

To: DHB Board

From: Margaret Hill, GM Strategy, Planning & Accountability

Date: 18 January 2012

Re: PALLIATIVE CARE

Background

In June 2011 a Palliative Care Steering Group was established after a review of South Canterbury palliative care services by Ruby Consulting was undertaken. The Palliative Care Steering Group was tasked with finalising the palliative services model of care, based on the recommendations of the Ruby Consulting review.

In the 2011/12 Annual Plan the sum of \$150,000 was provided to support the development of a new service model with the priorities for the use of this new funding to be agreed by the Steering Group.

Attached is the final paper that outlines the new model of care and details the direction the Palliative Care Steering Group believes will provide the South Canterbury community with an improved palliative care service. The priorities decided by the Steering Group have been based on the ability to fully utilise the funding to support the employment and development of the palliative care team.

The Senior Leadership team supported the recommendations made by the palliative care steering group as set out below at our December meeting. The Steering Group will now focus on the preparation of an implementation plan for the transition to the new model of care. The key recommendations in the report are:

- Employment 0.5 FTE Medical Lead Palliative Care
- 1.6 FTE Palliative Care Nurses transitioned to Clinical Nurse Specialist roles, and
- Increase 0.4 FTE Clinical Nurse Specialist
- 2012/13 Budget bid for additional 0.5 FTE Social Work
- Further advice provided to SLT on “one off” expenditure in 2011/12 using the underspend of the \$150K budgeted for 2011/12

Recommendation

That the Board:

- **Receives** this report
- **Endorses** the recommended model of care and the recommended use of the new funding budgeted to support the development of palliative care services in South Canterbury.

MARGARET HILL

Palliative Care Alliance- Palliative Care Model

INTRODUCTION

In late 2010 a review of South Canterbury DHB palliative care service was undertaken by Ruby consulting. This review undertook extensive consultation across Hospital Services, Primary Care, Community, NGO providers, Hospice and a number of other interested parties. In May 2011 an updated South Canterbury DHB Palliative Care Services model of care was finalised.

This proposed model identified the need for a defined local palliative care service with a single point of entry, to be delivered by a well networked and integrated service sector.

The aim of the service in its delivery of the palliative care in South Canterbury is:

- To ensure that South Canterbury residents have access to high quality coordinated secondary and palliative care in appropriate settings
- That residents of South Canterbury, who require palliative care, can access timely services and are supported to make individual choices to enable them to be cared for in their own environment and surroundings, as far as this is possible.

In June 2011 a palliative care steering group was established taking an alliance approach to the review with the guiding principles:

- Taking a whole system approach to make health and social services integrated
- Focussing on people, their families and communities, keeping them at the centre of everything we do;
- Enabling clinically-led service development; while
- Living within our means.

It needs to be acknowledged the co-operation that each of the representatives of the Alliance have displayed confirms the value of operating in a smaller centre where the different people who contribute to patient care are used to co-operating. It is evident that South Canterbury has most of the component parts of a very good palliative care service and that a large part of palliative care which is currently provided by the generalist service providers is provided to a high standard. As always, there is scope for this to be assessed and constantly improved.

There are many examples of individuals and organisations going the extra mile to assist patients during their palliative journey, and it is important to be cautious and to not disrupt the existing and functional arrangements but from the development of a new model these relationships could be improved.

The focus of all providers involved in palliative care needs to be on caring for patients in their own home if this is what the patient and their family desire. It is acknowledged that the choices may be limited for each patient by their clinical needs, but excellent palliative care should be available wherever the care is provided. Spiritual or holistic care of the patient is critical and while this document focuses on health issues this reflects only that these are the areas in which the alliance focus has been brought to bear.

The amount of funding available to enact the plans of the Palliative Care Alliance is finite but the possibility of seeking additional funding in time frames beyond 1 July 2012 exists. It is also possible, in the event that the funding is not fully utilized before 30 June 2012, that opportunities will exist to use some of the available funding for such initiatives as education of staff and clinicians, enabling the Liverpool Care Pathway (LCP)¹ to be introduced to a greater degree across South Canterbury Health Services and investment in equipment may be required for community support.

MODEL OF CARE

The palliative care steering group was tasked with finalising the model of care, for the delivery of palliative care in South Canterbury. The model was to be guided by the following purpose.

- Review the draft model of care developed by Ruby Consulting
- Ensure a Model of Care which will provide integration across tertiary, secondary and primary care
- Ensure a Model of Care which delivers palliative care to patients in their own homes or setting of their choice
- Ensure a Model of Care is patient focused and provides patient choice and decision making.

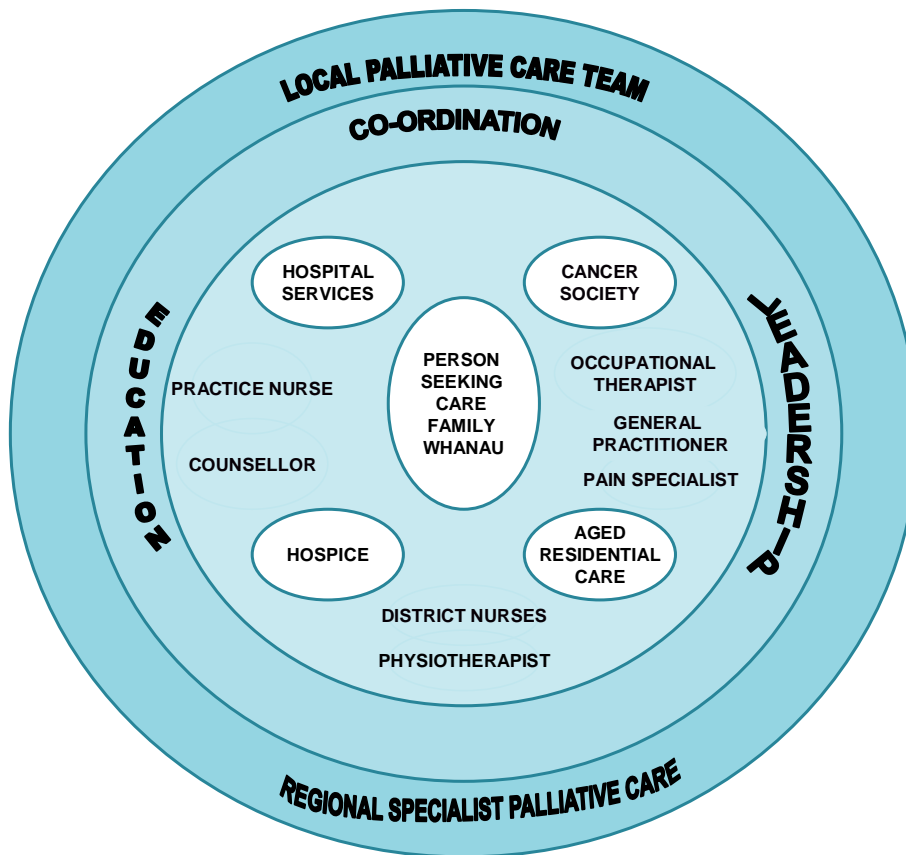
Included in the development of the model was the requirement to “live within our means”, while supported with \$150,000 of additional funding ring fenced to invest in priorities to support Palliative Care in South Canterbury.

The palliative care model reflects the need to provide a distinct local palliative care service, with a focused palliative care team that will provide a single point of entry for palliative care services, greater leadership, coordination, education and support for clinicians and patients using the palliative care service.

The service will be orientated to be patient centred, in that the service will “wrap around” the patient to ensure there is a clear and defined pathway that will not present barriers to accessing the right service(s) at the right time. The component parts of a patient centred service include; a commitment to transparency (openness and accessible), seamless

¹ The LCP is an evidence-based, integrated care pathway that was developed in the UK to transfer the hospice model of care into other care settings. The LCP guides health care professionals to deliver best practice care to dying patients and their families/whānau in the last days and hours of life, irrespective of diagnosis or care setting.

experience (services all well connected), engagement (between and within providers), and a culture which allows and encourages communication.



The model will allow the patient and family to be actively involved, and to be active decision makers of their planned care. Clearly the model will also be aligned to the National Framework where there is both a generalist or primary carer service and a specialist or second tier service. The specialist service is accessed according to need with awareness that both the Generalist and Specialist services are part of an integrated framework of care provision.

To meet the expectation of the new model the need for a 0.5 FTE medical lead and the transition of the current palliative care nursing roles to clinical nurse specialists (CNS) roles to support the palliative care pathway has been identified to provide a better focused palliative care service. The new team will be able to respond more effectively; provide knowledge, education, support and co ordination for the patients and for those health care workers caring for them.

The Palliative Care team will be based, in an “office” sense at a single location, but their care provision will be a virtual location in nature as the team will work across General Practice, Community , Aged Care, Hospital and Hospice settings. The core team members would include the Medical Lead , CNSs, Social Worker, with the District Nursing service, Allied

Health team members, Needs Assessment and Service Coordination (NASC) Service and other support service providers undertaking the core day to day service delivery.

In the first instance it is recommended that the Palliative Care team is employed by the SCDHB and operate in an administrative sense from the Primary & Community base in Woollcombe Street. This centre provides support to other community based activities of SCDHB and can provide the necessary administrative and other support services, which means the \$150,000 can be utilised for employing the team... More important than physical location is the availability to the Palliative Care team of the different elements of care that need to be available to the patients and their families, and of the members of the Palliative Care service being committed to work in an integrated manner.

The Palliative Care team is not there to replace current services that are available to the patient as these existing services are critical in providing care. The Palliative Care team is there to support; provide advice and follow the patient journey in a way that provides greater certainty that patients are receiving the necessary supports as per the needs and requirements of the individual.

The Palliative Care team will provide a single point for palliative care referrals. While these referrals can come from any number of providers or individuals, the patient's story with regard to the medical history and sequence of events during their illness journey, should only be told once. This will require a change to the referral process so no matter where the referral comes from there is a standard referral approach so the patient /family are not having to constantly explain and justify their entitlement to care and support. In saying this, it is acknowledged that the narrative the patient provides will change with their experiences and this is important to be heard and considered when considering the service response on each occasion.

Patients need to feel secure within the system and need to understand where the palliative care service fits in to their overall care. Information about their services, who will provide what, who to contact and what happens after hours is key to the patient/family. To underpin this we will need to have agreed consenting processes and agreed documentation

As noted above \$150,000 was ring fence to support the priorities of the Palliative care steering group.

Priorities agreed by the steering group are:

1. Appointment of 0.5 FTE Medical Lead \$115,000
2. 1.6 FTE Palliative Care nurses transitioned to Clinical Nurse Specialist Palliative Care (CNS) \$7,500
3. Increase CNS role by 0.4 FTE \$ 30,000
- 4 Social Worker 0.5 FTE \$45,000

KEY ROLES IN THE PALLIATIVE CARE MODEL

PALLIATIVE CARE MEDICAL LEAD ROLE (NEW):

This is an important role for South Canterbury DHB to appoint. It is suggested that, given the financial constraints, this role initially be 0.5 FTE in order that there is a daily presence both in the community and in the hospital service. The medical lead will be employed by South Canterbury DHB but a memorandum of understanding will be developed between South Canterbury DHB, and South Canterbury Hospice as it is envisaged that this person will be active both in community, Hospice, and hospital based environments. The primary objective of this person is to provide an excellent standard of clinical leadership for all staff in palliative care in South Canterbury and to see that appropriate medical and nursing care is provided for all Palliative Care patients in South Canterbury. In addition to these roles of education and leadership of palliative care services, the role will include assisting clinically when complexity exists and supporting the generalist service providers.

A close working relationship will be important between any General Practitioner(s) at the South Canterbury hospice and the Medical Lead and a similar close working relationship will need to exist with specialist teams such as the Pain Service and Oncology Service. Educational leadership of this service will extend across the District Nursing service and Allied Health, as well as General Practice teams and generalist hospital based clinicians.

Ideally this should be filled by a Palliative Medicine Specialist but consideration may need to be given to employing a Medical Officer of Special Scale (MOSS) as long as that person has demonstrated a special interest with experience and expertise in palliative care.

Recruitment might be difficult to a 0.5FTE position but if the applicant had some other medical skills they could contribute, such as Physician experience or General Practice skills, there is the opportunity for these to be used by SCDHB; with the thought in mind that the demand for Palliative Medical Care inputs will increase over time and thence there will be a potential for increasing the FTE of this appointment. In addition, the possibility exists for the appointee to have a Regional role in conjunction with adjoining DHBs..

It is important that the Medical Lead is accessible to providers across primary, secondary, Palliative care services and Aged Related Care service providers. The role of the medical lead will, of necessity, include liaison activities between all those providers of service and the patient and their family.

It is suggested that linkage of the Medical Lead into the existing relationships that are presently evident between CDHB and South Canterbury DHB specialist services would be helpful with the monthly phone calls, six monthly South Island meetings and annual Palliative Care meetings being important opportunities for these relationships to be strengthened. In addition, there could be the possibility of support for such an appointment with experiential learning from CDHB staff should an agreement be reached between SCDHB and CDHB.

CLINICAL NURSE SPECILIST PALLIATIVE CARE (NEW):

Palliative care nurses within the district nursing service are currently undertaking roles that are possibly more extensive than would be regarded as the responsibilities of a purely generalist service. On the other hand, some of the roles that are currently undertaken by the palliative care nurses are also not those of a nurse specialist.

It is suggested that 1.6 FTE of palliative care nursing should be transitioned to nurse specialist roles (CNS) with greater focus on leadership, education, and the management of care where there is complexity. The CNS roles would no longer sit within the district nursing service rather they form part of the Palliative Care team, acknowledging that their ongoing working relationship with district nursing is critical. It is recommended to increase the current 1.6 FTE to 2.0 FTE, to support the new palliative care team..

The key roles of the palliative care CNS would include the

- provision of specialist palliative care advice in all clinical areas in support of generalist palliative care providers,
- assisting in the coordination and transfer of care between generalist services and specialist palliative care services,
- attendance and undertaking of liaison activities at clinical meetings both within the hospital service and also at the South Canterbury Hospice clinical meetings.

The frequency of meetings and the attendees at these meeting should be determined by the participants, but the principles of inclusivity where there is relevance, and the acceptance that there is often a need for immediacy in this patient group may well result in these meetings being relatively frequent such as weekly.

It will be important to review the district nursing activity levels to clarify if there will be a need to augment the FTE component of district nursing services. The transition from palliative care nurse to CNS will need to be managed with orientation into the new roles in order that the skills required are consolidated within the Palliative Care CNS roles. It needs to be reinforced that the District Nurse role will remain important, and t Palliative Care CNS role is aimed at providing input and advice for the management of complex cases, as District Nursing service remains a critical part of the total Palliative Care service, as are Hospice, Age Related Care and Practice nurses.

One of the roles of the palliative care CNS will be to review and triage all palliative care referrals on their receipt at the community based clinic and to ensure that these patients are added to the palliative care register and that an appropriate member of the palliative care team reviews the patient in a timely manner. This may be the CNS or in the situation where there is evidence from the triaging process that such resource is not needed, a different service provider may be chosen by the CNS. Subsequent briefing at the Multi disciplinary team meeting would occur to obtain wider input.

While employment relationships will be with South Canterbury DHB a memorandum of understanding could be developed to reflect the desired close working relationship that is sought between the nurse specialists, the hospice, the hospital clinicians and community based clinicians. It is also expected that the CNS will have a presence in the hospital and

will work alongside Pain Clinic staff and Oncology clinical staff and the Outpatient services. It is hoped that these CNS appointments will enable seamless transfer of patients between hospital and community, specialist and generalist services, and ensure safe and efficient care delivery to patients and their families.

Between 5pm and 9pm district nursing cover will exist for the palliative care nurse specialist and a district nurse is on call after 9pm. Completion of care plans will enable continuity of care when the CNS is not available. Medical cover will be provided by the General Practitioner or the Emergency Department, depending on the time of day.

ALLIED HEALTH SERVICE: (Existing/ Potential New)

The components of the Allied Health services have a critical role in support of the patient and their family. An inexhaustive list includes social work services, pharmacy services, occupational therapy services, dietetic services, counselling services, spiritual advising services and Maori health support services. The importance of these skills being available when needed is undoubted, and the access to these skills through either a specific consultation or inclusion in the multi disciplinary team meetings is important as is the feeling by these parties of being part of a team and being valued.

It would be envisaged that as resources permitted there would be the allocation of dedicated time to the Palliative Care service by Social Work services. Social workers are able to bring to the team particular skills in working with families children and groups. They are able to enable the patients by locating them within a social and cultural context and access resources to help the family and individual resolve the issues they face. Currently there is no designated FTE of Social work skills, and it is important that this is regarded as a high priority in the near term. Their early involvement may well negate later more extensive social work or other allied health inputs. It is not realistic to expect social work skills and other allied health skills to be resident in the nursing component of the Palliative Care service.

GENERAL PRACTITIONERS (Existing)

Discussion with General Practice to date would suggest that the combination of patients being registered on Care Plus and the availability of funding through the Palliative Care program works reasonably well and while the fees are not regarded by all as generous it is regarded as recognition of time involved by General Practice in care provision in a critical time in their patient's journey. It has been noted that consideration of automatic approval instead of the current delay between application and approval would be reasonable, and a request for this to be actioned has been lodged.

One of the challenges for General Practitioners and members of the General Practice team is of being aware of the variety of skills sets and service providers that can be accessed to support the patient and their family. It is suggested that a revised referral form be developed with General Practice team input in order that the choices are clearly explained and further it is recommended that all referrals are managed via PRISM. Such a form could possibly be used for all transfers of care for this patient group.

This will enable data collection and future planning and development of the Palliative Care service. The General Practice team are critical to providing timely palliative care in all community settings. Providing well coordinated and supportive General Practice services in collaboration with formal palliative care services, as needed will hopefully enable this historically high commitment to continue.

General Practitioners have often provided after hours care in situations where the patient is terminally ill but some uncertainty as to when this might reasonably be expected has existed. A possible “trigger” for this increased responsibility could be the application for the additional palliative care fee subsidy.

The General Practice team, in conjunction with District Nurses, Aged Residential Care and Hospice nurses will continue to be the source of the majority of palliative care provision in the community. The transfer of patients from hospital services back in to the community will be facilitated by Palliative Care CNSs who will also be available to assist when care coordination is required or complexity of care provision is evident. It is anticipated that increased skills within the Palliative Care Team with the appointment of Palliative Care CNSs and a Palliative Care Medical Specialist or Medical Lead may result in increased transfer of skill to the GP team and increased involvement of the GP team in this important area of care. It is possible there will be an increase in the Palliative Care Team activity in the early stages of the provision of this new service.

Continuing education opportunities for General Practice will be enabled by the Medical Lead and the Palliative Care CNSs will also be focused on continuing education for Practice Nurses, plus ARC staff, District nursing staff and Hospital inpatient ward staff.

The Medical Lead will be having a presence in the community a significant part of the time, and it is anticipated will be active in community based consultations with General Practitioners and will be a source of advice and assistance when critical events such as consideration of admission to the hospice or management of symptoms is proving difficult. The Medical Lead will not, however, assume a personal patient load as the primary carer.

It is possible that the Medical Lead may be able to undertake consultations at the General Practice surgery such as presently exists with the Brief Intervention counselling service and this will further augment learning opportunities.

The current service provided by Dr. Mawson at the hospice is greatly appreciated by General Practitioners currently and it is important that his role continues in the future as per his wishes.

PAIN SPECIALIST TEAM AND HOSPITAL CLINICIANS (Existing):

The Pain Service have provided service above and beyond their duty over a significant period of time with very considerable inputs to Palliative Care provision across the DHB. Their role will continue to be critical but potentially could be altered only in as far as their clinical emphasis will potentially be more into provision of specialist pain advice and care. It is anticipated they would have a close working relationship with the Medical Lead and the wider Palliative Care team, and there would be opportunities for joint educational experiences. The work load experienced by the Pain Specialist team to date has been very

high and it is hoped that the appointment of a Medical Lead will enable this to be more easily managed. It has been suggested that the greater focus on palliative care services may result in an increase in the referrals to the Pain Clinic. Close monitoring of the activity levels of the pain Clinic will be needed, however with the appropriate primary care intervention it is hoped the new model would alleviate pressure on the pain service.

The existing good access and rapport between hospital clinicians and the Pain Service is important and this will hopefully be augmented by the addition of a Palliative Medicine Lead. The Medical Lead will assist in the transfer of care between hospital service provision and community providers and ensure that, from the patient's perspective, this is seamless and well coordinated.

SOUTH CANTERBURY HOSPICE (Existing):

South Canterbury Hospice has provided comprehensive care for many patients and its contribution has been greatly valued by everyone. It has an appropriately recognized role in the provision of specialized inpatient care and coordination of care to patients in the community as well as the roles of education and leadership within primary care and aged related care.

The staff have demonstrated an ability to foster relationships already with strong and functional relationships between Hospice staff and hospital based clinicians as well as General Practitioners and other clinicians in the community. In addition, apart from the medical inputs, the critical components of assistance from counsellors, Bereavement Support staff, and Spiritual support is evident. The key to success in the future will be the retention of these services and relationships and the continued effect of partnerships between these different groups and the Palliative Care Nurse CNS team and the proposed Medical Lead. There is, and will also be, an important relationship between the hospital inpatient and outpatient services and the Hospice. This will support the patient in their journey, providing optimal understanding of their situation by the patient and their family, and continuity of care between the generalist services and specialist services.

The Memorandum of Understanding between the South Canterbury DHB and the Hospice will need to acknowledge that the services share many patients and that both have similar aims in terms of outcomes for patients and their families. Inherent in the MOU would be a commitment to liaison and consultation about any issues that arise between the parties and a wish that such issues are addressed promptly and positively.

Clearly referrals will be received from General Practitioners, from District Nurses, from Hospital service providers and from other community based health professionals with a view to the provision of end of life care, and management of difficult symptoms and short term respite care.

That the aspiration is to preserve the benefits of all of these parties who contribute to palliative care services is evident, and ultimately there would appear to be a desire to ensure that the patient and their families receive safe, efficient and individually tailored services.

The evolution of a well integrated Palliative Care service is a paramount goal of the Alliance. As the service evolves it will be important to regularly review the service, its operation and

how it might provide the seamless, transparent, connected, and culturally appropriate service that is sought by all.

PATIENT/FAMILY :

This is probably the most overwhelming time of any person or their family's life experiences. It is critical that all the skills are available, at the right time, right place and by the right person. It is important that there is transparency as to what care is available and what assistance such care may include, and it is also important that the communications and contacts are culturally appropriate to the individual patient.

To this end it is suggested that both specialist and generalist members of the Palliative Care service will promote access to the website [AorakiHealthinfo](#). This site will explain the services, the service providers and how to contact them. The site is not password protected and is specific to South Canterbury and can be altered easily. The contents can be printed without difficulty by Providers, support organisations or at public places such as Public Libraries. We can assume that the feelings of "not knowing what is going on" being minimised will be helpful in the patient's and their family's journey.

It is also critical that the need for provision for an holistic approach to care that is aware of their spiritual needs and of their need to have time and places to talk and discuss their anxieties with a respected person is met.