



SMALL ACTS OF LOVE, GEELONG
Stories about dementia & love skills

Project partners



Australian Multicultural
Community Services



Acknowledgements

The Small Acts of Love, Geelong project was led by Australian Multicultural Community Services, in partnership with Celebrate Ageing Ltd.'s, Museum of Love. The Museum develops, collects, preserves and displays items documenting the importance of love in the lives of people with dementia – to help combat the dementia stigma that isolates people living with dementia and their family and friends.

We acknowledge the grant funding from the Australian Government to improve respite care for people with dementia and their carers.

We are very grateful to the couples from the Geelong Dementia Care and Support Program for sharing their stories and images with us so generously.

Thanks also to Dr. Medha Gunawardana (PhD), Bianca Glazebrook, Nalika Ahangama, Luisa Cano and Cindy Vercoe from Australian Multicultural Community Services.

Special thanks also to photographer Peter Foster for the powerful photographs for #TheKiss. Web: <https://www.peterfoster.com.au/>

We acknowledge the Wadawurrung people, traditional owners of the Geelong region. We recognise their continuing connection to land, waters and culture. We pay our respects to Elders past and present.

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Suggested citation

Barrett, C. and Beatty, R. (2026). Small Acts of Love, Geelong. Stories about love skills and dementia. Published by Australian Multicultural Community Services, Melbourne. Available from: <https://www.museumoflove.com.au/smallactsoflove.html>

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FOREWORD

Dr Medha Gunawardana

We are delighted to present this report on the *Small Acts of Love, Geelong* project. The photographs in this report are a joyful and heart-warming celebration of the importance of love in the lives of people living with dementia. The stories accompanying the photographs are testament to the love skills families and friends often need to learn, when someone has dementia.

As the Manager, Community Strengthening for the Australian Multicultural Community Services (AMCS) I am acutely aware of the importance of this project. Our mission at AMCS is to improve the wellbeing of all Victorians through care, support and empowerment, and help people access the support they need to live a better quality of life. Providing support to people living with dementia and their carers is an important part of that mission.

Our *Dementia Care and Support Program* supports people living with dementia and provides support and education for carers to enable them to continue caring for the person living with dementia at home. The program includes small group sessions in safe and welcoming spaces that enable carers to share experiences and ideas, build skills and confidence and connect with other carers.

As part of our *Geelong Dementia Care and Support Program* we worked with Celebrate Ageing Ltd to host the *Small Acts of Love Project*. The project involved a workshop, exhibition and gathering stories about love and dementia from nine couples. The stories, shared in this report, focus on the importance of love in their lives, the changes to relationships that arise when someone has dementia and the love skills they have developed to adapt to the changes. We also invited the couples to have their photograph taken sharing a kiss.

The beautiful photos of the couples, by Geelong photographer Peter Foster, were featured in an exhibition called, *#TheKiss Geelong*, at the Vines Road Community Centre for Valentine's Day, 2026. The exhibition provided an opportunity to engage the broader community in destigmatising dementia and to encourage other carers and people living with dementia to access support.

The stories from the project are shared in this resource to help other people living with dementia and their families build the skills they need to adjust to dementia changes. The stories are heartwarming – and at times heart wrenching. Dementia can bring complexities to a relationship, and new skills are often needed.

Talking about these complexities can be difficult – some carers reported feeling disloyal or guilty. But these conversations are vital. The exchange of love skills provides critical information to enable carers to continue caring for the person living with dementia. It can also provide critical information for carers to continue caring for themselves.

The evaluation of the workshop provided testament to the importance of conversations about love and dementia. Our hope now is that this report will give others confidence to talk about love and dementia – about what works and what is tough. These are conversations we must have to ensure people living with dementia and their carers have the support they need.



Dr Medha Gunawardana

Manager Community Strengthening
Australian Multicultural Community services

About the Small Acts of Love, Geelong Project

Love is a fundamental human need. It brings joy, nurturance, connection and a sense of belonging. Research shows we cannot thrive without love,^{1,2} it is the essence of what makes us human.

While love is generally considered a birthright, there is a commonly held myth that people living with dementia are less than human, and incapable of love.³ This myth contributes to a multitude of problems – including dementia stigma, which isolates people living with dementia and their families at a time when they most need human connection.⁴ A further consequence of the myth of the ‘loveless’ person living with dementia is the lack of support for building the love or relationships skills when someone we love has dementia.

This report describes a project focused on the importance of love in the lives of people living with dementia – and on the development of love skills. The *Small Acts of Love, Geelong* project worked with couples living with dementia to share their experiences of love and dementia and to build their skills in adapting to relationship changes that often occur when someone in the relationship has dementia.

The project was hosted by the Australian Multicultural Community Service’s Dementia Care and Support Centre in Geelong. The Centre offers support for carers and people living with dementia, through small groups sessions that include sharing experiences and ideas and building skills to strengthen support at home.

The project was facilitated by Celebrate Ageing Ltd.’s Museum of Love,⁵ an online collection documenting the importance of love in the lives of people with dementia. Celebrate Ageing is a charity combating ageism and building respect for older people.

1 <https://pmc.ncbi.nlm.nih.gov/articles/PMC7502223/>

2 <https://jaapl.org/content/38/1/104.full>

3 See chapter 58: <https://content.e-bookshelf.de/media/reading/L-13814114-2bea806191.pdf>

4 <https://www.dementia.org.au/sites/default/files/2024-04/inclusion-and-isolation-the-contrasting-community-attitudes-to-dementia.pdf>

5 <https://www.museumoflove.com.au>



Small acts of love

A dementia diagnosis can amplify the importance of love and lead to the prioritising of relationships – it can also result in changes to the way love is expressed. There is a need for people living with dementia, and those they love, to develop love skills to adapt to these changes.

The Small Acts of Love project helps people to build love skills when they or someone they love has dementia. The project critiques romanticised notions that present love as effortless, unflawed and endlessly happy. It draws on Erich Fromm's seminal work, *The Art of Loving*,⁶ to present love as a skill that can be built – and suggests these love skills are important tools for adapting to changes in relationships when someone in the relationship has dementia.

The symbol for Small Acts of Love is a rose tattoo. The rose represents the importance of love for people living with dementia and their families and friends. The thorns are the love changes or difficulties that often arise due to dementia. The leaves of the rose are the Small Acts of Love, or strategies people develop in response to the thorns, to maintain loving relationships. The symbol of the rose with thorns provides a powerful framework for discussions about love and dementia.

6 https://ia801309.us.archive.org/12/items/TheArtOfLoving/43799393-The-Art-of-Loving-Erich-Fromm_text.pdf

Aims

The aims of the Small Acts of Love, Geelong project were to support the carers of people living with dementia, and to assist carers and people living with dementia to build the knowledge and love skills to help the person living with dementia remain at home for as long as possible.

Participants

A project flyer was circulated through the Geelong area and participants who expressed interest were provided with an information sheet and consent form, that was signed before the workshop. Three couples participated in the workshop and a further five couples attended the photoshoot, including one carer who was unable to convince her husband to participate.

Activities

The project workshop was implemented in late 2025, with launch activities in early 2026 to coincide with Valentine's Day. The project involved two key activities, #SmallActsOfLove and #TheKiss.

The Small Acts of Love workshop facilitated conversations about love skills including the importance of love, love changes related to dementia and strategies for adapting to the changes. An important aspect of these conversations was giving participants permission to talk about difficulties they were experiencing.

Following the workshop, participants were interviewed to document their individual perspective on the workshop topics. Notes were taken during interviews and emailed to participants for editing and verification. The interview stories are presented in this report, alongside the participants' photographs – to raise awareness and support for other families living with dementia.

At completion of the workshop, a professional photographer took portraits of each couple sharing a kiss. The photographs are included in this report and were shared with the public in an exhibition called #TheKiss, Geelong. The exhibition provided an opportunity to encourage other families and people living with dementia to access support services.

Evaluation

Participants provided positive feedback on the project following the workshop, including the value of having difficult conversations about love and dementia and learning new skills from each other. Feedback included the following comments:

- "I enjoyed learning new information and the company of other participants. I learnt a lot"
- "Being able to talk about and share the difficult things, and not feel guilty about it, helped a lot"
- "It was good to share and hear about how others are dealing with and feeling about some of the hard things and realising you're not alone."

A confidential online evaluation will be provided to participants following the project launch and exhibition.

Insights from the project

While participants unreservedly shared their perspectives on the importance of love, there was some hesitation talking about love challenges. To address this hesitancy, we presented stories of challenges raised by participants from previous workshops. These stories seemed to give participants permission to speak about the difficulties they were experiencing, though many noted there were still difficulties they would not share with us.

The hesitancy to talk about love challenges is an important project insight – carers and people living with dementia need to be given permission to share love in all its complexity. Sharing stories about these challenges provides vital opportunities for carers to share strategies to enable them to work through the challenges and continue caring for the person living with dementia at home.

Other insights from the project related to the importance of love, the challenges, and strategies for working through the challenges.

The importance of love is emphasised across the stories presented in this report. The importance of love was reported to be amplified by dementia diagnosis, bringing some couples and families closer together. Dementia diagnosis was described as a reality check – resulting in love being given higher priority. Some couples reported feeling closer and reflected that caring for someone living with dementia would be a difficult task to achieve without love.

Insights on the challenges dementia can bring to loving relationships included less reciprocity or give and take. As dementia progressed, some carers found themselves needing to do more for their partners, with appreciation not being articulated by their partner to the same extent it had been previously.

The need to care for the person living with dementia resulted in some spouses feeling they had little space to care for their own needs. This could result in exhaustion, resentment, loneliness and guilt. These challenges were exacerbated by the withdrawal of support from family and friends, who were unsure how to respond to a person living with dementia.

Workshop conversations about the challenges also led to the sharing of Small Acts of Love – or strategies for addressing the challenges in ways that strengthened the relationship. These were particularly useful for couples with a recent dementia diagnosis.

Small Acts of Love included creating space in the relationship through activities that enabled the carer to be present – but engaged in a nurturing pursuit e.g.: gardening, craft, reading etc. Others described how dementia diagnosis provided an opportunity to attribute unwanted changes to the disease – not the person, thus relieving relationship tension.

A persistent thread in Small Acts of Love was building support to assist carers. This included reaching out to family and friends and asking for their help and accepting help when it was offered. It also included exploring options for home-based support services – and accepting service supports.

Particular mention was made of the value of the *Geelong Dementia Care and Support Program* – and the value of being with other carers and people living with dementia who were experiencing similar journeys. The exchange of information, skills and support in groups offered by the program were considered invaluable in supporting the carers to continue caring for the person living with dementia at home. Participants also noted that the Program Coordinator, Cindy made them feel valued and heard – and this was greatly valued.

This report has been developed to help share participants' stories and an exhibition of #TheKiss photographs from the project was hosted on Valentine's Day in 2026. A key message from the exhibition and the report is that love matters to people living with dementia and their care partners – and building love skills is important to adapt to the changes dementia can bring to a loving relationship.

We are very grateful to the project participants for sharing their stories – particularly the challenges and their Small Acts of Love. These very real stories open up new conversations about how we can support carers and people living with dementia to live their best possible lives at home.



JOYCE & NOEL

We met about 65 years ago in Geelong. Noel played footy with my brother Johnny, and they got on straight away, so Noel was always around at our house. There were four of us, one boy and three girls, and Johnny brought home two of his sisters' husbands. Both named Noel. So that's how we met.

Noel was always mucking around. Us three girls would be in the kitchen doing the dishes and Noel would come in and be stirring us all up and having a laugh. Our boyfriends were all in the lounge room, getting quite annoyed with him. That's why I didn't like him at first, because he was causing trouble between me and my boyfriend.

We all sort of hung out in a group and would see each other at footy matches or at my house. We both played sports individually and have had the same interests all the way through.

We weren't really that interested in each other romantically at the start, but we were both just always there. I think we tried to go on a date a couple of times. That ended up being cancelled, for one reason or another, before we eventually started going out. We dated for about 14 months before we got engaged, and then we were engaged for 14 months before we got married. We've been married for 60 years. It was probably meant to be when you look at it, but it was also a strange one when you really think about it because it could have gone either way. There's never been a doubt though, we've always just been.

We've always done things together, but we're not always, always together. We've both had our own individual things along the way, but even in business we were a team. I did the books and knew who was who, and what was what. Noel knew he could always phone and ask what was happening and where he needed to be.

We've always been each other's back stop and support. It's always been a comfort to know that we have each other, that other person, that confidant. We can talk to each other about things we don't even talk to our family about. Even going through hard times with health, business or whatever it may be – we can talk it over, have a conversation and can find a way to make it work.

We're just starting this journey and want to learn as much as we can. It's probably only been 12 months since Noel's diagnosis. I think love matters more with a diagnosis, of any kind, but especially this. It matters more because we know we've got each other. Noel knows he can rely on me, and I know that I can still rely on him, at this stage. If we didn't care for each other, it would be hard. You can't lie about these sorts of things.

I think we are closer together after this diagnosis. I was diagnosed twice with breast cancer and Noel was always with me. He was in the hospital every day – and those diagnoses were 23 years apart. He was such a comfort, he was so good. Now I want to be that for him. We'll just keep on being there for each other and supporting each other. I don't think I would say that our love has changed because of the diagnosis, I think it's got stronger, more dependable. We always knew that it was there, but we realise, even after all this time, what it means to still lean on each other.

Noel's dementia diagnosis hasn't changed a lot for us in so far as doing things, we still get out and haven't had to stop anything. We know it's still early. Noel has stenosis of the spine and had a brain bleed that is still there. We are trying to manage it without an operation. He has concussion, which affects his moods, and he can be a bit short tempered sometimes because of that. That's what we have to navigate now, not so much the dementia. If Noel has another fall, it would be catastrophic.

I am very over-protective and that's hard. Noel knows I'm being overprotective because I love him and then he gets concerned that I am worrying too much.

Noel has always been so active and that's a challenge now. It's hard for Noel to be told not to do this, and not to do that, or to be told that he can't go to the pool for two weeks - he has to sit there. He gets frustrated and I can understand him rebelling because he's always been so active.

We had an argument about it because Noel did something he wasn't meant to do, because it wasn't safe. Noel didn't understand why I was so angry, he didn't think he had done anything wrong. The argument was good in a way because it all came out and we were able to find a resolution. We have always been able to communicate with each other and so have been able to negotiate and come up with an agreement, so that we don't argue.

I would hate to lose our ability to communicate and negotiate. That might happen as we go along. Who knows? That's a part I don't like to think about, I don't want to think too far ahead along that line. Taking it one day at a time is a better strategy. For now, we just know that we are devoted to each other and can communicate like we always have throughout our marriage.



MAUREEN & ROBIN

Robin and I met 59 years ago in New Guinea. I went there because I had a broken heart. My brother was living there, and he told me there was only one person he didn't want me mixing with – that was his friend Robin. Well then Robin and I met and fell in love. He is still friends with my brother.

Robin and I went back to Sydney to get married, had our first daughter, nine months later. We have three girls, six grandchildren and six great grand grandchildren.

We moved around a lot because Robin was a pilot. We went from New Guinea to the Solomon Islands to Honiara, back to New Guinea and then Darwin. Robin moved from one job to another and when our third daughter was born, he went to Alice Springs to work for three weeks and came back four months later. It was work; he had no choice, but it was difficult. We went through Cyclone Tracy, lost everything and lived in a caravan with three kids for nearly three years while we rebuilt a house. In those early parts of our relationship, we had a lot of time apart.

We eventually moved to Sydney where Robin continued flying for another 10 years. One day he had to do a flight simulator activity and realised he couldn't do it. They sent him to a psychiatrist, and that didn't help. Then his GP identified he'd had a series of small strokes, and he got told he had to retire. We moved to East Gippsland where Robin was diagnosed with dementia. That was about 5 years ago. As soon as he got the dementia diagnosis, he had to hand over his driver's license, which was almost worse than losing his pilot's license.

I recently had a heart attack and Robin has gone downhill tremendously in the last month. I was worried about what would happen to him if I died, so we moved into a retirement village in Geelong. It has a nursing home attached to it, so he can go there if he needs to – in theory.

There are challenges to love with dementia. I have started to resent him a little and he gets annoyed with me for telling him to come and clean his teeth or something like that. Everything is a drama. The whole dynamic of being a couple has changed. It's like I have a toddler again. I have more of a caring role now than a loving wife role. People tell me that what I am doing is love. I feel guilty and maybe that means I do care and that's a form of love.

We live in a first-floor apartment and Robin stands at the window and gives me a running commentary on everything that is happening outside. It's so frustrating. He doesn't understand there are other people living here. Other people come and go in their cars, but every time a car pulls up, he thinks they have come to pick us up.

I can't put on my headphones because I feel like I am shutting him out and I feel guilty. So, I knit – it gives me something to do. My hands are doing something, and my brain is doing something, and I can just comment back to him.

Everything is stressful for Robin. Last week our daughter, and her family came around for dinner, and he was so stressed I thought - I can't do this anymore. I set the dining table with extra chairs and place settings, and he kept touching them and moving the knives and forks and wanting to know why things at the dining table had changed. He could sit in a chair and do nothing, but the anxiety from him is just overwhelming. He would ask me 100 times, who is coming. I think next time I'll put the family photos on each place setting.

Robin gets anxious when I leave the house, even if I am going outside to put out the rubbish. So, I have to ask him if he wants to come with me. I guess I'm a security blanket for him. I don't know if it's fear of being alone or what it is. If I go to exercise classes in the village I write on a whiteboard where I'm going and what time I'll be back, which seems to be okay. But there is not a lot of space – which is such a shift because for most of the early parts of our relationship he wasn't around.

I am sure that love matters for people living with dementia and their families. If I didn't love Robin, I would be dumping him somewhere and not visiting him. When he went into respite I visited him every day – it was more of a hassle than when he is at home. He was so unhappy and so angry about being there, because he thought he lived there. So, whenever I was leaving, he would ask me why I was going.

Most of our friends are spread across Australia and even though we have family here in Geelong, moving into the retirement village is the best thing ever for us. Now we have made friends in the Village and that's really nice. I have friends here in the Village, one had a husband with dementia, and the other had a mother with dementia. They are very understanding of what is going on. When things happen, they laugh with me.

Robin used to thank me for doing things. He very rarely thanks me now, but I'm sure underneath it all he is thankful. Our relationship is not the same as it was in the past. I have just accepted that. That's what life is. You sign up for better or worse. You didn't sign up for dementia, though. When you're young, you don't expect dementia.

We were never a lovey, dovey couple that held hands or things like that. We've never had that romantic love. But I guess there is still love. Our children and their families bring us a lot of love. It's lovely to see our grandkids grow up and see our great grandkids. That's all about love.



YVONNE & TOM

We met at a mission conference in Switzerland. Tom was the Canadian representative at the conference. I had just taken over responsibility for the Djibouti area of the mission I worked with. I had never done that sort of thing before – the logistics were complex. I asked in prayer for various things at the conference. Tom had covered all that sort of thing when he was in the army. He shared advice with me and prayed for me to receive the support I needed. Our relationship grew out of that really. That was in 1996, almost 30 years ago.

Tom was in the Canadian military for 35 years. Six months after he graduated from military college, the unit he joined was deployed to Germany. Tom was there with his first wife for a few years, and his son was born there. Then he was working in Britain, Cyprus and other parts of the world as well as in Canada. By the time we met at the conference in Switzerland, Tom's first wife had passed, and their adult son and his family were living in Canada. After the conference, Tom was teaching in Yemen, and I was in Djibouti. We wrote to each other a few times, not a lot. It was snail mail we didn't do emails in those days. Tom had Easter off work and came over to visit us in Djibouti, and he proposed to me on that trip. I told him that I would have to think about it. I knew it would be a big change all around.

Tom and I were engaged in 1997 in England. I was going to go and meet his family in Canada, but I got the news that Dad had cancer and our plans changed. Tom came to Australia to meet my dad. He met my parents and we were married the next year in Djibouti.

Tom has only recently been diagnosed with dementia. Love does matter; maybe it matters more when someone has dementia. Love helped Tom survive the death of his first wife and our love grew out of that. Love is important. When someone has dementia they need love - because they can't do everything themselves anymore.

Love changes with dementia. It needs more patience; there's a lot more patience required.

Tom can't do things quickly, and there are some things he can't do at all now. Tom has hearing problems as well, so he doesn't always hear what I say, and sometimes he guesses. That's one of the funny things, he guesses well. I have to recognise that it's not his fault that he can't hear and that he can't do this and he can't do that. I find myself needing to be more patient. We're working on that anyway. Thank the Lord.

One of the challenges for me is being very protective. I am mostly afraid that he may fall. Tom wants to bring in other people's bins and do all the other kind of things he has always done for people. Tom doesn't always remember that once he's walked someone's bin to them, he won't have anything to hang on to when he starts

walking back. I remind him to take his stick with him, or if I see he's walking down without the stick, I'll take it out to him.

Tom loves an ordered garden. We have raised garden beds now so there are no weeds there, but weeds grow in the pavers. I do worry about him falling over weeding. Sometimes I just have to let him do what he needs to do, and hopefully he won't get badly hurt. I pray a lot.

Caring for somebody is love. I express my love now by caring for Tom and helping him and trying to encourage him to go out when he'd rather sit at home. I am looking for ways for him to do things he would enjoy. I know he likes singing, so I am seeing where he might be able to sing. Faith is something that's been an important part of our lives. Our faith is a very strong point. Faith sort of overrides dementia and allows us to do things that we couldn't do before. One of my favourite Bible chapters is 1 Corinthians 13, it says:

*Love is patient, kind, not envious,
not proud, not dishonouring others,
not self-seeking, not easily angered,
not keeping a record of wrongs.*

*Love never fails;
but where there are prophecies,
they will cease, where there are tongues,
they will be stilled, where there is
knowledge, it will pass away.*

*These three remain: faith, hope, and love.
The greatest of these is love.*



ANGE & TONY

Tony and I met at a pub in 1972. I'd started my nursing training, and we kept dating until after I'd graduated. We were married four years later.

Tony was diagnosed with dementia two years ago and it has been horrendous. The hardest part is the denial of it by him. That shows up as aggression and it's pretty hard sometimes. I think the aggression is because he is frustrated, but it is hard to know. It's when I've been away in the afternoon for two hours or so, that mischief happens. Tony moves things or puts them away.

We went to the monthly support group and that was very, very confronting for Tony. As soon as he recognised where we were going, he told me he would not go into the building. He hasn't been to anything since.

My nursing background didn't help me much at the beginning, but it is starting to be helpful now. We are at the stage where I don't want confrontation or arguments. I just go along trying not to rock the boat by trying to be helpful or finding a mid-way point. Tony loves his gardening and I hate it with a vengeance, but I have to try and find a mid-way point more and do it with him.

We are currently in the process of assessment through My Aged Care. We're in the process of selling a property and combining our assets. Hopefully the services will help because we need somebody to help us mow the lawns. I can't do it all and Tony's shoulders are not the best. It's time for help. My fingers are crossed.

Love matters to people living with dementia. It matters more to Tony. I've noticed he is more clingy and I think our relationship is a safety blanket for him. Our love has changed, it's not that first bloom like when we met. We are on some sort of downward trend recently. His needs are constant. We've been together for a long, long time and it's a matter of staying together to the bitter end. That's what we got married for.

I have sleep apnoea and so I snore and have had treatments and an airway pressure machine, so I don't snore anymore. Once that happened Tony invited himself back into our bed - after about three years of not being there. Everything is good. Sleep is very, very important.

It's that 24-7 care that needs to be broken up. I'm lucky that I can still go to the gym, that gives me a break.

We have a son, who is 44 now and he is very good with his dad. I'm going out for lunch with my girlfriends on the weekend and our son sent me a message saying not to worry about Tony, he will take his Dad out.

I get frustrated, but then so does Tony. When there is frustration, he goes out to the garden, and I start sewing or doing something else. We get by. We have to have different activities to give us space.



JANICE & PHILIP

Philip and I recently celebrated our 55th wedding anniversary. We've been together probably about 58 years.

We knew each other, because we lived in a little town, and Phillip used to come and fix my parents water service that never worked. I thought he was just gorgeous, driving around in his truck with this Hawaiian shirt on. I think it was the only shirt he owned. He had a surfboard on the top of the truck, and I just thought he was the ants' pants.

We started dating when I was 17, but then Philip got called up to go into the army. He asked me to wait for him to come out – then we got engaged and had had three children and now have seven grandchildren.

I never had to want for anything, and I don't want for anything now. There's nothing that I can say that I really have to do, or places that I really have to go. I've been to lots of places around the world. I'm very happy that I've had a husband who's been able to do all these wonderful things and take us all around the place. We've travelled the world together and caravanned all over. We both played golf and we'd hop in the car or the caravan and off we'd go. We've had a lovely time doing that.

We've always been able to do things together and had the same interests. Now Philip doesn't remember anywhere we've been, but I've got those lovely memories and I can talk with him about it. He says he remembers but he doesn't. That's okay. I don't care what he remembers.

About three years ago I noticed that things weren't quite right. I'd tell Philip something, and then our children would tell me that dad didn't know. I started doubting myself at first but then we went to a doctor, and they confirmed that it was dementia.

The worst part was about 18 months ago when Philip wasn't feeling well, and they didn't know what's wrong. Phillip couldn't explain what the matter was. In the end I just threw my hands up and took him to hospital. They did tests and found out he has mesothelioma, from his days working in the gas industry. That's not a sentence you want to hear. It was a terrible time. I think as a person I've grown. I think I'm a better person now when I realise what he's having to suffer through. It's a good thing that he doesn't know what it is. I've told him but he just forgets.

Philip gets a bit puffed now when we walk because he's only got one working lung and with the dementia, it makes him a little bit apathetic. It's a case of him not wanting to do anything anymore. This is a person who has always kept our house immaculate. I have never had tradie. Philips always did that work - his whole life.

I'm becoming a little bit unmotivated because sometimes I can't do the things that Phillip did. When you start to become a little bit apathetic like that, then you can go down. You've got to keep yourself motivated into things. It's very hard. I tell myself don't worry about that, there's dust on the floor, don't worry about it. But I don't want to be like that. I was never like that.

It's a hard road but he has looked after me for 55 years and so now it is my turn to look after him. Sometimes I get a little bit angry because it's not his fault. We are all given a cross to bear and we have to bear it. We both have our faith; we belong to the Catholic church at Leopold. I do believe that I have somebody beside me and when things are not looking too good, I walk around the house and I say, please God help me get over this hurdle. We seem to be able to get over it together. I'm very lucky that I've got my faith. That helps us a lot.

I just feel sometimes like I can't do anything. I don't have much help, but what we can do, we do together. We go everywhere together. We go to book club and we go shopping. I get up early and have a walk and solve the problems of the world. I seem to be able to fix everything up when I get back home and what I can't fix, I just say, oh, well, that'll wait till tomorrow.

It would be good if I could get out and play some golf. I was a particularly good golfer, but I'm not doing it at all now, and that's a frustration, but that's okay. Philip's not playing golf now because he couldn't walk the course, so that's a bit sad. I don't know how long he's going to be around, I don't know how long I'm going to be around. We are on time bombs, but I want to be here with him. As much as I can, for as long as I can.

Love matters. I don't think you could get through this without love. I think our love is better now than what it was earlier on. When we were younger there was so much to do with children and sport that we probably didn't notice each other. It wasn't until the children left home and we looked at each other and thought, well, we're the only two here, let's get on with it.

I think our love has deepened as it's just the two of us again, back to where it was at the beginning. As much as I love the grandkids and the kids, I love Philip, and that's the most important thing. I need to be around here, for Philip.

I do wish I had my family around – someone to get on the other end of something and help me do it. Then it would be done. My family are busy and I don't like to bother them with what they probably think are very mundane things. I wish someone was here to just help me out with a few things that Philip doesn't understand how to do now, and that I can't do. We've brought our children up to be independent. I am not going to be here for very long and I don't want them hanging on my apron. They have got to live their lives, and they have done a really good job and I'm very proud of what they've done.

The challenges are that you can become very isolated. Our friends that we normally would have gone out with, sort of dropped away. They don't know how to handle being around someone with dementia. It's wrong because they could just sit with him and treat him like they've always treated him. Don't sit him in a corner because he can't talk as much and doesn't have as much conversation. Just talk to him. Say the same things again. He doesn't remember. Talk about the football, talk about the weather, talk about anything to him. It doesn't matter if he doesn't have an answer to it, that doesn't matter. People don't understand that, so they drop off.

The dementia care program that AMCS runs has been amazing. It's got us off the couch, so we're not looking at each other day in and out. I've had lots to do with dementia programs, and they are only for

the carer. What am I going to do with my husband? That's no good for me. Whereas with AMCS you bring your loved one. It's wonderful. The get him involved making and doing things. I can be in the other room and actually listen to what people are saying.

Cindy, the Coordinator, makes me feel so special. With Philip my head could be cut off, and he wouldn't even know it. Cindy makes us carers feel special, and because we feel special, then we can transfer that onto our partner. We've met lots of other lovely people through the program. Not necessarily the sort of people that I would have reached out to at other times - but having met these people, I know what they're going through, and I know how hard it is and my appreciation of these people is sky high.

There's almost a dementia merry go round, like you don't know where you get on, and you don't know where to get off. It's just an absolute maze out there. Cindy's the one who points us in the right direction. It has been amazing.

The man next door is also very good. Twice a week he takes Philip to the Men's shed and on Friday they go and have a cuppa at the nursing home with the old shedders. Philip loves that. We have had some respite carers. There's a nice fellow who's been coming in and looking after him for a bit and helped give us some respite, and we're in the midst of trying to get something going once a week.

The most important thing in our lives is our health, our happiness, and our peace of mind, and if you've got those three things, you're a millionaire and don't need anything else.



JIM & CORAL

Coral and I have been together for 65 years. You're in trouble if you think I'm an expert on any of this love business though. I don't know what love means. I think this love story business has all gone by the wayside.

We've been together for 65 years - is that love or is that just a putting up with one another? I dare say it started off with love and that we just learned to live with each other along the way, and it's great.

Coral and I met on the bus going down to the beach when we were 16. We didn't strike up a conversation but, did like kids do - we threw stuff at each other and pushed each other and things like that. Then we started talking, and then we became friends and then we went on a date. Now we have three daughters and four grandchildren. That's about our love story.

I wouldn't say that Coral has dementia. Coral has been classed as having dementia, but I don't find it that way. I do think that Coral forgets things, but then when you get to our age, we all start forgetting different things.

The kids were worried she couldn't remember things and said she needed to have tests. We went to the shrinks and did the tests, and they started looking and took brain scans. Then Coral saw two doctors that decided she is not eligible to drive, and that made it worse. Coral is still okay and does her own things. The only thing that happens is that she forgets stuff. Other than that, as far as I'm concerned, I don't think Coral's got dementia. Possibly she's on the way to dementia. Things haven't changed too much, other than the driving and forgetfulness.

We joined the AMCS carer's group and I wasn't really that interested because I don't think Coral has dementia. You can see that there are others further down the path than we are though. I think there are a lot of challenges the further you advance. I don't know how people handle it. I don't know whether I could handle it. I'd probably get right wound up if I'm honest. We have been there a few times, and I think personally it has helped me to see what other people are like and what they are doing and going through. It's helped me think a little bit more and be a little bit more careful of what I say, what I do and how I do it with Coral. I think that's a challenge for a start and I can see that the group will help me along the way.

Other than that, we are as we always have been for the last five or six years. We get on all right. We go for coffee and to the beach, and the Rippleside Park in Geelong. We just do our own thing – that type of stuff.

If we get on one another's noses, I'll go into one room and Coral will stay in the other. I'm in my game room or studio and Coral will stay in the kitchen. We do yell at each other sometimes, but I think everyone does

that too. Our daughters are in and out all the time and Coral often goes shopping with them. I still get to my football club from time to time, less often than I used to.

Coral's still very cross about having her license taken off her. She has never had an accident or anything in all the time that she's been driving. Then all of a sudden, they decided that she has dementia and that she has to give that up. I take her to the places we've always gone together. We go to the club occasionally. Coral has a go at the pokies, and I have a drink with a mate. When I say a drink, I mean a couple of beers and then I come home because you can't drive when you've got alcohol in your system and I can't afford to lose my license.

I take Coral anywhere she wants to go. It still impacts her independence though, and she finds that hard. I take her to her girlfriend's place, or to Ladies' Club on Thursday nights. It's an outing for her and that helps. One of our daughters, who isn't working at the moment, quite often takes Coral into town to have a look around the shops at everything – the dresses and what not. Coral quite often comes home with another pair of shoes and that's a good day out for her.

We generally like to go away for winter somewhere and warm up for two or three weeks. We like going on a boat cruise or travelling around Australia every other year. I can't drive for long distances now because of back problems and this last year has been one of the worst years for us with doctors and different things that have happened. We hope next year's better and that we can get out and about a bit more.



SUSAN & NORMAN

We are one year short of our 50th wedding anniversary. I grew up in a small town where Norm was the driving instructor. When he picked me up for our first lesson, he was wearing a western shirt with pearl buttons. I'll never forget his shirt! There was something about him though; he was a nice bloke.

I got my license and then later I found out my best friend was having advanced driving lessons with Norm - I was the most jealous I've ever been in my entire life. It was unreal. Circumstances conspired, and he agreed to give me some advanced lessons. That led to car clubs and competitions where sometimes I'd beat the blokes. One night, after a motorkhana, we were sitting in the main street having fish and chips when he kissed me. Well, my toes blew off! I'd never experienced anything like that before. We were married 18 months later.

To me, love isn't the soppy stuff. That doesn't last very long. Love is deep commitment, a deep respect, an appreciation of what the other person does; even if they don't do it the way you want. Love is deep inside, a heart-to-heart connection. It's not so much a brain connection. Fried neurons don't change love. I think love is the only thing that matters when someone is living with dementia - although, we haven't been on this dementia track for very long.

Norm was diagnosed just over a year ago but had been deteriorating before that. What the diagnosis did change for me was the understanding of some of his behaviours. Some of the things Norm was doing had me thinking maybe I'm not going to spend the rest of my life with this person. But after the dementia diagnosis, I understood that it was the disease talking. While understanding this, it still hurts to be ignored or to be looked at blankly. I've taken the support of dementia organisations, carers and everybody that can help me learn about this bloody awful disease. It's cruel.

There are challenges in our relationship. None that I want to talk about, but I will say that after the diagnosis I immediately went into overprotective mode and nearly smothered the poor man to death. I suddenly started treating him like he was completely decrepit. I have eased up a bit, but I am way more watchful than I used to be. I'm also more patient with the things that happen and don't happen. For a while there, I didn't know what the heck to do. Now I watch endless repeats of NCIS with him so we can hold hands watching the telly. Sometimes I put the headphones on and read a book at the same time.

One of the things I've noticed is that I get a bit lonely because there's no conversation anymore. We used to talk about all sorts of stuff and now we don't. We used to talk about books. Norm still reads and has an extensive collection of books that he is re-reading, but he can't tell me what they are about. When Norm was working, he would come home and tell me about the conversations he'd had with his customers who were travelling around Australia. He would talk about his work, and I would talk about mine. Our conversations were really stimulating. Now there's nothing. What he has to talk about is whatever he sees out of the window, or some headlines on the darn phone. I can be talking to him, and he sees some pigeons out the window and starts telling me about them. The conversation flicks. It's like flicking a channel. It can be really frustrating at times.

Often Norm counts everything and that drives me up the wall. He counts the pigeons and tells me about it, and then because of this disease he does the exact same thing about 30 seconds later. Sometimes I get wound up and I have to leave the room because I can't change the channel. It can be very isolating. I'm learning to change the topic too, which works sometimes.

Norm has never been a social man and lost touch with the people from work. In fact, a little while ago, he was telling me about someone from work that he had caught up with. I was curious so asked the person when they had last seen Norm and they hadn't seen him for a couple of years. These sorts of delusions are tricky to deal with. He says things that sound perfectly logical – but just aren't entirely true or in the same time zone.

We've had temporary carers come twice. I was a bit nervous about leaving him by himself, so we thought we'd test it out and see what it was like. Norm told me that they were both awful people and so boring. He also told me that the support sessions we attended with AMCS were boring, but while there he interacted, was cheeky and seemed to enjoy himself.

The thing that I'm doing now is putting his name down for a couple of places that have respite days. I'm trying to make it clear to him that I need the rest days and if he can't do respite, well then, I'm going to have to do something else. Norm knows that I've been looking around at aged care facilities, or I think he knows. I suspect the thing that will make a really big difference to our story is when Norm is not allowed to drive at all anymore.

The Carers Gateway has been brilliant; I've had one to one counselling sessions with them. Another place that's been absolutely brilliant is Dementia Australia. They have helped me learn about the evolution of a person living with dementia, and how to ask for help when I need it.

The carer's program with AMCS has also been brilliant. I appreciate it. I really like being able to go to the program with Norm. I talked it through with him and he thinks his time would be better spent at home, but he comes, and he's quite switched on when he's there and afterwards. It really helps with his cognition, even though when we return home, he sleeps for about three hours. I appreciate being with other people who are experiencing something similar, we have a little laugh, and all that sort of thing and maybe we can help each other.



Photo courtesy Titik and Geoffrey

TITIK & GEOFFREY

Geoffrey and I met in Bali in 1992. I was at hospitality school and was walking with one of my friends and we ran into Geoffrey; he was a friend of hers. Geoffrey asked me to have lunch with him and we started dating.

Because Geoffrey has such long legs and I am short, he would walk faster than me. Also, I would walk behind him because in Bali people would think I am a naughty girl. One day Geoffrey asked me why I walked behind him and I told him it was because we are not married. He told me he wanted to marry me – but I said I could not marry him because he had long hair and dreadlocks. So, he cut his hair to show me he loved me.

We got married in Java, which is my hometown. I didn't know Geoffrey had stopped taking his bipolar medication and he became unwell – so we came back to Australia as soon as possible. We now have two lovely children and one granddaughter.

Geoffrey was diagnosed with dementia two years ago. I didn't understand what was happening, but his friend kept calling me at work saying he was not well. He was paranoid at work and seeing things, so he couldn't stay at work. I decided to give up work earlier this year because he needs someone to be with him.

I can't go anywhere by myself. If I have to go shopping or leave home, I worry and have to quickly get back home. Geoffrey tells me to come back quickly and not go for too long. Before he had dementia, I would go to Indonesia to see my family. But now he worries if I am gone. I wanted us to go to Bali together. Geoffrey said, no way. He wants to be near the doctor.

Now I have to make all the meals, before he used to make his meals. Sometimes I am sick of cooking. But I have to cook for him.

Sometimes when I go out my daughter will come and sit with him, or he will go and stay with her. He is worst in the afternoon at 5pm. Sometimes he thinks there are people there, that aren't there. I tell him there is no one there. He thinks they are scary people, and they are giving him cheek. So, I have to close the door or curtains.

Sometimes he unpacks boxes, there will be books everywhere. If he is doing that, I will just stay in my room, watch the TV and have some space. Otherwise, I will go crazy. When I see he is happy doing what he is doing – I just let him be. His TV is different from mine. He likes different shows, so I bought a second TV so I can watch mine and he can watch his programs.

Now it is a different sort of love. Love now is to take care of each other. I care about him. When we married, I said forever. When we were young, we were happy and love was about being happy together. Now it's more taking care of each other.

Geoffrey won't come to the dementia group. It's difficult for him. He has a kitty at home. Every time someone is coming to the house he worries about where kitty is. He loves kitty very much. Kitty makes him calm. That helps me. if he is calm, I can relax.

I love him. Very much.

That's why I look after him.

He loves me. Of course.

I am here for him.

Useful information

Australian Multicultural Community Services

Australian Multicultural Community Services improves the wellbeing of diverse Victorian communities through care, support, and empowerment. We are a trusted multicultural organisation delivering tailored, Government-funded aged care under the Support at Home program, helping CALD seniors live independently. Our services include Australian Government-funded Dementia Care and Support Centres in Geelong and Melbourne.

Our Free Dementia Care & Support Centres

A free support program for both carers and their loved one who has dementia. Centre location options in: Metro Melbourne and Greater Geelong. Transportation support available upon request. Morning tea and lunch provided.

Our Multicultural Dementia Care & Support Centres make a positive impact for the caregiver and the individual.

Benefits for carers

- Enhance personal wellbeing and reduce stress
- Participate in small group sessions based on your preferences to exchange experiences and insights
- Skill development sessions to strengthen at-home care abilities & boost confidence
- Information sessions to improve knowledge of dementia care
- Referrals to relevant services
- Make connections with other carers in a relaxed environment
- Enjoy a delicious morning tea & lunch!

Benefits for people living with dementia

- Fun activities in a friendly & welcoming environment
- Improve quality of life
- Assistance with ways to stay at home longer.

More information

For more information and to join our program contact us

Email: sah@amcservices.org.au

Phone: (03) 9689 9170

Email: amcservices.org.au

The Museum of Love

The Museum of Love develops, collects, preserves and displays items documenting the importance of love in the lives of people with dementia – to help combat the dementia stigma that isolates people living with dementia and their family and friends. The Museum is an initiative of Celebrate Ageing Ltd, a charity combating ageism and building respect for older people.

More information

- <https://www.museumoflove.com.au/thekiss.html>
- <https://www.celebrateageing.com/>



Small Acts of Love is an initiative of Celebrate Ageing Ltd.'s Museum of Love

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<https://www.museumoflove.com.au/>

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