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Kate Grundy Chair Palliative Care Advisory Committee

Palliative Care New Zealand Scoping Report

Thank you for the opportunity to comment on the PCAC Scoping Report.

Our general comments are that we welcome the initiative to create an umbrella organisation to oversee the delivery of palliative care services in New Zealand. We believe the structure and mechanisms detailed in your report provide an excellent framework for the development of such a body. However, we offer the following comments for your consideration.

At present, your proposal is to have one representative on the Board to provide expertise on "psychosocial" aspects of palliative care. We believe it is over-simplistic to group the specialist disciplines encompassed by the term "psychosocial" under one heading. We do not believe one individual would have the knowledge and experience to adequately represent psychological, social, and spiritual specialties. We believe that the psychological, social, and spiritual needs of patients and their families in palliative care need to be recognised as distinct specialties, and given equal status to medical needs in terms of expert representation on the Board. We note that the WHO definition for palliative care for both adults and children (as outlined in your proposal) advocates a multidisciplinary team approach, and we believe that the Palliative Care NZ Board should reflect this in its representation.

In terms of our own specialty (mental health and psychological wellbeing), even a brief search of the literature (see below) indicates that mood disorders, anxiety, personality disorders, suicidal ideation, and cognitive impairment are common amongst the medically and terminally ill. Prevalence rates for major depression in palliative care are much higher than in the general population, ranging from 20% to 50%. Of much greater concern, the literature indicates that mental health problems often go undetected and untreated in palliative care settings. Emotional distress, adjustment, loss, death anxiety, pain, family dysfunction, and unresolved lifespan issues are also important psychological difficulties in palliative care.

A medical response (pharmacology) is one answer, but it is not always appropriate or effective, and may not be welcome to patients who are already heavily medicated or who do not wish to experience the possible side-effects of medicines during their palliative care. Access to community mental health team expertise is unlikely and, in any case, grossly inappropriate in the palliative care setting. We believe it is vital that the multidisciplinary team in palliative care include mental health professionals, and in particular, clinical psychologists. Evidence-based psychological therapies provide an effective and medication-free alternative, not only for patients and their families but for clinical and support staff also. We are concerned that mental health may be overlooked in service delivery, or that care teams will try to meet this need with 'supportive counseling', unless there is appropriate expertise on the Palliative Care NZ Board.

Furthermore, adolescents and children in palliative care, and as part of the wider family, require their own specialist assessment and treatment for psychological and psychiatric distress. These age groups require different approaches compared to working with adults. In addition, adolescence is becoming recognised as a distinct phase of life, and assessment and intervention of this age group requires its own expertise. Therefore we believe that the specialized mental health needs of children and adolescents (as being unique from adults and from each other) should also be recognised by specialist expertise at Board level.

We would therefore strongly recommend that Board membership includes at least one mental health professional, to ensure adequate expertise on the appropriate assessment and treatment of psychological distress and psychiatric disorder in palliative care. We also recommend that the Board includes people who recognise the separate specialist needs of children and of adolescents.

Yours sincerely

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