Submission
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INQUIRY INTO CURRENT AND FUTURE PROVISION OF HEALTH SERVICES IN THE SOUTH-WEST SYDNEY GROWTH REGION

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Inquiry into Current and future provision of health services in the South-West Sydney Growth Region

Thank you for the opportunity to make a submission.

I am making this submission as a member of CANAct, specifically the South West Sydney Cancer Advocacy Network. CANAct is a community of thousands of advocates under the auspices of the NSW Cancer Council. I have been a member of the CANAct for 5 years. Advocating for cancer patients, their carers and the community has been a way for me to pay forward the care and support I have received throughout my cancer journey.

I would like to start by thanking the Committee for this Inquiry. This is an important opportunity to address the growing need for health services from region that is experiencing significant population growth and to also deal with some of the underlying inequalities in health services for residents in South West Sydney.

My cancer journey spans over 30 years and I have seen some positive changes to the way we treat cancer and the way we support people affected by cancer. We do have one of the best health systems which, for the most part gives everyone access to quality treatment when you're sick. However, as medical knowledge grows, and technology gives us more options to not only treat illness but prevent illness, there are growing gaps that need to addressed - sometimes where you live can determine your health outcomes.

My story with cancer begins in 1988 when I was diagnosed with Hodgkin's Lymphoma at the age of 14. Back then, there were no cancer treatment services in South West Sydney so my mum had to drive me every day along the new Cumberland Highway to Westmead Hospital for radiotherapy. My mum would go to work each morning then leave and come home at lunch time to pick me up to take me for treatment. It was a long trip each day, with roadworks for the highway construction and me vomiting into a bucket all the way back home.

My cancer journey continues today. I am currently undergoing treatment for breast cancer – it has returned for the third time. Cancer has been unrelenting. I have also been diagnosed with skin cancer requiring surgery and precancerous cells were found in my thyroid resulting a total thyroidectomy.

Over my 30 year cancer journey and having to undergo treatment for five cancers I have undergone countless amounts of surgeries, chemotherapy and radiation; my need for urgent treatment has been met without delay. Mostly I've not needed to travel outside the area for treatment except for a clinical trial at Westmead Hospital. I was on a wait list at Liverpool hospital to have the thyroid surgery and as the lists were too long at Liverpool they moved all the surgeries to other hospitals so I ended up having it at Lifehouse. I also had my skin cancer surgery there too as that's where my specialist was.

It's people who make our health system work and the staff have been tremendous – they are dedicated and compassionate – working incredibly hard to meet rising demand for health services with the scarce resources they have. I know that they are making daily decisions to ration health services but for the most part, patients who are in urgent need of care, don't see this – what they see is their need for urgent treatment is being met in a timely manner.

My experience as a cancer patient in south west Sydney has shown there is a lack of allied health services in South West Sydney. Treating cancer is seen as treating just the malignant tumour but and individual's health is more than that. Cancer and health in general needs a holistic approach where the whole person is at the middle of all treatment decisions looking at the physical, social, psychological and emotional needs of the person.

A case in point is the lack of psychological support. I was not offered psychological support when I was first diagnosed with cancer. In 2015 when I was diagnosed with breast cancer, had a double mastectomy, chemotherapy, radiotherapy and hormone treatment; I was not offered psychological support.

Unfortunately, the cancer has returned and I was diagnosed with incurable and terminal cancer in 2017. Again, I wasn't offered psychological support. It wasn't until a year later, when things really built up and I had an episode that I was offered psychological support.

A psychologist is only available at Campbelltown Hospital part time, two days a week. Currently there is no psychologist available. The psychologist is currently on maternity leave but no-one has replaced her which has meant that I've had to access a psychologist privately, at my own significant cost.

The other example of the lack in allied health services for cancer patients is the lack of treatment for lymphoedema.

Lymphoedema is swelling to soft tissues, often in limbs as a result of the damage to the lymphatic system from cancer treatment. It's a chronic, progressive and painful illness. Lymphoedema can also lead to fibrosis which is hard painful lumps in the affected area, or serious infections like cellulitis that can require hospitalisation. People with lymphoedema are at a much higher risk of developing cellulitis than the general population, and early intervention is critical to stop it progressing.

According to Cancer Australia, conservative estimates suggest that one in five cancer survivors will experience lymphoedema, yet there is a real lack of access to treatment. At the current rate of 48,000 new cases of cancer being diagnosed every year, that's an average of 9,600 new cases of lymphoedema every year.

For something that affects thousands of people, lymphoedema receives little attention. A quick reference to lymphoedema was made by the physio who came into the hospital ward a few days after I had my double mastectomy and gave me a handout. At that time, I wasn't in a good space physically or mentally to take in this information. No further mention of lymphoedema was made to me again until I was diagnosed by my oncologist a few months later during a routine check-up.

I was referred to the public lymphoedema clinic. Whilst the staff were lovely and tried to help, the clinic was only staffed part time. They weren't able to provide the effective, ongoing treatment that I needed so in 2015 I started seeing a private lymphoedema therapist.

The therapist advised that I should come once a week. It cost $120 each visit and I couldn't afford it, so I went fortnightly. After a few visits, and feeling the financial strain, I negotiated with the therapist to get the cost down to $100 per fortnightly visit. I had 18 private appointments in 2016 alone and no public appointments during this time. My total cost of lymphedema treatment for 2015-2017 is now $4120.

Since then there have been improvements at the public lymphoedema clinic at Campbelltown Hospital including more staff and equipment. However, this has been made possible with community fundraising rather than funding allocated to the Local Health District.

Another gap in our health system is transport. Our health system largely leaves the transport to access treatment and health services to patients. With repeat treatments that often have significant side-effects, you can't drive yourself, family and friends are not always available and public transport, if it's available, is often not appropriate. Options such as taxis can be a financial burden.

The Cancer Therapy Centre is currently serviced by two community buses that provide transport for patients but they are totally funded by community fundraising by the Cancer Council in the Southern Highlands and 24 Hour Fight Against Cancer covers Macarthur area. Being able to get to your follow-up appointment, blood tests and other diagnostic services and attend multiple rounds of cancer treatment is as important as having quality health services available.

Sometimes Community Transport can be an option however it's often not an individualised service and not flexible enough to meet the needs of patients on cancer treatment regimes. The other barrier to using Community Transport is that often a patient needs to be eligible for a "My Aged Care" package or an NDIS package to access Community Transport services.

In conclusion, the quality and high standard of health services I have been lucky enough to have received is testimony to the commitment of the staff, who work above and beyond to make the most from the resources they're given - resources that don't adequately match the current health and future health needs of communities in Sydney's south west. However, a health system should not rely on the good will of overworked staff.

There are currently gaps in allied health services that need to be addressed before additional population places further strain on the health system. Non-urgent transport to access health services and treatment needs to also be seen as an integral part of our health system.

The Government is planning for continued and significant population growth in South West Sydney and already stretched health services will not be able to keep up with this growth. And it's not only the increasing population that will place a strain on health services in south west Sydney; our community faces additional social, economic and health challenges including, higher smoking rates, lower screening rates, lower household incomes, larger populations of communities from Culturally and Linguistically Diverse backgrounds.

The provision of health services should not be seen as a one dimensional treatment of an isolated and specific disease – we need to take a more holistic approach to health and invest more in allied health to support the social, emotional and mental well-being of patients and the community. And health funding should be seen as an investment and not a cost, it's an investment because every dollar spent today means less cost in illness, including mental illness, and hospitalisations tomorrow.

Again, thank you for the opportunity to make this submission.

Yours sincerely,

Angela Lonergan