

## **PALLIATIVE CARE PROVISION**

### **(a) Access and Choice**

- Adequate staff with an interest (GPs and home nursing), specialist home nursing (in palliative care), palliative care NPs, community palliative specialists (to assist in complex cases)- these health staff provide a skill mix to keep patients in the community as long as there is good family support.
- Specific provision for care in ACFs ie to assist the GPs and nursing staff who may be having difficulty in caring for complex and demanding cases-once again the aim is to keep patients out of sub-acute (palliative beds) or even acute beds in hospital. Our service does not provide care to ACFs as we are unable to meet an overwhelming demand (and hence the service was withdrawn).
- Access to palliative care services through the GP in community - GP can refer to domiciliary nursing or a specialist service. Role of GP is pivotal (providing the GP has an interest in palliative care). Some do not and will not follow up or prescribe opioids appropriately.
- Access to palliative care via specialist referral (in hospital, outpatient or to community services if appropriate). Most specialists eg medical oncologists (some of whom have good skills in palliative treatment) prefer to refer directly to palliative care specialists / consultant physicians.
- Tertiary/quaternary hospitals must have access to Palliative Care Services. However if inpatient care is needed (palliative inpatient care) then this is best served as close as possible to family. This model seems to work but could be improved. Family issues include travel, parking, associated financial burden and associated stress.
- Understanding what palliative care is, what it can provide and what it does not provide is important. Too often patients with serious illness are referred to palliative care with the expectation that more support will be given but that all the acute care will continue. Therefore education for doctors and patients is important during a transition from acute care to palliative care.

(i)Rural/Regional- no experience in this area but with any area of health care, you need committed people on the ground with access (formal) to help, advice, telemedicine etc.

(ii)Indigenous patients make up <1% of our patients. I am not qualified to comment.

(iii)Cultural diversity/language barriers are challenging but need to be dealt with in appropriately sensitive ways, with help from family usually. It is rare to need interpreter services in our district.

(iv) People with disability usually have extra support (eg from family or disability support services). Palliative care services must be an add-on in this situation (except in the setting of terminal/end of life care) to support people with an increasing burden of symptoms.

(v) I have no experience in dealing with children and adolescents and would leave comment to those, who are expert in this field.

## **(b)Funding Arrangements**

- Community; There needs to be better specific funding of palliative care work by GPs especially for home visits by GPs to palliative care patients. There needs to be an adequate financial reward for complex (and time consuming) work of this nature. Discussing deterioration, dying, death and the aftermath with patients and families is not easy (or pleasant) work. It is however important work. As in the US, patients could be registered as Palliative Care patients to assist in this process ( for funding)
- Funding for nursing palliative care patients at home should be brokered through the local health networks (and include GP input). This should be separate from other sub acute funding. Sometimes the time frame is very short. If care cannot be provided at home the patient winds up in an acute care facility (most likely) and ties up (inappropriately) an acute bed for a period of time.
- Funding for services:
  - Inpatient (beds)
  - Consultative (hospital)
  - Outpatient (ambulatory)
  - Community support (not ACFs)?
- Funding should come through the local health network but the network would need to provide one service with financial responsibility to the network under state/federal guidelines (not local). Co-ordination is the key.
- These services may need to go to tender so that they are provided in a cost effective way (even though palliative care services are time consuming they can still be provided in an efficient way e.g. appropriate time frames for home visits and outpatient visits).
- All of this requires co-ordination therefore the service requires a manager/co-ordinator in high population, large team services. This should not be a hands-on clinical person. In smaller services this would not be cost effective and the role of the co-ordinator may fall to a clinical person (significant time is taken up by this role).
- Funding for palliative care services has not been a priority for state health in my experience. Hence the need for specific funding from the Commonwealth (PCP funding). This has been ongoing and needs to continue otherwise services may lapse

if ongoing funding and monitoring do not continue. If left to their own, acute health services will drain resources for palliative care as they have in the past.

- Either state or federal supervision of service provision, standards and work load need to be instigated. This role needs to work with local co-ordinators to ensure adequate, timely services to palliative care patients and their families.

### **(c) Efficient Use of Resources**

- Relies on co-ordination of services (as described already), providing care at the appropriate time and place. This may be more challenging because of the fragmentation of health care responsibilities (the community and ACFs in general are funded directly by the Commonwealth. ACFs are provided with funds to provide palliative services but at least in our area there is no specific specialist service to assist in this work. This role falls on the GP (who can ask for help) and the generalist nursing staff in ACFs.
- It may be appropriate to have separate (and enhanced) federally funded specialist services (e.g. N.Ps and medical specialists) if the LHHN cannot provide this. A better arrangement would be for the LHHN to broker specific funding for ACFs so that nursing home patients do not miss out on appropriate specialist palliative care support.
- Community nursing can be too fragmented. We currently liaise with three different services, all of which are good but it is not an efficient system there are delays in discharging patients home because the domiciliary nursing services are full to capacity with palliative patients (some on subcutaneous infusions of opioids. Hence the need is absolute not conditional).

### **(d) Effectiveness of Palliative Care**

- Inpatient setting; Patients and families need to be seen as soon as possible after a decision to refer to palliative care is made. Plans need to be made for ongoing management and discharge to home, to ACF or inpatient specialist palliative care. This works better when a good team approach exists in the hospital. These decisions are often complex and emotional, particularly referring patients to ACFs or inpatient palliative care facilities ( as this often means the patient will not go home again).
- ACFs need to be able to accept palliative care patients more rapidly because time is limited (if medical assessment is correct). Specific palliative care beds requiring for patients requiring more complex care need to be supported by appropriate staffing level with a skill mix to match.
- A good working relationship and support for community palliative care nursing is very important. Our service has been able to hold a weekly meeting over the last 10 years to discuss our patients' care. I think this relationship is enhanced by the ability to hold educational sessions for community nurses. The same can be said about

providing education to GPs. It is difficult if not impossible to have any regular meetings with GPs other than educational meetings at night. These are usually attended by the same doctors who have an ongoing interest in treating palliative care patients.

### **(e)Workforce**

- It is important to remember that the palliative care workforce is very heterogeneous comprising GPs, specialists in other subspecialties eg medical oncology, general medicine and then fully trained specialists and physicians in palliative care. The nursing workforce includes inpatient nurses, clinical nurses, clinical nurse consultants and nurse practitioners, who I believe will slowly and surely have an increasingly important role in providing support to a depleted medical workforce. Many palliative care specialists in Queensland will be due to retire in the next decade.
- Everyone is aware of the baby boomer tsunami, which is just starting. This has the potential to swamp health care services over the next 25 years. Plans must be made to encourage medical, nursing and allied health professions to work in aged care not only to promote healthy aging but also to look after the patients who are deteriorating with chronic disease, organ failure and advanced malignant disease. The fact that GPs can train in palliative medicine (either at diploma level or full Fellowship level) has been a huge factor in providing specialist care. Without this avenue of training, specialist palliative care services in S.E. Queensland would be virtually non-existent.
- I cannot really comment on nursing training other than I believe in the role of the nurse practitioner and that it will continue to grow in importance over the coming decade.
- Career Medical Officers or Senior Medical Officers employment options should be explored by offering a second tier level for doctors who do not want to complete full specialist training. This might include the College of Physicians' graduate diploma with an 18 month training option. Those doctors with an existing Fellowship should be encouraged to complete full training.

### **(f)Standards**

- National standards are already in place. National bodies have been in place for many years and have been able to provide these to the palliative care community after much consultation. PCOC and NSAP need to be incorporated by all recognised Palliative Care Services that are large enough to do so. At present I feel the standards are adequate but are not fully tested (or implemented) probably because of inadequate funding for most services. The question that needs to be asked, is of

course, if standards are not met what will be the outcome. Will services be penalized or moved? Will there be a positive outcome? If standards are not met because of funding issues will they be addressed? Standards however are usually only addressed by organisations. What about the palliative approach in other settings? Who monitors the standards of the palliative care delivery in general medical wards, aged care facilities, or the GPs' surgery? What about the GP who refuses to prescribe adequate pain relief for a patient with advanced cancer or refuses to provide authority scripts for opioids?

### **(g)Advance Care Planning**

(i)Issues of death and dying need to be raised with the patient and family early on in the palliative care process. It may not be appropriate to do this at the time of first contact but patients need to be aware that it will be raised at the next visit. This should not be taken out of context. If a patient is referred at a very early stage, time (and timing) is not as critical. There is no reason that all discussions need to take place with the medical staff alone. Nurse Practitioners, Social Workers, or allied health (psychologists) could also have these discussions with the patient and family. Patients need an EPOA. It would be good to have an AHD (though the uptake for this is poor at best). Documentation for ACP has been recently developed in Queensland but I have no working knowledge of this other than it exists. Planning for death, dying and the care leading up to this stage needs to be openly discussed- but this of course is not an easy discussion to have.

(ii)I agree that national laws need to be developed in conjunction with the states. There also needs to be increased education for consumers of palliative care in ACFs, GP surgeries, hospitals and private clinics (some of the most difficult patients/families come from the private system where the possibility of deterioration, dying and death have never been addressed.)

(iii)I have no personal experience with electronic records but, where this is used (by GPs, hospital clinics, wards and private practice clinics) there is no reason not to have ACP in electronic mode. Once again the issue is not the record format or modality but whether or not the ACP has been done (and done properly). This is not like consenting to a minor procedure. Time and effort need to be put into a document that has major implications for the patient and the family. In a similar way, consent to have palliative care treatment, particularly inpatient treatment, is an issue that needs to be discussed. Not every patient and family accepts the palliative route. Just as a patient needs to give consent for a blood transfusion, consent for palliative care needs to be given, not assumed. This requires education and information for the patient and family (and if the patient lacks capacity then the attorney or statutory health attorney (family/carer) needs to give consent as they would with any other significant health matter.)

## **(h)Palliative Care Needs (research/information/data)**

The provision of palliative care is both nebulous and ubiquitous, making the collection of data very challenging. Palliative care and advice can be given in any health care setting (as opposed to hip replacements or coronary artery bypass surgery). The collection of data must therefore focus on the delivery of specialist palliative care in its various settings (community, hospital, etc). To achieve this, specific funding and workforce are necessary. This is in addition to the normal clinical funding. Basic research needs to be done on the need for a more widespread palliative approach.

How many patients in a general medical ward require palliative treatments as opposed to ongoing acute care?

How many patients in an ACF are approaching the end of life at any time and require palliative review (concentrating on comfort care, medication review, end of life orders and the all important family discussion)?

How many patients with palliative care needs die before getting to a Palliative Care Service?

Why are patients referred for palliative care services and why are some patients referred late?

Do patients with palliative care requirements get treatment in a timely manner?

How many patients miss out on palliative radiation therapy due to delays?

Much of this data may exist already but if it does it has not been widely disseminated to the Palliative Care Community.

Much work still needs to be done!