

# 24<sup>th</sup> November 2016 – 30<sup>th</sup> June 2017 ANNUAL REPORT

# **Shannon's Bridge Limited**

ABN 68 615 831 742



#### Our mission

Shannon's Bridge is a new not for profit volunteer organisation to help connect patients and existing palliative care services and supports.

We are here to support you 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.

## **Our vision**

Connecting patients and families with services to help with home based care at the end of life.

# **Our History**

Shannon McKnight was diagnosed with acute lymphoid leukaemia when she was 17. She spent almost all of the next two years in hospitals, having intensive treatments. When the treatments no longer worked, Shannon just wanted to go home and watch the lightning storms roll in across the paddocks. This is where she wanted to be. Unfortunately, there wasn't after-hours access to specialist palliative care support where Shannon lived with parents Jeremy and Belinda McKnight.

Connecting the McKnight family with services was vital to help make her wish of staying home a reality.

Shannon's Bridge is named in her honour to:

- Improving literacy on death amongst the public,
- Assisting people with Advance Care Plans in transition to their death.
- Linking patients and families with existing palliative care services and supports,
- Training volunteers to provide practical help to the public, patients, carers and their families,
- To promote the education of the public with the transition from life to death.

Everyone should have access to excellent palliative care no matter where they live.



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#### **ABOUT US**

#### **Background**

Palliative care is specialist care for people living with incurable and life-limiting illnesses with the primary goal of quality of life<sup>1</sup>. It involves a team approach with a focus on managing symptoms and helping the family unit adjust from the idea of treatment being used to cure their loved ones.

Death in Australia is more institutionalised than in the much of the world<sup>2</sup>. Studies consistently show that almost 70% of Australians would prefer to die at home, with hospitals their least preferred place. Over the past century, home deaths have declined and hospital and aged care deaths have increased<sup>3</sup>. Today only about 14% of people die at home each year. Over half the remaining deaths occur in hospitals<sup>4</sup>. With almost 70% of deaths "expected" our aim should be trying to improve the disparity between preferred and actual site of end of life care.

Regional and rural GPs can help patients navigate the confusing service networks and advocate for their wishes. This is demonstrated by an innovative model in Creswick and Clunes commenced in 2015. By improving access to expert and local care actual and preferred place of care and death was achieved for 91% of patients – without government or health service funding.

Community organisations are ideally placed to initiate and open the discussion about death and dying with patients and families but they need support to be sustainable. With highly trained health professionals with a passion for increasing our palliative care commitment to the region, **Shannon's Bridge** have an opportunity to extend an innovative model based on the Compassionate Community model<sup>5</sup> where local people can access expert and local care with the aim of not just a "good death", but better living – and to be where they want to be for whatever time they have left.

#### Shannon's Pack

A combination of emergency symptom control equipment & instructions to deliver the care and support for patients and families. The first pack was created when Shannon needed the contents to help make her comfortable at home when she was dying. We have sent out around 30 packs across Victoria. The Victorian Parliament's Inquiry into end of life choices identified after-hours access as one of the biggest hurdles to helping people stay at home for their terminal care. The existing palliative care services are brilliant but very few of them are able to offer after hours cover for their patients. As a result, depending on where a patient lives, they might be reliant on Ambulance services, local Emergency Departments and GP on call services for after-hours issues.

One way of tackling this hurdle is to provide GPs with emergency packs for use at home by the patient and their loved ones after training and education about symptom control and referral pathways. With generous donations from community groups and individual we aim to be able to supply Shannon's Packs to every interested GP practice, regardless of where they live.

<sup>&</sup>lt;sup>1</sup> Palliative Care Australia, *Palliative and End of Life Care – Glossary of Terms*, PCA, Canberra 2008

 $<sup>^2\,</sup>$  Sweissen, H and Duckett, S. (2014) 'Dying Well', The Grattan Institute

<sup>&</sup>lt;sup>3</sup> Higginson, I., Sarmento, V., Calanzani, I., Benalia, H. and Gomes, B. (2013) 'Dying at home - is it better? A narrative appraisal of the state of the science', *Palliative Medicine*, 27(10), p 918-924

<sup>&</sup>lt;sup>4</sup> Broad, J., Gott, M., Hongsoo, K., Chen, H. and Connolly, M. (2013) 'Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential care settings in 45 populations, using published and available statistics', *International Journal of Public Health*, 58, p 257-267.

<sup>&</sup>lt;sup>5</sup> Lord, J (2004) "Building A Good Life in Community – Ten lessons from promising initiatives across Canada", Summary of Research Completed by John Lord.

#### **Community Education**

Shannon's Bridge Directors have given presentations on the palliative approach and promotion of death literacy at community consultations in Talbot, Creswick and Ballarat and participated in the "Dying Well in Hepburn" Community Forums in Daylesford, Clunes and Creswick.

The network-focused model utilises the health literacy principles of education, communication, consumer participation and engagement, as well as respecting the attitudes and beliefs of consumers and promoting a supportive and positive organisational culture. By "bridging" the divide between the formal health services and community services, Shannon's Bridge is uniquely placed to foster the Compassionate Community philosophy.

#### **Volunteer Training**

Based on the extensive work of Palliative Care Victoria's Volunteer Training Manual and Compassionate Communities, Shannon's Bridge have been conducting training of volunteer groups. The accredited training has been made available without cost to communities and is able to be tailored to existing groups and their needs.





# **OUR PEOPLE**

# **Directors**

Name	Position	Dates acted (if not for whole year)
Dr Claire Hepper	Director	24/11/2016 – 30/06/2017
Dr Allison O'Neill	Director	24/11/2016 – 30/06/2017
Jeremy McKnight	Director	24/11/2016 – 30/06/2017
Belinda McKnight	Director / Secretary	24/11/2016 – 30/06/2017



Dr Claire Hepper Director



Dr Allison O'Neill Director



Jeremy McKnight Director



Belinda McKnight Director / Secretary

# **OUR SUPPORTERS**

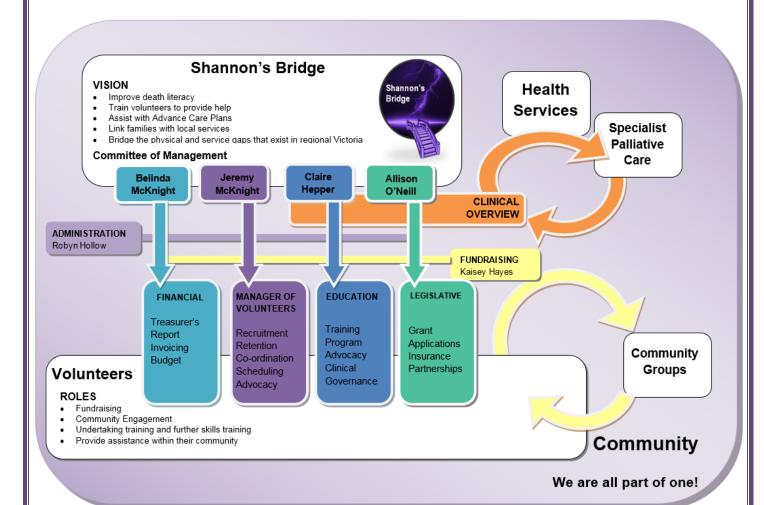






SECTION 2 GOVERNANCE

# **STRUCTURE & MANAGEMENT**





#### CHAIRPERSON / DIRECTOR'S REPORT

#### **Dr Allison O'Neill**

This first annual report for Shannon's Bridge allows a perfect opportunity to reflect on the first full year of the activities, and to plan toward the ongoing work and progress of the projects that have been initiated. This busy, exciting and productive year has done much to realise the vision which led to the establishment of Shannon's Bridge. In the early part of 2016, the paths of the Shannon's Bridge directors – myself, Jeremy McKnight, Belinda McKnight, and Dr Claire Hepper - came together through the life of the young, brave and inspiring Shannon McKnight. Shannon means a great deal to all of us, and will continue to motivate us as Shannon's Bridge continues its work.

Shannon wanted us to find ways to help others like her – people who find themselves at the end of their lives, and need help to be able to live and die in their own homes, supported to do the things which are meaningful to them. As a local doctor, I have seen this need in the lives of many local people, as has my colleague Dr Claire Hepper. Shannon, Jeremy and Belinda McKnight taught us a new way to meet this need, bringing wisdom that only personal experience can produce. Our immediate response as a small group of passionate people was to start with the first thing we could see would be helpful – the Shannon's Pack, a practical and useful tool we had created to help Shannon. The community response to an appeal to raise funds for further such packs quickly confirmed that many other people in the community understand how small acts can make a big difference in the care of people at their end of life at home. It was not long before we realised that with the encouraging swell of community support, we would be able to do much more than make a few equipment packs.

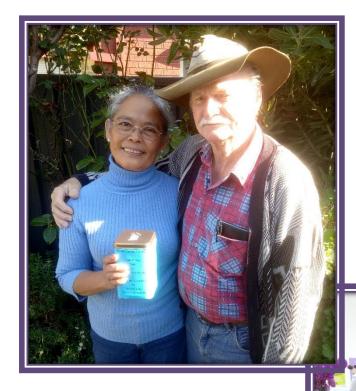
Shannon's Bridge was founded later in 2016. Despite the many excellent community resources, dedicated helpers and formal services, there most often remains a 'gap' between what is available, and the supports a person requires when they wish to die at home. These gaps take many forms, and are what Shannon's Bridge aims to address – to 'bridge'. By improving death literacy, promoting advance care planning, and connecting patients and families with services which assist with end of life care at home, Shannon's Bridge has been finding new ways every week to help individuals, their friends and families, and to grow the community we all live in.

With this beginning, the past year has seen us all get down to basics, and spend much time in building a careful foundation which will support the years ahead. In reality, this equates to much tedious paperwork, with the outcome that Shannon's Bridge Limited has been registered as an Australian Company in November 2016. With a constitution that reflects its charitable purposes, it was registered with the Australian Charities and Not-for-profits Commission in January 2017 and in February 2017 achieved full Deductible Gift Recipient Status. This was welcomed, as it recognises and encourages the generous community support which funds the work we have been and will be able to do. The 2016-2017 year has also seen the directors establish Committee of Management processes, financial policies, dedicated banking services and processes for accountability and transparency - all necessary tasks.

The activities of Shannon's Bridge in its first year have been centred on the community. As we have continued our fundraising and awareness campaigns, we have been encouraged to meet so many people who wish to help. We have been able to develop a volunteer training program and have delivered training to two groups of volunteers already. The willingness of individuals to volunteer and to undergo training, registration and paperwork has further affirmed the commitment of the

community to assist those within it. We look forward to continuing to focus on building our volunteer base and to support those who have undergone training, as well as further organise volunteer processes and to begin to implement delivery of help to those who require it.

This annual report details some of the actions and achievements of Shannon's Bridge in its first year. It has been exciting to feel the momentum continue, and indeed to gather speed, over such a short period of time. We would love to do 'everything' immediately, and are impatient to realise some of the possibilities we see in the future of Shannon's Bridge. With such successful beginnings, and the firm foundations of even better things to come, we can only thank all of our supporters – the many groups, individuals and services – who have helped to bring Shannon's Bridge to life.



#### **DIRECTOR'S REPORT**

### **Dr Claire Hepper**

Shannon's Bridge epitomises what I think is the future of Palliative Care in Australia – the linking of the formal health services and the informal and community strengths.

Dr Allison O'Neill and I were honoured to represent the team at the first Compassionate Communities Symposium, February 20<sup>th</sup> and 21<sup>st</sup> in Sydney. This highly successful forum has sparked a local collaboration between specialist palliative care services, health services, community groups and private organisations involved in care at the end of life.



I have been privileged to be involved in the evolution of this organisation from the determination of one family to provide access to palliative care without service boundaries, to a thriving and volunteer driven team which is recognised nationally. Our fledgling volunteer program is made up of highly motivated people with inspirational stories.

We still have a great deal of work to go but with the amount of care provided already in less than a year, I am excited to see what the next twelve months will bring. A personal thank you and acknowledgement to Jeremy McKnight, Belinda McKnight and Dr Allison O'Neill for their passion and amazing work ethic.



#### **DIRECTOR'S REPORT**

#### **Jeremy McKnight**

It has been a busy and productive year.

It has been a privilege to be invited to so many wonderful organisations, Community and Church groups, local town groups and friend circles.

With each group that we spoke to we gained not only generous donations but also valuable experiences from people who have been involved directly or indirectly with palliative care be it with a loved one, family member or friend.

Each experience that these people spoke to me about taught me and inspired us to continue to do whatever we can to raise awareness, understanding and aid for people in remote areas to assist in palliative care.

It was wonderful to watch as word spread and we started receiving calls from friends or people who had heard of us or read something and wanted some more information but the main question we received from anyone contacting us was

"How can we help?"

In the last year so many wonderful people have volunteered to help and brought with them such a diverse and unbelievable range of skills that they wish to offer to benefit others.

Dr Claire Hepper and Dr Alison O'Neill epitomize this. Both full time GP's who are dedicated to their patients and give so much to aid in the care of others.

That is why my wife and I are able to continue. The good will, the caring and love that continue to make this charity grow are beautiful.

Shannon wanted this to happen, and watches with a smile.



#### **OUR OBJECTIVES AND ACTIVITIES**

#### **Fundraising**

Fundraising has been an essential first step, and a necessary ongoing task to support the work of Shannon's Bridge. As well as a successful Trivia night and auction in August 2016, we have been

generously supported by individual donors and community groups. Funds have arrived from many sources. One of our volunteers recently requested donations in place of birthday presents, and we have even had the contents of 'swear jars' handed over for the cause. We have also had families who have experienced firsthand the needs that exist in end of life care at home, and have donated funds collected at funerals of loved ones. The community groups who have, as small and large groups, made commitments to hold events and donate funds have really helped to both raise awareness and to boost funds to progress our



activities. We hope you have all enjoyed your events, with great satisfaction in knowing that you have been helping others in your endeavours.

This year we received a large donation from the Oliver Foundation specifically to fund the Shannon's Packs, this will go a long way to making this resource sustainably available where and when it is needed. We will have an ongoing need for funds, both for recurring expenses, as well as to continue with existing and new programs. We have plans to hold events each year that will bring the Shannon's Bridge supporters together, and raise the funds we need to continue our work. We have also been busy writing grant applications to try to secure alternative funding for particular projects, and have recently had a small project "The Art of Bereavement" funded by the Grampians Regional Palliative Care Consortium.

#### **Community Engagement and Connection with Existing Services**

We have known from the outset, and learned more as we have spoken to people, that there is already a large amount of compassion being exercised in the community in which we are focussing our activities. Meeting with people and groups who are already helping people in need has been incredibly uplifting. One of the key aims of Shannon's Bridge is to connect patients and families with services that can help at the end of life. We have continued to forge links with both formal and professional services as well as informal community based services.

We have created a 'Help Enlisting Card' resource to assist families to access the supports they have, and to identify when Shannon's Bridge volunteers may be needed to fill 'gaps' in the support network. These cards have been trialled as we continue to develop the most effective ways to work with people who need help.

#### **Community Education and Development**

End of Life care is not primarily the domain of hospitals and medical specialists. Palliative care at end of life is 'everyone's business', and should be something the entire community values and contributes too. Raising awareness of the need for palliative care, and how the community can contribute to this has been a big focus of the media work and public forums we have been involved with in the last year. Knowing more about death and dying can go far to reduce the fear and uncertainty most people feel about this, and paves the way to discuss ways which can help for future care. Jeremy McKnight has been heavily involved with this work, bravely speaking from the heart,

and giving a message that has touched home for so many people. As well as speaking to multiple community organisations – 'anyone who will listen', Shannon's Packs and Shannon's Bridge has had considerable media attention, so much so that even when we have met people from interstate organisations, they have known about the initiative. This education, while intended to primarily benefit the community, has also gained the attention of formal organisations, and opened doors for advocacy for the needs of our community. We have also found considerable support – and volunteers – through these activities, and so Shannon's Bridge has grown.

#### **Director Education and Compassionate Communities.**

To prepare for a role as Shannon's Bridge directors, Dr Claire Hepper and Dr Allison O'Neill attended the Compassionate Communities Symposium in Sydney in February 2017. This was an excellent experience to understand how compassionate communities can and do work in Australia, and bring ideas to Shannon's Bridge to help locally. This also provided the ongoing opportunity for Shannon's Bridge to be involved with a new local compassionate community group. Others who attended this symposium, including Ballarat Hospice, have since initiated a local compassionate communities group who meet regularly at the Ballarat Cemetery, sharing resources and connecting with a common purpose, and Shannon's Bridge has been invited to participate in this wonderful new group. A local symposium has been proposed in 2018, and Shannon's Bridge is keen to be involved with this.

#### **Increasing Death Literacy**

One of the barriers to providing the help people need in their end of life care is that often, families will not understand what they need, until they need it. Death and dying are not subjects that are frequently discussed in our society, and even when faced with the reality of a life limiting illness, there can be some reluctance to discuss end of life care, and this can also be overlooked in the context of medical care. Without knowing more about what can happen, and what care options are available, it can be more difficult for an individual to express their wishes, and to prepare to meet future needs. This is why Shannon's Bridge also aims to increase understanding about death ('death literacy'), and to help people plan in advance for what they as an individual wish (Advance Care Planning). We have accessed useful resources, and spoken in many settings about this topic, as well as the work Shannon's Bridge aims to do. Most people want to talk about how they want to be cared for at the end of their lives, but few people have done so.

#### **National Palliative Care Week Activities**

One of the activities we completed this year was a focus on National Palliative Care Week. The theme for this year was 'You matter, your care matters. Palliative care can make a difference'. During this week in May 2017 Jeremy McKnight and Dr Allison O'Neill spoke to print, radio and television media, and we had static information displays in community centres and aged care facilities. At the end of the week we held "Tea and Biscuits" - open public events in Creswick and Maryborough, to promote Advance Care Planning and encourage the use of the Dying To Talk Discussion Starter (available online). We have further events planned for next year's National Palliative Care Week, and the 2017 Dying to Know Day.

#### **Volunteer Recruitment and Training**

This very exciting aspect of the growth in Shannon's Bridge has very much provided future direction and energy for Shannon's Bridge. The willingness of local community members to volunteer their time, resources and skills has led us in the direction of researching ways of best using time, as well as developing the necessary practical supports. Shannon's Bridge has secured appropriate insurance to allow for volunteer activities, and has produced its own volunteer training manual by

adaptation of existing resources to suit our purpose. We have held 2 training days, with a third planned in August 2017. We look forward to working alongside our volunteers, who have patiently waited through these months of planning, to assist them in providing real and needed help where it is and will be needed. There are never enough opportunities to thank you all.

#### Shannon's Packs

Where things began! The Shannon's Pack is a compact and portable equipment resource. The first Shannon's Pack was designed by Dr Claire Hepper after a visit to help Shannon. Inspecting the content of her existing home visit bag at this visit, it was clear to Dr Hepper that there were a few vital pieces of equipment missing which would have made the task at hand much easier, and that



the best way to ensure that those resources would be where they are needed when they are needed, would be to have an equipment pack available to the patient. The first pack produced has needed little adjustment, and providing these for other General Practitioners, patients and other health services was an obvious first aim for Shannon's Bridge. Careful purchasing and in-kind donations has seen the 'per pack' cost more than halve, and this, along with a generous funding donation to provide 80 packs, will mean it is possible for Shannon's Bridge to provide packs to supply the immediate need for them. We have been promoting these packs in medical settings, and have found GPs and other doctors in other remote and regional areas who have either been supplied with a pack, or who

can model similar ideas for their own regions. Closer to home, we have been able to provide packs to people living at home, wherever there is the potential for the pack to help ease a symptom or assist with end of life care. Quite often the packs, which can be restocked and prepared for reuse, are 'peace of mind', and may not need to be used at all. At other times, they have been used and been incredibly helpful in providing timely care for people at home.

#### **Equipment and Resources**

We have been aware that there are other practical things that can help with end of life care at home. Some of this we have already been able to purchase for use in our community. Examples include several 'Shannon's bags', larger stocked bags to support the use of the Shannon's Pack when doctors visit at home, and an oxygen concentrator. We do have a long 'wish list' of other equipment which would benefit the community – and so goes on the fundraising.

#### **Future Activities**

We look forward to providing you all with an update in future Annual Reports about the progress and activities in each of the above areas. There will be "more of the same", as well as new opportunities, and building on the foundational work of our first year.

SECTION 3 OUR FINANCES

#### TREASURER / DIRECTOR'S REPORT

#### **Belinda McKnight**

I'm not really sure that there is much more I can say that hasn't already been said but here goes....

I am so overwhelmed by the generosity of the amazing community's that we live in and near. Shannon's Bridge was started by a heartbroken family and two of the most amazing doctors. It began when it was recognised that there is a gap in services in outlying areas in Victoria and has grown from there.

The positive support (not just financially) that we have received along the way from media, community groups, family and individuals still never ceases to amaze me.

Financially speaking here are the highlights for the 2016-2017 Financial Year:

- Over \$48,000 received from Donations and Fundraising,
- \$24,000 in Grants both grants were received just before the end of the Financial Year.
- Over \$8,500 spent on Shannon's Packs,
- \$5,000 on legal fees and Insurance,
- \$1120 on Small Value Assets including an oxygen concentrator.



Section 3 Our Finances

# FINANCIAL STATEMENT

Starting Balance	\$0.00
Income	
Donations	\$48,579.63
Grants	\$24,000.00
TOTAL Income	\$72,579.63
Expenses	
Shannon's Packs	\$8,552.55
Small Value Assets	\$1,121.33
Fundraising Supplies	\$374.02
Postage	\$129.20
Training & Community Education	\$678.14
Legal & Insurance	\$5,025.30
Memberships	\$288.13
Printing & Stationery (some for Shannon's Packs and Training & Community Education)	\$3,429.43
TOTAL Expenses	\$19,598.10
Carry Forward Balance (Including Grants)	\$52,981.53

#### **ACKNOWLEDGMENTS & THANK YOU**

Shannon's Bridge would like to say a massive Thank You to all of our volunteers and community members in the townships of Creswick, Clunes, Carisbrook, Talbot, Maryborough and surrounds that have supported and continue to support Shannon's Bridge.

#### **Grants**

Oliver Foundation
Grampians Region Palliative Care Consortium



#### LOOKING TO THE FUTURE

Shannon's Bridge epitomises what I think is the future of Palliative Care in Australia – the linking of the formal health services and the informal and community strengths. Dr Allison O'Neill and I were honoured to represent the team at the first Compassionate Communities Symposium, February 20<sup>th</sup> and 21<sup>st</sup> in Sydney. This highly successful forum has sparked a local collaboration between specialist palliative care services, health services, community groups and private organisations involved in care at the end of life. I have been privileged to be involved in the evolution of this organisation from the determination of one family to provide access to palliative care without service boundaries, to a thriving and volunteer driven team which is recognised nationally. Our fledgling volunteer program is made up of highly motivated people with inspirational stories. We still have a great deal of work to go but with the amount of care provided already in less than a year, I am excited to see what the next twelve months will bring. A personal thank you and acknowledgement to Jeremy McKnight, Belinda McKnight and Dr Allison O'Neill for their passion and amazing work ethic.

Dr Claire Hepper.

#### **HOW YOU CAN HELP**

If you would like to help out by either volunteering your time, making a donation, leaving a bequest, supporting an event or fundraising activity or by becoming a corporate partner please contact us via one of the methods below.

If you make a donation via our bank account and would like tax receipt please send us an email with your details.

#### **CONTACT US**

