



Grampians Region  
Palliative Care **Consortium**

## Annual Report 2016-2017

### Members:

Ballarat Health Services  
Ballarat Hospice Care Inc.  
East Grampians Health Service  
Djerriwarrh Health Services  
Wimmera Health Care Group  
St John of God Hospital Ballarat  
Department of Health (non voting)

### *This report was prepared by:*

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## ***1. Chair's Message***

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Throughout the 2016-17 financial year, the consortium has continued to focus our efforts on the core objective of improving the quality of and access to palliative care services within the Grampians region.

This report details a broad range of projects, all of which are aimed at supporting and enhancing the provision of quality palliative care. Our funded services remain a core focus, and we are delighted to have supported the continued development and provision of high quality palliative care services within the Grampians community.

In April 2017, the consortium and the clinical group participated in a planning day to identify our priority areas for the next twelve months. The five priority areas in the End of Life Framework underpinned the discussions, it was an enjoyable day resulting in agreed areas of priority across the region.

The consortium has continued to be fiscally responsible, resulting in the achievement of a small surplus at the end of the 2016 – 17 budget cycle.

I would like to take this opportunity to thank Mr. John Koopmans, Department of Health and Human Services, for his leadership and guidance throughout the year. I would also like to express my gratitude to my executive consortium colleagues for their time, commitment and dedication to regional palliative care services throughout our region. I appreciate the support that they have given me as Consortium Chair over the last twelve months.

Thank you to Mr. Pete Marshall, Consortium Manager, for coordinating and managing consortium initiatives.

I would also like to acknowledge the support of the clinical group who work closely with the consortium to facilitate our shared objectives.

A last big thankyou to all staff who work in the palliative care services across the Grampians region for their ongoing dedication and commitment to patients, families and carers.

Michelle Veal  
Grampians Region Palliative Care Consortium Chair

## ***2. The consortium focus in the context of the Grampians Region***

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The total area of land in the Grampians is 48,618 sq km, and only 1% (approx.) of land region is zoned for residential, business or industrial use, with most being rural (approx. 79%) or public reserve (approx. 20%).

Population growth in Grampians Region has been lower than average since 2000, and this trend is projected to continue to 2022. There are higher than average percentages of children under 14 years, and persons aged 45 plus, while the 15 to 44 age group is under-represented. The Aboriginal population is higher than average, but levels of cultural diversity are low.



The rate of volunteering is the highest of all regions. Grampians has higher than average low-income individuals and households and the highest percentage of unemployed throughout Victoria, but low levels of housing stress. The year 9 educational attainment is the lowest of all regions.

Grampians Region has the lowest GP ratio per 1,000 population, but the highest rate primary care occasions of service at over twice the Victorian average. Grampians Region ranks 2nd among regions for HACC clients aged 0–69 per 1,000 target population, and for those over 70 years of age, 26.3% are HACC clients.

Compared to the Australian Population, the population in the West of the Grampians health region are on average 9 years older, and earn 14.4% less average total annual income.

	West Grampians	Vic	Australia
Median Age - Persons (years)	46.3	37.3	37.4
Median total income (excl. Government pensions and allowance) (\$)	38,479	43,867	44,940

In terms of health indicators, rates of asthma are higher than average across most of the region, as are rates of drug and alcohol clients and mental health clients. Some LGAs in the Wimmera have particularly high rates of overweight and obesity.

However, a breakdown into the broad areas of Wimmera (Horsham, West Wimmera, Hindmarsh and Yarriambiack LGAs), Central (Northern Grampians, Ararat and Pyrenees LGAs) and Ballarat (Ballarat, Hepburn, Moorabool and Golden Plains LGAs) shows significant disparities in local demographics.

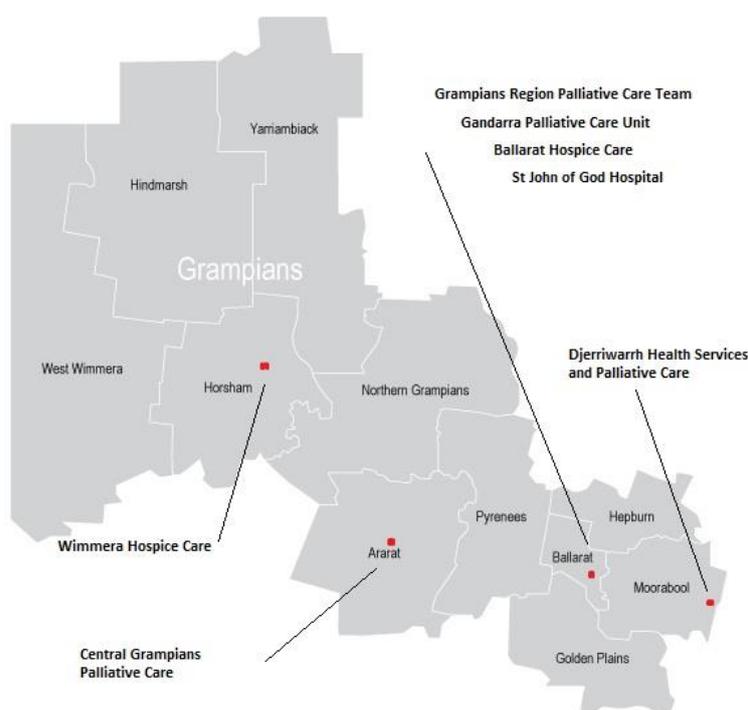
Table 1: *Population density and proportions of aged residents*

	Grampians Region	Wimmera	Central	Ballarat
Total population	220,878	16.5%	13.4%	70.1%
65+ (as % of popn)	16.4%	20.8%	20.6%	14.6%
Area sq. kms	48,618	28,222	13,370	7,026
% of Grampians area	100%	58.0%	27.5%	14.5%
Popn density (persons/sq km)	4.5	1.3	2.2	22.0

The Ballarat area has a vastly higher population density, accounting for 70.1% of the total population, but only 14.5% of the total land mass.

## 2.1 Factors impacting capacity to manage health issues into the future

The demographic data set out below (Table 2) shows that the Grampians region as a whole, and particularly LGAs in the central and western parts of the region, are facing significant issues that are likely to impact on the provision of palliative care.



A growing ageing population combined with reduced community working capacity lead to greater dependency.

This is currently reflected in high levels of people with need for assistance with core activities, and the percentage of persons aged 75+ who live alone, and exacerbated by high levels of disability support pension and age pension recipients, and high rates of those with profound disability living in the community.

On top of this, Grampians has a high rate of malignant cancers diagnosed, which is going to be one of the more significant drivers of increased need for palliative care.

Higher dependency ratios mean fewer people of working age. Dependency ratios for 2011 are higher than the Victorian average in all Grampians LGAs and are particularly high in Yarriambiack and Hindmarsh. This pattern will continue in 2021, with even higher dependency ratios. There is a general trend toward higher dependency ratios both now and into the future as you move across the West of the region.

Table 2: Current (2011) and projected percentage population over 65 years of age, and proportion under 15 and over 65, compared with proportion of working age population (Dependency ratio).

LGA	2011		2021	
	65+	Dep Ratio	65+	Dep Ratio
<b>Wimmera</b>				
Hindmarsh (S)	24.1	0.71	29.7	0.86
Horsham (RC)	17.6	0.58	21.6	0.67
West Wimmera (S)	21.5	0.67	25.8	.071
Yarriambiack (S)	24.4	0.72	28.6	0.76
<b>Central</b>				
Ararat (RC)	19.7	0.60	23.8	0.69
Nth Grampians (S)	20.1	0.59	26.3	0.70
Pyrenees (S)	21.9	0.62	26.7	0.73
<b>Ballarat</b>				
Moorabool (S)	12.5	0.50	17.6	0.61
Hepburn (S)	18.9	0.57	23.6	0.66
Ballarat (C)	14.9	0.51	19.1	0.61
Golden Plains (S)	10.4	0.50	16.2	0.59
<b>Grampians</b>	<b>16.1</b>	<b>0.54</b>	<b>20.6</b>	<b>0.64</b>
<b>Victoria</b>	<b>14.0</b>	<b>0.48</b>	<b>16.7</b>	<b>0.53</b>

These issues are exacerbated by a high and growing proportion of people in the community who need medical and daily living support, as set out in Table 3.

Table 3: *Aged and disability characteristics, Grampians LGAs*

LGA	% with need for assistance with core activities	% with severe and profound disability living in community	% of persons aged 75+ who live alone	Disability support pension recipients per 1,000 eligible pop	Age pension recipients per 1,000 eligible pop
Ararat (RC)	7.1%	5.1%	39.8%	102.9	746.9
Ballarat (C)	6.0%	4.4%	42.5%	86.5	764.5
Golden Plains (S)	4.7%	3.9%	30.6%	55.1	766.3
Hepburn (S)	5.9%	4.3%	41.2%	97.3	760.4
Hindmarsh (S)	8.2%	5.1%	40.5%	107.5	684.7
Horsham (RC)	5.7%	4.2%	43.2%	81.9	728.6
Moorabool (S)	4.9%	4.2%	36.2%	56.7	736.2
Northern	8.2%	5.8%	43.8%	126.4	770.6
Pyrenees (S)	7.6%	5.9%	37.0%	127.4	764.5
West Wimmera (S)	5.9%	4.4%	41.5%	76.6	674.3
Yarriambiack (S)	9.1%	6.4%	41.4%	130.5	642.9
<b>Grampians</b>	<b>6.1%</b>	<b>4.6%</b>	<b>41.0%</b>	<b>85.7</b>	<b>746.1</b>
<b>Victoria</b>	<b>5.0%</b>	<b>3.8%</b>	<b>35.9%</b>	<b>54.8</b>	<b>704.5</b>

The consortium has focussed many of the supported initiatives on the west of the region. While population numbers may be smaller than in the east (closer to Melbourne) the proportion of the population that is aged and/or disadvantaged (in many cases both) is very high. The Index of Relative Socio-Economic Disadvantage (IRSED) indicates that four of the ten most disadvantaged LGAs in Victoria are in the Grampians region: Hindmarsh; Northern Grampians; Pyrenees; and Yarriambiack. Add to this the decreased access to training and professional support for health and welfare staff that comes with small centres, and large distances to services, make this an issue of addressing the relative disadvantage experienced in the west.

The percentage of persons with need for assistance with core activities is higher than the Victorian average (5%) in Grampians region (6.1%). All LGAs have a higher than average percentage of persons with severe and profound disability living in the community, with the highest percentages in the west and central part of the region. The percentage of persons aged 75+ and living alone is also higher than average, but ranges from 30.6% in Golden Plains to 43.8% in Northern Grampians. The rate of disability support pension recipients is well above average in all LGAs other than Golden Plains and Moorabool. The regional rate of aged pension recipients is also above average, with the highest rates in Ballarat, Golden Plains, Hepburn, Northern Grampians and Pyrenees.

Table 4: *Total malignant cancers diagnosed per 1,000 population, and for males and females, in 2011, Grampians LGAs*

LGA	Males	Females	Total
Ararat (RC)	4.79	6.42	5.58
Ballarat (C)	5.98	5.21	5.59
Golden Plains (S)	6.37	4.90	5.66
Hepburn (S)	7.58	5.55	6.55
Hindmarsh (S)	7.49	6.48	6.98
Horsham (RC)	7.77	4.45	6.09

Moorabool (S)	5.01	5.83	5.42
Northern Grampians (S)	7.12	6.10	6.62
Pyrenees (S)	8.53	6.61	7.58
West Wimmera (S)	13.13	8.17	10.73
Yarriambiack (S)	7.21	8.46	7.83
<b>Grampians</b>	<b>6.45</b>	<b>5.56</b>	<b>6.00</b>
<b>Victoria</b>	<b>5.73</b>	<b>4.54</b>	<b>5.13</b>

The rate of malignant cancers diagnosed (Table 4) is higher for males, females and total persons in Grampians region compared with the Victorian average. The rates for total persons are highest in West Wimmera but are above the Victorian average in all LGAs.

The Central Grampians area in particular has higher than average rates on disability indicators, with each of the LGAs having higher than average persons with severe or profound disabilities, and higher rates of those needing assistance with core activities.

Grampians region does not stand alone on many of these indicators, as numerous studies have shown high levels of health inequality across areas of rural Australia. The challenge is exacerbated by limited resources spread across large geographical areas, and well-recorded difficulties in attracting skilled health care professionals.

The palliative care services in the Grampians region are committed to offering a high level of care, and the consortium is committed to supporting them in this regard.

## 2.2 The consortium focus

The broad focus of the Consortium is supporting improved access to, and quality of, end of life care for patients and carers in the Grampians region.

A major part of this is improving the capacity and functioning of both the funded services, and the broader health and community sector. Services are time poor, with skilled staff at times struggling to meet the clinical load, let alone to have significant involvement in development of new initiatives. The Consortium is consciously focussed on supporting capacity building to provide sustainable improvements in effectiveness and efficiency, and as part of this, effective and innovative use of technology would always be a priority for consortium support, particularly in rural areas, within the funded services.

1. Priority 1 - Provide effective workforce support and professional development
  - Support enhanced use of technology,
  - Broader use of consistent tools and resources,
  - Enhanced capacity and skills within Aged Care,
  - Supporting specialist staff skill development and educational opportunities,

Most of the resources utilised in end of life care will not be provided by specialist palliative care services, but it is to be hoped that it will be informed by specialist palliative care. The next focus then is on broader sector engagement.

2. Priority 2 - Broader sector engagement
  - More understanding and acceptance of Advance Care Planning,
  - Up to date and effective website,
  - Regional Information sharing,
  - Local community education and initiative support

By far the most support for people at the end of life comes from the community. People at the end of life need a community that is well informed about the end of life, and the support to maintain their links to the community. The focus then becomes providing effective and relevant support and information for carers and communities about end of life, death and a palliative approach.

1. Priority 3: Better support for carers
  - Funding resource development

The consortium has been well engaged in the consultations that supported the development of Victoria's end of life and palliative care framework, and consequent discussions about an evolving role for consortia within this future vision for end of life care. The framework '*has a particular focus on services and asks everyone working in health, human social and community services to consider the role they play in delivering end of life care.*' The initiatives of the Grampians Region Palliative Care Consortium sit well with this focus, and we look forward to developing this even more within the new framework.

### **3. Other Specific Groups**

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#### CALD

A relatively small proportion of the Grampians Region has come from non-English speaking backgrounds. Community members now living in the Grampians Region, but born overseas, include people from Chile, China, Croatia, Egypt, Germany, Greece, Holland, India, Iraq, Iran, Japan, Kenya, Lebanon, Malaysia, New Zealand, Nigeria, Pakistan, Philippines, Poland, Somalia, South Africa, Sri Lanka, Sudan, Thailand, Togo, United Kingdom and Vietnam and Yugoslavia.

#### Aboriginal and Torres Strait Islander

Data regarding the Aboriginal and Torres Strait Islander population can be found in the recent Department of Health publication - *Grampians Closing the Indigenous Health Gap Plan, 2009–13*.

Approximately 0.8 per cent of the region's population is Aboriginal or Torres Strait Islander, which equates to approximately 1,762 people (ABS 2006 Census), with numbers being broadly distributed across the region in a similar proportion as the general population. Table 6 shows approximate numbers associated with each of the Aboriginal community-controlled organisations (ACCOs).

Table 6: *Aboriginal and Torres Strait Islander population in the Grampians Region*

ACCO name	Catchment area local government areas	Number of Aboriginal persons (approx)
Ballarat and District Aboriginal Cooperative	Ballarat City Council, Golden Plains Shire, Moorabool Shire, Hepburn Shire	1,200
Goolum Goolum Aboriginal Cooperative	West Wimmera Shire, Horsham Rural City Council, Hindmarsh Shire, Yarriambiack Shire	350
Budja Budja Aboriginal Cooperative	Ararat Rural City Council, Pyrenees Shire, Northern Grampians Shire	200

Other data shows that the Grampians Aboriginal and Torres Strait Islander population is significantly younger than that of the non-Aboriginal and Torres Strait Islander population. Approximately 79% of the Aboriginal and Torres Strait Islander population is under 44 years compared to approximately 56% of the non-Aboriginal and Torres Strait Islander population.

The consortium welcomed the opportunity to provide an Aboriginal Health Worker scholarship for the PCV conference in July 2014.

#### ***4. Consortium Membership and Structure***

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##### Committee of Management for 2016-2017

Chair: Michelle Veal, Director Community Services, Ballarat Health Services (from May 2016)

Members:

Denise Hooper, Director of Primary Care, Wimmera Health Care Group

Carita Clancy, Executive Officer, Ballarat Hospice Care Inc

Peter Armstrong, Director, Clinical Services, East Grampians Health Service

Amanda Edwards, Director of Nursing & Midwifery, Djerriwarrh Health Services

Jane Bourman, (Clinical Group representative)

Melanie Mattinson, (Clinical Group representative)

John Koopmans, Department of Health & Human Services

Pete Marshall, GRPCC Manager

## 5. Member Services

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**Ballarat Health Services (BHS)** - Drummond Street North, Ballarat 3350. The catchment area consists of the whole of (but not limited to) the Grampians Health Region.

Gandarra Palliative Care Unit is a nine-bed inpatient palliative care facility providing end-stage care and symptom management for patients and their families who have been diagnosed with a terminal illness. The multidisciplinary team comprises of medical, nursing, pastoral and volunteer support as well as allied health professionals such as occupational therapy, dietetics and social workers.

Patients and families are encouraged to actively participate in all aspects of the patient-focussed multidisciplinary care and planning. The environment enables patients and families to maintain as much as possible their normal routine within a specialised setting.

The Grampians Regional Palliative Care Team (GRPCT) facilitates the ongoing development of palliative care services in the Grampians Region through clinical consultation, education, collaborative strategic planning, preparation of written materials and quality improvement processes. The GRPCT is committed to providing a variety of quality education to a broad range of health professionals who strive for better palliative care practices.

**Ballarat Hospice Care Inc (BHCI)** - 312 Drummond Street South, Ballarat 3350. The catchment area consists of the City of Ballarat, Hepburn Shire, Golden Plains Shire, Moorabool – West SLA, and west of the Ballan-Daylesford Road and Geelong-Ballan Road within the Moorabool – Ballan SLA.

Ballarat Hospice Care Inc provides home-based palliative care services that are patient-focussed for people living with a life-threatening illness. A multidisciplinary team of specialist health professionals and trained volunteers deliver quality end-of-life care with understanding and compassion through symptom management and medication. BHCI continues to support families following a death at a time when people are emotional and feel vulnerable.

Experienced palliative care staff provide expert pain and symptom management as part of any ongoing treatment, with emotional and other practical support services for patients and families. The focus is on providing quality of life, to end-of-life care, with palliative care an adjunct to ongoing treatment, which can be delivered from diagnosis to bereavement.

**Wimmera Health Care Group (WHCG)** - Baillie Street, Horsham 3400. The catchment area consists of the Statistical Local Areas (SLA) or the Rural City of Horsham and the Shires of Hindmarsh, Yarriambiack and West Wimmera.

Wimmera Hospice Care, auspiced by WHCG, is a palliative care service that supports people living with life-limiting illnesses and their families and carers. The WHC team supports patients at home, in aged care facilities and in hospital. The team works closely with patients' local doctors, nurses and allied health care teams. The focus is not just on physical problems but also the emotional, spiritual and social issues that can occur as a result of illness. A bereavement support program is offered to families and carers and funding can be made available for specialist bereavement counselling.

**East Grampians Health Service (EGHS)** - Girdlestone Street, Ararat 3377. The catchment area consists of the Shire of Northern Grampians, the Rural City of Ararat and the Shire of Pyrenees including Skipton (ie. Beaufort and Skipton Health Service).

Central Grampians Palliative Care (CGPC) is a community-based service auspiced by EGHS, delivering health care and emotional support to patients, and their carers, living with life-threatening illnesses.

CGPC aims to work with patients, their families and carers to achieve a level of care that optimises an individual's quality of life and to enhance dignity and independence.

The service liaises with a number of local health and community services to assist in personal care, symptom management, home help and transport. It also loans equipment and aids to enable independence to be maintained and to make home nursing care easier. EGHS has one inpatient palliative care bed.

**Djerriwarrh Health Services (DjHS)** - Grant Street, Bacchus Marsh 3340. The catchment area consists of the Moorabool – Bacchus Marsh SLA and east of the Ballan-Daylesford Road and Geelong-Ballan Road with the Moorabool – Ballan SLA.

Djerriwarrh Palliative Care (DPC) is a community-based service, auspiced by DjHS. The palliative care program offers co-ordinated care services for people with a terminal illness and support for their family at home. Care and support is offered including pain relief and management of other symptoms. It aims to be flexible and sensitive to the wishes and needs of clients and their families. A range of allied health services are available and a counsellor co-ordinates volunteer and bereavement services. DjHS has two inpatient palliative care beds.

**St John of God Ballarat Hospital (SJOG)** - Drummond Street North, Ballarat 3350. The catchment area consists of the whole of (but not limited to) the Grampians Health Region.

SJOG is a member of the St John of God group, which operates an organisation-wide Palliative Care Strategy that embodies an holistic approach to palliative care as an integral component of inpatient, outpatient and community services. The focus is on building confidence and capacity to equip caregivers with the knowledge and skills to manage and care for people at the end of life. The ultimate aim is to offer patients, with the support of their families and other carers, the opportunity to die with dignity and respect while minimising pain and suffering.

The implementation of its Pastoral Services Strategic Plan 2010-2014 took place during the year. The main focus is on strengthening professional practice, information and education, and data collection. The Murdoch hospital developed bereavement resource packages for carers, which have been introduced across all hospitals within the SJOG group.

## 5.1 Contact Details

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## ***6. Consortium Manager's Report***

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The focus of the 2016–17 financial year has been on effective use of available resources for improving palliative care provision in the Grampians region.

One of the main vehicles for improvement has been sector capacity building:

- Provide opportunities for staff to expand their skills by funding research opportunities and initiative development
- Provide support for external educational activities
- Supporting technology skills development and acquisition
- Region wide collegial support through the clinical advisory groups

The consortium has been fortunate to have the stewardship of a moderate underspend, and while there has reasonably been a focus on drawing that down, there has also been a strong focus by the executive on astute and targeted use of those funds.

The underspend has always focussed on 'supporting', rather than just wholly funding initiatives, and any funding that we do provide is matched by 'in kind' resourcing within the initiatives that have been undertaken. As a consequence, the ultimate value of the drawdown is increased, and if service development, staff upskilling, job satisfaction and ultimately retention were to be considered, the multiplier effect of innovative but judicious use of funding is even greater.

In addition, a quick look through the report will illustrate the wealth of resources that have been and are being developed to inform and support carers in the region. Similarly, we are delighted to have been able to fund a variety of initiatives targeting community understanding of, and attitudes to end of life care.

We are well supported in the Grampians region by professional and motivated specialist palliative care services, and it is to them that we owe the most credit for improvements in palliative care provision. The consortium role is to support them where we can.

I would like to thank the auspice, Djerriwarrh Health Services for their flexibility and support as we have worked through some of the structural changes required. I would like to particularly thank John Koopmans our Grampians Health Department rep, for our regular meetings, but also for the quiet way that he goes about supporting palliative care in the region. Thanks also to Michelle Veal of Ballarat Health Services, for the support that she has offered over the reporting year in her role as Consortium Chair.

Pete Marshall, Consortium Manager

## ***7. Core Activities***

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### **7.1 Clinical Advisory Group**

The Grampians Consortium Clinical Advisory Group (CAG) had 4 meetings during 2016-17, which were all face to face meetings. One scheduled meeting was changed to a combined strategic planning day with 3 consortium members in attendance.

During 2016, the clinical group decided it was beneficial to have bi-monthly clinical meetings, and have them all face to face. These face to face meetings are held in Ararat, as that offers the best compromise on the need to travel from across the region. They are resource intensive, and for some participants will mean losing virtually a whole day from work.

They do however; offer the greatest potential for networking and sharing, and the links and sharing occur at a much more significant level. In between these meetings, there is a more pronounced sharing online, and significant news, updates and discussions are utilised when appropriate.

Clinical meetings invariably have a full agenda, and face to face meetings offer invaluable sharing of knowledge and skills. While far from exhaustive, the following list provides a snapshot of broad areas covered by these meetings and/or the online network:

- Support and sharing around consistent use of clinical tools
- Nurse practitioner input and feedback from the PCCN
- Information and support for involvement in statewide initiatives and central data collection
- Input into consortium planning activity and data collection
- Information sharing and input into implementation of statewide initiatives funded through the consortium
- Development and review of Grampians based consortium funded initiatives
- Concept development and design of future consortium funded projects

## 7.2 Palliative Aged Care

The role of the Palliative Aged Care Resource Nurse (PACRN) has continued to support the embedding of a Palliative Approach in the 57 Residential aged care facilities (RACF) in the Grampians region. The role is clearly a resource and consultancy role and specifically not a clinical role. It has been a privilege to continue to work alongside the dedicated aged care staff in the Grampians region and the specialist services.

The PACRN has focused on supporting RACF link nurses, members of steering committees and their staff to complete self-directed online training and supporting them to conduct training in their own facilities using aspects and resources from the Palliative Approach Toolkit. The whole organisation approach has provided great opportunities for ongoing networking as there have been many changes in the roles of CEOs and managers of the RACFs. This has included the establishment of a new RACF and the renaming and refurbishment of others, also increasing numbers of beds available. This constant change in the region reinforces the need for the regular and ongoing facility visits and support with education for all staff.

Requests by RACFs for onsite education and discussions around their local experience have been a rewarding experience particularly in the rural areas to address the direct needs of that facility. Education around subjects such as Advance Care Planning and in particular the Medical Treatment Planning and Decisions Act 2016, due to be introduced in March 2018. Also looking at how this new legislation will impact both individuals and staff supporting the completion of these forms to guide their medical care into the future has been well received. Another focus of education has been to support and encourage the ongoing links between RACFs and specialist palliative care services (SPCS) in the Grampians region. These connections are invaluable to staff and residents in RACF to support the provision of care in the facility. This support assists in avoiding unnecessary transfers to emergency departments and admission to hospitals and thus reduces both caregiver and resident's distress as they are able to be cared for in their own facility.

The use of end of life care pathways has continued to be embedded at varying stages across the region. The Victorian End of life Care Coordinating program have recently developed an end of life care pathway called Care Plan for the Dying Person (CPDP) that can be used across all health care settings in Victoria and in particular acute wards. The majority of RACFs in the Grampians region have been using the Residential aged care end of life care pathway (RACEoLCP) previously developed by Queensland Dept. of Health and accessed from the [palliative approach toolkit website](#). The RACEoLCP incorporates the 10 core principles for the best care for the dying person and utilises the key elements of care necessary for achieving best outcomes for a dying person and their loved ones and so has continued to be used.

The PACRN is assisting some health services' end of life steering committees to discuss the implementation of the CPDP where there is a RACF onsite with the acute service.

Networking across the region has involved coordinated workshops and presentations with WestVic PHN. This has been rewarding for all those involved as the GPs who work in RACF have had the opportunity to discuss issues at the coal face and education of staff has been further enhanced by the expertise of the presenters.

Education around the topic "Understanding the dying process", has continued to be extended to environmental, cleaning, kitchen and general services including reception and leisure and lifestyle working in RACF. These 30 min sessions have been well received with comments such as "Thank you for involving us as we often felt left out and we had become good friends with the residents and their families". The continued use of one simple tool has been the use of the leaves logo that can indicate someone has commenced on an End of life care pathway (EoLCP) on the resident's door and care folder. Also placing the logo with just a room number at the sign on point for staff and at reception (out of public view) and in the kitchen area enables many staff to be aware without even having to say a word. This simple tool has enhanced communication across the facility so regular staff can acknowledge promptly that a resident is near death.

The PACRN has completed multiple sessions and workshops as outlined below with over 672 attendees and contacts interacting with Managers, Clinical Care Coordinators, and colleagues in the field and networking opportunities. The following sessions and workshops included topics such as recognising signs of dying, understanding the dying process, advance care planning, patient centred care, and oral care, assessment of pain, dyspnoea and delirium:-

- 10 (6Hr) Palliative Approach in Aged care workshops across the region
- 47 education sessions (1-3hr) aspects of a Palliative Approach in Aged care
- 19 education planning sessions with health services

Another key opportunity has been the ongoing support to students completing their Certificate 111 in Individual Support/Aged Care. I have provided a number of 3 hr sessions to discuss and debrief about their experiences for caring for residents both at end of life but also as part of their routine care and supporting them in recognising the signs of deterioration. The responses have been "I wished we had this earlier, it has really made things clearer" and "I now understand about why we don't push fluids at end of life" and "it has helped understand the signs of dying". These PCAs will be care providers in the future and assisting in their education is a rewarding part of the role.

In June 2016 Western Victoria Primary Health Network (WestVic PHN) held an aged and community care interagency forum called *Connecting Aged and Specialist Palliative Care Services*. A wide range of stakeholders, from across the Grampians Region, attended including general practice, residential and community aged care, general and specialist palliative care services. The discussion at the forum confirmed that General Practitioners and other service providers are unaware of available services and referral guidelines, there is a lack of communication between service providers, there are gaps in palliative care services in some regions and the responsibility for coordination of services is unclear. It was evident that navigating the palliative care system in the Grampians region is complicated. In October 2016, the PACRN and GRPCC in a joint project with Western Vic Primary Health Network, Central Highlands Primary Care Partnership and Project Consultant Kate Wise then developed a quick reference tool for referral to SPCS in the Grampians Region which was completed July 2017 and distributed to each member's data base.

Planned focus for the remainder of 2017 and early 2018 is to support RACF to complete after death audits to identify any gaps in the documentation of care of residents at end of life including recognising and documenting the signs of dying and seeking appropriate support from SPCS if required. This will provide a focus for further education in 2018.

### **7.3 Disability Palliative Care Project**

Formerly a consortium contracted project, from the 2013-14 financial year, funding for this initiative has been going straight to East Grampians Health Service (EGHS).

The contract with the consortium for the disability palliative care funding expired on June 30th 2015, and the consortium sought expressions of interest from the funded palliative care services in the region to operate the program for the next two (2) years - 2015-16 and 2016-17. However this approach was not able to be actioned as the funding for 2015-16 and 2016-17 rolled over to continue with EGHS.

In November 2016 the GRPCC Clinical Advisory Group recommended to the consortium a subgroup be formed (made up of Jade Odgers, Jane Bourman and Sharon Gibbens) to take this project forward. After discussions with DHHS disability senior staff this subgroup then formed the Grampians Disability Palliative Care Project Steering Committee. The steering committee is made up of representatives from our Specialist Palliative Care Services as well as the Disability sector and DHHS. After several meetings the funds are now with Ballarat Hospice Care Inc. as the fund holders, a position description has been finalised and a job advertisement for a 'Disability Palliative Care Project Worker' have occurred in the local paper running for 2 consecutive Saturdays. Ideally this position would be suited to someone already working in the disability or palliative care sector. It has been advertised as a temporary/time limited position therefore well suited as a consultancy or secondment position.

The Disability Palliative Care Project Worker will be engaged to build capacity of Residential Disability staff in the Grampians region, to provide an effective and appropriate palliative approach for residents. This will involve clarifying the respective roles of both residential disability and palliative care staff as part of the project, so they both understand each other's scope of practice, limitations, etc., and to support staff to adopt a palliative approach and improve end of life care for residents.

Main points:

- A regional approach underpinned by strong links and networks
- Identifying key staff within facilities who will participate in the program
- Engagement with service provider senior managers
- Engagement of specialist community palliative care services and the Grampians Regional Palliative Care team to support the provision of specialist palliative care as required.

The consortium believes that this will offer a unique opportunity to have the biggest impact from what is ultimately a small amount of funding.

### **7.4 PEPA**

During 2016-17 the Grampians Regional Palliative Care Team conducted x3 PEPA workshops across the Grampians region. They focused on Aged Care in the Stawell region with 25 participants attending. The second was a general PEPA workshop held in Horsham with 15 participants and the final workshop was held in Ballarat.

The consortium received PEPA funding in 2016-17 to run a Grief and Bereavement workshop with external facilitator's from the Australian Centre for Grief and Bereavement. This will go ahead during late 2017 and it is anticipated that it will be well supported.

### **7.5 Consortium Website**

The GRPCC website was originally established in 2008, however functionality was poor and information was limited in overall quality.

A renewed website went live in November 2013, and continues to be updated on a regular basis to the extent it has become a valuable information tool for many people from within the Grampians region. Analytics continue to demonstrate utilisation comes from approx. 25% of people in the Grampians region, 50% from other regions and 25% other countries. It also continues to demonstrate that increases in site visits are directly related to consortium activity, including PACRN education, Small Grant advertising, workshop registration and advertising of events. An important feature this year is the link available via the [Navigation Project Quick Reference Tool](#), to quickly access the Specialist Palliative Care Services and the referral process for this region

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## ***8. Service Support Activities***

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### **8.1 Provision of Professional Training**

The consortium has run workshops across the region during 2016-17. The Regional Team is the major provider of training in this region, with a varied and comprehensive program, and the consortium has targeted training which is complementary to their program, rather than competitive.

In addition, the consortium has specifically aimed to take training out to the more rural communities, particularly in the West of the region.

The palliative aged care initiative has been our main training focus for this financial year. The consortium in conjunction with the Regional Team have run 3 very successful ACP Facilitation Skills Workshop's which were held in Horsham, Ballarat and Ballan. All attendees indicating this was a valuable topic and much needed area for ongoing training.

The consortium also sponsored the Regional Team to run two Clinical Skills Workshops specifically aimed at palliative care nurses from all four Specialist Palliative Care Services.

### **8.2 Advance Care Planning Discussion Resource**

The consortium has developed a set of 'Wishes' cards that offer health and aged care facilities a resource to support end of life and advance care planning activities. Each of the 48 cards in the set has a different statement that expresses a wish that someone may have at the end of life. Examples are *'To be able to say goodbye to the ones I love'* and *'To know the truth about my condition, treatment options, and the chance of success of treatments'*. Participants sort through the cards until such time as they end up with the top 10 statements that best reflect their end of life wishes.

We have used these cards in group situations, during education sessions, as an adjunct to public events and individually, and the response has been enthusiastically positive across all formats.

We have gathered feedback on the cards as they are currently configured, and have found an overwhelming response. The main feedback we get is this activity gets people thinking and talking about the conversations that need to be had, especially with loved ones. We are currently in discussions around correct ethics before looking at producing them more professionally. All of the 'wishes cards' are numbered and we ask those who use them anonymously record their top ten wishes.

We now have analysis data from 343 respondents which shows the top 5 wishes that are most commonly chosen are:

- To be free from pain;
- To maintain my dignity;
- To have my family and/or close friends with me.

- For my family, friends and caregivers to respect my wishes even if they don't agree with them;
- To be able to say goodbye to the ones I love;

Being free from pain is a clear standout in this list, and it is clear that there will be little quality at end of life if your pain is not managed. Similarly, there were other areas such as being relatively free from anxiety, treated with cheerfulness and to not be left alone. But fascinatingly, while 74% of respondents had pain in their top 10, virtually every respondent chose an area associated with the themes of dignity, respect and family and friends. This therefore points to the absolute importance of services paying close attention to providing what could be termed the 'psychosocial' aspects of palliative care.

The data also points to the 'dying at home' theme as being a nice thing if it can happen without significantly impacting on my family and self-determination – in other words much more nuanced than just 'I want to die at home'.

### **8.3 Support for Professional Development**

The consortium agreed to support better access for palliative care staff working with palliative care patients throughout the region to attend conferences, seminars or educational workshops to further their knowledge and skills in palliative care.

The aim is to provide support such that both staff and agencies, particularly those with less immediate access to training opportunities, take up a greater range of options. The consortium recognises that staff are our most valuable asset, and that training is critical for the continued quality improvement of services.

The consortium has done this in the past by responding to particular events or circumstances, but has not had a documented process in place. This initiative aims to make more training opportunities viable, and reduce the need for case by case decision making regarding what might be funded. The initiative also covers backfill, as this is often the most critical factor in decisions to release staff.

Separate to the ongoing initiative, the consortium also funded five regional members to attend the PCV conference in July 2016.

### **8.4 Program of Experience – Motor Neurone Disease (PEM)**

The consortium recognises the importance of ongoing financial support to assist our SPCS with staff development and during 2016 assisted Ballarat Hospice Care Inc. with the cost of a PEM placement.

Mel Mattinson (Educator – Integrating Palliative Care/Palliative Care Nurse Specialist, Ballarat Hospice Care) attended 4 days of PEM in the second half of 2015 which was an opportunity to gain further insight and increase knowledge of the supports that are available for people diagnosed with Motor Neurone Disease (MND), their families and carers.

Mel attended 1 day at MND Association (Vic), Canterbury and 3 days at Calvary Healthcare Bethlehem, Caulfield Sth. The program provided an overview of the services that are provided by MND Association (Vic) and how people are supported at home with regards to provision of equipment, access to support staff (eg: Regional Advisors) and education for patients, families/carers and healthcare workers.

Insight into the multidisciplinary clinics (Neurology, Psychology, Respiratory, Dietetics, Physiotherapy, and Occupational Therapy), inpatient facilities and programs (Art Therapy, Music Therapy) that people with MND can access at Calvary Healthcare Bethlehem was gained.

Mel has been able to provide education to her colleagues, which has led to staff being better informed when supporting patients with MND, their families and carers.

Overall, Mel found participation in the program to be a valuable experience and would recommend it to those who have an interest or role in caring for those with MND.

## **8.5 Grief and Bereavement**

Ballarat Hospice Care Inc. was funded through 'The Helen Macpherson Smith Trust' to run a six-month project "Grief and bereavement – Looking to the future". Due to the limited and readily accessible grief and bereavement supports in the local area, and raised awareness in the community about grief and bereavement, the counsellors at Ballarat Hospice have become a hub for referrals and support seeking, for which they are not funded. It is from this increased and ongoing demand that the service has become aware of the need to find effective, efficient and sustainable ways to address these service gaps and build community resilience and cohesion through a greater understanding of the personal and professional impact of grief and bereavement in our community. The identified need in the community was addressed by way of the development and presentation of workshops to community and other organisations. The consortium gave administrative support to one of these workshops.

### **Key Findings**

- The six-month project time-frame was too short as we found organisations and staff schedule their training program up to 12 months in advance.
- Ideal length of workshop is 3 hours including break.
- The perceived unmet need was demonstrated by the demand for more workshops than we were able to deliver in the time frame.
- Participants consistently reported that after attending the workshop they had increased awareness about the nature of grief and bereavement and improved confidence in supporting other grieving people.
- Through five workshops, 80 participants were reached with information and education with the potential for these 80 people to share their enhanced learning within their families, communities and workplaces.
- The cost of delivering the workshops is a prohibitive factor for individuals and organisations and therefore may not be self-sustaining without funding or subsidy.

### **Key Recommendations**

Based on the key findings, it is recommended that:

- Any future workshops are scheduled and promoted 12 months in advance.
- Ballarat Hospice would need to introduce a fee for service model or source additional funding to trial the four-workshop model.
- Two trained facilitators deliver workshops as they need to be able to manage the unique group dynamics, level of participation and interaction for each workshop.
- Fact sheets and community resources are further developed including hard copy, on-line and web sites to efficiently address the needs of the local community.
- The self-care component of the workshop and resources are reviewed and expanded.
- Administrative support is included in any future workshop planning which is essential for arranging workshops, booking rooms and managing RSVPs. This would allow grief and bereavement counsellors to focus on workshop preparation and facilitation.

Ballarat Hospice Care Inc. continues to receive more requests for assistance than it can respond to. Initially four workshops had been planned but due to demand one additional workshop was accommodated.

During the project, there were three further requests for workshops that could not be delivered due to the time constraints of the project. These were from an Aged Care Facility, a Day Procedure Centre and a General Practitioner Special Interest Group, demonstrating the widespread demand. Interest was also expressed in the provision of short sessions on specific components of the workshops such as self-care for General Practitioners and general information for local Cemetery Trust staff.

It has been recommended by the GRPCC Clinical Advisory Group that more Grief and Bereavement education is one of the key priorities for future consortium funding.

***The need for grief and bereavement education and support is not limited to those who have accessed a palliative care service but impacts on all members of our community at some stage in their life.***

## ***9. Funding for Regional Service Based Initiatives***

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The consortium has been delighted to be able to provide funding support to a broad range of service based initiatives, all of which have relevance for improved provision of palliative care for the sector both within Victoria and more broadly across the nation. As pointed out earlier, the flow on effect of these investments is quite profound, not least in terms of professional development and professional job satisfaction.

Regular calls for submissions from funded services for potential project and resource development funding led to support for the following new and ongoing initiatives being approved by the consortium.

### **9.1 MND Changeover**

Jennifer Noonan from WHCG, who has done a very professional job of filling the MND role for our region, expressed her intention to retire in early 2017. The MND role covers the full region, and in particular is one that is best suited by being stable over a number of consecutive years. In line with the procedure for all changes in program auspice arrangements the consortium called for an expression of interest from our funded specialist services to manage the role into the future.

The management of the role is for the next four financial years (2017-18, 2018-19, 2019-20 and 2020-21), dependent upon the role continuing to be funded.

The EoI was sent out in late January 2017, and in the first instance the call was for an indication of each service's likelihood to submit an EoI. This indication was not binding in either direction, but did allow for better management of the process. A subsequent EoI for future management of the position was sent around, and I am pleased to announce that the Grampians Regional Palliative Care Team will manage the role in the future.

At the end of 2016, there were 17 people living with MND in the Grampians region (as registered with MND Vic). A look at the figures for the past 5 calendar years shows that the numbers regionally can vary significantly, but the overall trend across Victoria has been increasing numbers.

Year end	Grampians region	Victoria
Dec 2012	12	275
Dec 2013	19	315
Dec 2014	15	379
Dec 2015	13	380
Dec 2016	17	372

The current years funding is \$19,130, and although the overall numbers may seem quite low, it can readily be seen that travel across the region can be quite challenging, both in terms of time and cost, within that overall budget.

## **9.2 Extension of the Carer Package for Subcutaneous Medications**

This is an ongoing project within the Grampians Region and is managed by the Grampians Regional Palliative Care Team.

After successfully implementing the Carer package for safe administration of subcutaneous medications across the Grampians Region there has been a request for financial support to continue to provide this resource.

After consultation with the community advisory committee in early March 2016, the regional community palliative care providers requested that USB's and laminated reusable cards should be included. The original proposal did not include these products. An additional 150 packs including DVD, USB's, laminated carer cards, medication log and clear plastic sleeves were purchased at a cost of \$3500. There is still stock of these resources available at the GRPCT for ongoing use. A request was submitted to translate the video into another language which was funded by that organisation.

## **9.3 Carers in the Grampians**

The consortium was delighted to be able to financially support the GRPCT in the Carers in the Grampians project. The resulting resource was incredibly powerful, and will be a great resource for both carers and the community in general to broaden their understanding of the carer role.

The Carers project reveals the experiences of ten people caring for family members who were receiving palliative care. Talking openly about their parents, partners, siblings and children, the participants discuss what it's like to hear that there is nothing more the medical community can do, and the impact that had on their family member in palliative care, and on themselves. They reveal some of the joys as well as some of the challenges of caring for their family members, and what it was like for them dealing with grief. They share the benefits and difficulties of looking after their family members at home, and acknowledge how the experience has changed them.

In November 2016 the exhibition was launched at the Ararat Regional Art Gallery and then another exhibition was held in February 2017 at The Gallery at City Library Melbourne. A poster presentation was accepted at the National Palliative Care conference in Adelaide of this year.

Thank you to the palliative care services which supported the participants in this project which include Central Grampians Palliative Care, Ballarat Hospice Care Inc., Wimmera Hospice Care and Djerriwarrh Health Services.

## **9.4 Integrating Renal and Palliative Care**

Since 2009 Ballarat Hospice Care Inc. (BHCI) and Ballarat Health Services Dialysis Centre (BHS-DC) have been developing a framework to integrate renal and palliative care to improve outcomes for patients in the Grampians region with Chronic Kidney Disease (CKD) and End Stage Renal Disease (ESRD).

An article was published in the Renal Society of Australia Journal, March 2017

**Evaluating nurses' action outcomes and exploring their perspectives of implementing the POS-S (Renal) assessment tool for haemodialysis patients.**

This publication showed that between 11% and 24% of patient (n=54) indicated moderate to severe symptom burden. The progress notes showed that there were actions taken by the nurses to address symptoms as identified using the POS-S (Renal) tool. Focus groups revealed increased confidence/willingness to take ownership to effect change with in nursing roles, co-existing with prevailing persona, cultural and structural barriers which create a sense of powerlessness to effect further change. The conclusion highlighted that the POS-S (Renal) Tool is useful for identifying and tracking symptom deterioration, supporting nurse led actions to address chronic symptom burden and as a prompt for commencing conversations about End of Life (EoL) care. Renal nurses in regional dialysis settings face many challenges and require ongoing support and assistance to progress towards the adoption of timely advance care planning and the provision of patient-centred EoL care to their patients.

Elements of the project which are complete include:

- The POS-S (Renal) Tool is imbedded in the medical record at BHS, data is collected and exported to the parent renal hospital, Royal Melbourne Hospital.
- Relationships between the organisations are strong and the “door is always open”
- Appropriate referrals are received from renal nurses and the local nephrologist
- Resource manual reviewed and all in the Clinical Advisory group of the GRPCC agreed to workshop the direction of this project in context of local need and resources available through the Renal Clinical Network.

The next phase of this project will be to continue to expand the implementation of these findings across the Grampians region with the Clinical Advisory group of the GRPCC.

## 9.5 Palliative Care Navigation Project

### Overview of the issue

In order to address concerns that General Practitioners (GPs) and other service providers are often unaware of specialist palliative care services and referral guidelines, the Consortium (GRPCC), Central Highlands Primary Care Partnership (CHPCP) and the Western Victoria PHN agreed to work together to develop a clear pathway for referring services to access specialist palliative care services (SPCS) across the Grampians region.

The project aims were to:

- Improve patient outcomes and service delivery.
- Reduce avoidable transfers to the emergency department (ED).
- Improve the connections and enhance the patient journey between services.

The specific tasks of this project were to:

1. Map the referral pathways into the five Specialist Palliative Care Services (SPCS) in the Grampians region
2. Identify the information needs of generalist services referring to these SPCS
3. Develop and deliver a tool for referring to SPCS in the Grampians region
4. Assess the impact of the tool on addressing the information needs of services referring to SPCS in the Grampians region

### Data collection and development of the tool

Initially, the project lead conducted a search of publicly available information about each of the five SPCS in the Grampians region, followed by direct consultation, to collect information about the services and their referral pathways. Additionally, a survey designed to gather baseline information about stakeholder preferences and need for a quick reference tool was distributed both electronically and in hard copy to health care professionals on the contact lists of GRPCC, Western Victoria PHN and CHPCP.

A valuable side outcome of this process is that it prompted services to update their service summary, review their referral processes and clarify their catchment areas.

179 stakeholders completed the baseline survey, 83% of which were either GPs (n=36) or nurses (n=112). Others were a mix of aged care staff, community providers, managers and supervisors.

- 50% of respondents indicated a low level of awareness about how to make a referral to a specialist palliative care service.
- 71% indicated a strong likelihood of using a quick reference tool for referral to specialist palliative care services.

The information from both services and the survey was used to inform the development of a quick reference tool, with a focus on making it easy to use, accurate, consistent and succinct. It was determined that the quick reference tool should include the following information:

- Referral process for each service, including triggers for referral, referral criteria and tips
- Map showing SPCS catchment areas
- List of other services which support SPCS

The quick reference tool was uploaded to the Western Victoria PHN website, and the [link to the tool](#) was then launched via the extensive email lists of the partners.

To be effective into the future, the tool needs to maintain currency and relevance. A feedback process is and will remain in place, and staff resources will need to be allocated to updating and maintenance.

## **9.6 A Guide for Caring for People at the End of Life**

In 2015 the consortium supported Central Grampians Palliative Care to produce this guide that comprises a DVD, a key messages booklet and an attractive folder to store essential program information. The product was well received, not just on a client/carer level, but more from other Palliative Care providers who were searching for easy to access, compact training tools.

In August 2016, Palliative Care Australia featured an article about the resource that in turn generated more than 130 requests for a copy. The requests came from many health services and individuals from around Australia and also overseas- Scotland, Thailand and Ireland.

Youtube has also proven to be a valuable media for sharing information. One of the video segments “when death is near” has had over 150 000 hits. Other popular segments include practical advice such as hair washing in bed, using an overnight catheter and problems with a syringe driver, that have also attracted audiences of up to 10 000.

A poster detailing the DVD’s development and research was presented at the Victorian Integrated Cancer Service conference in May this year.

## **9.7 ‘Whispered Questions’ – Carers Education**

**Whispered Questions: identifying the confronting and often unspoken questions that provide valuable information to carers and patients requiring palliative care support**

In 2015, Mel Mattinson (Educator – Integrating Palliative Care/Palliative Care Nurse Specialist) and Liz Dawson (Supportive Care Team) from Ballarat Hospice Care, undertook a research project surrounding questions which may be considered ‘taboo’ and are often difficult for carers and patients to ask anyone. We know that they are likely to be questions that others want answered too. These have been identified as ‘Whispered Questions’.

Patients, carers and staff were invited to participate in a survey and a focus group session to help us gather a list of 'whispered questions', to explore why they are difficult to ask and determine what we can do to help patients and carers get the information they need at the right time.

Sixty-six questions were identified, from 44 participants, relating to topics including medication, treatment, relationships, legal issues, emotions, death and dying and managing after death.

It was found that carers and patients may be reluctant to ask some questions because they:

- are new to palliative and don't know what questions to ask
- avoid asking because they are worried about the answer
- are worried what other people will think
- don't want to stir up their emotions

Providing information in a range of ways including face to face, one on one, in small groups and in written formats are all important to consider when developing resources to address common concerns of patients and carers.

Thank you to the patients, carers and staff who participated in this research project. The consortium will continue to be supportive of this valuable resource.

## **9.8 Clinical Skills for Community Palliative Care Providers**

The Grampians Regional Palliative Care Team had the pleasure of running one clinical skills workshop that was specifically for our palliative care nurses across the region. This was a very successful day with attendees from all four community palliative care services. The second one of these days is booked for November in order to pick up palliative care nurses that were unable to make the first session and staff from our inpatient palliative care unit.

The consortium was delighted to be able to support the Regional Team in providing these two workshops for the region.

## **9.9 Remembrance Services**

The consortium has once again been delighted to support the specialist palliative care services in their remembrance initiatives.

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## ***10. Community Based Initiatives***

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The Consortium set up a process to offer small grants for a maximum of \$4,000 to community groups looking to manage a local initiative that meets the consortium strategic objectives. Background research on the experience of the Foundation for Rural and Regional Renewal (FRRR) and the Mercy Foundation, which both offer grants up to \$5,000, is that over hundreds of small grants the average amount funded is approx. \$2,500 - \$3,000.

This has been the experience of the consortium as well, with successful applications averaging funding of approx. \$3,200. The small grants had the following focus:

People with a life-limiting illness spend most of their time with family, friends and acquaintances in their own community at home, including disability and residential aged care facilities. Building community capacity in relation to life-threatening illnesses, dying, death and bereavement leads to better support and positive outcomes for people with a life-limiting illness.

Benefits of a community awareness approach to palliative care include avoiding unwanted hospitalisation/treatment, making and communicating appropriate care plans before future potential loss of decision-making capacity, appointing a decision maker for a person's best interests, putting in place enduring powers of attorney, making advance care plans, relieving family burden, dispelling myths and improving understanding of facts, personal peace of mind, autonomy and dignity at the end of life.

This initiative has generated new and innovative partnerships between local communities and the palliative care services, and significantly 'value-added' to the provision of excellent and responsive palliative care across the region.

More information on these community based activities is provided below.

### **10.1 EWHS – Dying to Know**

St Arnaud campus of East Wimmera Health Services organised a community event with the aim of starting a conversation about death and dying, in order to encourage their community members to have those much needed conversations with their loved ones about their plan for end of life. This included assisting their community members to write down their future health care wishes in advance.

The event called 'Managing your use by date' was presented by Molly Carlile (the Deathtalker). Molly has extensive academic qualifications in health, end of life care, counselling, education, and healthcare management and over 20 years of experience in the field. Molly supports people to become informed about death and grief in order to live life to the full. The event also featured speakers from EWHS and the consortium.

Aims were to encourage our community to:

- Consider making their end of life plans.
- Share these wishes with their families
- Be informed about end of life and death care options such as dying at home.
- Equip our community to support their family and friends experiencing death, dying and bereavement.

The community event was an adjunct to the existing EWHS implementation of the Advance Care Planning and Palliative Approach project across the health service.

This project has recruited: Advance Care planners who will work within the five East Wimmera health rural hospitals, and in the communities of Birchip, Donald, Wycheproof, St Arnaud and Charlton. This will ensure that the Victorian Health -Advance Care Planning - "Having the conversation" Strategy is embedded into practice. EWHS has also appointed five Palliative Support Nurses into their five residential aged care facilities to support residents with advance care planning, person centred case conferences and end of life pathways. This approach is based on the Palliative Approach toolkit.

The event had sixty-six community members in attendance all with positive feedback indicating it was very informative and encouraging. Almost half felt more confident in having conversations with loved ones as a direct result of the event.

It therefore has been successful in supporting the EWHS community to understand that death is a part of life and to feel confident to have those much needed conversations about planning for death.

## **10.2 Dying Well in the Hepburn Shire**

Adults and seniors residing in the Shire of Hepburn face the same health challenges as those in Ballarat, but are often unaware that they may have a choice to have end-of-life care at home. This is especially important in Hepburn Shire, as if hospital care is required, family members often have long drives to get to the hospitals in Ballarat, hence limiting their ability to support their loved one at this critical time.

The project aimed to help Hepburn Shire residents consider the possibility of dying well at home with the help of Ballarat Hospice. The 2 hr sessions, held in Daylesford, Clunes and Creswick used music, storytelling and poetry about death and dying, as well as stories from community members who had received the help of Hospice for family members. Also information from Hospice staff and Hepburn Health staff to engage participants in thinking ahead about dying and what is involved in preparing for dying well.

At the three 2 hr sessions there were approximately sixty attendees, where all participants seemed fully engaged, most stayed for afternoon tea and conversation with Ballarat Hospice and Hepburn Health staff. As well, nearly all asked to be included on an email list to receive the document, 'End of Life Paperwork', which was discussed during the session. The stories, songs and poetry were very well received, as were the personal stories and information offered by Hospice and Hepburn Health staff.

The benefits identified and results were:

- Participants will be able to think about end-of-life care in an engaging way and will learn about what Ballarat Hospice is and does, from feedback received following the session
- Participants will be able to talk with local residents who have had Ballarat Hospice help, through engagement during and following the session
- Participants will know how to access Ballarat Hospice services and how end-of-life care can be managed in one's home, through the stories, Hospice staff input and brochures provided

Feedback was invited informally, and quite a lot of positive feedback was received about the information provided and the format of the program. Participants were invited to leave their email addresses in order to receive the 'End of Life Paperwork' discussed during the session, and most did so. Ballarat Hospice will review referrals from Hepburn Shire for the next 12 months in order to see whether the increased information in the community results in greater access of Ballarat Hospice services.

## **10.3 End of Life Education Forum**

In conjunction with Ballarat Hospice Care, the Australian Catholic University and the Creswick Medical Centre, the consortium supported Hepburn Health Service (HHS) to put on a full day end of life education forum which was held in September 2016. The morning half of this workshop was open to all, and covered the following topics:

- Advance care planning and the delivery of palliative care
- End of life care for people with dementia
- Advance care planning from the consumer's perspective
- Palliative care for the LGBTI person

An additional afternoon program was specifically for HHS staff and volunteers:

- Palliative Care in Residential Aged Care – the Link Nurse Project
- What do our teams do well?
- What can our teams do better?

The event was attended by 50 staff and 30 community members, and feedback responses indicated that the LGBTI presentation was particularly appreciated.

## 10.4 RNH – Dying to Know

Rural Northwest Health ran five community events with the aim of starting more conversations about death and dying in order to encourage their community to start a conversation with their loved ones. These were held in Woomelang, Hopetoun, Beulah, Brim and Warracknabeal and were reasonably well supported by community members. Considering the remote areas of some rural townships RNH staff reached out to approximately eighty-seven of their community over all five events.

Session information covered enduring powers of attorney, palliative care, advance care planning and an interactive component where people were given the 'wishes cards' to identify the 10 wishes that were important to them when planning their advance care plan. A 'bucket list' enabled people to add their most important wishes to it.

The consortium support also included staff presenting at each of these sessions. A static display and printed resources to take away were available. The sessions also provided the opportunity for the RNH Wellbeing Co-ordinators role to be promoted as they can assist people with completing an advance care plan.

The benefits identified from these sessions were:-

- Importance of appointing enduring POA and changes that will occur in 2018
- Explanation and discussion informed participants about advance care planning
- The Wishes Card activities created interest among those who participated. Some participants found it challenging to narrow their wishes down to 10 from the 48 listed
- Promotion of the RNH Wellbeing Coordinators and their availability to assist with completing an ACP has seen a number of community members in Woomelang take up this offer.
- The Manager of the Woomelang Bush Nursing Centre reported that participants were still talking about the session the following day
- Verbal feedback from participants at the Warracknabeal session – reported the session as being excellent and that it was just what they wanted to know
- Bucket list wishes included – train from Perth to Sydney; fly to El Questro; trip on Ghan and to listen to my opera; Travel Australia, stay positive health, keep living, keep fit, days not long enough, don't be a burden on family; see some grandchildren married; have no more room on my present bucket list sorry!; to get my wellbeing information in order; to go to Canberra and back to Broome; to be alive for my grandchildren.

## 10.5 Shannon's Bridge – The Art of Bereavement

Shannon's Bridge is a new charitable volunteer organisation to help connect patients, families and carers with existing palliative care services and supports. We are here to educate and support communities with issues about illness, dying and loss. The aim is to remove the taboo and change attitudes about death and dying. The focus is on not just a "good death" but "better living".

Shannon's Bridge is based on the "Compassionate Communities" international movement to help people to live well within our communities to the very end of our lives.

The Art of Bereavement project funded by the consortium in 2016-17 will allow for distribution of handover bags to local facilities, while also providing art therapy sessions for bereaved individuals in the region. Bereavement support begins before death, and is a critical aspect of end of life care in our communities. Shannon's bridge identified some key opportunities to connect with families and look for simple ways to increase the support available to those who have lost loved ones. A Family Handover Bag is designed to replace the practice of returning a deceased person's belongings in a plastic or plain paper bag in Health Services or Residential Aged Care Facilities.

Participants with a broad range of grief experiences were recruited, and provided group sessions conducted by local Art Therapist Denise Longmire. With eight participants, the first session explored the individual grief experience of those attending, and offered a variety of art and talking based therapies to assist. With access to art equipment, and guidance from Denise as therapist, participants completed several projects which each offered a different therapeutic benefit. The session ended with a connecting exercise within the group. Immediate feedback from the group was positive, with many commenting that they had personally benefitted from the therapy. The group demonstrated great respect for the experience of others, and we thank all participants for being willing to work through vulnerabilities in a safe space.

The second session explored further aspects of grief and bereavement through art based therapies. We also joined together in beginning a banner which Shannon's bridge can use in the future to connect with the community. The Art of Bereavement project is now in the phase of product development, using the artwork from the group sessions to produce the handover bags for distribution to local hospitals, emergency departments and residential aged care facilities.

We have enjoyed running this project, and thank the consortium for the funding which has facilitated this work. Into the future this will benefit a large number of families in their time of grief and loss.

## 11. GRPCC 2016-17 Financial Statement

<u>Income</u>	
<b>GOVERNMENT GRANTS</b>	
<b>DH GRANT - PALLIATIVE AGED CARE LINK NURSE</b>	<b>82,849.00</b>
<b>DH GRANT - PALLIATIVE CARE STRATEGIC FRAMEWORK</b>	<b>127,500.00</b>
<b>Total GOVERNMENT GRANTS</b>	<b>210,349.00</b>
<b>OTHER INCOME</b>	
<b>Y7503-57001 Centre for Palliative Care Education &amp; Research</b>	<b>18,500.00</b>
<b>Transfer from contingency (Cost Code 0303)</b>	<b>50,000.00</b>
<b>Total OTHER INCOME</b>	<b>68,500.00</b>
<b>Total Income</b>	<b>278,849.00</b>
<b>Expenditure</b>	
<b>EXTERNAL CONTRACT STAFF</b>	
<b>GRANTS RECEIVED &amp; PAID TO OTHER AGENCIES (ACTUAL)</b>	<b>18,598.18</b>
<b>REPLACEMENT AND ADDITIONS- Computers and Comms &lt;\$1,000</b>	
<b>OTHER ADMINISTRATIVE EXPENSES</b>	
<b>COMPUTER - OTHER COSTS</b>	<b>606.35</b>
<b>RENTAL OF PROPERTY - OTHER</b>	<b>12,738.30</b>
<b>ADVERTISING</b>	
<b>ADVERTISING RECRUITMENT</b>	
<b>SECURITY COSTS</b>	
<b>PUBLICATIONS - (BOOKS/JOURNALS) INC SUBSCRIPTIONS</b>	
<b>LICENCE AND REGISTRATION (EXCL. MOTOR VEHICLES)</b>	
<b>MEMBERSHIP FEES.PROFESSIONAL FEES.</b>	<b>737.27</b>
<b>POSTAL SERVICES</b>	<b>20.00</b>
<b>PRINTING &amp; STATIONERY</b>	<b>1,175.67</b>
<b>TELEPHONE SERVICES</b>	<b>2,248.09</b>
<b>STAFF TRAINING AND DEVELOPMENT</b>	<b>91.54</b>
<b>CONFERENCES REGISTRATION AND ACCOMM</b>	<b>1,527.99</b>
<b>CATERING FOR MEETINGS</b>	<b>2,561.61</b>
<b>TRAVEL EXPENSES- OTHER</b>	<b>7,565.83</b>
<b>ADMINISTRATION FEE</b>	<b>5,031.82</b>
<b>Total Direct Expenses</b>	<b>52,902.65</b>
<b>Salaries &amp; Wages</b>	
<b>SALARIES</b>	<b>191,343.26</b>
<b>SUPERANNUATION EXPENSE</b>	<b>19,126.60</b>
<b>WORKCOVER - PREMIUM</b>	<b>2,181.41</b>
<b>Total Salaries &amp; Wages</b>	<b>212,651.27</b>
<b>Surplus / (Deficit)</b>	<b>13,295.08</b>
<b>B/FWD - Total Program Surplus as at 30/6/2016</b>	<b>94,057.44</b>
<b>Total Program Surplus as at 30/06/2017</b>	<b>107,352.52</b>