry cough, fatigue and muscle aches are signs of COVID-19 infection but are also normal side effects of some cancer treatments. If you have these, talk to your oncologist before going to the hospital.
- 6. Once wider COVID-19 testing is available - if it is possible to get the

test done at home, consider this rather than going to the hospital.

**7.** The early evidence indicates that cancer patients have a higher risk of contacting COVID-19 than others, so practice social distancing, hand hygiene and wear protective clothing if you do have to attend hospital. Once you come back home, have a shower and have the clothes cleaned separately.

Let us exercise self-control, be smart and practical and stay safe!

Source: https://ecancer.org Read the full article here

# **COVID Heroes**

When Stuti arrived at the pharmacy an hour away from her home, she realized she didn't have the right prescription papers.



A nearby bank kindly allowed her to use their printer, and afterward, she sent a message to fellow patients on which papers to bring so this wouldn't happen to them!





Ajith travelled 76 kilometres on his bicycle - from Nagercoil, Tamil Nadu to Trivandrum, Kerala to collect his wife's prescription.





# Chai for Cancer 2020

Launches on the second Sunday of May -

Chai for Cancer Day.

Chai for Cancer is an awareness and fund-raising campaign directed at supporting cancer patients who are coping with CML and GIST, both rare cancers requiring lifelong treatment. The brain child of Viji Venkatesh, Region Head (India & South East Asia) - The Max Foundation, Chairperson & Managing Trustee – Friends of Max. "It is a simple association between cancer and a cup of chai, which is every man's drink – it has recall value and brings a sense of comfort and normalcy to the feared condition" she says.

We believe that the Chai for Cancer campaign will not only spread a more positive outlook but also heighten the special needs of our patients who are dealing with a life-long diagnosis of cancer along with the present COVID-19 pandemic having a greater impact on them.



We request you all to support our patients through the upcoming Chai for Cancer campaign by hosting a virtual Chai for Cancer Adda!

> www.chaiforcancer.org Write to us at: chaiforcancer@gmail.com



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Address: Friends of Max, Secom Business Centre, A Block Basement, Shiv Sagar Estate, Dr A B Road, Worli, Mumbai 400018

Website: www.friendsofmax.info Website **Email** : friendsofmax@gmail.com

#### Facebook:

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#### To Donate:

Cheques should be drawn in favour of Friends of Max and couriered to our ofice in Worli (Mumbai);

To donate online visit www.friendsofmax.info; Receipts u/s 80 G of Income Tax Act, 1961 will be

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