

Holding up our end of the line

The role of civil society amidst the coronavirus crisis



A MEMBERSHIP ORGANISATION
FIGHTING CANCER TOGETHER

Murallitharan Munisamy is the Medical Director of the National Cancer Society Malaysia and a [UICC Young Leader](#). In this report, he outlines how the National Cancer Society Malaysia defined their role as a Civil Society Organisation (CSO) and adapted their services ensuring they could continue to protect and support cancer patients.

Defining our role

On the 16th of March 2020, it was announced that Malaysia would go into a state of lockdown, halting all activities with the exception of essential services and requiring individuals to stay within their homes. One of my medical colleagues texted me to tell me the news, adding “well, since you are not on the frontline, enjoy your couple of weeks at being at home.”

For me, and I guess for most of us in different countries going through various versions of an enforced ‘lockdown’, the question running through our minds at this time was, “ Are we part of the frontline in this fight against the coronavirus? If not, do we as CSOs working in the cancer space even have a role to play? Or should we take a backseat and let our communicable disease and public health colleagues lead from the frontline?”

On the eve of the Malaysian ‘lockdown’, NCSM’s senior management team met, and sitting together with the Society’s President and Chairperson of our Board, Dr Saunthari Somasundaram, we did some soul-searching to answer these questions. Funnily enough, the answer was quite quick in rising to the top of our minds.

If anything, we concluded, this was going to be a more trying time for cancer patients. As a Cancer CSO, we needed to be in position to be able to handle that for all our patients, especially those who have and continue to believe in us. So what did we do?



“Cancer was not going to come to a halt during this ‘corona crisis’, neither could we.”

We reviewed our activities, defining priority areas that could not be neglected during the lockdown and we identified ways to adapt these services to current restrictions.

Our priority areas

- Delivery of essential clinical services.
- Share evidence-based information
- Provision of online support services.
- Assist the most vulnerable.
- Advocate for cancer patients.
- Support frontline workers.

Adapting our activities



Delivery of essential clinical services

We reviewed and determined what in-person services we needed to carry out at this time. At the top of this list was NCSM's subsidised clinical services which are primarily utilised by public sector and low-income groups. Running a close second was the children's halfway home which allowed children from all over the country to receive treatment at the country's largest public sector paediatric oncology centre. Realising that halting these services would cause delays in cancer treatment for certain public sector hospitals, we strengthened our internal safety procedures such as instituting alternate work teams and regimented disinfection methods in order to ensure that our personnel were at low-risk of being infected.



Share evidence-based information

NCSM also fulfilled its role as a healthcare stakeholder involved in tackling the misinformation and 'fake' news being propagated on Covid-19, much of which has confused the general public and cancer patients alike. We switched our communications channels to running a structured programme of information provision, myth-busting and health promotion focused on cancer and Covid-19. We have also been actively working on educating our healthcare professionals. Most recently we organised an open webinar between Malaysian cancer stakeholders and an on-the-ground oncologist from Wuhan to obtain insights on how care was delivered amidst this crisis.



Provision of online information and support

We estimated that the lockdown was going to create a lot of mental stress and anxiety among cancer patients. This was because they had to deal with the fear of getting infected with Covid-19 as well as treatment issues due to delays in hospital appointments and the postponement of surgery and chemotherapy. We took our psychosocial support service fully online; enabling our clinical psychologists, counsellors and peer supporters to be able to respond to calls from all over the country; as well as providing access to video counselling sessions.

NCSM also began organising FB live sessions in multiple languages on coping strategies and mental health tips. Our cancer hotline colleagues began actively navigating patients, helping them to obtain new dates for surgery, directing them to different hospitals not involved in the Covid-19 response and in one case, even arranging for a terminal patient to return home from overseas to be with her family.



Assist the most vulnerable

We were quickly drawn to the plight of many of our low-income patients who were now stricken with financial difficulties during the lockdown since they could not work. This was especially worse for those in the informal sector who now had no source of income at all. The impact to them was devastating. Working with our wonderful supporters we have put in place a network providing patients with much-needed daily necessities.

Fight. Thrive. Survive.

NCSM presents a series of educational sessions for cancer survivors via Facebook Live.

Date : 24 April 2020 (Friday)
Channel : Livestream via the Facebook page of National Cancer Society Malaysia

10.30am - 11.00am (conducted in Bahasa Malaysia):
Topic : Kanser dan diet - "Saya menghidap kanser. Apa yang saya boleh makan?"
Speaker : Krystal Ng Lu Shin (黄露茵), BSc Dietetics (UnisZA), MSc Clinical Nutrition (UPM)

12.30pm - 1.00pm (conducted in English):
Topic : Cancer and diet - "I have cancer. What should I eat?"
Speaker : Krystal Ng Lu Shin (黄露茵), BSc Dietetics (UnisZA), MSc Clinical Nutrition (UPM)

2.30pm - 3.00pm (conducted in Mandarin):
Topic : 癌症和饮食 - "我患有癌症。我应该吃什么?"
Speaker : Kenneth Low Kien Yong (刘健泳), BSc (Hons) Food Science and Nutrition (UMS)

In collaboration with:

Contact us at: ☎ 1-800-88-1000 ✉ help@cancer.org.my



Advocate for cancer patients

During this time of the lockdown, it is necessary for us to continue advocating for cancer patients. How and why? As part of the lockdown, the government announced that no one was to be allowed to travel over long distances. Unfortunately, due to the fact that oncology units in the public sector are only in specific locations, many patients had trouble complying to the rule. Over the first few days of the lockdown, [patients were held up in roadblocks](#), or even not allowed to reach their hospital for treatment. Working together with other colleagues and organisations, we advocated to the government to allow an exception of the travel ban for cancer patients. Thankfully, in a matter of days, the government granted exceptions for them to proceed to receive treatment.



Support frontline workers

Lastly, we still felt that we had to do our bit for our frontline colleagues who at the time faced a shortage of Personal Protective Equipment (PPE). Working hand in hand with our supporters and friends, NCSM began an effort to purchase and supply needed PPEs to various public sector health

institutions. This was our effort to directly support our brethren working to detect Covid-19 on the frontline.

Conclusion

So far, these are some of the activities that we have carried out and continue to carry out amidst this pandemic. The reason I am writing this blogpost is not to trumpet the National Cancer Society of Malaysia's work or to ask for praise for what we did.

Rather, it is to share insights the questions that went through our minds as we tried to align our formative purpose during these troubled times. This may help our colleagues who might be facing similar circumstances in their own settings and provide some ideas on how to re-purpose their own CSOs at this time.

It is clear to all of us that in these challenging times, cancer CSOs may not be in the frontline per se. However, it is critical for us to continue to function, and even augment our function to ensure that cancer care continues. Failing which, not only would we be putting patients at risk, but also our health systems which would be swamped after the pandemic response by cancer patients presenting in more severe conditions.

