



When Caregiving Gets Tough

Carers share their experience of reaching a tipping point

Caregiving throws up many challenges, particularly if the person you are looking after has a life-limiting illness. As their health deteriorates, change becomes the norm, and there is no greater change than when a loved one needs to go into care. In this article, three caregivers share their experiences.

Managing the challenges

Caregiving becomes more difficult as the person's needs become greater. As April* says, "The little extra things just fit into daily life and you learn to adapt." Outside agencies

including district nurses and personal carers become part of the daily routine. Gwen* had a particularly busy household: "We had carers to

help with morning and evening routines – showering, dressing, having breakfast and getting ready for Daycare, followed by a carer at night to get him ready for bed." While that help is much appreciated, it can add its own pressure.

In Mid Canterbury, there are a number of organisations which can allow caregivers a break during the day. Looking back, Gwen observed that "these times of respite gave me some space but I didn't use them as I should." She advises

other carers at this stage to recharge their batteries, by meeting someone for coffee, reading a book or doing the garden. "Above all be kind to yourself."

The love and support of family and friends can make a big difference to caregivers. Maureen S. said, "I found it so important to be able to discuss my fears and concerns." For those without these networks, a counsellor or health professional is a good option.

Reaching a tipping point

Many carers reach a "tipping point" and have to make some tough decisions. Covid lockdowns were a major contributor for two of our caregivers. April found the disruption of normal routines difficult. "Respite was not easily accessed, Daycare was restricted and these were an important part of managing our days. We could not get out for social interaction."

For some, the decision to move their loved one into care is taken out of their hands, with a doctor making the recommendation, or it may be a joint or family decision. For others, it may be simply too hard to go on. "I hated not managing," April said, "but the body had just had enough and told me so."

Making it happen

Having to place a loved one in care is not easy. Maureen S. observed that "taking Russell to the care home was the hardest thing I have ever done in my life. My head knew this was the right decision but my heart just couldn't catch up and I'm sure it never will." Gwen had a similar experience: "I was so emotional - it was one of the worst days of my life."

When choosing a care facility, a doctor's assessment helps to determine the most appropriate level of care. Gwen and her daughter, armed with a list of questions, visited the three local homes available for dementia patients and chose the one they considered to be the best.

Adjusting to the new norm

Despite the emotional wrench of this change, our three caregivers have found positives in having their husbands in care. They look back and wonder how they managed. April observes that you have to adjust to living alone with a partner in care. She manages this by joining in activities at the care home as well as arranging home visits. Maureen S. says: "That overwhelming stress has been lifted from my shoulders. I know that Russell is extremely well looked after so that leaves me to be at my best when I go to see him."

* Names changed to protect identity

Thank you to our three caregivers for sharing their experiences. Their wisdom and courage is inspirational.



Principal Supporter: *Kate Murney*

Nuts and Bolts for Caregivers

Managing the paperwork can make a big difference

It is important to have personal affairs and papers in order if you are a caregiver. When you're stressed and under pressure, you cannot always find what you are looking for. Ideally this should be done while the person you are looking after can contribute. Consider having the following readily accessible:

Medical information

such as your GP, any prescription medication and blood type.

Power of Attorney

Make sure you have sorted out who has Power of Attorney. This is a legal document which sets out who can take care of your personal or financial matters if you can't.

Wills

Make or update your wills if necessary. Include bequests.

Bank accounts

If applicable, put bank accounts in both names. When one partner passes away, the remaining partner will then have access to funds.



Master folder

It's useful to have a folder with all your personal information in, including a paper copy. Think bank accounts, IRD, NHI and superannuation numbers. Have phone numbers for key people – power, phone, insurance, doctors, lawyers. Also where to

find passports, driving licence, birth certificate, marriage certificate etc. Don't forget passwords for getting into the computer and mobile phones! You could also include funeral wishes and a note of any items to be distributed to specific recipients, if this isn't covered in the will.

Advance Care Directive

This can help ensure that a person's wishes are known if they're unable to convey them personally. Your GP can help with this.



Social Media and other on-line accounts

Organise for a trusted person to have the authority to manage digital accounts for example: facebook, cloud-based resources.



Residential Care Paperwork

The paperwork involved in applying for care is daunting. The manager should be able to assist you with this.

HMC Data at a glance

In the last year

Currently supporting

106

Clients and their families

313

Therapy hours

61

Counselling hours

928

Volunteer client support hours

20

Monthly activities at the base

330

Biography hours

114

Volunteers

2239

Shop volunteer hours

4510

Total hours of HMC service in the past year

Best Wishes for Christmas and the New Year

From the Hospice Team



One Year On

Belinda reflects on a whirlwind year

It has been a year since Belinda took on her role as Manager of Volunteer Services with Hospice Mid Canterbury. And what a year it has been! ... Moving to new premises, major fundraising to make Havelock Street a permanent base, as well as the usual flurry of events leading up to Christmas and an official opening in May 2021. With Covid added to the mix, life has certainly been interesting.

Belinda's previous work with Idea Services meant that she was familiar with working with volunteers, but she acknowledges that working for Hospice is a unique experience. As she said, "I didn't really know what to expect but it has been a wonderful year ... busy ... but very rewarding."

Belinda gets deep satisfaction working with and for the Mid Canterbury community. For Belinda, it's all about the people: "Meeting them, helping them, seeing the enjoyment they get from the activities happening at our Hospice Home." On a daily basis, she can see the difference that volunteers and service providers such as therapists and counsellors make.

One of the Hospice's major achievements was the purchase of the Havelock Street base and Belinda is delighted with the difference that the building has made to Hospice services. "I love hearing the laughter and chat when we have activities happening. It really is a 'hub' with a heart."

The past year has seen unprecedented growth, with client numbers currently at 106, making an already busy job busier.

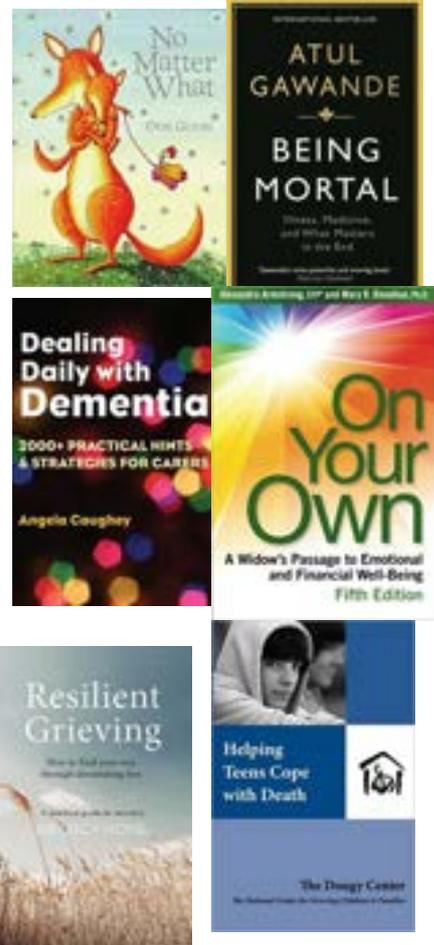
Looking ahead, Belinda is keen to build on the supports Hospice already offers, consolidating it as a well-accepted service for all those in our community dealing with a life limiting illness. There are challenges ahead, particularly with the uncertainty Covid has



Belinda getting into the festive spirit at Hospice.

brought, which has restricted the ability to engage with clients and their families as would normally happen.

Despite the uncertainty, Belinda takes heart from the very positive feedback she gets from clients and families about the difference Hospice Mid Canterbury services make in people's lives.



Hospice Library

At the base, we have a selection of books for all ages, on topics such as caregiving, resilience, dementia, end-of-life and grieving.

For children and teenagers, who may be sick or have a sick family member, the journey can be particularly bewildering.

The Hospice Mid Canterbury library has books both for those supporting children and teenagers as well as books which young people can read.

All the books in the Hospice Mid Canterbury library are available to borrow, free of charge.

On our Hospice Mid Canterbury website, there are detailed descriptions of all the books available. See

www.hospicemc.nz/books-lists

Thank you!

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:

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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 06-0837-0319291-00
- Cash or eftpos to the Hospice base, 70 Havelock Street.
- Cash for Hospice Mid Canterbury to Brophy Knight, 144 Tancred Street.

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 fundraising. If you do not wish us to keep your information, please advise us.

Supporter Profile - Kate Murney

Kate Murney is Hospice Mid Canterbury's principal supporter. She explains why she chose to become involved with the organisation.

I first got involved with Hospice in 2017 when a family member was diagnosed with a life-limiting illness. One of the volunteer biographers helped write a family biography, providing a written record of our lives till then. It was more for our grandchildren than anything else but it was a very positive experience for everyone involved.

After that, I started to get involved with the wonderful fundraising committee, and have helped to organise the Christmas Experience - visits to a variety of houses dressed for Christmas. This year, we also did a big fundraiser called "Bubbles and Bling," again with a fabulous team of volunteers.

My family strongly believes in supporting our wonderful community and I think the organisation has an important role to play when someone in the family gets sick with a life-limiting illness. It can be tough. It's amazing what a difference a Hospice visitor can make - caregivers can take a much-needed break, to go grocery shopping or even just to walk the dog. The support Hospice provides really can make a difference, not just for the client but for the whole family. We've been through this, and we know how much it can help. People shouldn't be afraid to reach out.



Kate Murney (right) with Hospice NZ Ambassador Jo Seagar