What do we know about people’s experiences of Palliative Care in MidCentral District Health Board?

A WORKING GROUP REPORT
EXECUTIVE SUMMARY

To drive and implement the Palliative Care Strategic Plan (2012), a Palliative Care District Group (PCDG) was established in July 2013. A working group was established to capture examples of and understand the diversity of patient, family and whānau experiences of palliative care to inform service delivery in this district. This information will then contribute to and underpin the work of all other working groups.

Through a number of sources including MidCentral District Health Board (MDHB) focus groups, local research, satisfaction surveys, compliments and complaints, theses, grey material such as newspapers and written thank you notes, the palliative care experiences of people within MDHB have been captured. It is through people’s stories that the essence of their experiences of care from their own unique perspectives can inform those who are responsible for providing care and services.

Major themes identified include:

1. The person, their family and whānau carers require personalised care.¹
a. The person requires focused, ongoing assessment(s) (which is inherently holistic – including cultural and spiritual care) of their symptoms, needs and concerns so these can be identified and addressed to support the best possible outcomes.

b. Families and whānau require focused ongoing holistic assessment(s) of their concerns and needs so these can be identified and addressed when actively caring and in bereavement.

c. The person, their family and whānau require information, advice and support with everyday aspects of care and of caregiving (e.g. medications, physical cares) and self care prior to and for family and whānau at time of death and in bereavement.

d. Personalised care creates a sense of feeling cared for and it is crucial to the perceived quality of care that care received is delivered with kindness and compassion. Feeling cared for is more important and valued than the physical place of care, and may mitigate the loss of being in a more desired place.

2. Personalised communication. The necessity of personalised communication that is timely, culturally appropriate, respectful, compassionate, kind, meaningful (e.g. verbal, non verbal, written) and demonstrates active listening with patients, families and whānau, was prominent and integral to positive experiences of receiving care and feeling cared for.

3. The environment care is received in is important. Receiving care in an environment that is welcoming and accommodating of the person, family and whānau is important, as are key attributes of that environment, including cleanliness, privacy and a sense of connectedness (e.g. to family, nature, the outside world).

4. Information availability and accessibility. Information is required regarding hospice and palliative care services, supportive services (e.g. home care and equipment), in relation to illnesses and caregiving that is accessible in multiple forms.

¹ References to personalised, person-centred and individualised care is increasingly evident in the health care literature. Kitwood (1997, cited in McCormack 2004) defines person centeredness as: a standing or status bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust¹. Such a definition is congruent with a holistic approach to care and the Maori health model Te Whare Tapa Wha.
5. **Connected, responsive and accessible services are required.** To meet the needs of this population these attributes of service delivery are required because they are supportive of all parties and reduce stress/distress.

6. **Support and collaboration navigating the illness journey is highly valued.** Knowing what to expect (e.g. potential symptoms, changes in condition, impending death) is valued when shared compassionately and collaboratively.

7. **Time matters.** Lifetimes, time together, not being rushed by health professionals and others, the opportunity to be present with loved ones and being given the time of others (family, health professionals) who support patients, families and whānau is highly valued.

8. **Most people are resilient during bereavement.** Many people receive support from family, whānau and existing support networks like faith and other community groups. However, the needs of those who are less resilient, with more complex bereavement and/or with poorer support networks need to be identified and addressed.

9. **There are significant gaps in the information available to inform service design within MDHB.** Specific gaps relate to the patient’s perspective, bereavement experiences of family and whānau and care in non-specialist (generalist or primary) palliative care services particularly the older person, those with disability and those in isolated communities (e.g. single men, refugees and new migrants).

**Limitations identified in service feedback.** Most frequently feedback from families and whānau to specialist services is positive. The paucity of complaints could be multifactorial (e.g. time, emotional labour required).

The following recommendations have been drawn from the section summaries of this report and are organised in alignment to the quality improvement and outcomes framework of MDHB. This framework is informed by the Health Quality and Safety Commission triple aim goals:

1. improved quality, safety & experience of care
2. improved health and equity for all populations
3. best value for public health systems resources.

The findings within this report and associated recommendations relate to key elements of integrated palliative care frameworks identified in the unpublished MDHB Palliative Care Quality Framework (2014).
Recommendations

Being willing and able to learn

- Establish a new, or increased focus, on populations under-represented in the information currently available for those receiving generalist/primary palliative care, including:
  - people with disabilities
  - older people and
  - those in isolated communities (e.g. single men, refugees, migrants new to New Zealand and prisoners).
- Establish new, or better utilise existing ways to engage with consumers for feedback regarding palliative care experiences.
- Establish new, or better utilise existing ways to engage with consumers for feedback regarding after-death care and the bereavement supports that are valued by family, whānau and carers.

Being consumer and community focused

- Utilise information obtained (e.g. via assessments, feedback, audits, research) to keep those with palliative care needs (patient, family and whānau) at the centre of services and inform service design.
- Information to be available within MDHB (in a centralised location) regarding how to access such things as equipment, health professionals, assistance with personal cares and financial assistance.
- Raise public awareness of what palliative care is and the palliative care services available in MDHB (written information and websites should contain relevant information, other public repositories of information). This includes information regarding after hours care, advice and support.
- Co-design methodology would be appropriate for developing palliative care information.
- Organisations to create and maintain environments conducive to the total wellbeing of patients, families and whānau.
- To enable and support families, whānau and carers to be present and participate in care (if desired/appropriate) when care is delivered in organisational settings.
- Organisations have supportive services (equipment and personnel) to enable care ‘in place’, be this within an organisational setting, in a person’s own home, or their family or whānau home as appropriate.

Getting it right

- Identify those with palliative care needs (specialist, generalist/primary) in a timely manner, through the use of systematic, accurate assessments.
- Collate and analyse data related to palliative care need from district-wide assessment data.
- Identify and trial appropriate tool(s) for assessing palliative care and associated needs including carer needs, and if appropriate adopt within services.
- Specialist palliative care services identify, utilise and disseminate best practice to support appropriate palliative care approaches.

Being up for the job

- Quality systems in place to ensure organisations (specialist and generalist/primary palliative care providers) are delivering quality palliative care and engaged in quality improvement.
- Professional development is available and promoted to strengthen skills related to communication, cultural responsiveness and spiritual care, in particular.
- Future strategic planning addresses the gaps within the work being undertaken in the current MDHB Strategic Plan (2012–2017).

The following report will:

- Identify the relevant service need of the population in MDHB.
- Provide a summary of information regarding the personal palliative care experiences of those requiring palliative care (the person, their family and whānau) from MDHB and New Zealand research that informs the recommendations.
WHY DO WE NEED TO KNOW ABOUT PEOPLE’S EXPERIENCES OF PALLIATIVE CARE?

Locally, nationally and internationally there is recognition that those who are users of services can provide core evidence to underpin service development and improvement activities. People’s stories provide the essence of their experiences of care from their own unique perspectives, whether that is as a patient, family or whānau. The mandate for this work comes from the MDHB Palliative Care Strategic Plan 2012–2017 (MDHB-2012), which outlines the five-year direction and priorities for palliative care service development in this district. Building on established regional programmes, it is informed by a vision that “all people with life limiting conditions live well and die well irrespective of their condition or care setting” (MDHB, 2012, pg 6) and its first goal is “The patient experience will be at the centre of service design”.

To drive and implement the Palliative Care Strategic Plan, a Palliative Care District Group was established in July 2013. A Working Group (Appendix 1) was established to progress the goal of understanding consumer experiences of palliative care. This group’s role was to capture examples of and understand the diversity of patient, family or whānau experiences of palliative care in this district to inform the delivery of this central goal. This information will then inform and underpin the work of all the other working groups.

The first task of this working group was to identify and review extant information. This included population data, service data (e.g. satisfaction surveys), findings from local and NZ research and a sampling from the international literature. Information was also sought from the ‘grey’ literature (e.g. newspapers) and from community groups.
SERVICE NEEDS AND PRIORITIES

Defining Palliative Care Need & Service Delivery

Palliative care aims to optimise quality of life until death for people of all ages who experience a life-limiting illness, by addressing people’s physical, psychological, spiritual and cultural needs. Palliative care services also support the person’s family, whānau and caregivers throughout the illness and after death. Palliative care is provided according to people's unique needs, whether death is days, weeks, months, or occasionally even years away. It may also be appropriate when palliative therapies aimed at improving quality of life are being given (Palliative Care Subcommittee, 2007). It is recognised at a national level that palliative care should be available wherever the person may be and in such a way as to meet their unique needs (Ministry of Health, 2001). Within MDHB, palliative care delivery is organised so that specialist palliative care is provided in the community by Arohanui Hospice (inpatient, community and day stay). In secondary care, advice and support are available from the Hospital Palliative Care Service. Primary palliative care providers play a significant role in the care of those with life-limiting illnesses. This includes staff in hospital settings (Palmerston North Hospital, Dannevirke Community Hospital and Horowhenua Hospital), General Practice Teams (GPT), the District Nursing Service (DN), community nurses such as the cancer support and long term condition nurses, Māori Health providers and Aged Residential Care (ARC) providers.

Projected Palliative Care Need

The National Health Needs Assessment for Palliative Care by the Palliative Care Council of New Zealand (PCCNZ, 2011) identified the number of people who “might benefit from palliative care in New Zealand on a national and regional basis”. Based on national population growth over the next 15 years, the number of adults dying in 2026 where palliative care may be of benefit is estimated to be 19,076. This is an expected increase of 23.5% (PCCNZ, 2013) based on current criteria for service provision. Critically this number is not a uniform increase in deaths over all age groups but rather a significant increase in the older age groups. However, it is recognised that age-related mortality is currently significantly different for Māori and Pacific groups. For Māori more deaths occur in the middle age groups (30–60 years). These projections provide an important context for the types of services, and places of service delivery, that are likely to be needed in the future and what types of service redesign may be necessary to address future need.
The MDHB district includes Horowhenua, Tararua, Feilding and Palmerston North. It has a large rural area and a population of 162,500 (in MDHB 2014/15 Annual Plan, pg 5).

The MDHB Health Needs Assessment (MDHB, 2014) shows that in terms of population patterns:

- The population of MDHB is increasing (2.3%), although at a slower rate than NZ overall (5.3%).
- MDHB’s percentage of Māori residents is higher than NZ overall (17.4% and 14.1% respectively).
- Ethnic diversity within the district is greatest in Palmerston North.
- MDHB’s population has a higher proportion of older people compared to NZ (16.5% and 14.3% respectively).
- The distribution of people aged 65 years and older is not even across the MDHB district – it is higher in Horowhenua and MDHB’s portion of Kapiti Coast (Otaki and surrounding areas).
- MDHB has a lower median household income compared to NZ.
- MDHB’s population has higher proportions of groups with higher health needs compared to NZ overall.

The highest causes of mortality in MDHB (and New Zealand) are: circulatory disease, cancer, respiratory disease, injuries, endocrine diseases (of which diabetes is the major contributor). Māori are over-represented (Ministry of Health, 2013) in these figures. Palliative care is appropriate in the final stages of all of these conditions, except injuries (where it still may be relevant depending on the case). In 2010 nearly 2,500 patients across the MDHB district met the criteria for palliative care. The projected increase in palliative care patients in 2026 would take this number to nearly 2,800 (PCCNZ, 2011).

**Place of Death: NZ**

Where a person dies is influenced by a number of factors such as age, ethnicity, deprivation and the underlying cause of death. National figures (Figure 3) indicate most deaths occurred in a hospital setting (34%), followed by residential care (31%) and private residence (22%). Few deaths occurred in a hospice inpatient setting (PCCNZ, 2013). The place where a person dies, whether it be at home, in hospital, in a hospice, or in ARC, is an important part of people’s wider experiences of palliative care. It may reflect a deliberate choice, be the dying person’s preferred place. It may reflect the resources available to family or whānau as caregivers, or it may be related to the need for specific types of care.

**Figure 3**

*Place of Death 2003–2007 (PCCNZ, 2011)*

New Zealand has a higher rate of death in ARC facilities for those aged over 65 compared with 17 other Western countries. As a result, those working in ARC have a significant role to play in supporting those requiring a palliative approach to care and care of the dying (Connolly et al, 2012). The Ministry of Health figures 2012/2013 demonstrate that almost a third (31%) of those admitted to ARC facilities (including rest home and dementia care) die within six months of admission and 41% die within a year of admission. Their experiences of receiving palliative care services in places such as an ARC facility are also likely to be markedly different if it is not the preferred place of care of the person or family or whānau.
It is important to know where someone dies, as this is a place where a positive difference to service provision and therefore personal palliative care experiences can occur. Obtaining accurate data for identifying place of death in MDHB is not possible due to collection methods. What is available is general mortality data.

In 2010, 1,302 people died within MDHB and 32% died within Palmerston North Hospital (n=426) (Ministry of Health Mortality Data, 2010). Accurate data for those who died in ARC is unavailable as the data collected is aggregated with all private hospitals including hospice services.

If, however, generalisations were made that MDHB data was reflective of national data, then ARC would be a significant place of dying. Arohanui Hospice discharges 10% of all patients to ARC for end of life care. ARC facilities in MDHB have a high number of internationally qualified nursing staff – approximately 34% (figures from phone interviews with managers). This is significant, as the beliefs, values and experiences of caring for the dying may differ significantly for those whose professional undergraduate education occurred internationally.
MDHB is committed to quality improvement as described in the Quality Improvement and Outcomes Framework (MDHB, 2014). Overarching this framework is the triple aim of improving the quality, safety and experiences of care, improving health and equity for all populations and providing best value for public health system resources. In order to achieve these aims, deliberate actions are necessary to enable the personal experiences of service users and their families and whānau to be communicated with services, understood and considered in service redesign.

The framework outlines the four key areas of focus for improvement including:

- Being willing and able to learn
- Being consumer and community focused
- Getting it right
- Being up for the job.

In order to achieve the above focus, the description of current personal palliative care experiences is necessary. For service design to be centred on the needs of the service users, their family and whānau, then a stocktake of current perspectives is required. The second part of the report provides those experiences.
Information regarding personal palliative care experiences was drawn from a number of sources.

**Specialist Palliative Care Services**
- Arohanui Hospice patient satisfaction surveys and complaints.
- Thank you cards/notes – hospital palliative care team, hospice staff.

**Primary Palliative Care**
- Community Palliative care; the evaluation of the Palliative Care Partnership programme (McKinlay et al, 2006).
- Forum information from the development of the MDHB Strategic Plan.
- Compliments and complaints information from acute care services.
- Feedback information from the Central Primary Health Organisation (CPHO).

**MidCentral District Health Board Research**
In MDHB, seven relevant research based articles, theses or evaluations were identified. These are:
- Culturally appropriate end of life care for Māori (Batten et al, 2014)
- Family members’ perceptions of declining oral intake towards the end of life (Raijmarker et al, 2013), and additional raw data is cited and referenced by interviewee and year obtained, 2012
- An evaluation using a patient held record for home based palliative care patients: A case study research project (White, 2012)
- An evaluation of the MDHB Palliative Care Partnership (McKinlay & McBain, 2006)
- All the comforts of home? A critical ethnography of residential aged care in NZ (Bland, 2003; 2006; 2006b)
- A Death of One’s Own: Understanding dying well for patients receiving palliative care (McNaught, 2002).

**National Information**
- The Voice of Experience: Part two (Cancer Control Council of New Zeland, 2010).
- From Care Giving to Bereavement: weaving the strands of identity (Lee, 2009) Masters theses, Massey University.
- A New Zealand literature review using the search terms patient/family experience of Palliative Care/NZ, and recent reviews. The timeframe for this search was between 2008–2014 and the search database used was EBSCO Host including CINAHL.
- New Zealand literature was also used from a bereavement support literature search. The search terms bereavement, support, palliative care were used and the time frame 2008–2014. Database used for the search was EBSCO host and included CINAHL.

**Grey Material**
- Newspaper articles and letters.
- Information gained from Funeral Directors.

**Gaps**
Information from the following sources was not available, as personal perspectives of palliative care and/or service are not routinely collected.
- **Aged Residential Care facilities:** satisfaction surveys are completed but there are no questions regarding palliative and end of life care. Bland (2006a, p13) noted that in her professional experience people in hospital level ARC were often too unwell to provide ‘formal feedback’.

- **Central Primary Health Organisation** does not collect any data on patient, family and whānau experiences of their palliative care services, however it does receive complaints and compliments and these have been included within the findings.

- **Acute care:** no mechanism for collecting feedback from patients, families and whānau regarding palliative care beyond the usual ‘Tell us what you think’ form within Palmerston North Hospital.

In relation to people’s experiences of health care and cancer care in particular, the fifth recommendation from the first national cancer survey of patients’ experiences of outpatient care recommended research into patients’ experiences across the cancer care continuum, including palliative care (Cancer Control Council of New Zealand, 2010, p8). The report also noted that “system-level research can help identify macro-system dimensions that can impact on the patient experience and the coordination of quality cancer care” (p8).
I don’t know if it was very clear (that the person was dying), well not clear to me that he was going to die because I didn’t know what palliative care meant until a month before he passed...

(Bereaved relative 11, p3 Raijmakers et al, 2012).

This section of the report presents key findings related to the person’s, family’s and whānau perspective to inform service design. Within the scope of the working groups brief, information was sought from relevant research within MDHB, relevant research undertaken in New Zealand, grey literature and service feedback within MDHB (Appendix 2). Recommendations will be made regarding addressing the gaps.

Within MDHB, few projects have been undertaken specifically focusing on the persons, the family’s or whānau experiences of receiving palliative care services in either the primary/generalist or specialist services. A research project focused on culturally appropriate end-of-life care for Māori has just been completed (Batten et al, 2014). The nine recommendations are congruent with the essence of the findings of this working group report in calling for an individualised approach to end-of-life care. Recommendation seven, pertaining to the education of health professionals regarding communication techniques as a core skill and recommendation nine regarding all services providing end of life care undertaking regular whānau-centred impact assessment have a particularly close resonance. Raw data from the research project has been an invaluable source of information to the working group. A selection of other projects, which collected data from slightly different orientations, also contains the perspectives of recipients of palliative care services. These include: White’s (2012) Master’s Thesis regarding using a patient held record for home based palliative care services; Raijmakers et als, (2013) investigation of bereaved relatives perspectives of patients oral intake towards the end of life; McKinlay and McBain’s (2006) evaluation of the MDHB Palliative Care Partnership; and McNaught’s (2002) PhD Thesis which focused on patients’ perceptions of dying well. Two, White’s (2012) and McKinlay and McBain’s (2006) work, are directly related to aspects of palliative care service delivery and contain the perspectives of service recipients.

Significantly, the least amount of information is available for the majority of those in need of a palliative approach to their health care – those people not receiving specialist palliative care services. This represents a limitation regarding understanding the person’s, their family’s and whānau experiences in MDHB and therefore how it can inform service design to meet their needs.

Two research projects related to palliative care in non-specialist environments were identified within MDHB. Firstly Bland’s (2003) PhD and subsequent publications (Bland, 2006a & 2006b) highlight the challenges facing ARC facilities in providing a ‘home’ like environment for residents including at the end of life. Despite the high mortality, death and dying was not explicitly discussed or acknowledged with residents. Secondly a research project focusing on staff perceptions of end of life care has been undertaken in ARC before (Marshall, Clark, Sheward & Allan, 2011) and after (Clark, Marshall, Sheward & Allan, 2012a) the introduction of the Liverpool Care Pathway (LCP) for the dying patient, and before (Sheward, Clark, Marshall, & Allan, 2011) and after (Clark, Sheward, Marshall, & Allan, 2012b) the introduction of the LCP in the acute hospital setting.
Nationally, publications containing the perspectives of patients, families and whānau were sought with a focus on the past five years. Those available include a publication from Egan’s doctoral investigation into spirituality (Egan, MacLeod, Jaye, McGee, Baxter, Herbison, 2011), Cultural perspectives on challenges to the use of hospice services (Frey et al, 2013), enquiry into patient and family perspectives of hospice services (Bray & Goodyear-Smith, 2013). Slater et al, (2013, p308) publication regarding 12 Māori cancer patients, their family and whānau experiences of health care services identifies three key areas, “the experience of support; continuity of care; and the impact of financial and geographical determinants.” While alluded to in the abstract, there was no specific discussion related to palliative care. However, all aspects of the journey can be seen as relevant in the palliative care phase. A unpublished qualitative study for a Masters thesis (van Aalst 2013 ) explored five patients and five family members experience of accessing a hospice service. Key findings related to the positive atmosphere, communication, relationships and the attention to the ‘little things’.

Other recent New Zealand publications provide additional relevant information related to palliative and end of life care. Kidd et al (2014) undertook a research study related to service access for Māori from a health literacy perspective. Key findings include difficulties related to late access/referral to palliative care services. This was sometimes related to health professionals reluctance to have difficult conversations regarding the need for a palliative approach, people could be reluctant to access service because of fears and misunderstanding, a perception that such services were Pākehā organisations (however once they were accessed, these were often found to be acceptable). Regarding health literacy, people required skills around managing the disease (medicines and patient care) and navigating the system. Robinson, Gott and Ingelton (2014) published an integrative literature review which highlights the paucity of information regarding the patient’s and family’s experiences of palliative care in hospital. Gott et al, (2013) conducted a prospective survey of adult inpatients in a NZ hospital. They identified 19.8% of adult inpatients met the criteria for a palliative approach.

Connolly et al, (2013) undertook a prospective follow up study ofARC. Their findings highlight the high mortality in this population and suggest that ARC facilities are de-facto hospices for older New Zealanders. These publications highlight the need for palliative care approaches and practices in acute inpatient populations and ARC.

Table 1 represents key elements within the palliative care journey. Information obtained regarding personal experiences was then mapped/themed against these to provide structure to the findings from MDHB and New Zealand. Quotations from local sources of research or feedback to services are utilised to bring the patient, family and whānau perspective to the foreground.
Included within this section is care delivered following the death of a person including bereavement follow-up, emotional and practical support.
PALLIATIVE CARE
NEED IDENTIFIED:
NAVIGATING SERVICES

That was in August/September, August I think it was, and they just virtually wiped him [removed him from their care] and said, “You’re under palliative care” (Bereaved relative 2, p5, Raijmakers 2012).

To deliver palliative care services to patients, families and whānau that appropriately meet their needs, it is necessary to understand their experiences of navigating services and the transitions between services.

This includes:
• Being identified as having a palliative care need
• Being referred to a specialist palliative care service (where appropriate)
• And/or receiving intermittent specialist palliative care.

People may be identified as having a palliative care need that can be met by their current primary or generalist provider (General Practice team, primary consulting team in hospital, Māori Health provider) or require specialist palliative care referral to either the hospital palliative care service (inpatients) or Arohanui Hospice (community, including Horowhenua Hospital, Dannevirke Hospital and ARC). The need for a palliative care approach may occur after a long illness and period of treatment (in either malignant or non-malignant conditions), a new diagnosis of advanced cancer, a sudden medical event (e.g. intracranial haemorrhage, leaking abdominal aortic aneurysm), following acute trauma (e.g. motor vehicle accident, failed suicide). Therefore services referring to specialist palliative care may include general practitioners (GP) or GP team members, Māori Health providers, the emergency department, specialist outpatient/ambulatory care clinics, medical oncology day ward, primary teams within the hospital, or other DHBs (specialist palliative care services or other specialties). To add to the complexity people may move in and out of specialist palliative care and acute care services. Both specialist palliative care services in MDHB have ‘referral guidelines’.

MDHB

A lack of community understanding and awareness of palliative care and hospice services was apparent in the forums held when developing the district-wide Palliative Care Strategy (MDHB, 2012). Confusion regarding terminology and language was also significant. People were not aware of what services are in place and could be provided. Quotes from the forums support this, for example:

[Not] Knowing what palliative care is and knowing what is available. Myths that once you go to hospice you die. Need fluidity between services (MDHB Strategic planning forum 2012).

Research related data collected from several sources indicates that the transition between services by referral to specialist palliative care could be traumatic. This is clearly evidenced in a summary case study included in Appendix 2, where a family carer of a person identified as needing palliative care struggles with the complex referral processes, without support to understand what the different services could offer. Sources of data include raw data from Raijmakers et al (collected 2012), as part of an enquiry into declining oral intake towards the end of life from the perspective of 23 bereaved relatives Raijmaker et al (2013) and McKinlay & McBain’s (2006) review of the palliative care partnership between Arohanui Hospice and General Practice teams (GPT). McKinlay and McBain included the perceptions of four current patients and five family members and three bereaved spouses and a carer (p41–45). Some people can feel abandoned, as indicated above, if the transition is abrupt. Becoming unwell and requiring more assistance could be a shock for patients (McKinlay & McBain). It may also be disheartening and result in the loss of hope (McKinlay & McBain).
Not all people can be nor need to be cared for within a specialist palliative care service. However, communication around access to specialist palliative care services can be challenging to manage. McKinlay and McBain (2006) found some general practitioners were confused regarding non acceptance of a referral by specialist palliative care services and the need to find alternative places of care (other than home, hospice or hospital) was a source of distress for family members. For example one bereaved person felt pushed into finding care in an ARC facility. The level of engagement with general practitioners varied, and was less satisfactory when locums were involved (McKinlay & McBain, 2006). Disjointed services that do not respond to identified palliative care needs in a timely manner are a core part of the summary case study (Appendix 2). As a result, the family can be left for a considerable length of time attempting to find their way through a maze of services and referrals, while caring for a dying relative.

Raijmakers, et al (2012) data includes references to general practice teams, home care and care in ARC facilities. A positive and supportive relationship with a General Practitioner (GP) could be central to supporting home care. The following participant spoke on several occasions of how crucial and supportive her GP was in enabling her to care for her husband at home. His lead in identifying that it was time for him to become the visitor rather than them visiting the surgery was highly valued and perceived as promoting her husband’s dignity. This participant also commented positively on the GP’s communication style and willingness to visit at home and review her husband prior to the GP’s morning surgery.

... the last time I took him I knew it was getting – I would have to put him in a wheelchair to get him there. My GP looked at me and he said, “I’ll be the visitor,” and the same as the blood people, cause he had Warfarin every week so they came here, but I thought it was beneath his dignity to have him shuffling in there at 94 (Bereaved relative 1, p3 Raijmakers et al 2012).

Slater et al’s (2013) study on Māori patient perspectives and experiences of cancer care including palliative care identified three themes of support including continuity of care and their experiences of support provided by the GP.

*Same GP yeah. She has got two files that thick. And she was the one that um, when I first was diagnosed she sent me to a specialist. So there was no shilly shallying (Slater et al, p311).*

Several participants made comments, both positive and negative, about care in the acute care setting in hospital. The acute setting in hospital and hospice environments were perceived as very different as was the focus or orientation of care. The following quote captures some interesting themes; the different orientations of the services and that the acute care setting in hospital is not regarded as an appropriate place to die – rather you are ‘shut out’ to die.

*I’m a great fan of hospice’s. I think palliative care is absolutely necessary and specialist palliative care is because most GPs have no idea of what to do. I think in the hospital they were sort of at a loss too because they’re not geared up to that. They shut you out to die usually. It’s only for accident people where they’re fighting to keep you alive and if you die in spite of it, but the notion is sort of slowly dying; its not something I think that the public health system and the hospital is geared to do... my father died in a hospital. I had to go to great pains to convince them that they were to stop any treatment at all and leave him be at the end cause they’re motivated by this notion that you’ve got to keep them alive. Whereas the palliative care people are motivated with quite a different notion and that is to make dying easy for them. In other words, you can’t do anything about it so you make it as easy as possible (Bereaved relative 7, 9 Raijmakers et al 2012).*
Moving between health care facilities and services could be stressful. The transition from acute setting in hospital to the hospice inpatient unit and subsequently to ARC could be particularly difficult. The following bereaved relative commented on this and was particularly sad, because ideally, the relative wished to care for the person at home but it was not possible.

... but a hospital’s a hospital. There’s four beds in the ward and there’s people coming and going, but the hospice was fantastic, just like a hotel really walking into that place. It’s well looked after as well, so... The rest home was good, but okay we were a bit disappointed, cause when they said she was coming to the rest home, they knew she was coming and the room wasn’t ready and that really downed me quite a bit. Okay there’s a lot more there’s only 10 up in hospice, patients and here [ARC] I don’t know about 50 or something, so you can’t compare the treatment that was in here. Of course the nurses are high standard up there, which they’re not at the nursing home. But when I seen it first, I thought well, I want you being at home, look after her [crying] (Bereaved relative 21, p2 Raijmakers et al 2012).

A local joint patient/family/primary/specialist service initiative is the patient held record (PHR). The PHR could be seen as exemplifying a tool to assist with navigating the specialist/primary interfaces and was evaluated by White (2012). Four patients and their lay carers were interviewed regarding their views and experiences of using the PHR, their perspective of it and things that influenced their engagement (White p53). The PHR helped them answer health professionals’ questions, supported their vigilance in their own health care (tracked information and appointments), and brought them back in the loop. Lack of engagement from health care professionals with their PHR was a source of concern particularly when patients and families were diligent in taking it to medical appointments to be completed.

Knowing who to contact and when, especially early in the transition between services is important. Participants in White’s study describe being unsure who to contact, the district nurse, hospice and/or the GP – and sometimes it would be different the next time a similar issue arose. Uncertainty regarding who to contact for what and when caused confusion and distress. For example:

Don’t forget that this is our first time around and probably our last... All I’m saying is that I found the procedures and what have you abysmal. We didn’t know where to go and when we did go it was to the wrong place. It was distressing (White, 2012, p60).

Once you are in the hands of the medical profession you have all different doors that you go to, you’ve got your GP, hospice, your specialist, your blood people, the lab. Who do we go to for what? (White 2012).

Fortunately most people do not become experts at navigating this part of the health care journey, unlike specialist providers for whom it is their core business. There was also a need for the movement between services to be easy. The summary case study (Appendix 2) demonstrates how families can become lost in the system, when navigation between services is not provided, and people are left to traverse the transitions (and gaps) themselves.
Kidd et al (2014, p.viii) found that Māori could be reluctant to accept palliative care services because of beliefs that they were only available for inpatients and significantly “that the purpose of the hospice was to hasten death; and that to accept palliative care was to accept that death was imminent.” Misperceptions of palliative care and hospice services within MDHB are not necessarily out of step with those nationally. An online survey (MacLeod, et al 2012) with 1011 participants regarding the purpose and practice of palliative care and hospices revealed variation in understanding. People over 50 years of age had a greater understanding of hospice activities while people under 30 years were less likely to be aware of the services activities. Understandably, older respondents were more likely to have had experiences with a palliative care service although people were not always sure which type of community or inpatient service they had encountered. More than half (65%) could not name their local hospice service although the majority (82%) believed “palliative care is an essential health service” (McLeod et al, p59). The researchers’ emphasise the need to educate the public so that the public understands the service and they are therefore sought appropriately when needed.

Bray and Goodyear-Smith (2013) investigated patients’ and family members’ perceptions of a hospice service. Key findings were related to the following four themes: the approach of hospice personnel to patients, quality of service, cultural barriers, and strategies for future improvement. The latter two were the focus of the article published which highlighted the following:

- Lack of public understanding and knowledge of hospice/palliative care
- Lack of awareness of services available
- Ethnic and cultural diversity and impact on accessing services
- Need to use ‘forums’ to educate/reduce barriers.

Slater et al’s (2013) investigation of the experiences of 12 Māori people with cancer, their family and whānau identified the importance of good support – from family and whānau, Māori Health providers, and non-government organisations (NGOs). Their GP in particular, when well known to them, was often important in providing consistent support and continuity of care. Support was valued holistically – be it in terms of time, information, psychological or practical support.

Communication

Effective compassionate communication regarding, diagnosis, prognosis and the transition between treatment and palliative care services is critical and covers the continuum of the palliative care journey. Having the right information at the right time, delivered in the correct manner by the right person is central for a satisfactory outcome. When communication does not reflect these standards it is harmful for the patient and their engagement in health services.

Dr told me I had bowel cancer and it was severe. No results back then, he was very rough, bordering on brutal. He said I might not last six months. Hope I never see him again (Customer feedback from Palmerston North Hospital).

In seeking information via the MDHB forums regarding palliative care, a participant made the following comment related to the need for information in order to plan ahead.

Need to plan ahead through the use of information (MDHB strategic planning forum)

Having available adequate time and opportunity to give and receive information is important. Participants (Slater et al, 2013, p311) commented on the lack of “opportunity” and ‘space’ to ask questions” and this related to appointments with GPs and specialists within acute care. At these times personal support was described as invaluable” (p311). Māori Health provider organisations were identified as important in helping patients, family and whānau understand the information related to their care within health services.

Kidd et al (2014) found many elements of health literacy related to communication. The reluctance of health professionals to have ‘hard conversations’ with patients, families and whānau could result in late referrals to palliative care services. This had a significant impact on the timeliness of referrals.

We were told on Monday, I brought him home on Wednesday and he passed on the Friday (Daughter Kidd et al p25).

This presented communication challenges for all, including palliative care providers who have not had an opportunity to establish a relationship and rapport prior to the person becoming imminently terminal.
Effective communication and understanding of information communicated at the time of transition is often more difficult because of the emotional and distressing nature of the situation makes it more complex. Pre-existing levels of health literacy on the part of the person and their family and whānau also impact on responses to the often overwhelming amounts of information given at this time.

You get the “oh well, we can’t do anymore. Do you have any questions?” You have just been told that your loved one is going to pass away shortly. Do you have any questions? Well – you know? All within five minutes. (Daughter Kidd, et al p26)

Section Summary

The following themes are significant when reviewing personal palliative care experiences documented in research findings, the literature, and the summary case study (Appendix 2) during the time of recognition of palliative care need and transition of care from curative intent to a palliative approach.

- **Communication** – This quality of communication had significant impact on the person, their family and whānau. Compassionate communication that was timely, inclusive and delivered in a way that was meaningful to patients, families and whānau was supportive. Poor communication included poor listening, not identifying and responding to concerns, and inadequate time which adversely impacted on the experience of care.

- **Information regarding palliative care** was required for the individuals receiving care and their family and whānau. Information needed to be given in a number of ways, verbally, written and available through a number of mediums. It needed to be clear and concise and accessible at the right times. Information was often required more than once (repeated, to include others etc).

- Individuals, families and whānau need to know what they can expect from services and those delivering services and therefore what services are unable to provide.

- Existing services needed to be responsive and accessible and needed to be delivered as they were required.
RECEIVING SPECIALIST PALLIATIVE CARE AND/ OR PRIMARY PALLIATIVE CARE SERVICES

To inform service design it is necessary and important to understand what it is like to be the recipient of palliative care services. Several studies contain data regarding either primary (generalist) or specialist palliative care providers, at times peripherally to the main focus of the enquiry. Information is also available in the form of feedback to service providers.

MDHB Specialist Palliative Care Services

Arohanui Hospice Specialist Palliative Care Service

McKinlay and McBain’s (2006) evaluation identified that patients and families were satisfied with the care received under the Palliative Care Partnership with the exception of one relative who felt pressured to place their family member in ARC. The need for people to go into ARC is a current issue and evident in data collected by Raijmakers et al (2013) from bereaved relatives.

The need for placement in ARC (rest home or hospital level care) for people in the hospice inpatient unit is frequently a source of distress for patients, their families and whānau as the unit does not provide ‘long term care’. In 2013/14, 10% (40/386) people were transferred to ARC care from Arohanui Hospice. The majority of others returned to private residences.

The Palliative Care Coordinators (PCC’s), who work in the community service, were identified as having a number of roles (McKinlay & McBain, 2006), with being ‘watchful’ seen as very important to the patients and also being a ‘key contact’. Patients and families and whānau found that knowing who their key contact person was is also important. The PCCs were highly valued by the bereaved carers interviewed, particularly when the person they were caring for was nearing the end of their life. The lack of this coordinating role is obvious in the summary case study (Appendix 2), where the family carer is left to try to navigate services and be watchful without the necessary skills and knowledge. In addition, no one took on the key contact role for this family.

McNaught’s (2002) patient participants identified important aspects of the hospice service for them. This included the hospice staff being able to visit when needed, access to day stay services, assistance with spiritual matters, information, being contactable (24 hours a day) and knowing who they were going to see (continuity of care). The participants also commented on staff members’ personal qualities (e.g. kindness, compassion).
Families/whānau and caregivers expressed the need for information about services that were provided and how services were co-ordinated. Having a key contact person and knowing who to go to was also identified as important by White (2012).

Quotes from the MDHB public palliative care forums, held when developing the palliative care strategy and from the research findings from culturally appropriate end of life care for Māori research project also illustrate the need for knowing who and when to call for further help.

... so there needs to be some better coordination obviously happening further back for you from a service point of view, so that you knew when you have this query you ask this person (Focus group 7, culturally appropriate end-of-life care for Māori study).

Accessing the right person at the right time is important (MDHB strategic planning public forum 2012).

Guidelines on what to do in an emergency and after hours (MDHB strategic planning public forum 2012).

24-hour care, you ring and they are there (MDHB strategic planning public forum 2012).

Thank you cards from patients and families also provide an indication of what is valued.

Thank you to the staff. The kind ‘voices on the phone’ for your support. (Bereaved family thank you card 2014)

Thank you for the excellent care I received during my stay at hospice. You are all wonderful (please make sure your boss reads this card too and thank him) (Patient’s thank you card, 2014).

It was good to be able to use the family room when the whole family came to visit. Gave much more space and comfort esp. with little children around (Family satisfaction survey, Arohanui Hospice).

The cleanliness and care were fine also the privacy and quietness at night were greatly valued, after spells in the general hospital. Similarly the room was pleasant and spacious and the garden view was a lovely bonus (Family satisfaction survey, Arohanui Hospice).

Palmerston North Hospital Specialist Palliative Care Service

Feedback to the hospital palliative care service from families identifies aspects of care that was valued. The following were specifically noted: the speed of response regarding an imminently dying person for rapid discharge home, team members’ interpersonal skills and qualities (empathy, caring, loving, compassionate, understanding, being the perfect person in the right job) and making a positive difference in providing detailed step-by-step explanations, courtesy, support, being reassuring, and enabling them (family and patient) to have the best possible quality time together.

Similarly to the Arohanui Hospice service, the inability to return home and need to enter a care facility is a necessity faced by people in hospital with palliative care needs. In 2013/14, 62 (or 10%) of those seen by the Palmerston North Hospital palliative care service were discharged to ARC. The service does not code discharges to ARC without follow-up from the Arohanui Hospice Palliative Care Coordinators (PCC), Therefore, actual numbers will be higher.
In data gathered by Raijmarkers et al in 2012 – the environment of the acute setting in hospital and hospice and their differences were commented on. A bereaved family member was distressed by the lack of cleaning in the acute setting in hospital, noting that her father’s room was not cleaned for a week. From one day to the next, items would remain on the floor. She asked one of the cleaners why they were not cleaning her parent’s room.

‘Oh cause there’s too many visitors.’ I said there is only one thing you have to ask, ‘can you please all come outside and I’ll clean your dad’s room’; I said, ‘is that hard to do?’ (Bereaved relative 5, p4, Raijmakers et al, 2012).

Other feedback within this document related to multi-bay rooms and the lack of privacy and the small size of single rooms to accommodate family when a person is ill in the acute setting in hospital.

A bereaved family member gave both the acute setting in hospital and the hospice a 10/10 in terms of the quality of care her husband received (Raijmakers 2013, p.7). However, this is not a universal experience and the overall impression is that there is significant opportunity to improve care in the acute setting in hospital and more modest opportunities within the hospice service.

National

Lack of awareness and understanding of hospices and palliative care services was also found to be a barrier to access of services in Frey et al (2013) study. A number of patients and families who had identified themselves as Asian, Pacific and Māori who had palliative care needs participated in the study with some participants who accessed hospice services as well as a number of non-hospice users were interviewed. They were asked whether, from their non-Western culture they perceived their needs were fulfilled with a Western perspective service such as hospice. They found that there was an absence of easily accessible information about services in their primary language. Bray and Goodyear-Smith (2013) also found cultural perceptions were significant, acting as a barrier to accessing hospice services.

Where appropriate service integration and linking occurred, it was viewed as a positive experience for families as seen in Bray and Goodyear-Smith’s (2013) study.

“Once the hospice logged with the Cancer Society, then they contact each other and make time so they won’t come at the same day or all in one week, you know? (Bray & Goodyear-Smith 2013, p210)”

The importance of a holistic approach to care was reinforced by a study into spirituality in specialist palliative care needs (Egan et al, 2011). His national study into spirituality (including staff, patients and family perspectives in palliative care services) identified the diversity of perspectives on spirituality, reinforcing the need for personalising care.
Communication

The importance of communication is highly prevalent. References are evident to the timeliness, manner, content, language and medium across most sources of information. Equally important was being listened to and heard (literally and figuratively).

Some examples include:

This is why I sat in my dad’s appointments so many times so that he can clearly understand what the GP is saying to him. Done that most of his days really. Because there is that barrier, language barrier amongst our whānau I must say. Their language (health professionals) is not the same as my language (Focus group 7, culturally appropriate end-of-life care for Māori study).

Use of language is important & “Definition and terms need to be explained” (MDHB strategic planning public forum 2012).

Need communication-link between service and family (MDHB strategic planning public forum 2012).

Don’t want to feel like a visitor (MDHB strategic planning public forum 2012).

Don’t want to feel dumb (MDHB strategic planning public forum 2012).

The perceived poor quality of the communication from medical staff with family members was central to the above complaint to Palmerston North Hospital (2014). The complainant conveyed his concerns two and a half years after his father died and demonstrates the impact on family when services/individuals do not meet people’s needs and/or expectations. Concerns related to inclusiveness in decision-making, knowing who to contact, clarity, explanations and what is recalled as an off-hand or glib comment by a health professional.

Clear, compassionate communication is crucial in meeting patients’ and family members’ needs. Getting it ‘right’ was profoundly important as evident in the recall of conversations with health professionals in Raijmakers et als, (2013) study. Some conversations recalled were clearly supportive and reassuring. Some failed to meet family members needs by being too ‘high’ or at times could be clichéd and perhaps appear glib.

Section Summary

When receiving palliative care the description of individual and family, whānau experiences were diverse – some were positive and others were not. Palliative care is delivered in a number of places and across a number of services including: hospital, home, hospice, ARC facilities. The themes expressed by family, whānau and people receiving palliative care included:

- Communication was again a significant element of care. The importance of language, the way information was communicated, who delivered the information were highlighted as important.

- Place of care was significant, e.g. hospice, hospital, ARC facilities but even more important than place of care was the perceived quality of care.

- Timing and responsiveness was valued and significant for those who needed assistance particularly after hours.

- The environment in which care is delivered especially an environment that welcomed and accommodated families and whānau as well were seen as an important aspect of overall care.

Palliative care is delivered in a number of places and across a number of services ...
MDHB: At Home

Family members of current patients and bereaved relatives identified a number of important issues for carers (McKinlay & McBain, 2006). For current carers these included the sense of responsibility for the person’s care, the emotional and physical stress of caring and of being sad and tired. They worried about making the right decisions in providing care, decisions regarding medications were a concern as was supporting the dying person regarding end of life issues. Caring was particularly challenging for older carers, those without local family, and those without transport. Engagement with general practice teams varied and was less successful when locums were involved.

Suggested improvements related to having someone to sit with their family member, help in addressing financial concerns, and a reduction in the duplication of services. While some found the shared care multidisciplinary documentation helpful, others did not. This was later evaluated by White (2012).

Family members valued highly practical support – including food, company and comfort. Suggestions from some bereaved family members included support such as night carer relief and assistance with providing personal cares for the patient. Some family members struggled with home management and financial costs, including making the necessary changes to their home to help care provision (McKinlay & McBain, 2006).

A recent investigation (Raijmakers, et al, 2013) regarding declining oral intake towards the end of life highlighted communication and the often disparate perceptions regarding oral intake between family, patients and health professionals. Declining oral intake was normal and expected from the perspective of staff, whilst a source of concern for some patients and their family carers. It could also be a source of tension and distress. Family members often went to extraordinary lengths to tempt the ill person to eat. Findings included the need for improved communication in different forms and increasing awareness of the different perspectives.

Contradictory messages about what is important, for example regarding adhering to dietary restrictions in the hospice caused distress, with some staff suggestion that certain foods were not a good choice and others saying it doesn’t matter – to have whatever he wants (Bereaved relative 12, p8–9 Raijmakers et al, 2012).

In gathering data many other pertinent issues and topics arose and provide information relevant to understanding carers’ viewpoints. The following quotes offer examples of different perspectives.

“I’ve looked after so many other people’s relatives, I’m not having anybody” (to GP). I didn’t want anybody sponging him or washing him or anything because it thought that was my privilege. And of course, if you do have the hospice girls come in, it’s a matter of just showering them and dressing; they don’t do all the time consuming cares, and he has an indwelling catheter in the last six months. He was at home all the time. Well they couldn’t do any more at the hospice than I was doing. I couldn’t have parted with him to go to the hospice, and I didn’t have the need to... and the fact that I had the support you know, with (General Practitioner) (Bereaved relative 1, Raijmakers et al, 2012).

Like you know there’s an older, um a nurse for older persons’ health. And she’s brilliant. And she’s the one that will come in and she’ll tell you “oh no, this is what you can expect” [about the person’s condition deteriorating]... and [she will] do the less clinical, even though she is clinical, the less clinical stuff about the stuff, yeah – “what you’re doing is kei te pai [okay, good]. Carry on, no he won’t want that. You know – what you’re doing, what you know is exactly how it should be. You were doing a great job”, and that’s often all whānau need (Focus group 7, culturally appropriate end-of-life care for Māori study).
Oh I want to know what I have to do for them physically to keep them comfortable and pain free. And this is their last 48 hours, isn't it whaea [older woman]?... I want access to the medical people or access to experts. So it might be access to medical people. It might be access to tohunga... all of those things that we'll need to send them on their way (Focus group 1, culturally appropriate end-of-life care for Māori study).

A number of comments during the MDHB public palliative care forums in developing the district-wide Palliative Care Strategy were related to the need for information and support regarding practical aspects of care. There was a need to know who to contact to gain practical support, particularly in emergencies and when needs changed.

A level of frustration was expressed by some families regarding the number of people involved in the decision making process.

Life, whilst caring for an ill person or being ill yourself, takes on a new busyness and complexity involving understanding an illness, what may happen, the management of medications, appointments and knowing who to go to when. Life is no longer normal.

A family member/carer noted:

> I am not aware of what the cocktail of drugs, or when they change it, is actually going to do to him, and therefore what I perceive to be scary – the medical fraternity obviously perceive to be absolutely normal. And there have been too many times to count when I’ve thought he’s almost on his final axis and then the nurse will come and say – ‘no he’s not dying yet’ and I’m like – what are you talking about-look at him – but she’s right (White 2012, p61–63).

A family member recalled being a carer for a prolonged period and not realising how low in mood he was getting and there was no one there to tell him. Eventually the hospice service and subsequently an ARC facility became involved. This bereaved relative was more than satisfied with the care provided by both. He recalled the hospice’s involvement.

> The day I got in touch with the hospice, it just took a big weight off my mind and everything I did from there went swimmingly... (Bereaved relative 12, p6 Raijmakers et al, 2012).

... a need to know who to contact to gain practical support
Health Care Facilities

Relevant health care facilities include the acute setting in hospital, the hospice and ARC. Health care providers often express their concern for family and whānau who can become very tired and fatigued while caring for a dying relative or friend. However, communicating this concern to family or whānau is not always perceived as helpful, reflecting the need for sensitive communication and not making assumptions as to what is important to others. A daughter was very happy with the care received in the hospice, however a staff member’s concern for her had an adverse impact that the staff member was probably unaware of.

> Once she’d [her mother] gone I felt a bit annoyed about it really cause I thought, I only had a couple more days after that, so what if I’d spent this time coming up here; it didn’t really matter. I’d been told I could, I wasn’t causing a scene, I was straight in her room. I didn’t even stay that long really, probably – sometimes it might have been nearly an hour, waiting to see if anyone else would come. Sometimes half an hour, but I certainly didn’t cause any noise or disturbance or anything, so I don’t see really why it mattered. And I was a wee bit upset about that because instead of her making me feel good she made me feel like I was an over anxious, you know... it’s like other people don’t have to come all the time; you know she made me feel like I was really on the edge and over reacting to it all. Whereas it was just a need in me too... It, maybe was her too, my mum I mean. She might have actually wanted me there; maybe I was feeling something, I don’t know. That hurt. Other than that it was good (Bereaved relative 3, p7, Raijmarkers et al 2012).

Communication

The above scenario exemplifies the importance of communication, of ensuring that the person’s needs are addressed, their concerns are listened to and that the messages sent and received are congruent. Kidd et al (2014) identified a number of communication processes used by health professionals that were helpful in supporting patients, families and whānau. These included 24/7 availability with someone to talk to, establishing a respectful rapport, educating carers, meeting regularly, using a communication book to record what was happening, indicating or signally future care needs to family so they could be proactive and/or prepared (p42–44). All these elements are evident in other sources of data, however they are missing from the summary case study (Appendix 2).

Section Summary

Family and whānau are partners in palliative care provision. There are many expectations placed on family, whānau and carers to support those who often have complex needs during the palliative care trajectory. From the few experiences that have been captured the following themes have emerged.

- **Communication** especially listening, nursing messages and understandings are congruent and assumptions are not made.
- **Caring** for those who require palliative care has a number of challenges particularly when the carer may have limited supportive family or friends, is often older and likely to have increased health needs themselves.
- Families and whānau need to have their concerns and **needs assessed** so that whenever possible they may be addressed.
- **Practical support for carers** is necessary, such as advice and support with medications and practical aspects of care, turning and night time cares.
- **Afterhours access to advice** and support is significant for families and whānau.
- **Coordinated care** is a requirement for the care to be effective. Many people are involved in delivery of palliative care, GP teams, district nurses, specialists, community nurses and families value the health professionals who assist in navigating and co-ordinating their care.
MDHB: Research

McNaught (2002) sought the views of 40 patients receiving specialist palliative care regarding their views of dying well using Q-sort methodology (40 statements). Importantly she concluded there is “neither total idiosyncrasy nor total uniformity in patients’ understandings” (McNaught, 2002, pviii). However, data was able to be clustered into four overarching accounts; a religious-oriented account, an independent account, an idealised account and a family-oriented account of dying well. Three statements were identified as least important in all accounts of dying well “dying at home, trying unconventional treatments [and] family keeping things to themselves” (p229). McNaught’s findings, that the patients did not rate dying at home as important as other aspects, is important in informing place of care at the end of life. This however may differ with different ethnicities, as Batten et al, (2014) identified that Māori prefer to die at home.

Significantly McNaught’s findings stress the importance of recognising differing perceptions of what people perceive as dying well, and that there are risks to the delivery of appropriately individualised care if a stereotypical view of dying well is assumed (p220).

Participants commented on the positive benefits of the Q-sort methodology, which required them to rank statements and in doing so build a ‘picture’ of what was important to them. Many participants asked for copies of the statements to use as a discussion point with families. For others, items were listed they had not yet considered and found this beneficial. Additionally some participants found it beneficial to discuss these issues with a person not directly involved in their care. Study participants acknowledged that what they ranked as most to least important may vary over time and the study was not prospective.

McNaught’s (2002) findings reiterate the importance of individualised or personalised care at the end of life.

The investigation of perspectives of declining oral intake towards the end of life (Raijmakers et al, 2013) included comments about end of life care.
The following quotes offer examples of different experiences and of the challenge and importance of identifying dying.

I think too, the biggest thing for us is we just weren't prepared for it, so quick you know. We honestly didn't believe when he came home from the hospice, that he would only have that short period. We thought the way they were talking here we'd, well we thought he'd be here 'till after Christmas, well that's what I thought anyway. You know, honestly didn't believe that it would just happen so quickly (Bereaved relative 2, Raijmakers et al, 2012).

Comments from bereaved relatives indicate that the PCC's from Arohanui Hospice play a key role in 'identifying dying' and communicating this to family and whānau carers and in preparing them for what might follow.

And she (PCC) was talking all about that (going into hospice) to mum and mum sort of, I think, felt I was, had enough, you know being through quite a bit with her and thought it was probably a good idea; and then I walked out through my house with (PCC) and she said to me then, “She doesn't look very well,” and I said, “No, no she didn't,” and she said, “You know she's dying.” “Mm? That's news to me. News to me, yeah”. And then she said, “Yeah, I could have a talk to mum and perhaps she could go into the hospice,” so I thought, well... oh she said I had to get real, so I thought well, I hadn't been in that situation before; I didn't know if I wanted to be. So she said she could probably come into the hospice and I thought, yeah I think I'll put her in there. If she bounces back and she's great I'll take her home again, which she said could happen you know, but of course she didn't come out so it was just as well (Bereaved relative 3, Raijmakers, et al 2012).

Not being alerted to the nearness of death affects people's experiences of care and highlights the importance of the navigation role health professional's play.

I don't know if it was very clear (that the person was dying), well not clear to me that he was going to die because I didn't know what palliative care meant until a month before he passed... So yeah I didn't realise that he was, you know, I took him in on Monday and he passed away early hours of Wednesday. So it was pretty quick (Bereaved relative 11, p3 Raijmakers et al, 2012).

This family member thought people must freak out about hospice because she recalled being reassured it wasn't just about dying. It would appear however that her family member died within a short time of being referred, in a way confirming why people are anxious about referral. Her only regret was having not realised how short time was; they would have spent more time together.

Preparing the family and whānau for what is to come next is a significant aspect of care provision. This was also conveyed in a comment from the culturally appropriate end-of-life care for Māori study.

... knowing to prepare yourself for that, so knowing that's a normal process of whatever she's going through... for them to tell you at the start, you might expect that after a little while she might – her appetite will go down, she won't want to eat and she might start vomiting. See if you knew that at the start you could have dealt with that a bit easier because you knew that was normal so... you could just straight away get the boil-up juice ready and... start doing all of those sort of things instead of going um... I need to ask somebody what do I do? What do I do with this? Well you already had the answers but needed that direction to be able to say, it's not permission, you don't need the permission, it's the direction for them to say right at the start... prepare for this and you'll know what to do you know, so that you could care for her the way that she needed to be (Focus group 7, Culturally appropriate end-of-life care for Māori study).

Data from each of these two studies indicate the importance of informing, guiding and preparing family and whānau for the changes that may occur in the condition of the person they are caring for.
Other Local Sources: Complaints and Compliments

Palmerston North Hospital

Ward staff members receive positive feedback from families and whānau of people who die in their care. It may only be conveyed in the moments of caring and in leaving the hospital, it may occur more formally via the Palmerston North Hospital’s “Tell us what you think” feedback forms or through other written notes. At times care is acknowledged in newspapers and in funeral services.

*I would like to thank all those who cared for... over the last years/months/days/hours dealing with cancer. Thanks for all your support.*

*Staff were great in talking to them and gave us all the time we needed to spend with dad. ICU was not busy but I think they cared about us just because they do and not because they had time.*

Negative feedback via a complaint (2014) to Palmerston North Hospital regarding the end of life care received by a family member in hospital demonstrates, by their absence key components of good service delivery and care. Concerns included the following: perceived poor communication from the medical team, concerns that a family meeting was arranged without all members being aware and therefore able to be present, concerns regarding fluids, perceived haste in decision making, lack of clarity about how to address their concerns, the limitation of the physical environment, and the complainants father ‘being shunted’ back to an ARC facility the day before he died. Regarding the physical environment the following comment was made:

*How terrible to try to comfort a dying parent in a hospital bed. In dad’s tiny private room, only one massive chair could be parked next to his bed. And from that chair you could not hold dad’s hand. The hospital bed was too big and too high. He lay there dying with people only able to hold his hand if they walked over to the bed and stood next to him, a few minutes a day (Family members’ complaint, 2014).*

Concerns regarding the physical environment and its limitations regarding the place, physical space, and facilities were conveyed by staff locally in both ARC and acute care (Clark, et al, 2012; Clark, et al, 2012; Marshall, et al, 2011; Sheward, et al, 2011).

Hospital palliative care staff members occasionally receive notes and cards from family and whānau members following the death of a person whose care they have been involved in, for example:

*Your care of [family member] made a significant positive difference to [family member] last few days and was very reassuring to our family. We were able to have the best quality time with him over the weekend because his symptoms were so well managed. We cannot thank you enough for your input and compassion (Thank you card to the Hospital Palliative Care Team, 2014).*

... knowing to prepare yourself for that, so knowing that’s a normal process of whatever she’s going through ...
Arohanui Hospice regularly receives donations, cards, notes, and acknowledgment in newspapers and in funeral services for the care they have given patients and families prior to and at the time of death. Generally these echo similar sentiments of gratitude for care.

Thank you very much for caring for our mum in the last week of her life. The hospice really does feel like a home away from home for patients and family – all credit to you. We hope one day the hospice will be able to support more people, and for longer stays (Bereaved family members’ thank you card 2014).

My sister was recently in your care. We want to thank you all for your kindness, compassion and support – not just to (sister and family) but to her wider family too. You people are amazing (Bereaved family members thank you card 2014).

Newspaper thank you acknowledgments following a death also frequently mention ARC facilities, the district nursing service and GPs. Similarly these services are often recognised and thanked in funeral services when they have been involved in the care of the deceased person.

A compliment received for a Central Primary Health Organisation (CPHO) cancer nurse described a daughter’s appreciation of the care given to her mother. She described the way the nurse had organised medical equipment and coordinated services that were necessary in the care of her mother. She also thanked her for qualities that were less tangible.

I would like to thank you for reassuring me that mum was ok and that it was part of the process and explaining what was to come and signs to look for, you spoke from the heart and about your experience and embraced us like your own, to have that quality in a person is priceless and I thank your organisation very, very much for their services but I also thank them for allowing you to have my mum and myself on your books (CPHO compliments, 2014).

Most relevant regarding patient, family and whānau perspectives in MDHB is the culturally appropriate end of life care for Māori research project which also includes data from other DHBs. Valuable incidental data is also evident in Raijmakers et al (2013) unpublished research data. Additionally local research related to patients perceptions of dying well (McNaught, 2002) provide information for consideration regarding the variable perception of what dying well means to patients and the risk of stereotyping care rather than personalising care.
National
Taylor, Ensor and Stanley (2011) conducted a retrospective chart audit of 1,268 deaths of people under a specialist hospice service over a three year period to identify factors influencing place of death. They found the most significant predictor of a person not entering a specialist hospice service was a person identifying with Pacific ethnicity. However, age, economics, ethnicity, marital status and whether or not a person physically enters a hospice inpatient unit for respite were linked to place of death. This study, while devoid of patient, family and whānau perceptions of the whether the place where end of life care occurred was preferred place of death, it does offer information that could inform further enquiry in the area. There may be regional differences, differences over time within districts, and it may inform how further enquiry into place of death can purposefully proceed.

Section Summary
The following themes have been drawn from experiences expressed by those in our district regarding the time of death.

- **Dying well is perceived differently for different people.** Personalised care is paramount to meet needs.
  - **Identifying and recognising** when a person is dying. However, when possible this information, compassionately communicated, is significant and highly valued by families and whānau.
  - **Communication** about dying in a manner that is empathetic, kind, compassionate and culturally appropriate is important for families and whānau. Who communicates, how they communicate and what is communicated is significant and needs to be individualised according to need including the use of interpreters, signing and visual communication methods.

- **Preparation** and knowing what to expect, at all times but particularly when the person was becoming imminently terminal was highlighted as valuable for families and whānau. It gives them time to gather, say what is important and complete any final things that may be essential to them.

- The significance of people being **given time** was highlighted by a number of families. It was important for families and whānau to be present, to not feel rushed and to have time to express their goodbyes in a way that was meaningful for them.

Who communicates, how they communicate and what is communicated is significant and needs to be individualised according to need, including the use of interpreters, signing and visual communication methods.
AFTER DEATH CARE

Very little information is available from bereaved families and caregivers regarding their experiences of the bereavement period. Arohanui Hospice service and a small number of ARCs have formalised and organised bereavement support programmes. Most involve recognition and acknowledgment of the death of a person, information for families on common feelings they may experience. The services that provide bereavement follow-up also provide opportunities for families to engage in rituals such as memorial services, writing in bereavement books and lighting candles. Despite these bereavement supports being available in a number of small places, no evaluation data is available.

The acute care settings within MDHB have no mechanism for family or carer bereavement follow-up. If the hospital palliative care team have been involved and perceive the bereavement may be complex, they can refer to the Arohanui Hospice service.

General practice teams may have follow-up with family members or carers if they are members of the same general practice, however, it is unknown if these groups have any systems or organised follow-up processes.

What is available is a small number of statements from the Palmerston North Hospital and Arohanui Hospice family or carer letter/cards that express how grateful families felt with the care their family members had received. Most of the cards referred to the care that the person received at time of death.

Comments included:

Even though my wife died in hospital, staff were very caring and could not do enough for us. They looked after me and let me say goodbye to her. Thank you (Palmerston North Hospital quality feedback).

My family arrived from out of town to visit my dad in ICU unfortunately it was too late. Staff were great in talking to them and gave us all the time we needed to spend with dad. ICU was not busy at the time but I think they cared about us just because they do and not because they had time (Palmerston North Hospital quality feedback).

A complaint included concerns regarding the documentation on the deceased person’s death certificate. The inclusion of dementia as a contributing factor was a source of angst and distress because this is not perceived to be accurate by the family. Death certificates are part of a person’s life, a family’s history, and the public record. The contents and their accuracy have a level of significance and meaning that reaches beyond the legality of certifying a death.
A very small number of articles have been published in New Zealand that refers to the family, whānau and carer experiences of bereavement support and care.

A recent exploration by Bellamy et al, (2014) of 28 older persons’ views and experiences of bereavement support and where they accessed this support found that family, whānau and friends played a significant role in supporting the bereaved older person. Previous life experiences and the fact they were older appeared to enable them to manage the practical and emotional changes associated with bereavement. It was found that resilience was associated with maintaining previously known social connections with community organisations and a public-health approach was the way to optimising bereavement support for the older person.

An unpublished Masters Thesis by Lee (2009) highlighted the transition from caregiver to the bereaved. She described the care giving role as a complex and dynamic process, also evident in the transition from care giving to being bereaved. She explored categories that allowed predictions to be made about people who were more likely to need help during bereavement. These included characteristics of the bereaved, relationships to the deceased, nature and manner of death, family dynamics and existing support.

Her thesis concluded that the experiences a caregiver has during the palliative care phase must “surely have an impact on bereavement.” (Lee, 2009, p128)

Her conclusions also state that increased awareness of the support needs and experience of caregivers is important and “recounting the narrative of the caregivers has been demonstrated as therapeutic.” (Lee, 2009, p128)

Section Summary

Whilst little information is known about family, whānau and carer experience regarding after death care, the above information allows us to draw these few conclusions.

- **Little is known** about the bereavement experiences of family and whānau in MDHB.
- **Communication** remains significant during bereavement. The importance of language, the way information was communicated, who and when the information is delivered, including alerting people to the dying process were highlighted as important.
- **Time** is valuable for families and whānau and allowing family to say good bye is essential.
- **Transition from caregiver to being bereaved** is highlighted as dynamic and a time that can be more challenging.
- **Most people are resilient** during bereavement and receive support from family, whānau and existing supports in place such as church and community groups. For those who are at risk of complicated bereavement, lack social networks, less resilient and identified as needing support this should be available and accessible.
- **Practical and emotional support is required** at time of death and following for families and whānau. Information is required in terms of what to expect emotionally and practically following the death of a person, such as preparing for after death rituals such as funerals.
- **Kindness and compassion** were important and valued by families and whānau.
- **Feedback** and an opportunity for family to give organisations information about what was valuable for them are not often possible. Most frequent feedback from families and whānau comes as praise and thanks. Very few complaints are made which could be due to a number of reasons including, time, emotional labour required to make a complaint.
SUMMARY

The compilation of this report, while not exhaustive, provides an opportunity for the personal palliative care experiences of the people within MDHB to be described, made visible and shared. It is the first step in achieving the goal of the MDHB Palliative care strategy that ‘the patient experience will be at the centre of service design’.

Through findings from local research, patient satisfaction surveys, national literature, grey material the experiences of people accessing palliative care and their family and whānau, a number of aspects or themes important in the provision of quality palliative care to have been identified. These are perhaps most profound and visible when absent.

The findings would suggest that one of the overarching elements of care that impacts on personal palliative care experience is that of communication in all its guises. It is not necessarily the content of what is communicated, when and by whom and through what channels or mediums (written, spoken, individually or family meetings) that predominates. Rather what appear most significant for people, families and whānau is the timing, the appropriateness, and how information is delivered – with compassion, kindness and responsive to individualised need that is recalled and remembered positively. The importance of being listened to, heard, and engaged with in a collaborative inclusive manner is highly evident.

Personalised care that is culturally appropriate and responsive had an impact on the experience of care. As described in the report, available research indicates there are a number of cultural barriers impeding rather than facilitating access to specialist palliative care services. The unique nature of the palliative care journey requires a personalised approach to care, including identifying and responding appropriately to cultural needs as this impacts not only on the experience but also what services were accessible.

There is little community understanding of the term palliative care and people expressed a need to know what the term meant and what services were available and provided. People valued the experience when services were responsive, coordinated, they knew who to access and when. Knowing about after hour’s services and how to access them was highly valued and contributed to a positive experience.

Caring for those who have palliative care need was described as both a challenging yet rewarding experience. Carers described needing information and providing practical, support to assist them in their roles and responsibilities particularly around medication management, practical physical cares and knowing what financial support they could access.

The physical environment of the place of care had an impact on the experience, especially for family and whānau. An environment that allowed the family and whānau to be present and accommodated their needs was seen as positive.

Death and dying are profoundly personal and variable however what appeared to be significant for families was the opportunity to prepare in some way and know what they could expect. Significantly awareness of dying influenced the time for families and whānau to say goodbye and be present. Whilst little is known of the care after death, what is apparent is that health professional qualities such as kindness, compassion, listening and allowing time added to a positive experience for families and whānau.
Getting it right

- Identify those with palliative care needs (specialist, generalist/primary) in a timely manner, through the use of systematic, accurate assessments.
- Collate and analyse data related to palliative care need from district-wide assessment data.
- Identify and trial appropriate tool(s) for assessing palliative care and associated needs including carer needs, and if appropriate adopt within services.
- Specialist palliative care services identify, utilise and disseminate best practice to support appropriate palliative care approaches.

Being willing and able to learn

- Establish a new, or increased focus, on populations under-represented in the information currently available for those receiving generalist/primary palliative care, including:
  - people with disabilities
  - older people and
  - those in isolated communities (e.g. single men, refugees, migrants new to New Zealand and prisoners).
- Establish new, or better utilise, existing ways to engage with consumers for feedback regarding palliative care experiences.
- Establish new, or better utilise, existing ways to engage with consumers for feedback regarding after-death care and the bereavement supports that are valued by family, whānau and carers.

Being consumer and community focused

- Utilise information obtained (e.g. via assessments, feedback, audits, research) to keep those with palliative care needs (patient, family and whānau) at the centre of services and inform service design.
- Information to be available within MDHB (in a centralised location) regarding how to access such things as equipment, health professionals, assistance with personal cares and financial assistance.
- Raise public awareness of what palliative care is and the palliative care services available in MDHB (written information and websites should contain relevant information, other public repositories of information). This includes information regarding after hours care, advice and support.
- Co-design methodology would be appropriate for developing palliative care information.
- Organisations to create and maintain environments conducive to the total wellbeing of patients, families and whānau.
- To enable and support families, whānau and carers to be present and participate in care (if desired/appropriate) when care is delivered in organisational settings.
- Organisations have supportive services (equipment and personnel) to enable care ‘in place’; be this within an organisational setting, in a person’s own home, or their family or whānau home as appropriate.

Being up for the job

- Quality systems in place to ensure organisations (specialist and generalist/primary palliative care providers) are delivering quality palliative care and engaged in quality improvement.
- Professional development is available and promoted to strengthen skills related to communication, cultural responsiveness and spiritual care.
- Future strategic planning addresses the gaps within the work being undertaken in the current MDHB Strategic Plan (2012–2017).
REFERENCES


**APPENDIX 1 – WORKING GROUP MEMBERS**

<table>
<thead>
<tr>
<th>Name</th>
<th>Description</th>
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<tbody>
<tr>
<td>Dr Lesley Batten</td>
<td>Research Centre for Māori Health and Development, College of Health, Massey University Palmerston North.</td>
</tr>
<tr>
<td>Dr Jean Clark (Chairperson)</td>
<td>Clinical Nurse Specialist Hospital Palliative Care Team Palmerston North Hospital, Education and Research Unit, Arohanui Hospice. Member of Palliative Care District Group.</td>
</tr>
<tr>
<td>Reverend Anne Chrisp</td>
<td>Anglican Minister.</td>
</tr>
<tr>
<td>Jane Cullen</td>
<td>Service Improvement Leader, Central PHO.</td>
</tr>
<tr>
<td>Gaye Fell</td>
<td>Community Representative on Central PHO Board and Member for MDHB Consumer Advisory Panel (CAP). Member of Palliative Care District Group.</td>
</tr>
<tr>
<td>Amanda Gill</td>
<td>Clinical Quality – Arohanui Hospice.</td>
</tr>
<tr>
<td>Chrissy Karena</td>
<td>Māori Advisor, Public Health, MDHB (resigned due to change in employment).</td>
</tr>
<tr>
<td>Bridget Marshall</td>
<td>Palliative Care Network Co-ordinator, MDHB. Member of Palliative Care District Group.</td>
</tr>
<tr>
<td>Kaye Allardice-Green</td>
<td>District Nursing Service (resigned due to change in employment).</td>
</tr>
</tbody>
</table>
## APPENDIX 2 – SUMMARY CASE STUDY

<table>
<thead>
<tr>
<th>Day of event</th>
<th>What happened from the carers perspective</th>
<th>What should or could have happened?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>An elderly woman presented to Palmerston North Hospital from her home with a pattern of deterioration (expected by clinicians), but she was significantly frailer.</td>
<td>Communication with family, re change of condition.</td>
</tr>
<tr>
<td>+2</td>
<td>Discharged from hospital with advice given to contact her GP for follow-up and access to next level of support as she was expected to live for only another 7–10 days.</td>
<td>Liaison with PEDAL of RAH service to ensure follow up and appropriate support on discharge.</td>
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<td>+4</td>
<td>Two days later the woman was sleeping all the time and unable to take more than a few sips of fluid and little or no food. Her carer (son), in his late 60s, was providing full cares, including bed baths as his mother was unable to get out of bed. The GP was contacted and a message left for the GP to call back.</td>
<td>Responsive and timely care by GP team.</td>
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<td>+8</td>
<td>Four days later, after no contact from the practice, the son phoned the GP practice again and spoke to a nurse. No reason was given for the practice not contacting the son, however a District Nursing (DN) or hospice referral was offered. The son declined the hospice referral and accepted the DN service support.</td>
<td>Accurate information about service options and what services are provided sensitive communication particularly when introducing the concept of transition to palliative care.</td>
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<td></td>
<td>That afternoon the practice nurse rang the son to say the DNs could not accept the referral and offered a hospice referral again. The son then accepted the hospice referral and was informed to expect contact from the hospice in the next 24–48 hours.</td>
<td>Health professionals need to know about services available and accurate reporting requirements for services and their legal and ethical responsibilities in making referrals.</td>
</tr>
<tr>
<td>+14</td>
<td>The son went to the GP practice, as he had not heard from the DNs or the hospice (on investigation the hospice had received a referral but had declined as there had been no assessment by the GP and the referral was unclear and lacked detail of what was needed). The practice arranged for the GP to do a home visit the following day at 4.30pm.</td>
<td>Phone contact could have been made by the practice to the son. Action on a declined referral could have been followed up.</td>
</tr>
<tr>
<td>+15</td>
<td>The GP cancelled the home visit and requested the son bring in the woman to the practice. The woman was now bedridden, and had been eating and drinking minimal amounts for the last two weeks and her frailty had increased. There was no equipment available to enable transfers. The son ended the call stating the family would be complaining to the Health and Disability Commissioner. The GP called the carer and again asked that the son bring the woman to the surgery and stated that the district nursing referral would be written. This, however, required a visit from GP. It was agreed that the GP would home visit that evening. The carer was not told of the cost of the home visit.</td>
<td>The GP visit was extremely delayed. (and the request to bring the patient to the surgery was inappropriate) Information should have been given to family that there would be a cost to a home visit that exceeded that of a consultation.</td>
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<td>+16</td>
<td>The following day the DN visited to provide support.</td>
<td></td>
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<tr>
<td>6 months later</td>
<td>The woman was still alive, having been assessed as requiring hospital level residential care and admitted into an ARC facility.</td>
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This case study, which arises out of a complaint made to CPHO has been used with the permission of the carer.

While there were many times within this personal end-of-life journey where intervention, using accepted and current protocols, policies and standards and services, would have likely made a positive difference, the family member would have been unaware of these and instead would have only been aware of the urgent need for appropriate care and support at a critical time. The only thing the son formally complained about was the cost of a home visit (10 days following the home visit the carer received an account from the GP for $273.50).

The carer felt this cost was unfair and unreasonable and therefore complained to MDHB.

The carer was advised by a patient advocate to contact the Medical Council. Upon complaining to the Medical Council, the carer was told by the Medical Council Complaints Triage Team that this fee was not exploitative and that the carer should contact the PHO.

The PHO has completed the complaints process and with the permission of the people involved is using this scenario to inform quality improvement.

There were multiple opportunities where intervention, using accepted and current protocols, policies, standards and services would have made a positive difference.
Issues Highlighted in this Case Study

There were a number of aspects of this case that illustrate less than optimal care experience for the patient and the carer. The carer complained about the fee for a GP home visit, however there were many issues that extend beyond financial cost.

These issues include:

• Timely access to help and support was not provided
• Fear, a lack of explanation and knowledge of palliative care and palliative care services, may have initially been contributing factors for the carer not accepting the hospice referral
• A lack of seamless transition between services, including appropriate follow up of referrals is evident, as are services working in silos
• The number of people involved who the carer needed to make contact with is a burden for carer, especially when services are not integrated and coordinated
• The expectation that a carer can assess and undertake complex care is unreasonable, especially without appropriate support
• The expectation that a carer can be an effective advocate and can coordinate services is unreasonable without appropriate support
• The expectation that a carer can independently navigate within and across complex services is unreasonable
• The lack of a personalised care approach is evident and it left this family unsupported and without appropriate care.

Photo Credits

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