

# Carers

*news*

Summer 2016

*Aged Care  
Reforms*

Home Care Packages Update

*Carer  
Story*

Lorraine's Story

*National Carers  
Week Round Up*

Carers Count

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## Message from Caroline

Welcome to the Summer Edition of Carers News.

There are over 2.8 million carers in Australia, providing in excess of 36 million hours of unpaid care each year. We celebrated National Carers Week in October by raising awareness of the valuable contribution and role you play in the life of the person you care for. 'Carers Count' was the theme for 2016 and I hope that you were able to participate in an event or activity, or seek out supports available to you.

On behalf of the Victorian Government 154 carer support groups received small grants from Carers Victoria to plan events for National Carers Week. This year, interest in the grants increased and we were very pleased to advocate for and receive additional funding for National Carers Week activities. If you would like to share your photos with us, please email these to [publications@carersvictoria.org.au](mailto:publications@carersvictoria.org.au).

On pages 10 – 11, you can read about National Carers Week events and about our 'Carers in The Kitchen' workshop\* with My Kitchen Rules finalists, Helena and Vikki Moursellas. We are hopeful that in 2017 we can extend this program subject to funding availability to more carers.

We welcomed the Andrews Labor Government's announcement in National Carers Week, that will develop a Carer Statement in partnership with Carers Victoria. To deliver real and sustainable outcomes for carers, Victorian carers require a whole of government state-wide strategy – we are ideally placed, and are looking forward to working with the government to develop and implement this.

We have commenced our Mingle program for 2016. Last year, 1073 carers attended; an increase of 25



percent on 2015 and we are hoping you will continue to help us spread the word and identify hidden carers in your community. We now have over 7100 members and look forward to growing this number each year.

The new Home Care Packages have been implemented and so we have focused this issue on Aged Care. The aged care system is undergoing reform and can be complex. We hope you will find the articles on pages 8 – 9, 12 – 13 and 14 – 15 informative and the practical tips useful.

We continue to advocate for all carers and recently completed Information Roadshows in five regional and rural centres, promoting NDIS readiness and preparing carers for consumer directed care in aged care. Other achievements can be found in our Annual Report (2015 – 2016), see our website [www.carersvictoria/publications/governance](http://www.carersvictoria/publications/governance).

Another timely piece of information is that the Commonwealth Government is seeking feedback on its draft Integrated Carer Support Services model. This is an important opportunity for carers to tell government about the services which work best for them. Go to the website: [www.engage.dss.gov.au/a-new-integrated-carer-support-service-system](http://www.engage.dss.gov.au/a-new-integrated-carer-support-service-system) to make a submission or complete the carer specific survey.

I hope you enjoy reading this edition and the summer.

**Caroline Mulcahy**  
CEO, Carers Victoria

\*This event was not advertised and each service nominated a few carers for the pilot program.

# What's happening at *Carers Victoria*

## Warning on Scams

The Australian Competition and Consumer Commission (ACCC) has warned Australians of a new scam involving Centrelink impostors trying to trick vulnerable victims into transferring money and disclosing sensitive personal and financial information.

Scammers pretend they are public servants from Centrelink and the Commonwealth Department of Human Services, then obtain the victim's personal and financial details. See [www.scamwatch.gov.au](http://www.scamwatch.gov.au) for more details.

## Mingles 2016 Update

Our Mingle events (October to November 2016) were well received with over 680 carers coming together across Victoria to enjoy a

break and catch up with each other and Carers Victoria staff.

This year's theme was 'Connections' and many enjoyed the good company.



Above // Carers enjoying themselves at the Mingle event

## Recent Submission Responses By Carers Victoria

Carer's Victoria's policy team submitted a response with seven key recommendations to Victoria's Clinical Mental Health System Plan Discussion Paper. Prepared by KPMG for the Victorian Department of Health and Human Services, this Plan aims to provide clear direction for the design, capacity and configuration of clinical mental health services across Victoria. It will articulate the system design needed to support achievement of the outcomes in Victoria's 10 Year Mental Health Plan, including providing the foundations for clinical service planning into the future.

Carers Victoria responded to the Turnbull Government's

announcement of their marriage plebiscite bill in Parliament. Our response outlined our concerns about the negative impact on LGBTIQ carers surrounding the debate on their right to marry. Carers Victoria acknowledged the diversity of views about how marriage equality could be achieved; however we received an overwhelmingly large proportion of feedback from the LGBTIQ community who were against a non-binding plebiscite process which could cost \$525 million dollars. Carers Victoria supports the introduction of marriage equality being resolved as quickly and as respectfully as possible.

Carers Victoria recently submitted a response to Infrastructure Victoria's draft Victorian 30-Year Infrastructure

strategy (October 2016). Carers Victoria provided an initial submission in March 2016 on the consultation paper 'Setting objectives and identifying needs for Victoria's 30-year infrastructure strategy.' Infrastructure can moderate, sustain or increase the responsibilities associated with a caring role. Carers Victoria strongly supported the priority placed on investment in social and affordable housing for vulnerable Victorians to significantly increase supply for people in care relationships and to enable people with disability to live more independently.

See [www.carersvictoria.org.au/publications/policy-submissions](http://www.carersvictoria.org.au/publications/policy-submissions)

# Lorraine's Story

Lorraine is an active and social lady. She moved to the Rutherglen area 13 years ago to be near to her daughter who has helped her with caring for her son Ken. She has been a carer for Ken all his life. Ken is now 50 and has a mild intellectual disability, epilepsy, galactosemia (a rare genetic metabolic disorder) and is now starting to develop signs of dementia.

**K**en cannot live alone due to his epilepsy and intellectual disability. Ken goes to a supported employment program, a Timber Workshop five days a week, where he makes garden stakes. While Ken is at work, Lorraine spends her days working part-time at her daughter's shop helping with Tatts Lotto.

*"I love the socialising aspect of working there; it keeps me busy and active."*

She enjoys being a grandma and being with her grandchildren.

Two nights a week Ken is in respite accommodation in Wodonga with a paid carer who cooks meals and ensures he is well looked after.

"He has a great social life and has made friends there. They go out bowling, to the pub."

Lorraine has done a lot of learning and developed 'coping abilities' to care for her son and her own self-care. Her time-out is gardening which she loves.

Over the years, since Ken has been a small child, she has attended lots of information sessions and carer support groups.

She found out about the Disability Support Organisation (DSO) carer sessions through the Benalla Carer Support Group and signed up for the Benalla sessions. While she knew some of the information, attending these sessions has helped her gain confidence to approach the NDIS planning stage for Ken.

"I feel really confident now approaching the NDIS. I have plans already drawn up for building a unit for Ken. I have approached local service provider Uniting Care to get Ken on to the Assisted Independence Course. The assessment will help with the planning for his needs with the NDIS funding.

It has enabled me to see what other carers are able to access, especially in the way of supported accommodation. I am really looking forward to Ken being assessed for an individual support package under the NDIS and not having to rely solely on Aged Care Package for respite."

She found the disability and aged session was 'well explained' and 'generated a great conversation among the group'.

Attending the DSO sessions has inspired Lorraine to help other carers to be

proactive with approaching local service providers in her area.

*"I wonder how other carers are coping at home on their own and with the NDIS approaching. NDIS is rolling out next year for us and so there is a real need in this area for more sessions, people can plan and figure it out."*

## More Information

Under the DSO Project Carers Victoria has worked with Carer Support Groups to assist carers of people who need assistance to make decisions. Over the past 12 months Carers Victoria has provided education and training workshops and facilitated group sessions.

Contact us on **1800 242 636** for more information.

# Harlene's Story

**W**hile on holiday last October, Australian actress Harlene Hercules received a phone call she never expected. Harlene's father Doug, 73 at the time, had been admitted to hospital in the early hours of the morning after suffering a fall at Crown Casino. Hospital staff said Doug was intoxicated and confused and tests were being run to find out what was wrong. Stricken with panic, fear and anxiety, Harlene says this event changed her life.

*"Throughout that year my Dad, who lived independently, was still cooking, going to the shops and taking care of himself. I had stepped in to assist when he had a few banking or finance issues and I noticed he was starting to have difficulty with understanding these things," Harlene recalls.*

Doug spent several weeks in hospital as staff completed further tests. Eventually the diagnosis given was cognitive impairment. Doug's memory was gone; he was agitated and confused and could no longer make his own decisions or look after himself. Doug was then transferred to Glenlyn Aged Care Facility.

"Although Dad is living at Glenlyn, I am responsible for his wellbeing and am always on call. I am now my Dad's Enduring Power of Attorney. I take on everything from finances, medicine, optometry, dental, haircuts, taxes,



Above // Harlene, who cares for her father.

right down to his clothing. Dad needs clothes that are easy to take on and off and he needs special underwear for his hips, so it is my job to make sure he has everything he needs," Harlene explains.

It's been almost a year since Harlene was first supported from Carers Victoria when Doug was first admitted to hospital.

"The hospital gave me a Carers Victoria pamphlet and I read about the counselling service," recalls Harlene. "I was paired with a counsellor who was able to understand my particular situation, support my needs and help me deal with the grief I was experiencing. I know these counselling sessions were an essential part of my healing."

Although the past year has been difficult for Harlene, she says there

are rewarding aspects to being a carer. "Because of my Dad's predicament, I really try to seize the day," Harlene says.

*"I want to personally enjoy life more, make sure I have more laughter in my world, be even more quirky than I already am and try to find joy in life always because things can happen very quickly."*

Harlene's advice to other carers is to 'seek counselling if you have not already done so, look after yourself, make time to stop and relax, find hobbies and enjoy life.'

**Harlene, Victoria**



# Getting Connected with Technology

According to the 'Australian's Digital Lives' – ACMA Communication report 2013 – 2014 series, 92% of Australians use the internet. Of these 68 per cent are older Australians (aged 65 and over) and they are increasingly using mobile phones to access the internet.

**H**owever, there are still approximately 1.1 million people (as at June 2014) who have never accessed the internet. Income and age are the main factors associated with being offline. 70 percent are people aged 65 and over 83 per cent earn an annual income of less than \$30,000<sup>1</sup>.

With the advancement of online digital technology, in addition to the associated financial costs, some people may find it daunting to get started due to fear of technology, breaking a computer or digital device, online security or feeling self-conscious about their digital illiteracy.

The benefits of being online include decreasing isolation. People can

socialise on the internet by keeping in touch with family and friends via email, seeing, hearing them on the screen (Skype or Facetime calls) or join like-minded communities online or even blog (write about things which interest them on their own website). Being online can also help expand interests and hobbies, provide an opportunity for home shopping, playing games, or learning new things via video tutorials. Many of these activities help to keep the mind active.

## How to Get Started

### A Computer or a Tablet – which device?

A computer or laptop provides a separate keyboard, mouse and screen

for viewing. A tablet might be easier for some people as it is an extension of the normal interface between the hand and the brain. Tablets have a touch-screen interface and are easier to learn to use for daily tasks like reading emails, video chat calls, or browsing the news. However, the touch screen might be difficult for some people to use due to arthritis or poor circulation in their fingers. Additional assistive technology like stylus pens or speech recognition software might be useful for these individuals. On many tablets like the iPad3 and on some android devices, speech recognition software comes as part of the standard set up.

<sup>1</sup> 'Australian's Digital Lives' – ACMA Communication report 2013 – 2014 series - [www.acma.gov.au](http://www.acma.gov.au)

## Resources

### Local Libraries

Many local libraries offer free computer and internet classes from basic through to advanced.

### South Australia

In South Australia a number of libraries run Digital Hubs.  
[www.libraries.sa.gov.au](http://www.libraries.sa.gov.au)

### Tasmania

Linc Tasmania offers free use of computers and the internet. They run beginner courses and workshops on how to use your tablet or mobile phone. [www.linc.tas.gov.au](http://www.linc.tas.gov.au)

### Victoria

#### Victorian Tech Savvy Seniors

This gives older people, especially those located in regional and rural areas of Victoria, an opportunity to learn how to use digital technology. They also have some training centres which offer training in languages other than English.  
[www.seniorsonline.vic.gov.au/age-friendly-partners-program/tech-savvy-seniors](http://www.seniorsonline.vic.gov.au/age-friendly-partners-program/tech-savvy-seniors).

### Broadband for Seniors

Across Victoria, Broadband for Senior kiosks offer free access to computers and volunteer tutors to help Seniors learn basic information about computers and stay connected with friends and family on the internet.  
[www.bfseniors.com.au](http://www.bfseniors.com.au) or call 1300 795 897

### Resources Online

There are many free online tutorials and videos to help people get online and learn about computers. Here are some of the following:

#### Carers South Australia

[www.carers-sa.asn.au](http://www.carers-sa.asn.au)

Carers South Australia has a great resource specifically written for carers who may be new to searching for services/resources on the internet (Carers Online Resource).

They also have a series of Digital Literacy program workshops on the Carers SA YouTube Channel ([www.youtube.com/user/CarersSA](http://www.youtube.com/user/CarersSA)) for carers who are starting with tablets and want to know about getting online and cyber security.

### Skillful Seniors

[www.skillfusenior.com.au](http://www.skillfusenior.com.au)  
This site teaches basic online computer navigation skills and has interactive animated tutorials.

### GCF Learn Free

[www.gcflearnfree.org](http://www.gcflearnfree.org)  
This site has online literacy and technology skills with over 750 lessons.

### Microsoft Accessibility

[www.microsoft.com/enable/](http://www.microsoft.com/enable/)  
This site has tips for people to change the screen settings to make the computer easier to use, like the use of a screen magnifier, customising background screen colours and more.

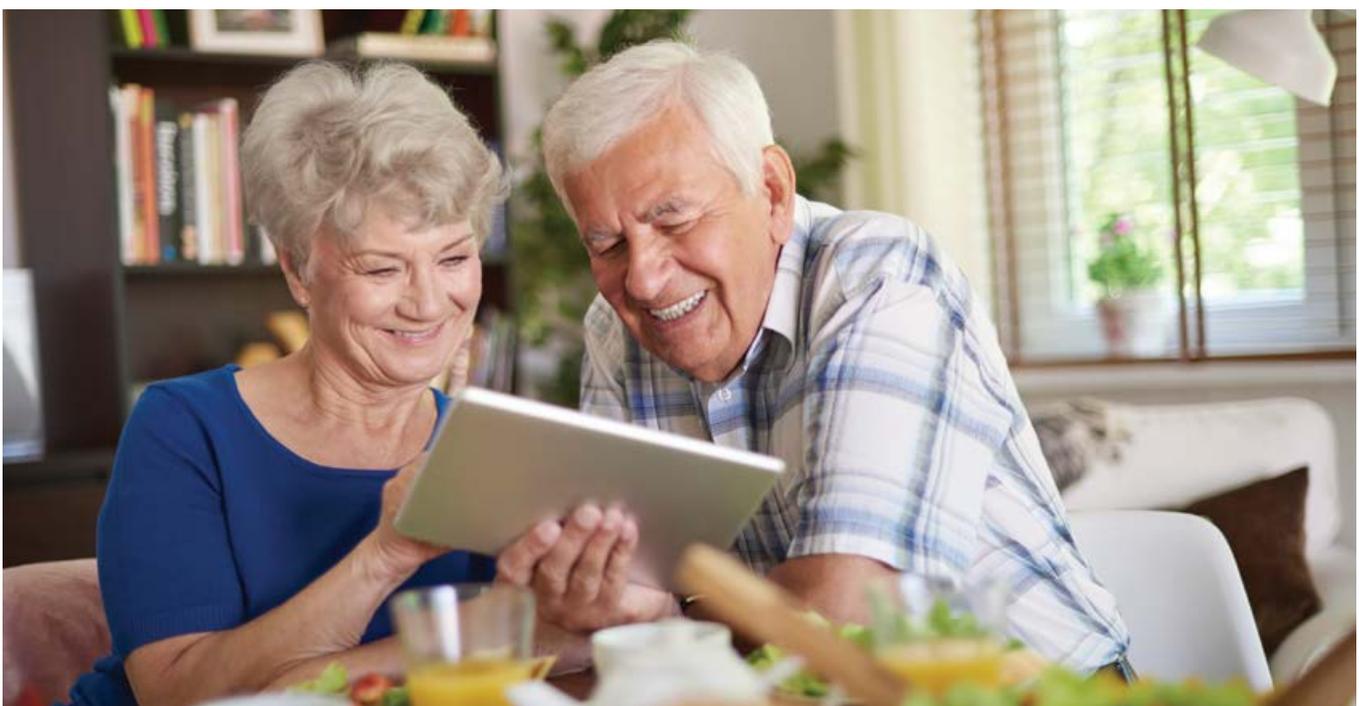
### Good 50

[www.good50.com](http://www.good50.com)  
This has a larger text on the search page and the optional high-contrast setting which makes it easier for people to access content on the web.

### For More Information

Digital Inclusion for Older People article (2016)

[www.myageingparent.com](http://www.myageingparent.com)



# Aged Care Reforms – Home Care Packages Update

## Case Study

Sally cares for her mother Rose who has dementia. Rose is 85 years old, receives the full age pension, lives at home and has been getting some basic daily personal care and social supports. Sally feels Rose now needs additional support services to continue at home.

Sally rings the government My Aged Care phone line on 1800 200 422 to discuss Rose's needs. They take all Rose's details and refer her to the Aged Care Assessment Service (ACAS). The assessment takes place in Rose's home, with Sally present, and all her needs and concerns are discussed including Rose's language, cultural and religious needs. ACAS determines Rose is eligible for a

Home Care Package providing for high care needs and she will also receive additional services through the dementia supplement.

Sally gets information on a number of local organisations that manage the Home Care Packages. She is contacted by one which has a suitable package available soon. Sally has been caring for her mum for many years and feels she needs regular breaks. She organises the extra hours of respite with the existing care workers Rose already knows and trusts. Sally is planning a holiday next year and knows Rose will be able to have residential respite care for that time.

## Costs of Aged Care at Home

### Home Care Package

The government subsidises aged care and, if your personal circumstances allow, it is expected you will contribute to the cost of your care. There are two types of fees:

- A basic daily care fee (\$9.97 per day or \$139.58 per fortnight)
- An income-tested care fee (assess by Centrelink)

In Rose's case, as a full age pensioner, she will not be asked to pay the income-tested care fee. The maximum basic daily care fee (currently \$9.97) is set by the government but some organisations are able to reduce this amount.



## Carers Associations Advocacy

The Carers Associations recognise that having a range of respite options is vital for the health and wellbeing of all carers. It is central to maintaining the care relationship and enables carers to continue the care at home.

In the aged care sector respite is available under both the Commonwealth Home Support Programme and Home Care Packages. However the system is complex and can be confusing to navigate, especially during times of stress or emotional upset. The Carers Associations and Carers Australia are working with the National Aged Care Alliance, the Council of the Ageing (COTA) and Home Care Today to advocate for carers. In particular, we are advocating for:

- General improvements to the My Aged Care website and phone service
- Better access to respite options
- Service providers to simplify the monthly financial statements outlining how Home Care Package funds are spent and
- Carers to have access to integrated carer support services in their own right.

We believe service providers should work with carers to ensure the care and services selected within a Home Care Package are directed towards meeting the needs of the care relationship as well as the individual person.

### For More Information

Call the Advisory Line 1800 242 636.



## February 2017 – You Choose Your Home Care Service Provider

From February 2017 a person who is eligible for a Home Care Package will choose the organisation to provide their services. This is a big change for older people and their carers. The organisations managing Home Care Packages are called service providers. All service providers are approved by the government and must follow the home care standards; however, they are not all the same. The following are some things to consider when choosing a service provider:

- Check out the service provider's website.
- Does the service provider directly employ the support staff who work with you or do they work through another agency?
- How does the service provider support you in managing your own package?
- Can the service provider arrange for specialised support e.g. a worker who speaks your language?
- What does it mean if I have my package fully 'case managed' and what does this cost?
- What does it cost if I do more of the coordination and administration? Is there training on how to do this?
- Is there an exit fee charged if I want to move to another service provider?

# Every Carer Counts



National Carers Week 2016 was celebrated throughout Australia from 16 – 22 October with numerous events held across Victoria, South Australia and Tasmania

## Carers Victoria

Carers Victoria kicked off National Carers Week with our first Mingle event in Caroline Springs where over 140 carers enjoyed lunch and were treated to entertainment from 'The Connectors' and singing duo 'The Hoffmans'. Parliamentary Secretary for Carers Mary-Anne Thomas announced the Andrews' Labor Government will develop a Carers Statement in partnership with Carers Victoria.

We hosted a 'Carers In the Kitchen' pilot workshop\* with *My Kitchen Rules* finalists, Helena and Vikki Moursellas. Carers cooked simple Greek dishes, enjoyed a meal and socialised with other carers. Parliamentary Secretary for Carers Mary-Anne Thomas attended the afternoon session and enjoyed chatting to the carers.

We hosted morning and afternoon teas in Melton for the Aboriginal and Torres Strait Islander community. Florence Williams from Autism Queensland spoke about Autism Spectrum Disorders. This was followed by many events across the week, from film screenings at Sun Theatre, Yarraville, young carer lazer tag and bowling day trips, workshops to morning teas and lunches. All activities were hosted by local carer support groups and Carers Victoria staff.



Above // Caroline Springs, Mingle. L to R: Councillor, City of Whittlesea and Carers Victoria, Carers Advisory Group member, Christine Stow, General Manager – Policy, Strategy & Public Affairs, Carers Victoria, Annie Hayward, Board member, Carers Victoria, Sue Peden, CEO, Carers Victoria, Caroline Mulcahy, Parliamentary Secretary for Carers, Labor Member for Macedon Mary-Anne Thomas.



Above // Carers Victoria, Carer and Community Educators, Helen Carr, Annie Keogh and Sonia Savannah entertain as 'The Connectors'.

\*This event was not advertised and each service nominated a few carers for the pilot program.

## Carers South Australia

South Australia celebrated with many events including luncheons, barbeques and afternoon teas. Carers enjoyed a bus trip to Koppio and Coffin Bay and some of them found themselves back at school at the Koppio Museum.

During National Carers Week, Carers SA held the 'Young Carers - What's Next?'. Over 60 professionals attended to discuss good practice with renowned Keynote Speaker Associate Professor Mathew White, The Director of Well-being & Positive Education at St Peter's College, Adelaide.



Above // Staff at Carers SAParot Augusta ready for Carers Week activities.



Above // Carers enjoyed bbq at CRCC Murray Bridge.



Above // Carers found themselves back at school at the Koppio Museum.

## Carers Tasmania

Despite blustery weather, Carers from across Tasmania came together to celebrate Carers Week.

Events were as diverse as the Launch of the Tasmanian Carer Policy in the South, carers participating in 'K's for Carers' walks and lunches across the state, the Choir of High Hopes singing on the lawns of the Glenorchy City Council, and the Young Carer BBQ in the North West, where Young Carers dressed up, had races, and a hand bag throwing event! Carers Tasmania would like to thank all involved, and acknowledge those unable to attend due to caring commitments.



Above // The Choir of High Hopes singing on the Glenorchy City Council lawns.



Above // Carers enjoying 'K's for Carers' walk.



# ***Finding Your Voice: How To Be Heard***

Carers Associations advocate for the rights and interests of carers and the people for whom they care on a systemic level; however, advocacy also happens every day through individuals speaking up for themselves.

**A**dvocacy can best be described as the protection and promotion of human and legal rights.

Carers are an important source of feedback for service providers. Good services welcome feedback, including complaints.

You and the person for whom you care also have rights in relation to the services. Some rights are protected by law and others are written down in service charters. Check with specific service providers for their guidelines.

Both State and Federal legislation has been enacted to formally recognise carers. These acts are: Carer Recognition Act 2010 (Federal); Carers Recognition Act 2012 (Victoria); Tasmanian Carer Policy 2016 and Carers Recognition Act 2005 (SA).

# Tips On Being Heard

When you want to provide feedback, think about moving up the ladder of escalation to get your point across. Steps to take include:

## 1 Identifying the best person to receive the feedback:

For example, if you have concerns about a service or worker, speak to the worker directly. Ensure you document when you spoke to the worker and what you spoke about. Try saying 'you have arrived late or left early on X number of occasions and when I asked you to do a task, you said you did not have time to do it on (dates)' instead of 'you are lazy and avoid work at all costs'.

## 2 If the situation does not improve speak to the service manager:

Many organisations have dedicated complaint departments; others may deal with complaints via their insurance company. An organisation's website may be the best place to find this information, or simply call the organisation.

## 3 Choose how you will communicate at this point:

Formal feedback can be lodged in writing (including online), face-to-face, or via telephone.

## 4 Consider external assistance:

There are a number of agencies and advocacy bodies which can help when raising a complaint.

**When making a complaint to an organisation it is important to take some time to prepare and consider:**

- When the best time to discuss a complaint would be. In a heated situation, conversations can go round in circles. By taking time out to gather

information and consider concerns in-depth, the feedback can be more effective.

- Make an appointment or set up a scheduled meeting.
- Prior to meeting, ask the contact person who will be present. If you feel there are too many people, ask why the people need to be present. Let them know who you are bringing to the meeting.

### What to include when providing feedback:

- Details of who was involved, including the service provider's details.
- Contact details so the provider can make a formal response.
- Details of the consumer (e.g. name, short history if relevant) if complaining on someone else's behalf.
- Summary of what happened; include relevant dates and locations.
- Copies of any relevant documents.
- A list of questions which require a response.
- Details of what is hoped to be achieved by making a complaint; try to set realistic objectives.

**Record keeping** – Regardless of how you provide your feedback, ensure you keep a written record, either as minutes or a simple summary of decisions. After a meeting or a phone conversation, write to those involved summarising the discussion. They will then be obliged to affirm the record or amend it in writing.

**Making decisions** – If it means having to wait a few days and it's not life-threatening, tell the person you need some time to discuss with everyone

involved in the situation. If you decide on an option, agree to trial it for a period of time then meet to discuss how things are working.

### Use assertive language techniques:

- **No need to over explain or over apologise** – Assertive people speak clearly, directly and succinctly.
- **Avoid hesitant language** – Replace words like 'possibly', 'maybe', 'hopefully', 'sort of', and 'kind of' with words like 'definitely', 'can', 'will' and 'must'.
- **Know when to keep quiet** – After assertive people have stated their position they keep quiet and wait for the other party to respond.

If you are not satisfied with the response, you can complain to the appropriate Ombudsman or Commissioner. If you are still not satisfied you can make an appointment with or write to your local Member of Parliament or councillor.

For a list of useful contacts see your local Carers Association websites or call the Advisory Line **1800 242 636**.

### For More Information

Rights and recognition of carers and relevant legislation :  
[www.carergateway.gov.au/government-policies-and-strategies-for-carers](http://www.carergateway.gov.au/government-policies-and-strategies-for-carers)

The Tasmanian Carer Policy 2016:  
[www.dpac.tas.gov.au/divisions/csr/policy/Policy\\_Work/carer\\_policy\\_and\\_action\\_plan](http://www.dpac.tas.gov.au/divisions/csr/policy/Policy_Work/carer_policy_and_action_plan)

# Advanced Care Planning

If the person you were caring for was no longer able to make decisions about their health, how would anyone know their wishes for end of life care?

People often assume that if and when the time comes, those who are close to them will know what they would want. But experience demonstrates that interpreting someone's wishes and preferences can sometimes lead to acrimonious and uncomfortable seemingly disagreement within families and between carers.

To provide clarity of preferences, an Advance Care Plan is recommended.

## What is an Advance Care Plan?

Advance Care Planning is a mechanism for documenting a person's preferences for future healthcare, with the aim of providing clear guidance to their loved ones, carers and clinicians. It involves discussing and documenting their preferences based on their personal values and goals, particularly around the key issues of longevity, dignity, pain and suffering and autonomy.

As part of the Advance Care Planning process the individual appoints a substitute decision-maker to make healthcare decisions on their behalf if they are no longer in a position to communicate their wishes. This is usually a family member or friend, but could also be you as their carer.

Although the logic of preparing an Advance Care Plan is self-evident, the majority of Australian's don't have one in place.

## Why is an Advance Care Plan important?

An Advance Care Plan is intended to bring peace of mind to the person knowing that their wishes will be respected. It also takes the stress off substitute decision-makers who otherwise carry the burden of wondering whether or not they 'got it right'.

Few of us like to think about how we will experience our final years and if we will be in a situation with limited choices. But an Advance Care Plan actually extends our ability to make decisions about future healthcare, and should be seen as a tool of empowerment rather than a reflection of diminishing health.

## How do I help the person I'm caring for create an Advance Care Plan?

The beginning of the Advance Care Planning process commences with a difficult conversation. This could be with a GP, a family member or you as their carer. Generally this tends to take place when end-of-life is imminent which makes the conversation even more difficult. Often family members are unwilling or

unable to initiate the conversation and even health professionals can struggle to introduce the notion of preparing for end-of-life.

Nevertheless it is important for people to consider what would happen if they could no longer voice their wishes, what quality of life means to them and what makes their life worth living.

While it is possible to specify whether particular procedures are acceptable (resuscitation, intubation), research suggests that most of us struggle to envisage ourselves in hypothetical medical scenarios. But whilst our views on specific medical treatments might change over time, our values tend to remain constant.

US surgeon and public health researcher Dr. Atul Gawande recommends asking questions such as 'What are your goals?', 'How important is it to you to have more time?' and 'What trade-offs are you willing to make?'. Considering and prioritising the importance of managing pain and suffering, longevity, dignity and independence helps to inform which types of medical treatment would be consistent with their values and goals.

Whilst there is not one standardized Advance Care Plan form, most states

and territories offer templates that can be followed. Alternatively, Advance Care Plans can simply be a written letter or document that an individual has completed with witnesses.

Starting the conversation with the ones you care for about their future health and end of life care can be difficult. But discomfort and awkwardness is more than made up for by the ease that Advance Care Planning brings the individual you're caring for and yourself.

**Zoe Dragwidge, Health Issues Centre**

Health Issues Centre support and inform consumers and the health sector to partner for health care improvements.

#### Contact

Danny Vadasz on 03 9664 9343 or see more at:  
[www.healthissuescentre.org.au](http://www.healthissuescentre.org.au)



### National Resources

**Advance Care Planning Australia**  
[www.advancecareplanning.org.au](http://www.advancecareplanning.org.au)

**Palliative Care Australia**  
[www.palliativecare.org.au](http://www.palliativecare.org.au)  
(02) 6232 7000

**Royal Australian College of General Practitioners**  
[www.racgp.org.au/your-practice/business/tools/support/acp](http://www.racgp.org.au/your-practice/business/tools/support/acp)  
1800 472 247

### Tasmanian Resources

**Guardianship and Administration Board**  
[www.guardianship.tas.gov.au](http://www.guardianship.tas.gov.au)  
1300 799 625

**Office of the Public Guardian**  
[www.publicguardian.tas.gov.au](http://www.publicguardian.tas.gov.au)  
(03) 6165 3444

### Public Trustees

[www.publictrustee.tas.gov.au](http://www.publictrustee.tas.gov.au)  
1800 068 784  
**Hobart:** (03) 6235 5200  
**Launceston:** (03) 6335 3400  
**Devonport:** (03) 6430 3600  
**Burnie:** (03) 6430 3600

**Advance Care Planning**  
[www.dhhs.tas.gov.au/palliativecare](http://www.dhhs.tas.gov.au/palliativecare)  
1300 135 513

### Victorian Resources

**Office of the Public Advocate**  
[www.publicadvocate.vic.gov.au](http://www.publicadvocate.vic.gov.au)  
1300 309 337

**Guardianship and Administration**  
[www.vcat.vic.gov.au/disputes/guardiansadministrators](http://www.vcat.vic.gov.au/disputes/guardiansadministrators)  
(03) 9628 9911

**Department of Health – Advance Care Planning**  
[www.health.vic.gov.au/acp](http://www.health.vic.gov.au/acp)  
(03) 9096 1350

**State Trustees**  
[www.statetrustees.com.au](http://www.statetrustees.com.au)  
03 9667 6444

### South Australian Resources

**Advance Care Directiveness**  
[www.advancecaredirectives.sa.gov.au](http://www.advancecaredirectives.sa.gov.au)  
**Office of the Public Advocate**  
[www.opa.sa.gov.au](http://www.opa.sa.gov.au)  
1800 066 969 or 02 8342 8200



# Jaeyden's Story

## What is your caring situation?

I care for my Mum, who has a very serious chronic medical condition. I am her primary carer. When I look back I realise I have been caring for her since I was 10 years old, but no one recognised that I was in the role of carer until I was thirteen.

I manage our finances for shopping and bill paying. I cook, clean and do the washing. I look after Mum's medication (which is quite a complex task) and keep an eye out for her so I know she is okay. I organise and attend appointments and communicate with all those who are involved in caring for Mum. I support her emotionally when these appointments are tough. When there is something our family needs, I contact service providers and find out what is available.

## What are your biggest challenges?

I am in year eleven and very dedicated to my study. I am determined to go to university, and have very clear plans about what I want to do. Finding time to fit in all that I need to do is hard, it's a real balancing act, and finding time to be a 'normal' 17 year old can be hard.

Caring is both emotionally and physically draining and I need to make sure I take some care of myself to keep going.

## What are your biggest rewards?

I am really happy that because of my care, Mum hasn't needed to go into



Above // Jaeyden, Young carer

a nursing home. I have learnt how to do so many things people my age aren't even thinking about, like how to communicate with service providers and medical professionals, and daily living skills and budgeting, which will no doubt be useful!

## What support has been the most important in your caring role?

I have had help from a youth program at Anglicare, Primary Health Tasmania and Carers Tasmania, and our GP. Having friends to talk to is very important, but I have lost some along the way. I think being self-aware and knowing I have to be emotionally strong keeps me going.

## If you could change one thing as a Young Carer (or for Young Carers) what would it be?

Every young carer and their situation is different. Even though we are young, we need to be treated as both an important person in the life of the person needing care, but also as an individual.

**Jaeyden, 17 years old, Tasmania**

Jaeyden is a member of the Australian National Young Carer Action Team (ANYCAT).

ANYCAT is a group of young carers who with the support of Carers Australia and the Carers Associations participate in advocating for Young Carer rights and raising awareness of Young Carers across the country.

# Book Review:

## *Not Just Imyjen's Mother*

### *By Christine Stow*

"I had the privilege of being one of the first people to read Christine's wonderful book 'Not Just Imyjen's Mother', Christine's story will move and inspire you as she shares her empowering journey. She is a great role model as a mother, carer and advocate for children with disabilities and their carers."

**Dr Vessn Grubacevic, Founder of Qt, Author and Speaker**

In 'Not Just Imyjen's Mother', Christine Stow takes us on her journey from a travelling corporate high-flying achiever, married with one healthy child, Auraria, to entering the world of disability with her second child, Imyjen. Imyjen we discover is diagnosed with Schwartz-Jampel Syndrome (SJS), a rare genetic disorder that affects bone and muscle development as a baby. Showing depth of character and courage, she explains the initial shock and despair to mastering challenges and the joy of having her daughter, Imyjen. We follow Christine's transition to her new life of being a carer, single parent of two and advocate.

Christine includes advice on self-care, gratitude and keeping positive – how through determination she decided she wouldn't be defined by the disability of her daughter.

"Along this journey, I've had to become flexible. Living with a child with special needs brings many ongoing implications. There are impacts

on how you think, your financial situation, your emotional and mental health. It's like a hedgehog of needles sticking all over your being. Things you can plan for and things that...well, you never envisage!"

Christine shares advice on navigating the NDIS and how to approach working with service providers while dealing with life's demands of work and caring for a disabled child. She describes her self-education process on the disability sector by initially working and attending support groups.

She includes a wealth of good advice for carers – from selecting service providers, childcare, looking at schools to making time for yourself.

*"Imyjen brings a very special love. She's taught me to see things differently, to do things differently, to work around her care."*



**Above** // Councillor, City of Whittlesea and Carers Victoria, Carers Advisory Group member, Christine Stow at 'Not Just Imyjen's Mother' Book Launch with Senator Mitch Fifield and her daughter, Auraria.

### About The Author

Mother, carer and advocate for children with disabilities and carers. Christine Stow has been a keynote speaker for CEOs, health service providers, carers, disability organisations and MPs about how they could provide better services across the disability sector. After working as regional coordinator for a disability service, Christine stood in the State Election (2006) with other advocates on disability issues. Since 2014 she has been working as local Councillor for the City of Whittlesea. Christine is a member of Carers Victoria's Carer Advisory Group.

'Not Just Imyjen's Mother' (Busy Bird Publishing) ISBN 1925260992, 978192526099, is available for download Kindle edition on [www.amazon.com.au](http://www.amazon.com.au) for \$11.99.

Or hard copies can be purchased online from [www.christinestow.com.au](http://www.christinestow.com.au) for \$30 + \$10 P & H.



Feta Saganaki with Cherry Tomatoes recipe,

## Take a Break

9		8	2		6			
4		3	7			6	2	
	6	2		1			9	
	3	6	8		5	2		9
7				9		3		6
						1	7	
6		1				8		7
	5	7		6	1	4	3	2
	2		5	8	7		6	

## Sudoku

Answers:

1	9	6	7	8	5	4	2	3
2	3	4	1	6	9	7	5	8
7	5	8	3	2	4	1	6	9
5	7	1	4	3	6	9	8	2
6	8	3	2	9	1	5	7	4
9	4	2	5	7	8	6	3	1
4	6	7	8	1	3	2	5	9
8	2	9	6	9	5	7	3	4
3	5	1	5	4	6	2	8	7

• First select a number/operator and then apply it to a sudoku cell.

## Feta Saganaki with Cherry Tomatoes, Honey and Walnuts

Serves 4

### Ingredients

- 350 g Greek feta
- 100 g cherry tomatoes, halved (all types of tomatoes will work for this recipe) 40g walnuts, roughly chopped (almonds will also work for this recipe)
- 1 tablespoon sesame seeds
- 1 teaspoon dried oregano
- Pinch of salt
- Pinch of white pepper
- 1 tablespoon runny honey
- ¼ cup olive oil

### Method

1. Preheat the oven to 180°C.
2. Crumble the feta into a baking dish and scatter the tomatoes, walnuts and sesame seeds on top. Season with the oregano, salt and pepper.
3. Pour over the honey and olive oil and bake in the oven for 25 minutes, or until just golden.

### Tip

For something different, try replacing the honey and walnuts with prawns.



Carers Victoria hosted a 'Carers In The Kitchen' pilot workshop\* with My Kitchen Rules finalists, Helena and Vikki Moursellas in National Carers Week. They cooked Feta Saganaki with Cherry Tomatoes, Honey and Walnuts.

Left // Carer and Helena at 'Carers In The Kitchen' session, National Carers Week

## Simple Greek Food for Friends & Family

My Kitchen Rules finalists Helena and Vikki Moursellas take you home to the simple Greek food they love to eat with their friends and family. From simple recipes for tzatziki and marinated olives, through to a beautifully slow-roasted pork belly and a twist on a classic Greek dessert like Sticky Baklava Fingers, this is a fresh new take on Greek family

food. Each recipe is accompanied by a personal story and photos from the girls' own collection. For more information see their website [www.vikkiandhelena.com](http://www.vikkiandhelena.com)

Available on Booktopia \$30.75, Kindle edition \$15.21, eBooks \$19.99, Google Books \$19.99, Kobo \$19.99.

Publisher: Hachette Australia (February 24, 2015) ISBN: 9780733633195 or ISBN-10: 0733633196.

\*This event was not advertised and each service nominated a few carers for the pilot program.

Recipe reprint permission by Helena and Vikki Moursellas. From Taking You Home: Simple Greek Food for Friends and Family.

# Carers Cottage

“Just a brief note to say a big thank you for organising the Carers Respite Cottage at Officer for the weekend just gone. It was wonderful and came at a well-needed time for myself and husband. We came back home with batteries fully charged!” **Maria, a carer**



Carers Cottage Interior



Carers Cottage Exterior



Above // Carers Cottage Interior

Caring for yourself is just as important as the person you are caring for.

The Carers Cottage is surrounded by majestic gardens and serene view of the Shire of Cardina. The Cottage is intended as a place of respite for carers away from their caring relationships. Although in tranquil surroundings, the Cottage is only a five minute drive to local shops, a pub and a medical centre.

It can accommodate 10 guests. There are two double bedrooms, one twin room and a room with bunk beds. There is a large kitchen, dining room, two sitting rooms and one sun room, as well as a master bathroom and

powder room in addition to an ensuite.

The Cardina Shire is a 45 minute drive along the Monash Freeway from Melbourne. The area features potteries, wineries, restaurants and cafes, recreation reserves, adventure playgrounds, working farm and nearby tourist attractions like Puffing Billy and Emerald Lake Park.

There are a number of walking tracks nearby including the Cardina Aquaduck Walking Track. This five kilometres track is set in the foothills of the Dandenong Ranges and is an excellent trail for easy walking and cycling.

## It has the following facilities:

- Swimming pool and towels
- Central heating and cooling
- TV and DVD entertainment unit
- BBQ and outdoor courtyard
- Undercover parking
- Fully equipped kitchen
- Freshly washed bed linen
- Tea, coffee, sugar and a small UHT milk are provided on arrival
- Early check in and late check out can be pre organised prior to stay.

## More information

For more information or to book call Carers Victoria's Advisory Line 1800 242 636 or email: [carerscottage.officer@carersvictoria.org.au](mailto:carerscottage.officer@carersvictoria.org.au)

**Please note:** All guests must be 18 years of age or older. As the Cottage has been set up as a place of respite for the carer to be away from the normal caring routine, care recipients are not eligible to stay at the Cottage.



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