



S·A·R·R·A·H

Services for Australian
Rural and Remote Allied Health

**Submission to the Senate Community Affairs
References Committee**

Inquiry into Palliative Care in Australia

February 2012

INTRODUCTION

Services for Australian Rural and Remote Allied Health (SARRAH) commends the Australian Government for its efforts to understand and hopefully reform the palliative care system across the nation and are thankful for the opportunity to provide a unique Allied Health Professional perspective to the debate.

SARRAH is nationally recognised as a peak body representing rural and remote Allied Health Professionals working in both the public and private sectors. SARRAH's representation comes from a range of allied health professions including but not limited to: Audiology, Dietetics, Exercise Physiology, Occupational Therapy, Optometry, Oral Health, Orthotics and Prosthetics, Pharmacy, Physiotherapy, Podiatry, Psychology, Radiation Science, Social Work and Speech Pathology.

These Allied Health Professionals have significant roles and provide a range of clinical and health education services to individuals who live in Australian rural and remote communities. Allied Health Professionals also work in other human services areas such as education, disability, aged care and child protection and family welfare systems. Consequently, this submission from an Allied Health Professional perspective is multiprofessional and multisectorial in nature. Allied Health Professionals are critical in the management of their clients' health needs, particularly with chronic disease and complex care needs. Allied Health Professionals are an integral part of palliative care services as they work across the primary and acute health care services continuum.

The Allied Health Professional, especially in rural and remote areas across Australia, is required to adapt to workforce shortages and is well versed in the interdisciplinary and team approach to health care, especially for management of chronic disease and to improve health behaviour. Patients and their families requiring palliative care services rely on their Allied Health Professional to be confident and competent in a range of techniques and interventions which would be considered specialised within a metropolitan context.

It is noteworthy that in many smaller and more remote Australian communities, people in need of palliative health care are reliant on nursing and allied health services because of workforce issues. When these health professionals are well supported the need to access specialist and hospital services is reduced. Travel away from the local community and associated support is expensive and distressing for the patient and their families and can be avoided.

It is repeatedly demonstrated that skilled and supported allied health services are essential to improving the quality of life and better health outcomes for rural and remote Australian communities.

SARRAH maintains that every Australian should have access to equitable health services wherever they live and that allied health services are basic and core to Australians' primary health care and wellbeing. It is the Government's responsibility to ensure the provision of this care.

This submission outlines a definition of palliative care and the current need for allied health services in particular across rural and remote Australia.

DEFINITION OF PALLIATIVE CARE

For the purposes of this submission, SARRAH is using the World Health Organisation (WHO) description of palliative care as:

'being an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness; and
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

WHO Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multiprofessional approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

CURRENT NEED FOR ALLIED HEALTH SERVICES

It must be clearly stated that in Australia, allied health services are under-utilised in the current health care system which is effective at channelling people requiring palliative care services into the acute tertiary service system, but which may ignore less expensive wellbeing and health services along the continuum of care. A large proportion of these services could be based around allied health models of care where the patient and their family or carer are empowered in self-management yet feel comfortable to quickly access the need for specialist Allied Health Professional attention.

Those who live in rural and remote areas have additional issues to consider when managing life-limiting complex illnesses. Allied Health Professionals caring for these people also have additional considerations due to fewer community resources to access. Patients and families have to manage alongside many challenges including access to services, transport, time away from home for investigations and treatment. Isolation and loneliness can also be a very real issue for those in rural and remote areas. SARRAH believes that a rehabilitation approach is important when considering palliative care services.

Why are allied health services required by people with life threatening illnesses?

We present cancer and its treatment as an example of why allied health services are required by people with life threatening illnesses. Cancer and its treatment can have a major impact on a patient's ability to carry out usual daily routines. Activities most people take for granted such as moving, speaking, eating, drinking and engaging in sexual activity can be severely impaired. Cancer rehabilitation aims to maximise physical function, promote independence and help people adapt to their condition. A range of Allied Health Professionals provide rehabilitation services and, through developing self management skills, patients can take an active role in adjusting to life with and after cancer. Allied Health Professionals providing rehabilitation for cancer patients may include Occupational Therapists, Physiotherapists, Dietitians, Speech Pathologists and Exercise Physiologists.

There are other cancer related symptoms which can require therapeutic intervention from Allied Health Professionals including anorexia, breathlessness, fatigue, weight loss, asthenia, pain, lymphoedema, loss of mobility and function or impairment in activities of daily living, communication and swallowing difficulties. The symptoms vary according to the stage of the cancer journey and cancer type.

For example, cancer cachexia or 'wasting syndrome' is a complex condition which can develop in many types of cancer, more commonly lung cancer and cancers affecting the digestive system. It is most common in advanced cancer, occurring in up to 60% of patients, but can also appear at any stage of the cancer pathway. The treatment of cachexia requires a multiprofessional approach including Speech Pathologists, Physiotherapists and Dietitians. Swallowing difficulties, or dysphagia, are experienced by people who have been treated for head and neck cancer and the seriousness of effects depends on the type and nature of treatment and size and location of the tumour.

SARRAH agrees with the Productivity Commission's finding that palliative care services should be core to all aged care services and Allied Health Professionals are considered essential to all aspects of palliative care.

All palliative care patients are likely to need allied health services at some stage in the disease or illness journey. Patients' needs differ according to their individual problems and may require assistance from Allied Health Professionals during active treatment, in advancing disease, during remission, long after treatment has ended or at the end of life. Palliative care requires a multiprofessional team approach because of the variety of potential problems patients may face during the course of illness.

One of the challenges facing patients with chronic and life threatening illness in rural and remote communities is quick access to allied health services at times of change in their disease state. Travel is sometimes difficult and outreach services in Australia are difficult to maintain. Palliative care services need to support patient partnerships that include negotiating clear expectations when their health deteriorates to the level where self control is no longer an option. SARRAH supports the work being done at a national level on advanced care directives. Allied Health Professionals must be involved at assessment of patients' needs at the various stages of the palliation pathway including end of treatment, survivorship and end of life to ensure that the appropriate service is identified and provided as circumstances change.

In a 2004 study in the UK to examine rehabilitation goals of cancer patients, participants emphasised that reviewing goals at different stages of their 'cancer journey' was crucial, because their needs and wishes changed throughout the trajectory of their illness. Results also showed that 65% of goals were related to self-management. If these findings were extrapolated to an Australian context it is apparent that access to allied health services is currently far below patient expectation; even in a metropolitan setting.

Allied Health Professionals are central to maximise patients' ability to function, promote their independence and help them adapt to their condition. The aim must be to maximise patients' dignity and reduce the physical, psychosocial and economic effects of chronic disease. However, the use of Allied Health Professionals in palliative care requires a better understanding by the workforce, service managers and planners and people with life threatening illness or disease because much more can be done to divert patients from the acute tertiary care system.

A further challenge facing palliative care patients residing in rural and remote Australia is access to specialised equipment allowing them to be cared for at home. Equipment such as electronic beds and pressure care mattresses, wheelchairs or hoists and slings are often expensive and/or difficult to access for patients residing in rural and remote settings. Whilst SARRAH acknowledges the Australian Governments funding allocation to improve palliative care support and services it is difficult to obtain information on what proportion of program funds are allocated to people residing in rural and remote Australian communities. Palliative Care Australia were asked for information on this matter however they do not hold national data on the proportion of funds allocated to these communities. Consequently, it is SARRAH's belief that all national palliative care policies and programs must be 'rural and remote proofed' for people residing outside metropolitan areas.

Why aren't palliative care patients receiving appropriate access to allied health services in rural and remote Australia?

The reasons for the current lack of involvement by Allied Health Professionals in palliative care in rural and remote Australia are complex but this submission focuses on just three primary causes.

The first is the undersupply and generally high turnover of Allied Health Professionals in regional, rural and remote communities. Although the workforce initiatives have come a long way since the 1990s the demand and need for services has grown exponentially and there are still serious supply problems of allied health services. Palliative care patients and their families need immediate access, at times outside of business hours, and this core service should be available seven days a week.

SARRAH recommends that Commonwealth funded initiatives designed to strengthen the allied health workforce in regional, rural and remote Australia be maintained and enhanced to better support palliative care services.

A secondary recommendation is that the Commonwealth use existing programs such as the Medical Speciality Outreach Assistance Program to ensure better access to allied health services to Aboriginal and Torres Strait Islanders who require palliative care services.

The second relates to the structure and systems supporting Australia's health care system which still relies heavily on coordination of all health services by a medical practitioner. Allied Health Professionals practice autonomously and do not always require a medical practitioner's referral. However, when people require allied health services and are unable to find them, they go to a medical practitioner for cross referrals or as a substitute for the more appropriate allied health intervention. Because the medical profession is effective at funnelling patients through the community systems into secondary and tertiary services, patients can be quickly referred up the system requiring greater and more costly services which could be prevented by access to the appropriate allied health service in the first instance. To counter this system requires a sensible and thorough assessment process by front line health care professionals whether they are Nurses, Doctors or Pharmacists. This lack of understanding and the misconception that allied health services are additional and not integral to patient care means that Allied Health Professionals contribution may not be valued as a service by patients and other health professionals.

The solutions to the issues described above are complex but it is essential that all Commonwealth initiatives acknowledge the multiprofessional nature of the health workforce. Critical macro reforms such as the establishment of Medicare Locals provide a major opportunity to support palliative care services in the bush and must take affirmative action to support allied health participation. The national coordinating body for Medicare Locals should not be a rebadged Australian General Practice Network organisation but rather focus on a multiprofessional approach to the delivery of health services.

SARRAH recommends that the Commonwealth use the Medicare Locals as a platform to strengthen multiprofessional palliative care services in the bush.

Another key area of national reform currently being implemented which will positively improve palliative care services is the Patient Controlled Electronic Health Record (PCHER).

SARRAH has been involved in the extensive consultation process and is excited by the opportunities that will be offered to patients with chronic and life threatening illness in terms of service coordination by linking disparate parts of health and wellness services system. The PCHER will give enhanced control to patients who need a range of palliative care services.

SARRAH recommends that the introduction of PCHER have specific targeted promotion to patients in need of palliative care services in regional, rural and remote Australian communities.

The third reason is that palliative care is currently considered a speciality area of practice requiring additional expertise and competence not available at the generic undergraduate levels in most allied health courses. A great deal of work needs to be done under the auspice of such agencies as Health Workforce Australia in partnership with Allied Health Professional organisations like SARRAH and the Australia and New Zealand Allied Health Leaders and Managers Organisation (AHLANZ) to develop a competency framework and associated credentialing process so that access to response and appropriate services can be provided within patients local community wherever possible. There are also telehealth considerations which will be assisted, hopefully, by the National Broadband Network rollout.

SARRAH recommends that a specific project be supported by the Commonwealth and undertaken in partnership with Allied Health Professional organisations to develop a competency framework for palliative care providers with an emphasis on strong multiprofessional practice.

Strong multiprofessional allied health practice within palliative care can be described as:

- A focus on patient centred goals which aim to optimise independence, improve quality of life and mood, ameliorate symptoms, maximise wellbeing, and facilitate an individual remaining in their preferred place of care.
- A multiprofessional approach across organisations to promote continuity of care.
- Continual assessment of an individual's needs and strengths.
- Forward planning – anticipating the needs of the individual.
- The ability to react quickly to changing needs.
- Supporting individuals and their families through periods of transition.
- Assisting in dealing with issues such as a reduction in ability and preparing for end of life.
- Swift and timely access to equipment and resources.
- Competent and confident staff.
- Patient/carer education.

The impact of effective allied health services on the health and wellbeing of palliative care patients.

Effective allied health interventions have a significant positive impact on the lives of people living with cancer in many areas including quality of life, physical fitness, mental health,

fatigue and pain. Of the tens of thousands of Australians diagnosed with cancer every year, one-third live in rural and remote areas. But cancer sufferers in remote areas are 35 per cent more likely to die within five years as compared to patients in major cities. As well as a higher mortality rate, rural residents have higher rates of bowel and prostate cancer. Other diseases such as cardio respiratory illness have much higher prevalence rates in rural and remote communities. Patients with cancer and cardio respiratory illness have proven improvements to health and well being as well as quantity of life through allied health interventions.

'I feel safer and more confident. I'm able to get on with life. Not being independent got me down'.

Preventative interventions.

- Evidence suggests early physiotherapy to be an effective intervention in the prevention of secondary lymphoedema in breast cancer patients after surgery.
- A 2005 study in the United States showed that rehabilitation intervention by means of nutrition education could improve both physical and emotional wellbeing in breast cancer patients post treatment.
- Well resourced cancer rehabilitation teams can reduce excess bed days and possibly readmission rates.
- The benefits of exercise and physiotherapy programs for patients with advanced pulmonary disease are well known.

'Without my Dietitian I just wouldn't have known what to do. Because of radiotherapy, my mouth was full of ulcers and blisters and hurt like you wouldn't believe. I couldn't really talk or swallow. She gave me some supplement drinks that helped tremendously. I just cried till she came along... She understands how important good tucker is to me.'

Restorative and supportive interventions.

- There is evidence that physical activity interventions by professionals including Physiotherapists and Nurses improve patients' quality of life, strength and fitness and reduce fatigue.
- A 2004 study on the effects of nutritional management in cancer patients demonstrated that nutritional support intervention led to significant improvements in energy levels, exercise capacity and weight gain.
- Evidence suggests that intervention related to diet leads to improvements in body weight and survival for people living with cancer.
- In England the Macmillan Nottingham Lung Cancer Care service has shown that intervention from supportive and palliative rehabilitation care services including Dietitians, Occupational Therapists and Physiotherapists improved survival, decreased length of hospital stay and had a positive impact on place of death. Between 2006 and 2009 the number of patients who died within a 6 month period of follow up fell from 74% to 58%, average survival increased from 52 days to 109 days

and there were fewer deaths in hospital. The total number of inpatient days decreased from approximately 1500 to 650 days.

'The guidance and reassurance that I'm receiving has given me the confidence to overcome not only physically but especially emotionally my fears in moving forward and in facing the changes in equipment which are necessary for my deteriorating condition'.

CONCLUSION

Australia should be justly proud of its health system which offers a range of palliative care services however these services across the nation are fragmented and not coordinated. Access to allied health services by patients requiring palliative care is not adequate and access is even worse in regional, rural and remote Australia.

The challenges experienced by all health professions in rural and remote regions to support palliative care patients in their community currently lead to the increased likelihood of admission to institutional care in metropolitan areas. The low home death rates in rural settings may pose particular hardship for rural families who may need to travel extensively or temporarily relocate to be closer to the hospital where their loved one is dying.

Those who live in rural and remote areas have additional issues to consider when managing life-limiting complex illnesses. Staff caring for these people also have additional considerations due to fewer resources to access. Patients and families have to manage alongside many challenges including access to services, transport, time away from home for investigation and treatment. Isolation and loneliness is a real issue for those in rural and remote Australian communities.

There is strong evidence about the health, social and economic benefits of allied health services component in supporting people with chronic and life threatening illness or disease.

SARRAH, as the peak body representing Allied Health Professionals delivering health services to people residing in rural and remote communities across Australia, is well positioned to work with Governments and other stakeholders to address the issues raised in this submission.

Selected Reference List

1. NICE (2004). Improving Supportive and Palliative Care for Adults with Cancer
2. NCAT (2009) Cancer and Palliative Care Rehabilitation Workforce Project: A review of the evidence
3. www.cancerhelp.org.uk
4. Allied Health Professionals Federation (2011) Allied Health Professionals: specialist clinicians at the heart of health
5. www.asha.org
6. Robert J et al. (2009) www.medscape.com
7. Pearson D (2008) End of Life Care. Don't die of boredom: enabling occupation at the end of life
8. Watterson J et al. (2004) International Journey of Therapy and Rehabilitation. Rehabilitation goals identified by inpatients with cancer using the COPM
9. National Council for Hospice and Specialist Palliative Care. NCHSPCS (2000) Fulfilling Lives. Rehabilitation in palliative care.
10. Macmillan (2010) Grimes C. Guidance for the Nutritional Management of Cancer Patients
11. <http://www.cancer.nhs.uk> (Rehabilitation Workforce Project)
12. Macmillan Cancer Support (2008) It's No Life: Living with the long term effects of cancer
13. Armes J et al (2009) Journal of Clinical Oncology. Patients' Supportive Care Needs Beyond the End of Cancer: A Prospective, Longitudinal Survey
14. Denton et al (2007) Clinical Oncology. Life after cancer treatment -- a spectrum of chronic survivorship conditions
15. DH, Macmillan Cancer Support & NHS Improvement (2010) The National Cancer Survivorship Initiative Vision
16. Centre for Workforce Intelligence (2011) Allied Health Professionals: Workforce Risks and Opportunities
17. NCAT(2010) Cancer and Palliative Care Rehabilitation Workforce Project: Project overview report
18. <http://www.cancer.nhs.uk/rehabilitation>
19. National Assembly for Wales (2007) Review of Cancer Services for the people of Wales
20. Dietz JH Jnr (1980) Postgraduate Medicine. Adaptive Rehabilitation in Cancer
21. The importance of physical activity for people living with and beyond cancer: A concise evidence review. Macmillan Cancer Support 2011
22. ADVISING CANCER SURVIVORS ABOUT LIFESTYLE - A SELECTIVE REVIEW OF THE EVIDENCE. National Cancer Survivorship Initiative Supported Self-Management Workstream. 2010.
23. <http://www.nursingtimes.net/nursing-practice/clinical-specialisms/practice-nursing/powerful-evidence-of-growing-roleof-specialist-nurses-revealed/5027698.article>

24. Lacomba M (2009) British Medical Journal. Effectiveness of early physiotherapy to prevent Lymphoedema after surgery for breast cancer: randomised, single blinded, clinical trial
25. Scheier et al. (2005) American Journal of Clinical Oncology. Interventions to Enhance Physical and Psychological Functioning Among Younger Women Who Are Ending Nonhormonal Adjuvant Treatment for Early-Stage Breast Cancer
26. Lundholm et al (2004) American Cancer Society. Palliative Nutritional Intervention in Addition to Cyclooxygenase and Erythropoietin Treatment for Patients with Malignant Disease: Effects on Survival, Metabolism, and Function
27. Department of Health (2008) Framing the contribution of allied health professionals
28. Can we talk about work? Encouraging health and social care professionals to talk positively about work to people affected by cancer. Research report commissioned by Macmillan Cancer Support April 2011, delivered by RS Consulting
29. Biggerstaff B and Doyle N (2009) MIMS Oncology and Palliative Care. Expert Opinion: providing high quality rehabilitation services
30. Wilcock A (2010) Macmillan Cancer Support. Annual report of Nottingham Macmillan Lung Cancer CARE service
31. http://www.dh.gov.uk/en/Aboutus/Chiefprofessionalofficers/Chiefhealthprofessionsofficer/DH_4136332
32. Pearson D (2008). Macmillan Occupational Therapists in the UK: An exploratory survey of their employment profile and working practices
33. College of Occupational Therapists (2004) Occupational Therapy Interventions in Cancer
34. Rosenberg, J. and Canning, D. (2003) Palliative Care by Nurses in Rural and Remote Practice, An Evaluation Report Queensland Health Southern Zone, Centre for Palliative Care Research and Education, Floor B, Block 9, Royal Brisbane and Women's Hospital Herston 4029 Queensland
35. D Goodridge, J Lawson, D Rennie, D Marciniuk, Rural/urban differences in health care utilization and place of death for persons with respiratory illness in the last year of life: Rural and Remote Health 10: 1349. (Online), 2010