Mr Chris Tallentine MLA
Chair
Joint Select Committee on Palliative Care in Western Australia Legislative Council
Parliament House | 4 Harvest Terrace | West Perth WA 6005
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5/07/2020

Dear Chris and Committee

Response to Inquiry into Palliative Care in Western Australia

Thank you for the opportunity to present our opinions of the palliative care needs of Western Australians, particularly those living in Albany and the surrounding Great Southern district of regional Western Australia. This submission is in two parts, firstly focussing on Albany Community Hospice specific needs, and secondly expounding our recommendations for regional palliative care, based on our =Great Southern experience

Part 1; Albany Community Hospice, (ACH) is held in high regard by the citizens of Albany and its surrounding community, and was also commended highly by Hon Roger Cook MLA, Minister for Health (visit February 2020) and the Life Choices Joint Select Committee (visit 2017-18). All acknowledge that our unique community owned and operated facility, that is a nationally and State accredited private hospital, is committed to compassionate and clinically excellent palliative care for patients and their families experiencing the end stage of life.

ACH also provides excellent palliative care each year for approximately 150 patients, (diagnosed with a potentially life- limiting illness), who need symptom control, pain management or clinical care (transfusions, infusions etc) or for respite care for their loved ones/carers. Our provision of excellent palliative care is why 55% of our patients go home after 5 - 8 days, until they need further symptom management, or because they wish to die at home.

In this part of our submission, there are 5 aspects for your consideration. They are dealt with below;;

1. Adequacy of bed day rates
    - Whilst our bed day rate, negotiated with WACHS in fixed-term contracts, must remain confidential as per our agreements, it is recognised by both parties to be less than the actual cost of service provision. This has been the case for the whole 30 years that ACH has operated, to the extent that up to $250 000 is raised annually to

ensure ACH remains operational. This is a huge ask of the community and it is to the absolute credit of local businesses and volunteers that extensive selfless efforts are made each year to see Hospice remain financial.

- The cost of operating a small hospice is higher than operating larger ones. ACH urges the Government to acknowledge the important purpose and value of smaller hospices. They customise and personalise palliative care to specifically meet the needs of patients, ensure they have access to their own doctor, and save them and their families the angst of relocating, or dying in unacceptable and unsupported circumstances.

Recommendation;The quality of palliative care and the quality of life to the end of life needs to be recognised and a higher bed day rate, closer to the actual cost of provision, should be funded.

2. Seamless transitions from a patient's perspective is essential for palliative care patients.
    - Please can the Government address the 'red tape' and other administrative barriers so that transition across each patient's services can be cooperatively planned and seamless in the patient's experience.

    Recommendation; This requires health services to commit to trust and a willingness to share across services with the focus being on the patient at the centre.
3. Increasing general practitioner skills in palliative care by facilitating their access to specialist palliative care facilities like Hospice , is integral to improving the delivery of compassionate and clinically excellent palliative care to patients generally.
    - As an example, ACH has 56 accredited GPs, who have met our palliative care admission parameters, as approved by our Medical Advisory Committee. This ensures they gain increased exposure to new treatment trends and specialised experience in palliative care when they have patients in the Hospice.

    Recommendation; Facilitating access to Hospice facililities and increasing training to improve all GPs' palliative care skills is beneficial to all patients needing palliative care in the community.
4. Importance of community partnerships in providing pal-care services in the regions.
    - ACH has operated successfully for 30 years, meeting the needs of around 250 families annually. In that time ACH has developed administrative and financial systems and corporate knowledge that could be invaluable to other communities aspiring to provide hospice care. ACH is willing to share our expertise for a modest fee, and to support the establishment of Hospice care in the regions.
    - It is our recommendation that regional WACHS boundaries be flexible to enable such cooperative arrangements to proceed – for example Esperance is on the brink of seeking to establish a hospice, potentially with funds from a local foundation. ACH has offered mentoring guidance and is considering provision of contracted payroll, administration etc. One of the potential 'barriers' is ACH being in WACHS Great Southern and Esperance being serviced by WACHS Goldfields.

    Recommendation; That 'in principle support' and streamlining of processes be given for a hub and node model of hospice care. This is an opportunity to ensure many more regional people get improved palliative care, especially for end of life, within or near their home health centre with access to their own doctors.
5. Importance of having centres of excellence in the regions such a ther ACH model whereby we have employed a research nurse for 2 years, using funds from a generous benefactor.
    - Having a focus on research is enabling us to liaise with Palliative Care Clinical Studies Collaborative (PaCCSC), under the University of Technology Sydney

(UTS) University working with its IMPACCT centre - The Centre for Improving palliative, aged and chronic care through clinical research and translation. IMPACCT focuses on optimising the health and wellbeing of individuals living with life-limiting illnesses and their families. This ensures ACH aspires to the highest standards in palliative care, and, inspires all our nursing staff to be innovative and accountable and to feel increased professional value.

- ACH is contributing to developing a strong evidence base for the delivery of high quality palliative and end of life car, with a unique and particular focus on how palliative care translates in the regions

Recommendation; Allocation of funds for regionally focussed palliative care research is urged.

6. Importance of volunteers in providing rural palliative care and organisations like ACH need for support of their training and recognition.
    - ACH has up to 80- volunteers registered and trained to ACH induction standards. These volunteers fulfil various roles that add value to our guests and families experience and help ACH with roles like reception meet and greet, preparation and serving of some meals, handyman work, gardening and patient comfort and support.
    - Whilst our volunteers are willing and generous and capable, there are aspects of listening, assessing, empathising that need particular skills that would be invaluable in improving their care role with patients.
    - They especially need guidance in how to understand the specific needs of each dying person.

    Recommendation; that funds and resources be provided to support volunteer training in palliative care.

In the second part of our submission, we express concern that there is insufficient support for many patients who have been diagnosed with a potentially life-limiting illness.

1. After such a diagnosis, many patients and their families aim to continue living at home, with a family member (or several), who live in the same residence, becoming the principal carer.
    - As symptoms worsen, it can become untenable for the carer and the palliative care provided is likely to be seriously compromised.
    - The carer may also be elderly or frail, and the emotional and physical needs of their loved one become a burden and impact seriously on the carer's health and wellbeing.
    - Instead of the end-stage-of-life being a compassion-filled time of comfort, it becomes stressful and exhausting for both the patient and carer.

    Recommendation 1; Provision of funds for in-home paid respite care for up to a week in every 2 months is needed. (This used to be available but appears to be hard to acquire now.

    Recommendation 2; That facilities, like ACH, be approved for funding under WACHS and Private Health for the provision of respite palliative care – also for one week blocks, in which symptom stabilisation can occur, and the carer can be revived.

The Board, Management and clinical team of Albany Community Hospice continues to be passionately committed to providing the best palliative care to as many patients as possible in our region. We urge the State Government to support us as we keep on seeking sustainable options and keep on striving for excellence in palliative care.

Yours sincerely,

Jane Mouritz and Fiona Jane
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Albany Community Hospice