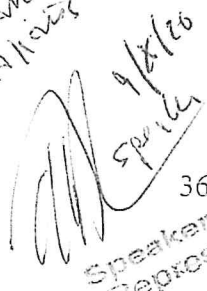


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to
This letter number is
great importance related
Health issue. Please refer
copy to D/POM c/o from
by chair of Joint Affairs
Committee of


Speaker
House of Representatives

364, Manvel Dimech Str., Sliema, SLM 1058
Tuesday, 6th October, 2020

The Right Honourable Speaker Dr. Anglu Farrugia
House of Representatives Parliament of Malta

Dear Minister Speaker,

My name is Lara Said. I am 52 years old. From the onset I apologise for not contacting my district Members of Parliament and/or lodging a petition purely through the Parliamentary website but the importance of my message is such that I deemed it more appropriate to try to establish a more personal connection with you all through a letter. I have multiple myeloma. Myeloma is incurable but manageable. My current fourth line of treatment involves Pomalidomide, Dexamethasone and Daratumumab. The first two drugs are supplied by the government. Daratumumab is not. Until the end of October, Daratumumab is funded by the Malta Community Chest Fund (MCCF). I am grateful for MCCF for providing such funding. Beyond October, I should switch to a monthly protocol. In accordance with MCCF regulations, and rightly so, I need to re-apply through my doctor and my case reconsidered regularly. Access to quality healthcare is an important standard of care, access to opportunity to quality healthcare is equally critical. This is associated with indicators such as quality of life and overall survival rates. This latter responsibility should not be foisted by government onto a charity. The ethical considerations here especially are a minefield. At least this is my interpretation.

I am a type of person who enjoys keeping herself informed. I read in Chapter 4, page 55, of the National Cancer Plan, 2017, that: *'All patients should have access to a uniformly high quality of care in the community or hospital wherever they may live to ensure the maximum possible cure rates and best quality of life. (Calman-Hine report, 1995)'*. Thanks to the sterling care and service especially by my team of doctors and nurses I feel that I am in receipt of excellent primary care. I however do feel that an important aspect of my treatment is not yet consistent. Treatment that is more likely to allow me improved odds of survival in the medium (up to the next 3 years) and possibly the longer term (beyond 3 years and up to 5 years) At my age and worldwide, there are increasingly a significant number of myeloma patients, even with a late stage diagnosis as myself, ineligible for an autologous stem cell transplant, as myself (on the basis of current medical technology), and who more prone to relapse, who have also beat the ten years odds. There are considerable and noteworthy differences and variations in the funding of Daratumumab across the EU. Yet, other European countries appear to offer alternative routes, as well as, a variety of pricing plans/opportunities in connection with its acquisition. I feel that the National Cancer Plan has currently failed me and other similar myeloma patients if not all other patients in my same funding predicament; whether they are aware of this or not.

The aim of this letter of mine to you dear Speaker of the House is that I hope to gain the attention of the Prime Minister Dr. Robert Abela. Professor Edward Scicluna and Dr. Christopher Fearne and the Leader of the Opposition especially, as well as, all members of Parliament. This plea of mine offers the House of Representatives an opportunity to govern together and address an unfair blip in an otherwise proud-to-have healthcare system. A succession of prime, economic and health ministers have been more concerned about the

financial bottom line, in connection with cancer, rather than on the equitable provision of life-extending treatment for its electorate. I also understand that sustainability of such expensive treatment and the maintenance of such provision is likely to be a critical issue. I now take the liberty to ask:

1. Why, at this time in my life, a citizen, who has consistently and dutifully paid her taxes and gainfully contributed should resort to charity?
2. **Why may I, as well as other cancer patients, of all ages, and their families, not assured the peace of mind of knowing that funding for treatment is likely to be regular and consistent?**
3. Why is there no provision of such critical treatment, for as long as is medically appropriate, according to pre-determined gold standard medical criteria?

My answer to these and my many other questions, is that I have not been successful in discovering. You see, I am an educator not a journalist. I especially want you to acknowledge the many difficult decisions that professionals in the medical field are faced with when recommending a person for funding to MCCF. I would like all members of Parliament to sit down with themselves, your political conscience, if any, and consider whether the lives of its electorate, whomever they may be are worth it. How would you feel if this happened to you? Or to a member of your family? Perhaps it already has? Fortunately, similarly to myself, you possess the competence to argue for your rights in ways that other less socially and less educationally privileged citizens may be unable to.

I would like to stress that I am deliberately setting out **not to ingratiate myself** with any of you. The importance of my argument is such that it is not only those who pander to societal and increasingly political whims who should be in receipt of their rights. The concerns I have highlighted are critical to the well-being of Maltese society at large. I also hope that a courageous few of you might support my case and I do so look forward in engaging with anybody who is interested in supporting and/or critiquing/questioning my cause. I especially look forward to my cause being supported by more, if not the majority, of the House. My sense of current disenchantment with the current state of politics and society in Malta is such that I feel that I am likely to fail because it appears that the voices of individual people, especially the more vulnerable, appear to be no longer heard. Everything has become transactional nowadays. I hope to be proven wrong and that my cynicism and disenchantment are merely the product of my current cancer-ridden psyche coupled with the COVID-19 pandemic. Ultimately, I just want somebody of you to care enough for me and all other Maltese, Gozitans and anybody else residing in Malta and Gozo.

I thank you dear Speaker and all Members for your time and attention.

Yours faithfully,



Lara Said
Ph.D (UCL, Institute of Education)
79442919, 21338964
lara.said@um.edu.mt

cc: Members of the House of Representatives
His Excellency, The President of Malta, Dr. George Vella