

7 February 2022

Mental Health Select Committee Parliament House George Street BRISBANE QLD 4000

By email only: mhsc@parliament.qld.gov.au

Dear Committee,

Inquiry into the opportunities to improve mental health outcomes for Queenslanders

Cancer Council Queensland welcomes the opportunity to provide information to the Queensland Parliament's Mental Health Select Committee *Inquiry into the opportunities to improve mental health outcomes for Queenslanders* (**Inquiry**).

Cancer Council Queensland partnered with Lung Foundation Australia and Arthritis Queensland to provide another submission to this Inquiry, which highlights the needs of people who experience comorbidity of chronic diseases, chronic pain and mental health. This submission focuses on the mental health needs of people who are affected by cancer, including the needs of people with clinically diagnosed mental illness as well as psychological distress experienced by people who have received a cancer diagnosis in their lifetime and their family and carers.

To address the mental health needs of Queenslanders affected by cancer, we propose that the Inquiry should recommend:

 increasing mental health services for people affected by cancer, including qualified psychologists and counsellors who understand both mental health and the cancer experience;

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- implementing distress screening tools at different points across the cancer trajectory (including time of diagnosis, treatment, rehabilitation, end-of-life and bereavement) to assist with early detection of mental health concerns for people affected by cancer, including cancer survivors and their family and carers;
- increasing awareness of Cancer Council Queensland counselling services so cancer clinicians and general practitioners can refer people for support;
- improving links to practical support services to address emotional burden from financial and other demands;
- increasing peer support programs to provide emotional support for patients, carers and family members from people with shared experiences;
- improving targeted person-centred approaches, particularly for priority groups including First Nations people, people living in regional/rural areas and adolescence and young adults; and
- enhancing support services for mental health workforce.

About Cancer Council Queensland

Cancer Council Queensland is focused on improving cancer outcomes for all Queenslanders through information and services, advocacy and research. Cancer Council Queensland is a member of the national federation of Cancer Councils across Australia. You can find out more about us at <u>www.cancerqld.org.au</u>.

People affected by cancer, including people who have received a cancer diagnosis and their family and friends, often need support and counselling to cope with feelings of stress, anxiety, fear of recurrence and adjusting to changes. This need may be heightened for people with existing or underlying mental health conditions. Cancer Council Queensland offers counselling services within a stepped model of care for anyone experiencing distress due to cancer.

People affected by cancer and mental ill-health

On average, one Queenslander will be diagnosed with cancer every 20minutes.¹ A cancer diagnosis, and subsequent treatment and rehabilitation can be a highly stressful time for the person diagnosed and for their loved ones. A significant proportion of people with cancer also have poor mental health.² One in two cancer patients experience mental ill-health at some point during the cancer trajectory, including clinically significant emotional distress and/or unrecognised or untreated psychosocial conditions as a consequence of cancer.³ This is associated with the patient's reduction of quality of life, impairment in social relationships, longer rehabilitation time, poor adherence to treatment, fear of recurrence and abnormal illness behaviour.

There are shared risk factors between cancer and mental health issues, especially anxiety and depression, including smoking, alcohol and an unhealthy diet.⁴ People with mental illness are more likely to be diagnosed with certain types of cancer, present at a later stage



and die earlier from cancer. Sadly, there is a higher fatality rate from cancer in people living with a mental illness than the general population⁵ and a higher rate of suicide in cancer patients.⁶

There is a need, therefore, for clinicians working with cancer patients to screen for mental health concerns, including suicide ideation, and offer appropriate services and support. In a similar way, mental health workers can connect clients to cancer screening services for those at risk of cancer.

Counselling support and early intervention can also help identify the underlying cause of psychological distress, and where possible, address these issues. For example, this may involve practical assistance with housework or financial support or connections to peer-support to help with social isolation. As a cancer patient explains:

"Receiving a cancer diagnosis is challenging on its own. But along with the diagnosis, I felt a lot of financial pressure ... I learnt to speak up and let people know when I needed help." (Sandra)

Recommendation: increase awareness of co-occurrence of cancer and mental health issues

Mental health support for people with cancer and their family/carers

Psychosocial support needs to be provided to cancer patients to address their mental health needs across the cancer trajectory. The International Psycho-Oncology Society (**IPOS**) Standards of Quality Cancer Care⁷ underline that psychosocial cancer care should be recognised as a universal human right and quality cancer care must integrate the psychosocial domain into routine care. It is recommended that distress should be measured as the sixth vital sign after temperature, blood pressure, pulse, respiratory rate and pain.⁸

One way of detecting psychological distress is by following Optimal Care Pathways⁹ that show the importance of supportive care screening, assessment and referral to appropriate health providers or organisations required to meet the identified needs of an individual, their family and carers. However, distress screening is not routinely performed at different points in the pathway. It is common for psychological distress to be experienced by people affected by cancer at different times during the cancer trajectory; during diagnosis, treatment, recovery, fear of recurrence or loss. A range of support services are needed to address the type of support required at these different stages. Carers also report feeling psychological distress and requiring support. The wife of a cancer patient explained their need for psychological support during the cancer treatment process:

"....and that's the time when you're more in limbo, because there's no support (...) And that's what I would love to change for more people, not just doctors, but just the psychologist to come and—because it's very emotional—it's such an emotional rollercoaster for him and



for me, because I don't know what to say or don't know how to make it better or to help him through. And I spent many days crying, yeah, I did. It was awful" (Wife of Cancer Patient¹⁰)

Another carer, a mother of a child cancer patient, also noted the need for emotional support:

"The medical care was amazing during (my son) Max's cancer treatment. He also saw a physio and dentist at the hospital and had regular heart scans. However, the one area that I didn't feel was covered was his emotional wellbeing and mental health." – Tamara¹¹

Psycho-oncology support can include specialist clinical care, education, spiritual support, and peer support. For people with pre-existing mental illness, the experience of cancer diagnosis can exacerbate their illness. Additional support may be required to address their needs.

For people affected by cancer and mental illness, it's important to ensure early identification and intervention that is targeted to their need. This may involve self-directed online support, for people with general distress about their cancer diagnosis, or it may involve psychological support for more complex mental health needs. Addressing mental health in the early stages following a person's cancer diagnosis would likely lead to improved outcomes and the prevention of some future mental health problems and associated disabilities. To achieve this, appropriate, affordable, and easily accessible services need to be provided to encourage people with cancer to seek mental health support.

Recommendation: Introduce distress screening for people affected by cancer, including family and informal carers, across various points of the cancer trajectory

Our Cancer Counselling Service for people affected by cancer

Cancer Council Queensland offer Cancer Counselling services with a nurse counsellor or psychologist who are trained to help specifically with cancer-related challenges such as adjusting to life with cancer, stress and difficulty coping, depression, anxiety, sleep difficulties, uncertainty about the future, fear of recurrence and bereavement support. These services are offered to people affected by cancer, including someone who has received a diagnosis as well as their family or friends.

Counselling at Cancer Council Queensland is provided in a stepped model of care depending on the type of support the client needs. Most referrals for counselling support come through our 13 11 20 service and only a small proportion are from GP referrals.

There are different pathways of support offered to people, depending on their need. A person may be directed to a nurse counsellor who provides guided self-help over the telephone. If further assistance is needed to address high levels of distress the person will be referred onto a psychologist. This more intense, one-on-one support is provided over the telephone or face-to-face. These services are offered free of charge with costs covered by Cancer Council Queensland or bulk-billed to Medicare if the client has a Mental Health Care Plan from their GP.

Other forms of support include group programs and online workshops focusing on wellbeing and coping skills. Cancer Council Queensland also offers a Peer Support Program that



brings trained peer support volunteers into our accommodation lodges and selected treatment facilities to provide support and information to cancer patients, their carers, and family members. Peer Support Volunteers provide appropriate emotional support by:

- Providing peer support based on a shared experience
- Reducing feelings of isolation and stigma
- Communicating hope and optimism
- Giving emotional and informational support, and
- Providing information about other supportive services that may be of benefit to the patient or carer.

The aim of the counselling and support services offered by Cancer Council Queensland are to offer short-term, psycho-oncological support focused on the cancer experience and associated anxiety and depression. These services are not intended for people with complex mental health conditions who require ongoing, long-term support. Additional support is needed for people with complex mental health needs.

Recommendation: Increase awareness of Counselling services offered at Cancer Council Queensland for clinicians as well as people affected by cancer

Workforce capacity

While there is recognition of the need for greater psychological support across the cancer trajectory, a key barrier to accessing support is workforce capacity. Many psychology and counselling services are stretched to deal with the current demand and there are long wait times, especially for new referrals.¹² Numerous psychologists across the sector are ceasing to accept new referrals; with a recent survey undertaken by the Australian Association of Psychologists Inc (**AAPi**) showing that 47% of psychologists cannot accept new clients.¹³

The Cancer Counselling Support at Cancer Council Queensland notes that the increase in demand could be due to the conflation of the following issues:

- The COVID-19 pandemic. Prior to the pandemic 1 in 100 psychologists were unable to accept new patients, it is currently reported that 1 in 5 psychologists are now unable to accept new patients.¹⁴ Psychologists who are still able to take on new patients have wait time of up to 6 months.
- Introduction of temporary telehealth Medicare item numbers with the ability to provide sessions via phone in addition to video calls. Prior to the temporary items being introduced, there was requirements on distance between psychologist and patient and the need to see a patient within the first 4 sessions face-to-face. None of these requirements exists with the current temporary item numbers.
- Introduction of up to 20 sessions in a calendar year covered under a mental health care plan. This is resulting in psychologists holding onto clients for longer and



booking concurrent appointments more often, which in turn fills up their calendars with the extended number of available sessions.

Additional pressure is also placed on community counselling services due to lack of availability in private clinics and limited workforce capacity for psychologists to help with complex mental health. The following case illustrates the extent of this problem:

"Recently, a health professional referred a private patient to a community mental health service, as the next appointment availability was over two months' time, the health professional decided to do a second referral to our Cancer Counselling Service. The patient has long-standing mental health issues and needs to be provided support by a long-term mental health service. We are finding this is happening increasing. Health professionals are trying to use short term services like ours to support clients with long term mental health conditions, due to the lack of services and capacity issues within the services that do exist."

On top of this increased demand, there is also recruitment issues and a shortage of available psychologists to meet the specific demands of cancer patients. Cancer Council Queensland has been attempting to recruit psychologists during 2021. This has included three attempts in Cairns, two attempts in Brisbane and an attempt in Rockhampton. From all these attempts, there was only one successful recruitment. Only a handful of applicants who applied for these roles were registered psychologists, most of which were new graduates who unfortunately are not suitable for the role. Those applicants who have had suitable experience generally have no psycho-oncology experience.

These demands place additional pressure on the existing workforce delivering mental health care, with many maximising the number of clients they are seeing in a day. This has associated pressure on the mental health of the staff and could lead to burn-out. According to the AAPi survey of psychologists 87% worked more hours in 2021 than in 2020; and 37% felt their own mental health was a "little worse" compared with the previous year.¹⁵

There is a need for greater training of health providers who provide care to people with mental health conditions and cancer, to recognise issues and refer to appropriate services. Mental health professionals reported not knowing enough about cancer screening and available cancer services.¹⁶ Similarly, people living with a mental illness reported that cancer screening professionals often lacked an understanding of their situation, psychological symptoms and the side-effects of medications used to treat such conditions.¹⁷ Cancer screening professionals reported not having training in mental health.¹⁸ Operational changes, supported by appropriate resources are important to improving the integration of mental and physical health care and improving patient outcomes.

To take pressure on the existing mental health system, greater investment could also be placed on peer support opportunities for cancer patients, family members and carers. Peer Support helps to address the needs of people who require emotional support from people with similar experiences to themselves. If additional support is needed to address more complex mental health needs, then psychology services still need to be available to address this. There is need to increase the workforce capacity for offering psycho-oncology support for people experiencing mental illness and cancer.



Recommendation: Increase awareness of Cancer Council Queensland counselling services so cancer clinicians and general practitioners can refer people for support.

Recommendation: Increase peer support programs to provide emotional support for patients, carers and family members from people with shared experiences.

Recommendation: Recognise the need for qualified psychologists and counsellors who understand both mental health and the cancer experience.

Impact of Covid on mental health and services

The COVID-19 pandemic has placed additional stress and pressure on people affected by cancer. Mental health has been impacted by the perceived lack of guidance and disruptions to the delivery of cancer care, along with economic and social impacts of the pandemic, are effecting people's mental health.¹⁹ Cancer patients and survivors described feelings of stress and anxiety associated with these rapidly unfolding changes, and highlighted lack of communication from their healthcare provider in some instances:

"[My] annual check-up with the surgeon was postponed for the duration. I had my annual mammogram prior to this. . . had to assume that the results were OK as no-one contacted me." (Cancer Survivor)

The added social isolation resulting from avoiding COVID-19, and changes to face-to-face appointments and support people to attend treatment has further exacerbated mental illness for people affected by cancer.

"...while I'm always afraid, I am more afraid as to the treatment as I think my husband won't be allowed [to attend the appointment]." (Patient)

Specialised Support for Priority Groups

Targeted person-centred care is required to address particular needs of priority groups including First Nations people, people living in regional/rural areas and in lower socioeconomically disadvantaged areas and adolescents and young people. For these groups, the impact of cancer is higher and so are the potential mental health impacts. As the following cancer statistics reveal:²⁰

 On average, First Nations people in Australians were 14% more likely to be diagnosed with cancer and 20% less likely to survive at least five years after diagnosis compared with non-Indigenous Australians. Survival for Indigenous Australians was lower in regional and remote areas than in other areas.



- Cancer incidence rates were slightly higher in regional areas, while survival declined with increasing remoteness, at least partially reflecting poorer survival for Indigenous Australians in more remote areas.
- Compared with people living in the least socioeconomically disadvantaged areas, cancer incidence rates for people living in the most disadvantaged areas were 5% higher, but survival rates were almost 20% lower, and cancer mortality rates were over 40% higher.

Adolescents and young people who experience a cancer diagnosis are another priority group. Adolescence and young adulthood (AYA) is a time of great stress and vulnerability.²¹ To best support AYA patients with cancer, a preventative approach to their psychosocial management is recommended that involves a structured, age-appropriate psychosocial assessment throughout the cancer trajectory.²²

To address the mental health needs of priority groups with cancer, a person-centred approach is required that identifies the specific needs of the person with cancer and any significant others, such as family members and carers. Approaches may involve specific peer support programs and other online support services targeted to specific needs.

Recommendation: Improve targeted person-centred approaches, particularly for priority groups including First Nations people, people living in regional/rural areas and adolescence and young adults.

Thank you for the opportunity to provide this submission to the Inquiry. If the Committee has any queries, please contact James Farrell, our General Manager, Advocacy, on

Yours sinderely.

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or

Chris McMillan Chief Executive Officer Cancer Council Queensland



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