Senate Inquiry into Palliative Care Provision in Australia

Summary of Recommendations – Peter Cleasby

That Palliative Care provision be based on an assessed needs approach.

That Specialist Palliative Care be recognised as both an appropriate and necessary care provider, and an essential best practice care facilitator and enabler of palliative, supportive and end of life care across all care settings.

That Specialist Palliative Care Services receive the increased resourcing required to meet increased and increasing demand.

That Commonwealth funded regional cancer centres be required to demonstrate the integration of Specialist Palliative Care Services into the operation of those centres. Further, that the resourcing to provide Palliative Care in these centres be separately funded and additional to existing Palliative Care budgets.

That on-site Specialist Palliative Care Hospital Consultation Teams be an expected part of Acute hospital service provision, and that this be a reported item in the My Hospital data.

That state and territory Palliative Care peak bodies be funded to be one stop access points for information about Palliative Care services and access pathways. Information on advance care planning may also be provided as requested.

That Palliative Care peak bodies, national, state and territory, be tasked and funded to develop and make available training resources and programs designed to better equip volunteers, families and carers of persons receiving end of life care in community settings.

That the quality of end of life care in Hospitals and RACFs needs to be more rigorously assessed by the relevant supervising and accreditation bodies.

That Palliative Care be recognised as having Acute as well as Sub-acute dimensions, and that policy and planning documents and processes incorporate this reality.

That appropriately resourced Specialist Palliative Care Services working collaboratively and in partnership with a range of care providers across all care settings be recognised as the best practice model for palliative care provision for most of Australia.

That increased numbers of Palliative Medicine Advance Trainee positions be funded.

That the succession planning concerns of rural Specialist Palliative Care Nurses be addressed through funded experience opportunities for other nurses (beyond PEPA).

That the Palliative Care Standards, and the related NSAP, are valuable points of reference for Specialist Palliative Care. However, the existing Standards require review to make them more relevant to Specialist Palliative Care services operating as Hospital Consultation Services and Community services.

That the existing Palliative Care Standards are not appropriate to be used as is in non Specialist Palliative Care contexts. The National Palliative Care peak body, in consultation with Aged Care bodies, should develop a set of non-specialist aged care specific standards address the use of the palliative approach etc.

That for "Dying in Place" to be realised an "End of life care" quantum payment is needed to permit additional care resources to be accessed. This is especially critical in free standing low care RACFs where 24 hour monitoring is not present.

That Advance Care Planning initiatives be understood by government, policy and planning agencies as not equating to quality end of life care.

That the processes around Advance Care Planning be recognised as a more realistic outcome that the production of Advance Care Directives.

That opportunity to incorporate Advance Care Directives and decisions from Advance Care Planning discussions be clearly incorporated into any national electronic health care record.

That local processed be employed to prevent unnecessary repeated questioning of individuals or their substitute decision makers about documented care wishes and preferences.

That future funding around Advance Care Planning not be drawn from Palliative care program funds, as this is a health system wide initiative not restricted to the palliative care space.

That it be understood that more research and more data investment will not change the fact that existing demand for Palliative care is not being met, that demand will increase, and that if action is not taken soon to appropriately resource Specialist Palliative care to play its foundational role then it may lose the capacity to recover.

The provision of palliative care in Australia

Submission by Peter Cleasby, NSW.

The factors influencing access to and choice of appropriate palliative care that meets the needs of the population.

The provision of Palliative Care in Australia is less than uniform, with diversity in agreement as to the target population and also the type of Palliative Care available and supplied. The way in which the term Palliative Care itself is used has become fraught with confusion. For the purpose of this submission Palliative Care is that care provided by specialist clinicians whose full time role is palliative care. The term "a palliative approach" (or "palliative care approach") was in part devised to differentiate between Palliative Care, and palliative type care provided by non palliative care specialists.

So, the factors influencing access to and choice of appropriate palliative care hinges strongly on the word "appropriate". Palliative Care Australia sought to speak of needs based palliative care and this is still the best approach. Specialist Palliative Care Services are required to meet complex palliative care needs in all care settings. Non specialist (or generalist) providers, such as General Practitioners, staff in RACFs and acute hospitals, should reasonably be expected to have the capacity to meet noncomplex palliative health needs. Regretfully this ideal is most commonly not realised.

Despite the millions of dollars poured into educational initiatives such as "Guidelines for the use of a palliative approach Residential Aged Care" the staff churn rate and general health practitioner discomfort with dying mean that little ongoing benefit has been realised. In part, this is why the second role of Specialist Palliative Care Services is so vital – to support other health care practitioners so that clinical capacity is grown in these non-specialist domains.

As per the NSW Palliative Care role delineation framework, the palliative, supportive and end of life care needs of the Australian population should be met by the most appropriate provider. Specialist Palliative Care Services will contribute that care at times, and will work closely with others to achieve that care outcome many other times. Yes, there should still be a population section whose palliative, supportive and end of life care needs are not complex, who should be able to have those needs met by GPs, RACF staff, Hospital teams etc. However, without a strong and well resourced Specialist Palliative Care sector as a foundation stone, sub optimal or inappropriate care is the outcome.

To speak of choice in relation to Palliative Care implies an informed and considered approach to the issue, such as which car will I buy or what retirement village will I move into. Palliative care is linked in the minds of the public with the end of life, and this is a topic that still most Australians choose to avoid until it is upon them. In my experience a terminal diagnosis is not usually engaged with a clear and rational mind. This is a time of great distress for individuals, for their families and carers. Health literacy is poor across a range of areas, and it may be pie in the sky to believe that substantial changes to health literacy around palliative and end of life care is possible.

Despite this there is a case to be made for centralised information service advice access points in each state. I believe that the level of complexity about services requires the most informed information provider. I would recommend that the state and territory Palliative Care peak bodies be tasked and funded to provide such information, and to include advice around the Advance care Planning options in their respective jurisdictions.

My view is that it is the role of Government to ensure that the people of this country have access to the palliative, supportive and end of life care they need when they need it. At the moment even this is not a given. In NSW years of funding neglect, and a failure to improve Palliative Care resourcing to meet the real and growing demand from non-cancer population groups (including dementia) has resulted in a significant access gap even in the metropolitan areas, let alone regional and rural areas. This vital baseline needs attention and rectification before any choice driven system can even be contemplated.

I will not address the specific population groups you include. This is not to say that there are not particular issues and needs for these important groups and areas (there are!). I will note that a lack of access to Palliative Medicine Specialists in regional and rural NSW is a significant issue, and the use of telehealth and formal partnerships between metropolitan and rural areas may be a way ahead.

What I wish to say clearly to the inquiry is that there are real issues and needs for the groups not mentioned in your subsections. The need for quality end of life care in Acute hospitals, where about half of all Australians die, is palpable. Every major hospital in Australia needs an on-site Specialist Palliative Care consultation service as a minimum level of care provision. Let me note that the proposed activity based funding model may not be supportive of such consultation services — this is yet to be seen. The potential benefits to the health care system from such Palliative Care Hospital Consultation Teams can be found in the overseas literature which I am sure has been researched for you.

Allow me to be clear here. In policy documentation and in broad commentary I believe there is an assumption about what Palliative Care is needed and how broadly it is provided. The need is underestimated and provision is certainly under resourced. The level of existing provision, no matter how you define it, is highly varied across Australia, and greatly under delivered in areas such as NSW. It is broke in places, barely existing in others, but the foundation to fixing it remains appropriately resourced Specialist Palliative Care Services working collaboratively and in partnership with a range of care providers across all care settings. This is the best practice model, but it is not to be found in many parts of Australia.

The funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent

In seeking to address this issue I wish to note another example of "language confusion". The term "sub-acute" can be used as a funding type classification (as in Palliative Care, Rehabilitation, Geriatric Evaluation & Maintenance and Psychogeriatric). A consequence of this usage is to then engage in linguistic logic such as this:

If Palliative Care is a sub-acute funding classification, then Palliative Care is itself sub-acute.

Wrong.

Back in the mid 1990s when the original Sub-acute and Non Admitted Patients data was being collected Palliative care was largely practiced in sub-acute facilities such as Hospices. This is no longer the case. In my own clinical lifetime, and now every week, I see an increase in the complexity of the palliative care needs of individuals. This is in part a consequence of the increased oncology treatment periods for persons with a range of cancers, and partly because of complex symptom loads being demonstrated in non-cancer groups. The growing experience of multiple morbidities is a further factor. There is a significant and increasing component of "acute" palliative care practice, and this is most safely provided in acute care facilities. Individuals with these care needs would be inappropriate to manage in a sub-acute facility.

To fund palliative care service provision a model that incorporates acute care needs, sub-acute care needs, community support and care, and bereavement care is what is required. Again, Specialist Palliative Care Services need to be the funded foundation, with collaborative service provision models with generalist services.

It has been suggested that Medicare Locals be the fund holders for community palliative care service provision. Where no Specialist Palliative Care Service (SPCS) exists this may be a functional option. However, many existing SPCSs exist across multiple care settings, including community. A Medicare Local driven model would cut across this functional expertise. Indeed, it has been suggested that the Specialist Palliative Care Service that crosses care settings, that delivers input into public and private hospitals, that supports GPs and RACFs, that brings their expertise to people in their home or other care setting, is the kind of flexible non-siloed type of service that should be a template for the future. I believe that the Palliative Care Service of the future will take its' expertise to wherever the individual with palliative, supportive and end of life care needs is located. Palliative care bed access, both acute and sub-acute, will be a tool, a resource, not a raison d'etre.

The recent COAG sub-acute related funding was a mixed outcome for Palliative Care. In most rural areas of NSW comparatively little (or none) of this funding found its way to improve or expand Palliative Care Service delivery. One growing regional /rural area health service is reported to have only committed "half a social worker "position as its palliative care component of the COAG allocation. The metropolitan picture was a little more positive. The irony was that overall in NSW, those areas with larger Palliative Care Services tended to receive a better proportion of the COAG enhancement funding, while those with little received very little indeed. I note to the inquiry that the COAG sub-acute enhancement funding ends on June 30 2013 and there is growing concern among those Palliative Care Services that funded additional positions (mapped against agreed increases in activity) will not continue.

It can be argued that Palliative, Supportive and End of Life Care remains undervalued by our treatment and cure driven health care sector. It is often an afterthought, in planning and funding. Until Palliative and End of Life Care is as valued and respected as, say, cardiology or oncology, by healthcare administrators, planners, fundraisers, politicians and the community, then this area of health care will remain ignored. Until it is needed.

The efficient use of palliative, health and aged care resources

I recall a meeting of many senior Palliative Care clinicians held in Sydney a few years ago to discuss their views on a new state framework. The collected wisdom in that room, representing services across the state, clearly stated that transparency of funding was their number one issue. The first reasonable question to ask in considering Palliative Care resourcing is "Is the money allocated for palliative care service provision being used for that purpose?". The second reasonable question is "is the allocated resourcing enough to allow a certain level of service provision?". Once these questions are adequately addressed then the question of "efficiency" can be introduced.

Regretfully we have inefficiencies because Palliative Care is not accessed, or not available. Specialist Palliative Care has been demonstrated to deliver a cost benefit to the heath care sector. This is especially the case with Palliative Care Hospital Consultation teams in the acute sector. If the option of referral to such a team is not available then there is an increased likelihood of medically futile options being adopted.

Regretfully not all Palliative Care teams have embraced their legitimate role in relation to the non-cancer population. Some teams remain Cancer services, while others are reporting non-cancer referrals of 40+% of total referrals. This situation is not helped in NSW where there has been no adjustment to Specialist Palliative Care funding to address the existing and growing demand from the non-cancer sector.

The data is not clear as to whether Palliative Care contributes to a reduction in length of stay. I have witnessed rapid discharges to facilitate a family decision to care for a dying relative at home. More importantly, I have seen thorough Palliative Care assessment and planning result in a successful hospital discharge (ie one that does result in a readmission within 48 hours). I have witnessed similar cases where Palliative Care were not consulted and readmission has occurred.

Not all aged care providers have embraced the palliative approach nor that end of life care is a core service provision. There are many excellent examples of high quality care provision, of appropriate consultation with Specialist Palliative Care, of a proper understanding of the impact a resident's death can have on other residents and staff. These examples need to be seen as the expected normal rather than the outstanding exception.

The effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities

Again, what is effectiveness? Is it that symptoms are well controlled, that families and carers are well prepared and supported, that spiritual and cultural expectations are respected, that psychological and social needs are addressed, that end of life care is expertly provided, that a comfortable, safe death is realised, that care preferences are respected, that preferred place of death is realised, that appropriate bereavement care is provided? For Palliative Care to be effective then all of these dimensions must be included.

The palliative, supportive and end of life care needs of Australians may be met in all of the locations mentioned above. I would contend that that which is required to deliver effective palliative care in all of these care settings is not equally available or accessible.

With about half of all Australians dying in public hospitals the quality of end of life care is a neglected priority. Standard use of end of life care pathways (or similar care organising tools) is still not common in many locations, or even within individual hospitals. Access to on-site Palliative Care Hospital Consultation Teams is not a given. This is a priority area, yet there are mixed messages and expectations confusing the appropriate goal of care in the acute care sector.

It is with regret that I observe to the Inquiry that a small but possibly growing phenomenon of care discrimination against patients identified as, or labelled "Palliative Care" is being reported from the acute care sector in general, and in Emergency Departments in particular.

It is in the community that local collaborative teams, including General Practice, Community Nursing, Palliative Care and other care services, can demonstrate great flexibility. However, I need to note that the increasing non-availability of General Practitioners after hours and on weekends, and even more so the loss of home visiting, is restricting home based palliative care provision in a range of locations. This existing and growing reality makes home based medical review difficult if not impossible, while home deaths can become crime scenes when a doctor cannot be contacted to provide a death certificate.

The composition of the palliative care workforce

There are workforce shortages in a range of health care specialities and Palliative Care is no exception. In the Specialist Palliative Medicine area these shortages have three compounding dimensions. Firstly, there is an absolute shortage of Palliative Medicine Specialists across Australia against existing positions. Second there is a substantial and growing gap between positions currently funded, and the number of positions required to meet the unmet and growing demand for Palliative Care. Thirdly, due to the history of the creation of Palliative Medicine positions a cohort of early appointees are at or beyond retiring age. In NSW Palliative Medicine positions in and outside of Sydney have taken years to fill. There is a real need to increase the number of Palliative Medicine Advanced Trainee positions to meet the growing workforce gaps.

Palliative Care developed in Australia as a nurse led health care movement. In the community and in hospitals Registered Nurses who had self taught, gone to the UK, or completed cancer nursing courses (as there was no locally available Palliative Care nursing courses) became local experts who gave pain and symptom management advice to other health care providers (especially General Practitioners) and who became integral in supporting individuals and their families / carers at end of life. Even in the light of the staggered rise of Palliative Medicine, experienced specialist Palliative Care Nurses, and more recently Palliative Care Nurse Practitioners, are the cornerstone of Palliative Care provision in rural areas, in rural and smaller hospitals, and in the community (including RACFs) in all parts of Australia.

Palliative Care Nurse Practitioners are one possible workforce initiative that may address certain gaps and needs. Care needs to be taken to ensure that only Nurse Practitioners with appropriate

Specialist Palliative Care experience are recruited to Palliative Care specific positions. New funding is required to create Palliative care Nurse Practitioner positions as they provide a different service to existing experienced Specialist Palliative Care Nurses.

Many rural and regional areas in NSW have single or few Specialist Palliative Care Nurses. There has been great concern expressed by these core service providers that there is no capacity in the system to permit reasonable training of leave relief personnel, not to permit succession planning. The Program of Experience in the Palliative Approach (PEPA) is not designed to meet these workforce needs.

Of course, the best Palliative Care is multidisciplinary, and care provided by larger Palliative Care Services by definition is required to be so. In smaller teams and in various care settings a "pop-up" multidisciplinary team can be created by using available generalist services in collaboration with the single or small number of Specialist Palliative Care clinicians.

I emphasise, again, that Palliative Care for the majority of persons in Australia is best delivered either directly by, or in collaborative partnership with, a Specialist clinician or clinicians. The past attempts to build generalist capacity in advance of its need have not proved sustainable, due to turnover, loss of key personnel, loss of funding etc. A "pop-up" or "just in time" model sees the Palliative Care team or specialist clinician equipping the providers at the time of need.

From a community perspective I acknowledge two additional members of the care team. It is well documented that the number of carers available is related to the likelihood of a home death. Family members / carers are crucial members of the care team, who need skills training and support as they participate in 24/7 care. In addition, palliative care trained volunteers often provide a range of supports that contribute to the total care delivered. Both these groups have knowledge and skills needs that could be improved through the development of training resources and interventions. State and territory peak Palliative Care groups would be appropriate to include in any such initiative.

For almost a decade I have offered two observations regarding aged care and Palliative Care. Firstly, as average length of stay in high care RACFs fell below six months, those facilities became "Hospices" without an operational sense of that role. Secondly, that the concept of "Ageing in place" inevitably becomes "Dying in place". Yet "Dying in place" represents the greatest potential mismatch in palliative care provision. I refer here specifically to the situation where a free standing low care RACF has a resident to starts to rapidly deteriorate (starts to actively die). Across NSW I have heard reports of such facilities boldly claiming to be able to keep the resident with them (which is desirable) while not being willing or able to provide the 24 hour care and supervision that quality end of life care requires. To be told that a facility wants to keep a dying resident yet only has one afternoon of registered nursing hours a week indicates that the facility does not understand what is required, or does not wish to hear. For "Dying in place" to be realised there is a need for an "end of life care" payment quantum that will allow extra nursing hours, including overnight, to be provided over 2 – 4 days.

Palliative and end of life care is as central to RACF care provision as Dementia Care, or activities programs. The palliative approach is the central care philosophy in High Care whether this is recognised or not. If the average length of stay is six months or less then end of life care is "core business". Do existing education and training arrangements reflect this reality in their content? Of further concern is the fact that the majority of aged care provision, in residential and community settings, is not provided by Registered or Enrolled Nurses, but by workers with a Certificate III level of preparation, perhaps. These staff are highly representative of everyday Australians, and bring with them a range of misunderstandings, fears and discomforts around death and dying. These staff, plus the trained nurses and the general practitioners, plus the cleaners and hotel services staff, need to be equipped and supported to accept death as a natural event, and end of life care as a particular challenge and opportunity. Uncomplicated symptom management and end of life care should reasonably be expected to be managed in High Care RACFs, and by EACH and EACH-D providers. All RACFs should, as part of accreditation, be able to identify their local referral process for seeking Specialist Palliative Care support and advice. (Note please that Specialist Palliative Care Services need to be resourced to meet such requests in a timely manner.)

The adequacy of standards that apply to the provision of palliative care and the application of the Standards for Providing Quality Care to All Australians

The Australian Palliative Care Standards are a useful guide for Specialist Palliative Care Services only. The results from NSAP indicate that Specialist Palliative Care Services across Australia have areas for improvement in relation to these standards.

The existing standards have a history linked to Palliative Care service provision in Hospices and other Palliative Care inpatient settings. The existing standards have language and elements that do not translate automatically to Specialist Palliative Care consultations services, in either hospital or community care settings. I understand that these gaps and issues will be addressed in the next revision.

The point I wish to make, clearly and loudly, is that the wholesale porting of the existing Palliative Care Standards to Aged Care or generalist care settings is intellectually and functionally inappropriate. The correct course would be to develop a set of palliative approach care provision standards, designed for the non-complex and non-specialist setting. These may be a relative of the existing standards, indeed they should be. We do not expect the General Practitioner to deliver cancer related care equal to an Oncologist; it would be wrong to use standards developed by and for Specialist Palliative Care in a generalist / aged care / non-specialist context.

Advance care planning

While government's support for initiatives in Advance Care Planning is to be commended there is a twofold risk in this investment. Firstly, the process of planning ahead, of having timely discussions about present and future care options and pathways, of identifying a substitute decision maker, can be lost by an inappropriate emphasis being placed on written documents (eg advance health directives). Secondly, there is growing evidence of a mistaken belief creeping into policy that

"doing" advance care planning directly impacts upon the quality of end of life care. It has long been normal Specialist Palliative Care practice to have difficult discussions and to explore options. When key family and carers are permitted to be participants in such conversations then they report a higher degree of satisfaction with their perception of end of life care. At the heart of this is that the dying individual's wishes were heard and, where possible, respected. Please note, as an aside, that just because an individual expresses a wish to die at home does not mean that a home death can occur. Let it be clearly noted that even where high level support has been given overseas the percentage of the population completing advance care planning related documentation remains small. The better investment is in our health care culture and processes.

It is well known that advance care planning discussions can have natural trigger points. These can be disease related (diagnosis, exacerbation), event related (repeat hospital presentations) or even age related (40, 50, 60 etc.) These discussions need to be more naturally part of these moments.

In NSW the Guardianship Act has a significant impact on the substitute decision maker identification processes, and this works against a single Australia wide legal framework at this time. The recent national guidelines were a positive advance in trying to minimise differences. It is worth noting that NSW decided not to implement specific ACP related legislation, and that recent court judgements have supported NSW's decision to rely on common law rights.

A national electronic health record will need to have a visible option for recording both an individual generated advance care directive document, and/or a values type document, and/or information about substitute decision makers, and/or information about advance care planning discussions held. There must be the capacity for the individual to change these details, plus a one off method of validating existing information upon a hospital admission. It would be a most unfortunate new reality if every new attending medical or nursing staff member wanted to "just check that these are still your wishes / preferences". Annoying and intrusive.

The decision to include reference to advance care planning in this inquiry is simultaneously reasonable and yet reflected of a confusion around "palliative care". As mentioned above, advance care planning type discussions have always been part and parcel of Specialist Palliative Care practice. However, money was taken from the Palliative Care program budget and used to fund Advance Care Planning related projects that were not driven by Specialist Palliative Care. Advance care planning needs to be part of the health care pathway for all terminal illnesses: Dementia, end stage cardiac and respiratory, Motor Neurone Disease, Cancer, Chronic Renal failure etc. Funding for Advance Care Planning needs to come from acute care, chronic disease, primary care, cancer care and other funding streams. Palliative Care in Australia is so under resourced that Palliative Care monies need to be used to fund direct service provision.

Availability and funding of research, information and data about palliative care needs in Australia

There are times when I believe Palliative Care is the most focussed upon health speciality in terms of data and reporting, in a way that is disproportionate to its size. Clinicians in small services, without the luxury of data managers, despair when another data collection is expected of them. There is merit in getting something that reflects the multifaceted reality of modern Palliative Care service

provision in place, but only if it meaningfully contributes information that has value to those collecting it. It is my personal view that Palliative Care Outcomes Collaborative (PCOC) does not fit with a Specialist Palliative Care Service that provides consultation and support only. PCOC data elements have their origins in inpatient related data, and up until last year I could not see the data collection requirements as fitting with a consultation service.

People facing death need support, symptom management and end of life care that is relevant to their particular needs. Studies have already indicated that the symptom burden in most non-cancer terminal conditions is as great (if not greater) than that for persons dying from cancer. Increasingly more and more Australians will have an anticipated death. We know the need is there, and rapidly growing. We know that Specialist Palliative Care not only provides direct care for complex situations, but also provides advice and support for the whole range of non specialist care teams in all care settings. My view is that you do not need more data, you need more service provision.

Concluding comments

Health care in Australia has become trapped between two sets of resource intense dominions. On one side is the public hospital system, with intense emphasis on "on stretcher time" and "surgical waiting lists" and demands for the latest equipment and drugs. Elsewhere is General Practice, where significant assumptions are made about General Practice's willingness to be available to provide those services assumed of it, when these are businessmen who make decisions based on more than perception of clinical role. It is time to evolve health care thinking and provision beyond these reference points

While the sixties, seventies and eighties saw advances in medical treatments and interventions, and an era when cure at all costs was expected, we now are in a place when our corresponding investments in Palliative Care and Aged Care in the more recent decades appear well short of the mark. Not unlike the period in NSW when a redistribution of health resources was seen as appropriate ("Beds for the West"), we are now greatly in need of a substantial shift in health care resources to Palliative and Aged Care services. I urge all governments to begin ramp up this resource shift before reasonable goals of care become unobtainable for many.

Peter Cleasby Profile

Presently

President, Palliative Care NSW

Member, NSW Health Minister's Palliative Care Expert Advisory Group

Member, NSW End of Life Care Working Party

Member, NSW Advance Care Planning Advisory Group

Member, NSW Dementia Advisory Group

Chairperson, NSW Palliative Care Advisory Group

Manager / Director, Central Coast Palliative Care Service

Former Positions

Clinical Nurse Consultant, Central Coast Palliative Care Service Lecturer, Charles Sturt University Bathurst Community Oncology & Palliative Care Nurse, Illawarra Area Health Service Registered Nurse, Haematology Oncology, Westmead Hospital