Hello,
Welcome to the 2016 Winter edition of the Bethanie Dementia Matters Newsletter, this is provided for people living with a diagnosis of dementia and their carers. As it stands now the number of people living with dementia is expected to triple by 2050. Whilst we expect that we may discover a new drug to slow the progression of dementia I do not expect that the total number of people living with dementia will be dramatically less than predicted.

At Bethanie and in our communities we need to enrich the lives of people living with disability and provide them and their families with a sense of hope, enhance quality of life, support care partnerships and work together to reduce the stigma and myths about dementia. I invited Julie Goyder to write an article about the art of storytelling when caring for someone who has dementia, her story is insightful about being the wife of a husband living with Parkinson’s dementia.

I hope that this newsletter gives you some insight into how partnerships of care make a difference. I welcome your feedback. If you would like to contribute to the next 2016 Spring Edition please contact me at dementia@bethanie.com.au

Warm Regards,

Michelle Harris
Dementia Consultant
Age Link Theatre

“RECAPTURE THE MOMENT An Enchanted Afternoon.”

Jenny Davis from Age Link draws us into a creative world of drama and theatre, which enables the person with dementia to have a voice - most importantly to be heard.

At Bethanie as part of the dementia approach to care we focus on wellbeing and maximizing quality of life at every stage of dementia. We are focusing on what people can do rather than what they can’t, and recognising the contribution they have made to society is the best way to affirm their value. Pele Reeve is the facility manager at Riversea she met with the families recently and discussed this unique opportunity to work with Agelink.

Agelink Theatre and Bethanie residents living in Riversea are rehearsing in a new project to be staged at Subiaco Arts Centre on September 10th at 2pm.

The residents and their families’ staff and volunteers are invited to participate in the music, anecdotes, recorded voices, poetry and possibly interpretative dance, we are involving people living with Dementia, who enjoy a little attention in a performance piece that will underscore the value of a purposeful and dignified life for all.

Participants from Riversea will join us on stage in a choir or as a featured guest, have their voice recorded or simply have a chat and share a few stories. This event will be advertised in August 2016 via the Bethanie website. You can visit the Age link website at www.agelink.com.au or contact Michelle via Dementia@bethanie.com.au.

Cast L to R: Craig Skelton, Alinta Carroll & Nick Maclaine
Julie’s and Antony’s Story

My husband, Anthony, has been in the high care section of a nursing home now for four and a half years. He has Parkinson’s disease Dementia (PDD) and has just turned 80. His loud, exuberant, gregarious, easy going, energetic personality hasn’t changed at all except in decibels. The quietness that comes with the PDD is both physiological (the muscles of his face and throat don’t work very well any more) and cognitive (he has forgotten, to some extent, how to form sentences in the usual way).

Obviously I know how to ‘read’ Anthony and to interpret what he might be trying to say; I also have the time to wait for him to answer a question I might ask because I am there most afternoons for a few hours. Nursing home staff, however, often don’t have time to wait for Anthony’s answer to their greetings as they flit in and out of his room like rare birds - beautiful but unintentionally elusive.

I’ve become friends with so many of the staff over the years and this staff/resident/family rapport means that when anyone enters Anthony’s room and I am there, Anthony is included in whatever brief conversations are had. One of the things I always do now is to ensure that Anthony is somehow included in the exchange. I do this by either squeezing the arm I am already holding and saying something like “Can you believe it, Ants, about the carer’s dog?” or telling the staff member something about Anthony in order to get the attention on him (i.e. “Anthony ate an entire cheesecake the other day!”)

This didn’t used to happen. The carer would bring Anthony’s clean washing in and chat to me about her sick dog; the carer would deliver Anthony’s lunch and thank me profusely for being there to feed him as she had "so many feeds now"; the carer would come with Anthony’s medications, gently spoon the pill+ yoghurt concoction into his mouth but talk to me, not Anthony.

There are so many varieties of story: true, fabricated, remembered, misremembered. When I first met Anthony, 40 years ago, he told me that the great big, long-legged spider I’d just successfully killed in his kitchen, was his best friend, Mathilda. I was mortified until he laughed his guffaw - a sound I barely remember now.

Storytelling is one of the most beautiful human attributes and, in the context of Dementia care, I think it needs to be embraced as a resource. For example, if I tell Anthony I am going home, the daily goodbye scene is heartbreaking for both of us and terribly confusing for him. If, on the other hand, I tell him I am going to the markets, and ask him if he wants oysters or crabs, and he says “both”, I can leave for home knowing that he will not remember tomorrow that I didn’t come back. Many of the staff have now begun to mention me to Anthony frequently (e.g... “Where’s your beautiful wife?”) At first I thought this was upsetting Anthony because he would say things to me like “Oh it’s you they all love” - argh - but I now think it’s good that I am mentioned so frequently. Maybe that is comforting to him. The next thing I want to ask staff to do is to reassure Anthony that I will be back soon - always, no matter what time of day or night.
A special Guest Book and Communications

A Guest Book can be a great way to connect a person with memory loss with the family through personalized notes and/or photos/pictures.

When choosing a guest book, think what would fit in with your loved ones personality. For a label for the book, ask and you could get a creative answer or just simply Sue’s book or Dad’s book preferably with a favorite photo. If you live miles away, ask the OTs for the emails to be enlarged and put into the book as well as a large sign for the guest book so the book has a special place. A book mark is helpful, a thick wide ribbon or personalized to suit.

The guest book can be a shared activity for those of us who enjoy doing scrapbooking or children and grand-children can put special borders/stickers on the pages as well as photos

The shared activities can be extended by things such as a digital slide show of family photos or use of an iPad or phone for spontaneous shots with Grandma or Grandpa. There are also talking photo albums to record friends and family special greetings.

If a person has early memory loss they may like a bright colored notebook next to the phone e.g. date, name of caller, we talked about. Ask the Occupational Therapist for suggestions re the guest book and phone notebook. Where required you may like to assist the person to call an old friend or relative and then encourage writing this in the guest book as a warm reminder of the conversation and friendship.

You can also further involve your loved one with memory loss perhaps by encouraging writing some happenings for that day when you visited. “We had such a laugh today when …” “I love chocolate.” Where someone may have significant memory loss, it can be reassuring to have read out snippets about happenings in the family. This is more calming and diverting than just a list of who has visited. Where someone may not recognize a name, ask those visiting regularly to place their photo/name in the book.

As well as in the front of the book you can have a summary e.g.: a photo with” This is my grand-child Sonia, she loves horses “or on a separate laminated sheet next to the guest book [ask your OT’s advice] Where a guest book may not be appropriate then with each visit you can go over photos of significant people and preferred activities/things. Alternatively help your loved one phone while showing the photo of the person you are phoning.
The most important thing about a guest book or a phone record is that it reminds the person with memory loss that they are loved and appreciated. Covers can be very simple perhaps blue with a red heart, covered with a bright colored fabric or with favorite photos.

Please feel free to contact for further details - Memory Nurture [www.memorynurture.com](http://www.memorynurture.com)

**Younger Onset Dementia Research Project**

Being told you, or someone close to you, has a diagnosis of young onset dementia is a life changing moment and will have an ongoing emotional impact on each individual. There may be confusing emotions, great sadness and grief for the loss of the life that had been planned or for the changes you will need to make over time. Alongside the grief there may be other emotions including anger, frustration, fear, guilt and despair. These are all normal, understandable responses to the unexpected life change you are dealing with.

*Dementia is classified as being younger if you are diagnosed at aged 65 or younger.*

There is much more research and education required to support the clients and their family and the care provider.

*Bethanie in collaboration with Edith Cowan University, The Lovell Foundation, Mercy Health Care and Anglican Catholic Homes are preparing an education package on Younger Onset Dementia and in doing so would to survey our staff to work out current knowledge and training needs. A link to the survey will be sent to all Bethanie staff in June 2016, once the survey results are reviewed we are planning to trial the new Younger Onset Education toolkit with staff at Bethanie Beachside and Bethanie Mount Claremont and South Perth Community Care.*

Thank you in advance to all the Bethanie staff for completing this survey. Our objective is to be able to provide a personal service for those in need and at the same time ensure our staff are confident and competent to provide the care with the family.
Providing Community Care for Younger Onset client in Geraldton

Glen receives community social support from our team in Geraldton. Community Care is an important aspect for Glen and his family, it provides him with choice and meaningful engagement, the staff focus on what he can still do and what he enjoys, like going to the beach and attending the social centre.

His family have started a care partnership with Bethanie in Geraldton and have support and understanding on what services can be available now and in the future.

If you know someone living with memory loss call 131 151 and ask for the Bethanie support options team.

Spirituality and Care Partnerships

Over the last few days I have been reading a number of articles that highlight the impact on the caregivers of people with Dementia. In the Applied Nursing Research Journal Bomin Shim, Julie Barroso, Catherine L Gilliss and Linda L Davis highlight that there is significance and meaning in caregiving for one with Dementia. “Dementia caregiving can be burdensome with many challenges, especially for spousal caregivers who are elderly and may have limited resources and chronic conditions of their own.”

The article goes on to suggest that Caregivers can choose to make their experience with their loved ones meaningful and most do because of their love – reliving past help, love expressed and connection all help give significance to their Caregiving. They also highlight the 1959 work of Victor Frankl, who suggests that true meaning in life is found through forgetting the self in favour of serving a cause or loving another person. But what happens when a Caregivers role needs to be relinquished?

In “The Dementia, where people grieve the living” by Margaret Burin it follows the journey of caregivers who have to do exactly this - give up their role as the care needs of their loved one have become too great for them. The article highlights the distress that such as situation can bring to a caregiver as well as the person with dementia. A feeling so real that impacts all of life.
It mentions that because of the anxiety of relinquishing care very little seems good enough and definitely not homely. The article also talks about the real feelings of Grief and Guilt that most Caregivers experience. These are very significant feelings and can bring mixed and overwhelming emotions for people.

Bethanie sees that Dementia is not only a physical ailment but a journey of the body, mind and spirit. It is a journey for not only the person with Dementia but their loved ones and key caregivers as well. That is why Bethanie partners with families and caregivers to have the best possible care. We journey together as together we care for those with Dementia.

Bethanie supply Chaplains who are trained to help connect with the individual and their family and caregivers and therefore bring a sense of meaning and purpose to life. As the article in Applied Nursing Research suggests we can all find purpose and meaning within Dementia – it may just take a little help.

If you want to chat to one of our Chaplains please contact Bethanie on 131 151

‘Living with Memory Loss’ 2016 Dementia Seminars

About the Seminars
This seminar outlines a pathway toward creating a more inclusive society that values people whose cognition is different. Our aim is to reduce the stigma and myths about memory loss, and at the same time provide information and access to resources, which help you to stay connected, promote your wellbeing, inclusiveness and quality of life. Please come along if you have just received a diagnosis of dementia, or you are living with memory loss, or are a supportive carer looking for more information about respite, therapy, community care or villages. This is a free event, but bookings are essential.

- Churches of Christ Geraldton 1st June 7pm – 9pm
- Bethanie Geraldton Social Centre 2nd June 1pm – 3pm Afternoon tea provided
- Bethanie Beachside Lifestyle Village 29th July 2pm - 4pm
- Bethanie Waters Lifestyle Village 30th September 2pm - 4pm Afternoon tea provided
- Bethanie Dalyellup 25th November 11.30am - 12.30pm Morning tea provided
Useful Websites

- Wisdom Activities: wisdomactivities.com.au - catalogues posted
- The Independent Living Centre - ilc.com.au
- Montessori Books /resources - demetiashop.com.au
- USA - Best Dementia Products best-alzheimers-products.com
- USA - The Alzheimer’s Store - www.alzstore.com
- UK - shop.alzheimers.org.uk/category/gifts/Further enquires re gifts that may be suitable feel free to contact info@memorynurture.com

For more information call Bethanie on 131 151 or visit www.bethanie.com.au or

The National Dementia Helpline on 1800 100 500. This is a telephone information and support service available across Australia or

Memory Nurture on 0402 943 053 or info@memorynurture.com.
Experiences of Dementia
Thoughts, Feelings, Responses and Actions

The Dementia Partnership Project would like to invite you to join us for a free pilot workshop that aims to shift paradigms from understanding a person’s thoughts feelings and actions as ‘behaviors of concern’ to understanding them as an expression of experience.

This new paradigm may help us to rewrite the ‘behavior’ story, to adjust our perceptions and the way we relate to people and to ourselves.

Contact Alzheimer’s Western Australia for information about the 2016 Education Sessions available from Geraldton to Bunbury on 9388 2800.

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i Applied Nursing Research 26 – “Finding meaning in caring for a spouse with dementia” by Bomin Shim,
iii The Dementia Ward, Where people Grieve the Living, Margaret Burin, ABC network, 11 May 2016