

Living with Dementia – a Caregiver’s Story

Anne * had four years of intensive nursing training but nothing really prepared her for her husband’s decline into dementia. She saw the first signs ten years ago, when she noticed Barry* was no longer doing the things he had previously enjoyed. He said he had fed the chickens even though she knew he hadn’t. When he was out with company and attending different meetings, he appeared quite normal but at home, there were angry outbursts that were quite out of character with the gentle, loving man she had married. A psychologist specialising in dementia told Anne that she could see nothing wrong with her husband.

The diagnosis of dementia came two years later when Barry had a stroke. A brain scan confirmed that parts of his brain had died. For Anne, it was a relief, confirming what she knew. From then on, supports were put in place by her GP. The occupational therapist helped as did Dementia Canterbury and Barry began at the Park Street Day Centre one day a week. Over the next eight years, Barry slowly deteriorated: personal care became more of an issue, but Anne was a nurse and used to such things. In fact it was the angry outbursts that were the most difficult, particularly at “sundowning” time. People with dementia often get very agitated at the end of the day. It’s a lonely business

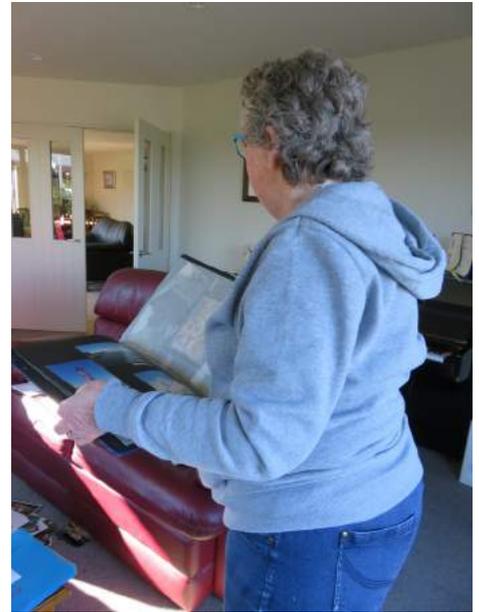
when the person you love has started to disappear.

About three years ago, Canterbury District Health Board provided carers to come in a few times a week and then at the start of this year, twice a day, every day.

At the end of last year, Anne put a referral in to Hospice Mid Canterbury. Barry surprised her by being very positive about having his life story written and each week looked forward to the biographer coming. With some prompting from Anne, he was able to remember much of the life he had lived and he now enjoys showing visitors his life story. Anne also requested some massage for herself because she was sore and tired from being the sole caregiver. She found the massage relaxing, and with the help of a Hospice Mid Canterbury counsellor, was able to get some perspective on her situation and some strategies to help her manage.

Sadly in the middle of this year,

“No matter how hard it is, ask for help. You can’t do it on your own.”



Anne

Barry deteriorated to the point where Anne and her children had to put him into care. Anyone who has had to make this difficult decision understands the pain and guilt and sadness that continue long after the person has gone into care. Anne continues to cry as we talk. “I cry at the drop of a hat,” she says. Everything is still very raw.

There have been some special moments. Anne was missing Barry and when she visited him in care, she told him to shove over in the bed and got in with him. He put his arm around her and she put her head on his shoulder just as they used to. “I love you, Anne,” he said, remembering her name for the first time in a very long time. A little while later the nurse found them both fast asleep in bed together.

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Anne has advice for caregivers in a similar situation. "Make sure you look after yourself. Keep up your social contacts and keep up some exercise. No matter how hard it is, ask for help. You can't do it on your own."

She also wishes she had worked on an Advance Care Plan while Barry was able to understand what it was about. She is sad that she and Barry can no longer do the things that they had planned. "Do things as a couple while you can."

It is clear that after forty-eight years of marriage, Anne still loves Barry deeply.

* Names have been changed to protect the person's identity.

If you or someone you know has a life-limiting illness, call Hospice Mid Canterbury to discuss ways we might be able to help.



Korowai Course

Hospice Mid Canterbury, working with Penney Kemp and Raewyn Jenkins from Nurse Maude Hospice, recently ran a two day Korowai Course for caregivers to help them navigate the difficult journey after a diagnosis of terminal illness.

Guest speakers included Jane Smith, palliative care clinical nurse specialist; Dr Lee Anderson, palliative care consultant, as well as nutritionists and occupational therapists from Ashburton Hospital.

The course was well received by the caregivers, who said that it provided them with useful information as well as a sense of support.

Donors & Supporters

Thanks to everyone who has given us their support through cash donations and providing their services. We are very grateful. Thanks especially to the following:

- Julie Mantz
- David Williams
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- Ashburton Masonic Lodge
- Maureen and Langtry Maginness
- Subway Ashburton
- John Wright
- Carol Gunn
- Jeremy Casey and Kim Solly
- Ralph Tompsett and Fleur Mulligan
- Dynamic Computer Solutions

Plus the many businesses, trusts and individuals who are supporting us in a number of ways.

Hospice Services

We provide:

- **Sitting (to give the carer a break)**
- **Recording of life stories**
- **Transport**
- **Counselling**
- **Bereavement support**
- **Massage**
- **Reiki**
- **Reflexology therapy**
- **Books**
- **Pet care**

Donations to Hospice Mid Canterbury

If you wish to donate to Hospice Mid Canterbury, you may do so in a number of ways.

- Internet banking at ANZ 06-0837-0319291-00
- Cheque or cash to Hospice Mid-Canterbury c/- Brophy Knight Ltd, PO Box 314 Ashburton 7740
- Drop off at the Hospice Office, Community House, 44 Cass St.

All donations over \$5 are tax-deductible.

The Privacy Act of 1993 requires us to advise you that we keep contact information of supporters on file to help us with fund-raising. If you do not wish us to keep your information, please advise us.

**Hospice cares for
people in any
place they call
home.**

Writing Life Stories – Hospice Mid Canterbury

Mid Cantabrians are a modest lot. Ask them to bake a cake, fix a roller door or change a light bulb and there'd be a queue. But ask them to talk about themselves and there would be a deafening silence.

This is often the dilemma faced by Hospice Mid Canterbury when talking to clients about having their own biography written. The common response is: "My life isn't very interesting. I haven't done much." However people are much more comfortable when they are asked to get a few of their stories on paper.

If clients choose to get those life stories down, Hospice Mid Canterbury has a team of trained biographers who work with the person and record their memories and stories. It is a free service.

A biographer will come into the home, usually once a week, for an hour, to record the client's stories



Some of the biography team at one of their recent workshops.



John and biographer Bryan share a laugh as they work on John's biography.

and then type them up. Some biographies are completed in a few weeks, while others take longer.

Biography has become one of Hospice Mid Canterbury's most popular services. It allows the client and often the caregiver to reflect on the person's life. Hospice Mid Canterbury manager, Christine Wilson, says: "It is the retelling of the stories that has proved to be the most therapeutic element of biography writing. This is just as important as the biography itself."

Photos can be included in the document which becomes a valuable family record.

As one client said: "We all have a story to tell, and our experience with Hospice Mid Canterbury has been very positive for ourselves and our family."

If you have a life-limiting condition and are interested in having a biography written, or know someone who is, contact Hospice Mid Canterbury 3078387 or 0272278387.

Palliative Care Lecture Series 2018

Hospice Mid Canterbury hosts the 2018 Palliative Care Lecture series at Rosebank Residential Care Community Lounge on the first Thursday of every month 7.30 – 8.30am from February to December. Upcoming topics include new cancer therapies and rehabilitation in palliative care.

A light breakfast is provided, sponsored by Harvey's Bakehouse. If you are interested, please email edu.mc.hospice@gmail.com for your details to be added to the mailing list. You will receive an invitation and a flyer each month.

Hospice care is free of charge for clients and their families.

Hospice - Myths and Truths

The Myth

You only have contact with Hospice when you are fast approaching death.

The Truth

Hospice support is available to you as soon as you are diagnosed with a life-limiting illness. You can remain weeks, months and even years with Hospice Mid Canterbury and we will continue to support you and your family as required throughout the journey. Hospice wraps around the whole family, so all our services, including counselling, massage and reiki, are available for caregivers as well as clients. Support for the family can continue after the death of a client if required.

Hospice Shop Fashion Parade

The Mid Canterbury Hospice shop put on a fashion parade like no other at a recent Netherby Women's Institute meeting.

Our intrepid volunteers modelled clothing and accessories carefully selected from the Hospice Shop. Jane Wright's compering skills were tested as she tried to match shop manager Tracey Fuller's wonderful descriptions of the outfits with whoever appeared from the dressing room.

There were no size zero models in sight. In fact, these were models

who smiled, talked and interacted with the audience. Donna obligingly paused mid circuit to take off a shoe and check the size for a prospective buyer. June kept the audience entertained with a series of one-liners. "This is a size 18 but of course I'm normally a size 10!" and "The pants are the model's own – from the Hospice Shop of course."

Although it was a hard act to follow, Jane Wright then talked to the audience about the work of Hospice Mid Canterbury.



June entertaining the audience in her flash outfit.

Introducing ...

Christine Dean - Trustee



Christine is a founding Trustee of Hospice Mid Canterbury. As a practising health professional, she has had many years of involvement supporting palliative care in the Ashburton community and was delighted at the opportunities that involvement with Hospice Mid Canterbury Trust presented. "It is rewarding to work alongside a superb group of committed volunteers and staff. They ensure that we can offer those in need the regular support necessary to live well in the community at the end of life." Christine also helps to facilitate the highly regarded monthly Palliative Care lecture series with national and

international speakers presenting on a wide range of relevant topics. "As a trustee, I have been privileged to help set the direction and to help build the strong and sustainable foundations necessary to deliver exceptional support to those affected by a terminal illness."

Karen Hungerford—Volunteer



Karen's involvement with Hospice Mid Canterbury began in 2015, firstly with baking. In 2016, she joined the Funding Committee and has been involved in various fundraising events since. She takes the minutes for both the Funding Committee and the Hospice Mid Canterbury Board. She also records

all donations to Hospice as well as writing thank you letters to all donors. Karen got involved because she could see what Hospice could do for people in need: "I had looked after both my parents at home while working full time so could see the benefits of these services. My father would have loved to have had his biography written as he was always telling us about his early years and working life." Karen says that the benefits both clients and families receive make a real difference to their lives. She also thoroughly enjoys working with other volunteers: "It is a pleasure working with like-minded people". She also enjoys the education sessions that Hospice Mid Canterbury offers.

Check out our website

www.hospicemc.nz

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