

**Submission To:**

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**Submission to**

**Commonwealth Funding and  
Administration of Mental Health  
Services**

**From**

**Amaranth Foundation Ltd.**

**August 2011**

**Introduction:**

Amaranth Foundation was founded in 2009 in response to an identified need in rural and regional communities for an organisation to identify and respond to the social, emotional, psychological and existential needs of people living with advanced chronic and life limiting illness, their families and care givers.

Amaranth has its main office in Corowa and outreach clinics across the Riverina, including Cootamundra, Junee, Temora, Coolamon, Tumut, Adelong, Brungle, Tumbarumba, Albury/Wodonga, Chiltern, Wangaratta, Corowa, Leeton, Narrandera, Griffith, Mulwala and Howlong.

The Foundation's employs Accredited Mental Health Social Work clinicians, who have advanced standing within the social work profession. We believe that our social workers have to have advanced clinical skills in the assessment, diagnosis and provision of planned therapeutic interventions for a variety of high prevalence mental health conditions and psychological problems associated with living with a life limiting or terminal illness.

The Foundation is involved in developing competency standards for social workers in end of life and palliative care, in conjunction with the Australian Association of Social Workers (AASW), Palliative Care Australia (PCA), the Psycho-oncology Cooperative Research Group (PoCoG) and Oncology Social Work Australia (OSWA) as well as providing input into the primary health responses to a national approach to end of life care. The CEO is the Education Executive Chair for Oncology Social Work Australia, and is active in developing national education and Practice Standards for Oncology Social Workers. The Foundation has received Commonwealth funding to further develop the framework and model of primary health care across rural communities for people with advanced chronic and end of life care.

Amaranth, in 2010, developed a partnership with the Respecting Patient Choices Program®, developed by the Austin Hospital, Melbourne, and has developed resources suitable for rural consumers, their families and care givers in Advanced Care Planning (ACP) and Compassionate Conversations®. As a part of this program all staff, including Social Work students and administrative staff are qualified ACP facilitators. We have commenced an initiative with NSW Ambulance in the promotion and support of the Protocol P1 Palliative Care - Care Plan across the Riverina, to support out of hours clinical and psychological support for people with terminal illnesses and their families.

Amaranth Mental Health Social Workers provide case management, psychological screening and assessment as well as the delivery of planned therapeutic interventions, for a range of high prevalence and some more complex, mental health issues and disorders. Referrals can be received from any source, however the majority of referrals are received via other mental health practitioners and the person's general practitioner under the Chronic Disease and Better Access Mental Health initiative, and all services are bulk billed.

**Response to the Discussion paper on Commonwealth Funding and Administration of Mental Health Services – Relevance of Better Access Mental health funding for people with life limiting or terminal illnesses.**

**Whilst mental illness does not threaten life or decrease life expectancy of itself, it can have a severe impact on a person's health and wellbeing<sup>1</sup>.** Many people carry mental illness into their final years of life. Having a terminal illness and a coexisting mental illness is a very complex situation and requires a specialised knowledge and skill base, both in the diagnosis and treatment of mental illness and in end of life and palliative care. Applying a generic mental health response and strategy to this population group will not attend to their overarching and immediate issues relating to their terminal or life threatening illness.

**Mental illness in the terminally ill is under diagnosed and undertreated.** People generally underreport their distress and there is an expectation by health care professionals and the community at large that dying people will and should experience depression, anxiety and sadness. Whilst existential and psychological care are considered crucial to the provision of quality end of life care, people continually report that theirs, their families and care givers needs in this domain are not addressed.

Research has shown that GP's and other medical and nursing clinicians face significant challenges in discussing death with their patients and families, exploring the patients emotional responses to terminal illness and also specific outcomes for the patient and family. This has been shown repeatedly in research conducted by the psycho-oncology group and medical practitioners themselves.

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<sup>1</sup> DoHA (2010) Draft National Palliative Care Strategy : *Supporting Australians to live well at the end of life.*

Some issues identified from the literature in the treatment of people with a mental illness and who have an advanced progressive disease and are terminally ill:

- The utility of psychotherapy to this population group needs specialised training and may not work quickly enough to be of primary therapeutic value for patients with limited life expectancy<sup>2</sup>
- Clinicians report that they are uncomfortable in probing too deeply into the psychological experiences of their patients<sup>3,4</sup>
- Clinicians score reasonably well in identifying people who do not have depression, but they miss those that are depressed unless they present with particularly obvious signs and symptoms<sup>5</sup>.
- The consequences of failing to treat depression successfully can lead to greater difficulty in managing the patient's physical symptoms and helping to resolve social and existential concerns. For many this leads to an earlier admission to an acute or aged care facility<sup>6</sup>.
- Previous research suggests that terminally ill cancer patients who wish to accelerate their death were more likely to report dissatisfaction with emotional support and communication with their health care providers<sup>7</sup>.
- Chochinov et al (2009) stated that **many patients have occasional transient periods of distress or demoralisation during their course of their advanced illness**. Although they are usually not considered to be experiencing a mental disorder during these periods, some may **qualify for a diagnosis of adjustment disorder**. Even if not formally diagnosed with a mental illness or disorder, **many people with significant distress may value the opportunity to receive supportive care addressing the source of that distress**<sup>8</sup>.
- **A life threatening illness is clearly a major stressor that may precipitate an episode of depression in individuals who are particularly vulnerable**<sup>9</sup>

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<sup>2</sup> Chochinov et al (2009) *Psychiatry In Palliative Medicine*

<sup>3</sup> Chochinov et al (2009). pp40

<sup>4</sup> Kelly.B et al (2008) *General practitioners' experiences of the psychological aspects in the care of a dying patient*. Palliative and Supportive care. 125-131

<sup>5</sup> Chochinov et al (2009)

<sup>6</sup> Chochinov et al (2009)

<sup>7</sup> Kelly.B et al (2008) *General practitioners' experiences of the psychological aspects in the care of a dying patient*. Palliative and Supportive care. 125-131

<sup>8</sup> Chochinov et al (2009) pp 50

<sup>9</sup> Chochinov et al (2009) pp51

- The sense that a person is a burden on one's family members is a common experience among the terminally ill and is consistently associated with depression and suicide ideation.
- **Screening for depression does not necessarily lead to better outcomes. The issues related to depression and palliative care are complex when patients may not be screened until too late to introduce an optimal intervention<sup>10</sup>.**
- It is important to accurately diagnose anxiety disorders because they have the potential not only to cause extreme distress but also to interfere with appropriate medical management.
- **Depressed people were particularly at high risk of suicide ideation and are four times more likely to report a high desire for hastened death than those who were not diagnosed with major depression**
- Hopelessness is significantly related to suicide ideation and stronger predictor than severity of depression
- **Pre existing psychiatric disturbance increases the risk for the desire for hastened death and suicide ideation.**
- **How people die matters.** How we care for people at the end of their life matters, as well as the care and support provided to their families and care givers during this time and into their bereavement.

The data regarding mental illness in Australia is equally relevant to the population living with a life limiting illness as with other members of the community. **Having a life limiting illness does not preclude the possibility of also having a pre-existing mental illness or one developing as a result of the psychological impact of the diagnosis or prognosis.** Many people experience symptoms of Post Traumatic Stress Disorder as a result of a serious complex medical condition.

Delivering the right care at the right time and in the right place is a challenge the health system needs to meet. There is an emerging understanding of the need to improve the experiences of people as they approach the end of life<sup>11</sup>. Ensuring appropriate, timely and acceptable care is provided to all Australians at the end of life is not just the responsibility of the palliative care community, but rather everyone's business.

In a recent study on psychological support and interventions following a cancer diagnosis found that all patients diagnosed with cancer had some

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<sup>10</sup> Chochinov et al (2009) pp55

<sup>11</sup> PCA (2010). *EOL Towards Quality at End of Life*. Vol 2.No1.

level of mood alteration, and one in five people had serious symptoms that progressed to a clinical depression<sup>12</sup>

A diagnosis of mental illness in the terminally ill cannot be treated separately from the nature and impact of the person's illness and the reactions of the family and care givers to the realisation of impending death and bereavement. This interrelationship and co-dependence of symptomology is often neglected in mainstream mental health and psychological services. It is for this reason that specialised mental health services have to be available to serve this cohort.

Despite its ubiquitous nature, the literature consistently indicates that psychological distress in palliative patients tends to be under-diagnosed and under-treated. Given its effect on patient well-being, social functioning, perceptions of symptom distress and length of hospital stay, research suggests that the **importance of proper recognition and treatment of psychological distress cannot be overstated**<sup>13</sup>.

Amaranth Foundation therefore believes that quality end of life and palliative care requires that both at a clinical and service development level that people living with a life limiting or terminal illness, their families and care givers deserve care that places them at the centre of that care, and that care is provided in a manner that responds to their individual and collective needs across the care continuum. Current literature and quality systems must drive service improvement to ensure that end of life and palliative care upholds the WHO definition of Palliative care, and that the Australian standards for quality palliative care and good mental health care form the bedrock of this care.

#### **(a) The Government's 2011-12 Budget changes relating to mental health;**

Amaranth Foundation supports changes to the funding of mental health in Primary Health care and is cognisant of the need for a review of the way people access services and the way evidence based support, care and therapy is being delivered. Our social work clinicians have all provided services under the ATAPs program with Divisions of General Practice, however the limited criteria for eligibility and consolidation of services in many of these programs continued to alienate the most vulnerable and needy in many rural communities. This environment which in many cases was about client through

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16 *The Australian* 30/06/10 pg 7 Support: *Depression, cancer's forgotten side effect*

<sup>13</sup> Kelly.B; McClement. S; Chochinov.H.(2006) *Measurement of psychological distress in palliative care*. Palliative Medicine. Vol 20. 779-789

put and administrative processes, and not necessarily about effectiveness or timeliness of the interventions, made working in these clinics very ineffective and unsatisfying. This opinion is well supported by the review of the ATAPs program. Additionally under ATAPs, Social Workers are considered inferior to psychologists and clinical psychologists, both in the professional context and remuneration, when in reality they were seeing the same patients and doing the same work, albeit differently and with a different, but equally competent and professional skill set.

### What is Social Work?

Social work operates at the interface between people and their social, cultural and physical environments. According to the AASW Code of Ethics 2010, Social Work practice may include:

- engaging in interpersonal practice including casework, counselling, clinical intervention; work with individuals, families, partnerships, communities and groups; advocacy; community work; and social action to address both personal difficulties and systemic issues
- undertaking research, social policy development, administration, management, consultancy,
- education, training, supervision and evaluation to further human wellbeing and social development. **In all contexts, social workers maintain a dual focus on both assisting human functioning and identifying the system issues that create inequity and injustice.**

The Better Access model of Mental Health provision allowed social workers to provide services outside the ATAPs service model and provide an effective and evidence based assessment and intervention service that for many patients was preferable to that provided by psychologists and clinical psychologists. It also ensured that people received the care they required in the place of their choosing. It enabled people to access "person centred care". The changes proposed will force rural people to access services that are geographically isolated from their communities, increase their costs and further alienate a person from the support and care that is currently provided in their community. It further forces rural people into a very prescriptive medical model of psychiatric medication regimes, expensive gap payments, long waits for appointments and very little choice of clinician.

**Amaranth is a unique Mental Health service**, providing psychological assessment and evidence based therapeutic interventions for a cohort that is underrepresented, under diagnosed and undertreated. Many GP's do not recognise or seek to refer patients expressing anxiety, depression, hopelessness or even a desire for hastened death, to qualified mental health practitioners.

The proposed changes to the funding model will reduce the argument for GP's to refer people coping with the effects of living with dying, living with uncertainty and living with the effects of complex and chronic illnesses. We have evidence that the psychological care and support provided by Amaranth Social Workers, has reduced crisis admissions to acute facilities, has delayed admission to aged care facilities, reduced hospital stays, increased carer satisfaction and reduced carer strain.

In many instances we have worked with people who have expressed a desire for hastened death, or suicidal ideation in developing a sense of hope and meaning and addressed issues related to hopelessness, despair and demoralisation. This can be effectively managed and provided for via the *Better Access* program. These people would not fit any eligibility criteria for ATAPs, Headspace or EPICC programs. There is evidence that GP's and practice nurses are unwilling and in many cases avoidant in the provision of psychological support for this cohort. In rural areas specialist palliative care services are having their funding reduced or in competition with sub acute models of care, with services concentrated in regional centres and not accessible by the majority of people living in the small rural or remote communities. In these rural services, there are no social workers, psychologists or other mental health practitioners working to support the psychological and psychiatric needs of this cohort.

The *Better Access* program supports people in usual and familiar settings, minimising disruption to a person's life and avoiding the risk of pathologising symptoms of distress. For some people, these services prevent them requiring a stay in hospital, or for the cohort of people with terminal illnesses, can increase total suffering and increase the burden of care.

### **Case management funding.**

Providing funding for case management and increased supportive care is a great improvement in the way mental health will be accessed, however case management is a skill that is poorly understood and poorly delivered currently in many of the HACC and CRCC programs around the region where case management is a core deliverable for HACC eligible clients. There is no requirement that organisations or clinicians understand or have competencies in delivering evidence based case management or care planning. This will further alienate and disadvantage the most vulnerable people in our society who will not have the capacity to critically assess the quality of case management or advocate for more appropriate or timely services. The Case Management Society of Australia (CMSA) has developed Australian Standards and best practice in delivery of case management as a core skill. The Australian Association of Social Workers (AASW) has case



management as a core Practice Standard, but it is only Accredited Mental Health Social Workers that have specialised Mental Health skills and advanced knowledge of mental health diagnoses and treatment modalities. The flexible care packages for people with more complex mental health issues will not receive the care and support they deserve if these standards are not prescribed and met. Psychology does not have case management or advocacy as a Practice Standard or is it considered a core competency of their profession.

It is surprising that the Government chose this model to support those with more complex mental health issues. This may force people to work with several clinicians – a case manager, a therapist, the GP, and to ensure that continuity of care and seamless coordination of care occurs. This model is being developed for people with chronic and complex illnesses in the community, and currently this coordination and continuity is proving to be just rhetoric with little evidence of improved health and psychological outcomes.

#### **Client Feedback.....**

*“This program offers something different – good psychosocial support for the families when they need it... Time to talk to families is so important, it allows us to do the nursing better and worry more about symptom control. Having a social worker was crucial to the success of the psychosocial supports and advance care planning. They knew when to refer and we worked well as a team. That’s the best approach – working as a team. ” Claire (Community Nurse)*

*“I was hoping a semi trailer would just hit me” When my husband died of dementia in a facility, I thought that I couldn’t go on. I thought that I just couldn’t handle life with out John. The GP sent me to the Amaranth SW. I really gave thanks for that day they came. They gave me a sense of being normal and having hope. I could talk about John’s dying and how I had cared for him for so long. They understood when I told them I felt I had failed him..” Jean (husband died of dementia in a Residential Aged Care Facility)*

*“When my mum, Maree, was told she was palliative it was like we had entered a big black hole. Heading in to a rural community where palliative care appeared to be outside everyone’s boundaries, along came Amaranth and without your endless support, both emotional and social, my family would not have been able to care for mum at home. Through your guidance mum was able to die with peace and dignity and surrounded by her family at all times and we were so proud to be able to do this for such a beautiful lady and mother. I am so happy to see you have Amaranth in place and I know that you will help so many more families out there who are swept in*

*to this 'black hole'." Lynette (Daughter of Maree who died of Melanoma and secondary's)*

*"I was told to stop work and get my things in order. I was told that I may have 12 months. The Amaranth Social Worker has helped me to work through any anxiety, to be mindful, to break feelings down to what they really are. I am more hopeful now. I know that being anxious about leaving my children, and feeling that I have no control are just feelings and thoughts. I can take charge and not just let things happen. I am not dying, but living with dying. That's what our conversations have shown me."*  
*Christine (Mother 42, with ovarian cancer and 2 teenage children)*

### **Costs of service delivery**

According to a report by the APS, the current maximum cost to the taxpayer for 18 sessions of psychological services from a psychologist, social worker or occupational therapist, ranges between \$1468.80 (generalists) to \$2156.40 (clinical psychologists). The Department of Health and Ageings' own figures estimates that, by itself, the cost of one bed day in a specialist mental health facility in 2009 was \$1002 alone.

It has been repeatedly proposed by the Government since the Commonwealth budget was released that consumers who require more than 10 sessions of psychological services will still be able to access a total of 50 sessions with a psychiatrist per year. Psychiatric services are clearly of high value to some patients, however the cost of these services, ranging from \$250 to \$400 per consultation, are far more than the cost of services provided by social workers, psychologists and other mental health professionals. Our experience is that few psychiatrists offer therapeutic interventions, relying on medication and other more invasive regimes. The availability of psychiatrists in rural and remote communities is variable, and not many people are willing to be referred to these services, or fit the eligibility criteria for their care. **In the Riverina there are very limited psychiatrists in the public sector.** Even though some GP's have embraced telehealth and the new Medicare items for specialist consultations, this does not replace effective psychological support that is face to face and within the person's own community. My experience has been that psychiatrists do not work effectively with the multidisciplinary teams within communities, further alienating and siloing the person's clinical and mental health care.

### **Two tiered system**

It appears that the two tiered system for psychologists and clinical psychologists and also the far reduced rebate for Accredited Mental Health Social Workers sets up a system that is confusing and discriminatory. Many of

the clinicians are providing similar services to similar clients, with similar costs and very similar expertise. To say that a clinician, accredited or registered by their professional organisation as having the necessary mental health expertise to work with this cohort, does not have the necessary skills to provide the evidence based services required on an individual basis, judged by the rebate paid in recognition of expertise and skill, is admitting that the system is flawed and unable to ensure quality assurance systems across all clinicians. The tiered system also fails to recognise the skill of social workers and occupational therapists in working with people from a rehabilitative and holistic or systemic approach, favouring the biomedical problem saturated model preferred by psychologists, clinical psychologists and psychiatrists. The rebate for social workers fails to take into account the additional costs providing services to rural consumers.

This disparity needs to be addressed and the rebate paid to social workers, occupational therapists and psychologists – clinical or counselling, needs to be equitable. An additional rural component to the rebate needs to be applied to ensure that rural and remote clinicians are able to continue to provide the high quality service that rural consumers deserve.

### **Reduction in psychological sessions**

The reduction in the number of psychological sessions to 10 and the removal of the "exceptional circumstances" option that is so necessary for those individuals suffering from more severe mental disorders such as the psychotic disorders, and in the terminally ill cohort, when death becomes imminent and there is evidence of increased psychological distress, hopelessness, demoralisation, desire for euthanasia/suicide ideation, despair or depression, leaves these people without further options for their care. This is unacceptable and will further add to their distress if they have already engaged with a mental health clinician in that calendar year. It is not appropriate to refer these people to a psychiatrist at this point, but the exceptional circumstances provision enabled them to continue with the same clinician that had built up rapport, and ensure that their care was continuous and placed them at the centre of this care.

Many terminally ill people disclose previous sexual assaults, experience recurrent and multiple losses, describe trauma and long term distress that often does not become apparent early in the sessions and becomes more important as death approaches. Many people take 5-6 sessions to gain trust and rapport with their clinician, so then to only have 4 sessions to provide an

effective intervention for them for a range of complex issues is disrespectful, lacking in evidence to support such restrictions, and far too prescriptive. It will cause immeasurable harm to this cohort.

Taking money from one group of critically unwell people (and not just the worried well, as described in many reports) to support non tested mental health provision in another area, such as the case management approach being developed, is irresponsible and reprehensible. It is a retrograde step for mental health in this country.

The Commonwealth Department of Health and Ageing, Palliative Care section, funded Amaranth to pilot a model of "Primary Health Specialist Social Work Mental Health service delivery", to identify and support rural people who have terminal illness, their families and care givers ( the Unit of Care) and a co-existing mental health problem. This model has been extremely successful with over 350 patients and care givers referred to the service over the past 18 months. In previous research projects (2006-2009) where this model was being tested, over 700 people were effectively supported until death and their families into bereavement. The sustainability of this model was ensured by working effectively with the person's GP and local multidisciplinary health care team, under the Chronic Disease TCA and Better Access Mental Health Care Plans. Changes to the Better Access program will put the viability and proved effectiveness of this model in doubt.

The *Better Access* initiative has allowed psychological service providers, such as Amaranth Mental Health Social Workers, in regional and remote areas to offer Government subsidised services to local people. With the proposed policy shift towards agency based services at Headspace, EPICCC, and other agencies, there will naturally be a resulting move away from the local access that was previously available for people in rural and regional Australia. Service provision in large centres benefits a select cohort living in densely populated areas, however, this should not come at the cost of psychological care in geographically distant locations. It is unacceptable to rely on web based approaches as a replacement for face to face services in remote locations, especially when we currently have programs in place that allow for practitioners in distant locations to offer high quality psychological services in a cost effective way. This implies that a one size fits all approach will be good enough. On top of the cost shifting away from services in remote areas, the proposed change in policy will inevitably result in increased travel costs for people who will be forced to access centre based services in more

populated regions. The fee for service structure of the *Better Access* program has meant that consumers can receive services in their own communities, retaining a sense of personal dignity, regardless of their circumstances. The shift towards funding NGOs to provide agency based services, or requiring people to see a psychiatrist rather than a psychologist, represents a significant departure from the purpose of the program.

For people living with life limiting and terminal illnesses, their families and care givers, the *Better Access* program in its current form was beginning to offer some hope in the identification, assessment and provision of high quality, evidence based therapeutic interventions for a range of serious mental health problems and psychological distress.

*“I did not understand what help was available. We had never needed assistance before, while aware of its existence, we didn’t realise what it really was. We`are just so grateful for all the help we are receiving. The Social Workers came and talked through issues that were really difficult, but we all wanted to do this. It is the Elephant in the Room, isn’t it. Our GP was involved too. Please continue this service in our region. We could not have kept Mum at home for so long without it. We have struggled emotionally, physically with Mum’s condition but it was possible due to this program,. I cannot thank Amaranth Foundation enough for their overall love, expertise and support of our family. The attention and timely response to needs is incredible. Everybody involved is to be commended. I only hope that these programs are extended to meet overall increasing needs in our community” (Female daughter 52 yr old caring for her Mother with advanced dementia.)*

*“Palliative Care is only available 5 days/week during office hours only. All extra time is not approved, so if clients require any services they have to call OOO. Continuity of care is an issue if only it could be provided during working hours. We don’t do the psychological care well enough though. We need more support in this area. People suffer unnecessarily and are very alone. If there is a statement about suicide, then they have to ring Assess Line and that is very medically based – not what people want. They don’t understand about terminal patients.” (Community Nurse in small rural community of 5000 people).*

*“Suicide ideation in this client group is very real, but it needs a different response – it can be prevented with good mental health care early in their disease progression. It can be talked about openly, and people helped to feel less hopeless. The reasons are similar to suicide ideation in the general population, but these people need something different – they are facing death anyway eventually. They need to talk about dignity, hope and meaning. Amaranth is addressing this very important need.” (Intern psychologist in rural community.)*

*Recommendations:*

1. *That the fee for service Better Access program with 12 sessions being provided and the capacity of an additional 6 under exceptional circumstances remain unchanged*
2. *That parity and equity in reimbursement for Accredited Mental Health Social Workers, Clinical and Counselling Physiologists be addressed, recognising equal work for equal pay.*
3. *That an additional rural component be added to the Better Access rebate for rural mental health clinicians in recognition of the increased costs of servicing rural consumers.*
4. *Case management programs being developed ensure professional competence in delivery of case management as a core skill set, with knowledge of essential elements and professional skill sets required. Quality assurance programs and evaluations of the effectiveness of these programs to be embedded in program delivery*
5. *Additional referral pathways to Better Access be investigated for rural people to address the inequity of timely availability of GP's. In many instances, patients have had to wait 6 weeks to see a GP to receive a referral for psychological services, which in this population, can be too long to wait. We recommend that 3 sessions be allowed to be funded with a Mental Health clinician prior to a GP referral to enable accurate screening and assessment of mental health problems or distress for people with terminal or advanced chronic illnesses. This would be similar to a shared care model of mental health care for people with advanced chronic or terminal illnesses.*
6. *That people with life limiting or terminal illnesses be recognised as a special sub set of consumers having mental health issues and psychological distress deserving of high quality, evidence based interventions focussing on preserving dignity, hope and meaning and addressing distress, despair and demoralisation.*

Thank you for the opportunity to provide input into this important Government Inquiry into the funding and administration of Mental Health Services. I would be more than happy to discuss any of the points in this submission and explain further this model of specialist mental health care provided to people with advanced chronic or terminal illnesses under the Better Access model with you.

Yours sincerely,

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CEO

**Amaranth Foundation**