

A Heartfelt Letter to a Patient

Dear Ibrahim,

I was thrilled to receive your email with updates from your recent trip. It came at just the right time to cheer me up, as I was mourning the death of one of my patients (one of the first patients on our home ventilation programme who survived eight years after his initial injury) and swamped with a whole host of deadlines.

It is great that you have represented Singapore at the International Scientific Meeting. You – a young tracheostomised, ventilated Duchenne muscular dystrophy patient with your motorised wheelchair and portable ventilator – flying halfway across the globe to deliver a speech on water conservation and the available options for emerging third world countries; wow! Was there difficulty in getting yourself heard in the auditorium with the microphone? Did your cuffless tracheostomy allow good enough speech quality? I am glad that you've learnt to tolerate it, as I believe the cuff's resistance to airflow would always lead to poorer speech quality. I am also glad to hear that your mum and dad enjoyed the trip; their chests must have swelled with pride when it was announced that you won the Best Presentation Award.

Now, permit me to switch to a more sombre topic. Jennifer, our nurse, has been asking about your form on advance care planning. When (if I may ask) would you feel ready to complete it? OK, I know I am supposed to fully respect your wishes and that you are free to do or not do it, but I am worried...

Your last echocardiogram showed that your ventricular function has worsened. It is true that you are feeling better, now that we have stepped up your heart medication (ACE inhibitor and beta blockade). But we have had difficulty with that, as you know, because your blood pressure level is often on borderline low. What's more worrying is that your ECG still shows frequent irregularities (ectopic and occasional bigeminy) and you have steadfastly refused an implantable defibrillator.

Have you thought about what might happen if you were to suddenly succumb to a run of arrhythmias and have a cardiac arrest? If you were alone, you might just pass away. However, chances are that your mum and dad would be around to call 995. They would start to do cardiopulmonary resuscitation and the paramedics would continue upon their arrival. At the hospital, if they successfully revive your heart but find that you have suffered brain damage, should they continue to treat you aggressively? Should they put you in the intensive care unit and administer heart supporting medication infusions or implant a defibrillator then? What if you suffered ischaemic injury to your kidneys and liver? I know your mum and dad would not bat an eyelid about asking to put you on dialysis, but seriously, would that be in accordance with your wishes?

You have told me before that what is most important to you now is that you still possess full intellectual capacity and the capability to express your deepest emotions and your

most abstract engineering calculations. Despite the fact that you can only move your right hand enough to operate your motorised wheelchair and type with a mouse; despite the need for continuous ventilatory support through your tracheostomy; despite how you need to be hoisted in and out of your wheelchair and need help with bathing, dressing and using the toilet; you feel fully alive as a human being.

You have told me that you do not fear death. As a Muslim, you submit to the will of Allah and trust that He will always look after you in the best possible way. You have also told me that should you lose the ability to communicate your thoughts audibly or through electronic interfaces, and if you need dialysis or if you lose the ability to taste your favourite dishes (*mee soto* and *soup kambing*, is that right?), you would think that it is the time you want to forgo aggressive life support. You have told me but not your parents. You fear that it would hurt them.

However, they need to know. They need to know your wishes and why your wishes are as such. Otherwise, as parents, they would do anything to keep you (or rather, your very injured self) alive. I am sure that they would empty their life savings and even sell the roof over their head just to do that.

The reverse is also true. If you happen to unfortunately be hospitalised for pneumonia, many doctors may not know that you can be stabilised with injection antibiotics and that the cough assist machine would keep your airways reasonably clear. They would look at you and say: "Poor guy, already on 24-hour ventilation. What quality of life is there?" If you are drowsy from delirium, they may persuade your mum and dad that there is nothing more they can do — which would be a disaster, right?

Therefore, you should complete the form. Express what gives you meaning in life and what is important to you! And then enunciate under what circumstances you would want life-sustaining measures continued or stopped. It would prevent unnecessary tragedies and heartaches.

Can I just make an appointment for Jennifer to visit you? I will send her along with your favourite *soup kambing*. ♦

Yours always,

Dr Chan Yeow
Director
Home Ventilation and Respiratory
Support Service

PROFILE

TEXT BY
DR CHAN YEOW

Dr Chan Yeow is an anaesthesiologist and intensivist at Tan Tock Seng Hospital, and Director of the Home Ventilation and Respiratory Support Service. He gets a great kick when ventilated, tracheostomised patients can speak audibly, return home and do things they enjoy. His other interests are in philosophy, medieval history, Romance languages and walking.

*Disclaimer:
The characters depicted in
the letter are fictitious.*