



Caladenia Dementia Care

Covid 19 Response 2020

FEBRUARY 11

Caladenia Dementia Care
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Caladenia
DEMENTIA CARE

Preamble

A little context

Caladenia Dementia Care in Mooroolbark has been operating as a service and support for people living with dementia and their carers for the last 38 years.

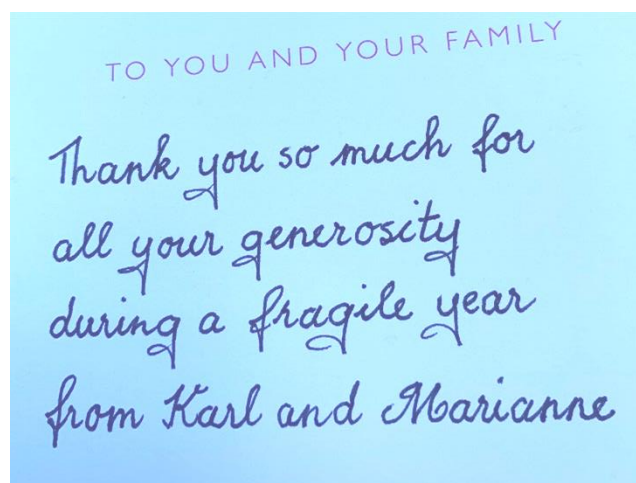
The service started as a carer support group in 1983 from borrowed premises, and grew from there to the vibrant and responsive service it is today.

Prior to Covid-19 the service ran over 60 hours a week of dementia specific social and respite programs both from our venue in Mooroolbark and in the local community.

The service also provided carer support in formal and informal settings such as meetings and lunches, and carer advocacy, support and referral where appropriate.

With 19 dedicated staff and 55 skilled and enthusiastic volunteers, the organisation provided over 29,000 hours of programs and services during the 18-19 financial year. At the beginning of 2020 we were on track to open further services to fill identified gaps in social outings for people with younger onset dementia.

Caladenia is the local dementia resource in the Outer East of Melbourne and has strong relationships and partnerships with the Yarra Ranges Council, local CHSP and HACC PYP Providers, as well as enthusiastic participation in networks with other providers of dementia services.



Caladenia believes strongly in improving outcomes for all people with dementia and their carers, across age groups, funding streams and areas, breaking down some of the artificial barriers that are created by funding streams, geographic boundaries and income sources.

Covid-19

March 2020

The Covid-19 Pandemic quickly moved from a rumour and a concern for management, to a once in a lifetime event that changed the way that we, and every other service in Victoria operated.

Advice from Government was never specifically aimed at CHSP funded social support programs, although other support services had specific instructions to continue to deliver services to the frail and vulnerable in our community.

Caladenia has hosted the local social support providers network for over 30 years, and Caladenia's CEO has chaired the network for the last nineteen years. The Social Support Network quickly checked in on each other for news and instructions, smaller organisations gaining benefit from the information coming from much larger organisations.

Network members decided to close face to face programs almost simultaneously, for a tentative period of four weeks. Network members checked in on each other regularly with "welfare checks" as this was an incredibly stressful time with very little specific direction. Managers and leaders were having to adapt and react almost daily to the changing situation, and having to carefully monitor many different sources of restrictions and advice as it related to staff, volunteers, clients, funding streams, age groups and geographic areas.

Most social support groups in the Outer East concluded that the Health Advice restricted face to face services, but also that social support organisations, and in fact all funded organisations were expected to continue to provide services to our vulnerable clients in whatever way was possible. Organisations were permitted to substitute phone calls and videoconferencing for face to face services, and also to deliver tailored activities to their clientele.

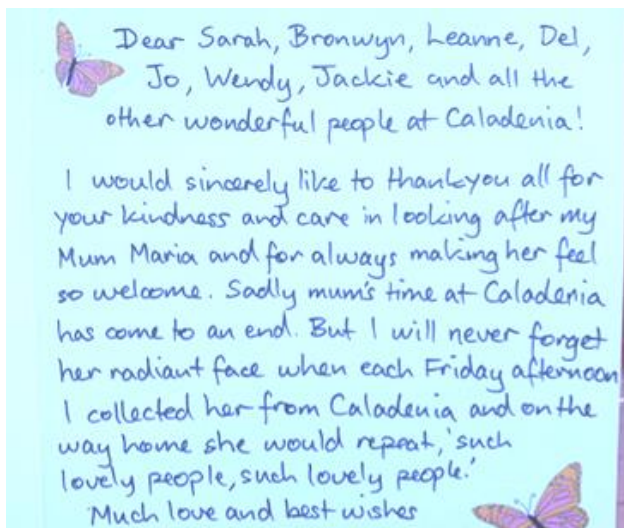
And as programs ceased on, March 18th, 2020, so the innovation began. Simultaneously as the leadership team began assessing needs and trying to predict what our Caladenia Community may need to see us through the closures, the staff began calling all clients, their carers, and all our volunteers to let them know what programs and services had been cancelled, and what would be offered as an alternative.

It was an incredibly stressful time for all, but the Caladenia team worked together in an exemplary way to make sure that they were providing at least some service to our clients and carers.

The Staff Team

Caladenia staff are trained and experienced people who provide person centred programs for people living with all stages of dementia. The core values of our staff and the culture within is a service where all services and care are delivered with respect and dignity.

Caladenia has always attracted individuals who excelled in their chosen field. The staff team are highly dedicated and every individual has a genuine love for the work they do. The staff team is made up of individuals with high creativity, great people skills and a desire to really improve the lives of people living with dementia. The staff members deliver face to face services to people in such a way that they feel involved, needed, and among friends, and that much is made of strengths, without focussing on weaknesses.



When team members were informed that they would no longer be working face to face with clients, they were disappointed but understood the reasons why. The staff began to work in a very different way to that which they had been familiar. There were no Position Descriptions or task lists for the brand new work they were asked to undertake.

Making Activity Packs takes a very different skillset from working in a face to face program, many of

our staff were not highly skilled with technology but rose to the occasion from the moment of the very first zoom staff meeting. Staff were also learning to work around each other, to stay the mandated 1.5 m distant from their colleagues and to keep themselves and their surrounding sanitised.

During the lockdowns in Melbourne, staff had to work from home. A challenge for anyone used to working in a team, but even more of a challenge for those who have spent their careers providing face to face care. Caladenia's Board approved the purchase or loan of office furniture, and also offered a contribution towards laptops and office software.

During the second lockdown in Melbourne, the leadership team identified that some staff members were struggling with the isolation, and instigated daily zoom social catch ups hosted by one of the leadership team, as well as a social "Quiz Night" where staff could have a laugh and get together informally. Staff members were phoned regularly by the WHS officer and

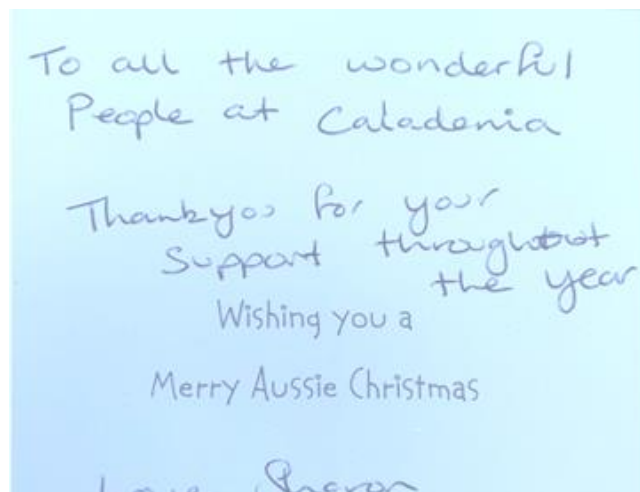
encouraged to speak freely and without reprisal about any issues they may have encountered with their changed working conditions and changed work tasks.

All things considered, the Leadership team was able to respond to any concerns very quickly and work to resolve them, and the Team Members themselves proved resilient, flexible, and in many cases individuals have embraced the chance to learn new skills they had not had the opportunity to learn before.

The staff team must be congratulated for what they have achieved through 2020, and feedback from the Caladenia Community reflects this.

Programs and Services

There were times pre-covid that we talked about “The Day Centre of the Future”. The leadership team had talked about the possibility of using zoom or similar to connect with clients while they were in respite or unwell. Or to connect with those reluctant starters in a less confronting way. When the programs closed in March of 2020, those plans were dragged out into the light.



Activity Packs

Caladenia's Activity Packs are 20-30 pages of puzzles, crosswords, information and stories to read, jokes, comics and mindfulness colouring.

These were hand delivered during most of Covid, but during the lockdowns, they were assembled at home and posted.

The Activity Packs were also uploaded to Caladenia's website for anyone to use freely. The links were posted to many dementia support and activities Facebook groups during Europe's hard lockdown, and from website analytics, we know that the packs were accessed 243 times between December 23 and January 14, and they were downloaded in the Australia, the UK, South Africa and the US.

ZAP (Zoom Activity Programs)

A Zoom account was our first purchase that was covid-specific. The Zoom Activity programs ran four times a week throughout 2020 and were very popular for those who could access the technology. There was small growth in numbers over the lockdowns, as people learned how to use the technology from family members or friends.

The staff quickly learned that Zoom is a very different platform from having a chat in person and had to adapt the programs quickly to a more structured format. Quizzes, games, Bingo and music videos were popular, and members brought their hobbies or completed projects to show the other group members. Carers were often able to use the time for themselves, as their loved one was engaged with the ZAP.

The ZAPs continue whilst we build up our groups again, and will continue into the future as an alternative option to face to face programs for those who are reluctant starters, or in respite.

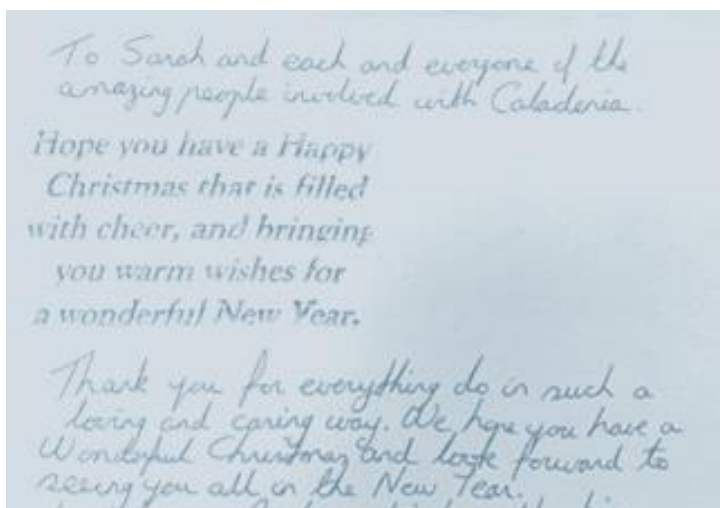
We are now looking at introducing a project where technology, training and support can be supplied to all who are interested as we recover from the pandemic.

Phone Calls

Every client on our books received weekly phone calls to both check on the carer, and to provide a social chat. Some of these calls were booked specifically for a time and a duration, to allow a carer to make other calls or attend to chores. Caladenia staff could be booked to provide respite and diversion over the phone.

It was through these phone calls that staff could assess a carer's wellbeing, both mental and physical, and report back if they thought that extra assistance was needed. In the beginning while people were still in shock, Caladenia staff were delivering milk, toilet paper and essential grocery items to families until they got their families or online services sorted out.

The Caladenia leadership team was able to contact support agencies and put in referrals for extra services where needed. Over 1400 phone calls were made by staff during covid.



Caladenia Volunteers who wanted to stay involved and useful were also given lists of four or five clients to call weekly. This meant that the client was receiving more than one call, and was also able to talk to different people each time. Volunteers were supported to report any concerns back to the staff for follow up, and wrote short notes on all calls.

Other Activities

The creativity and drive of the Caladenia Staff team has been amazing. The staff never stopped trying to think of different ways to relive the carer's burden and to improve the day for the person living with dementia.

1. Joke of The Day. When the programs closed, Caladenia's CEO undertook to write an email to everyone in the Caladenia Community daily. There were updates when there was a change, and members of the Caladenia Community shared photos of projects, children, gardens and baking. Members of the community asked for solutions to problems, "How do I stop the crows eating my poor dog's bones?" was one question that engendered some creative and useful advice! The emails also included a link to Caladenia's YouTube Channel where one staff member filmed herself telling a joke and uploaded it daily. There are 280 Jokes of the Day that are now on our YouTube Channel – and that's how many daily emails went out. The jokes catered to a different cohort, and many people spent time looking up jokes and sending them in for Jo to read out.
2. Lucky Numbers. When the programs closed down, we were left with a pantry and several cupboards full of perishable food items. One of our Team leaders devised a lucky number game where the numbers were delivered out to all the caladenia Community, and each day there was a draw, which was recorded and uploaded to YouTube, and the prizes were chocolate biscuits and mars bars to start with, but by the end prizes were UHT milk and gravy powder. The videos and announcement of winners went out in the daily email, and the prizes hand delivered with the activity packs.
3. Caladenia Community Project. The Community Project was a huge success. The staff made up over 100 packs of cardboard people shapes, glue, glitter, materiel scraps and accessories and delivered these to everyone in the Caladenia Community. Individuals were asked



to “Make a Person” and return it to Caladenia where they would be displayed on the wall to show that even though we were apart – we were still together. The Community Project is still on display, and members enjoy finding their own creation or commenting on all the different “people”.



4. Caladenia Program on DVD. It was recognised early on that our clients with advanced dementia and reduced cognition were not benefitting from any of the services we had provided so far. We were keeping in regular contact with their family members, and hearing over and over again that they wished there was more stimulation. The staff at Caladenia decided to put their dignity on the line and produce a DVD that could be played at home. It included a flower slide show to music, some musical items, a musical “guess this song”, a cake decorating demonstration and so much more. Carers could bring Caladenia’s programs into their lounge room in a small way, and if nothing else, provide a laugh for families. We copied 70 DVDs and distributed them to all our families. The feedback was overwhelmingly positive.

5. Gifts and Surprises. Caladenia wrote birthday cards and delivered them with cupcakes and a candle to every volunteer and client who had a birthday during 2020. We also delivered Mother’s day gifts, Father’s Day Gifts and cards, and during Volunteer Week there was a selfie portrait of all staff delivered along with an official volunteer badge.



At Christmas time Kate Swaffer kindly donated 70 of her poetry book to be given as gifts to the carers, these were gift wrapped and sent out with custom Caladenia Cards and Chocolates for our clients and volunteers



6. Christmas Bauble Project. This project was similar to the Community Project and craft kits were sent out to all to enable them to complete a personalised Christmas Bauble to return to Caladenia for display on a tree here. Once complete a video was made, and shared so all could see their creative efforts on the tree.



7. Staff Welfare. Caladenia's staff worked incredibly hard during 2021 doing tasks they were unfamiliar with, and often working from home instead of the centre. The Leadership team organised drop offs of chocolates with little poems, certificates and special pens, gift bags and other little items of gratitude.

Partnerships and Opportunities

Partnering with other Social Support Groups

When it became apparent in March 2020 that Covid-19 was going to greatly impact the way we work, the CEO turned to the Social Support Network for support and for information. The Network members include Councils, standalone organisations and large agencies, and in March the information coming through official channels was sparse, contrary and lacking details. As a group, many of the network members decided to pool information, and share any information and insights into how to respond to these unprecedented challenges.

The support shown to each other by the members of the Social Support Network was a lifeline during those early weeks when information was scarce and direct instruction were non-existent. As a group, members were able to close down programs in a uniform way, with a consistent message to clients across the region.

Each centre stayed in touch, a weekly “welfare check” email started to go out, just checking in with managers and co-ordinators who were experiencing high levels of stress as they responded to the changes occurring almost daily.

Each agency made similar decisions as to how to continue to provide services in a remote way, and a new language was born, we talked about Activity Packs, Welfare Calls and Zoom and Skype programs. The generosity of the social support groups in the Outer East was clearly evident, as organisations shared their activity packs, craft ideas, quizzes and other programs freely.

Partnering with Eastern Volunteers

In mid-March 2020, Eastern Volunteers put out a call to their network members for both volunteers, and those needing volunteers. Eastern Volunteers could see the need for volunteers who were able to start immediately to do a range of supporting and welfare roles within our community. Things like delivering prescription medications, doing emergency grocery shopping, and assessing all registered clients for their changed needs due to the pandemic.

I immediately contacted the manager of transport at EV and offered members of my team to assist with whatever was needed as a priority. Caladenia staff were qualified and trained, and suddenly did not have a job to do, and Eastern Volunteers had a large number of vulnerable clients to reassess as a priority to ensure they had access to services and supports whilst isolating at home.

A team of Caladenia staff made over 1100 calls in the weeks between April and August 2020. Those same staff completed 900 Covid Specific Assessments and developed the same number of

Covid Care Plans for Eastern Volunteer Clients. The same process was repeated simultaneously at Caladenia with our own 72 clients.

A small team of Caladenia staff continued to call a regular roster of vulnerable clients for weekly welfare/social calls. These calls not only checked on very isolated and vulnerable people in the community, but provided a social life line to these clients during the long Winter Lockdown.

Dementia Knowledge Network

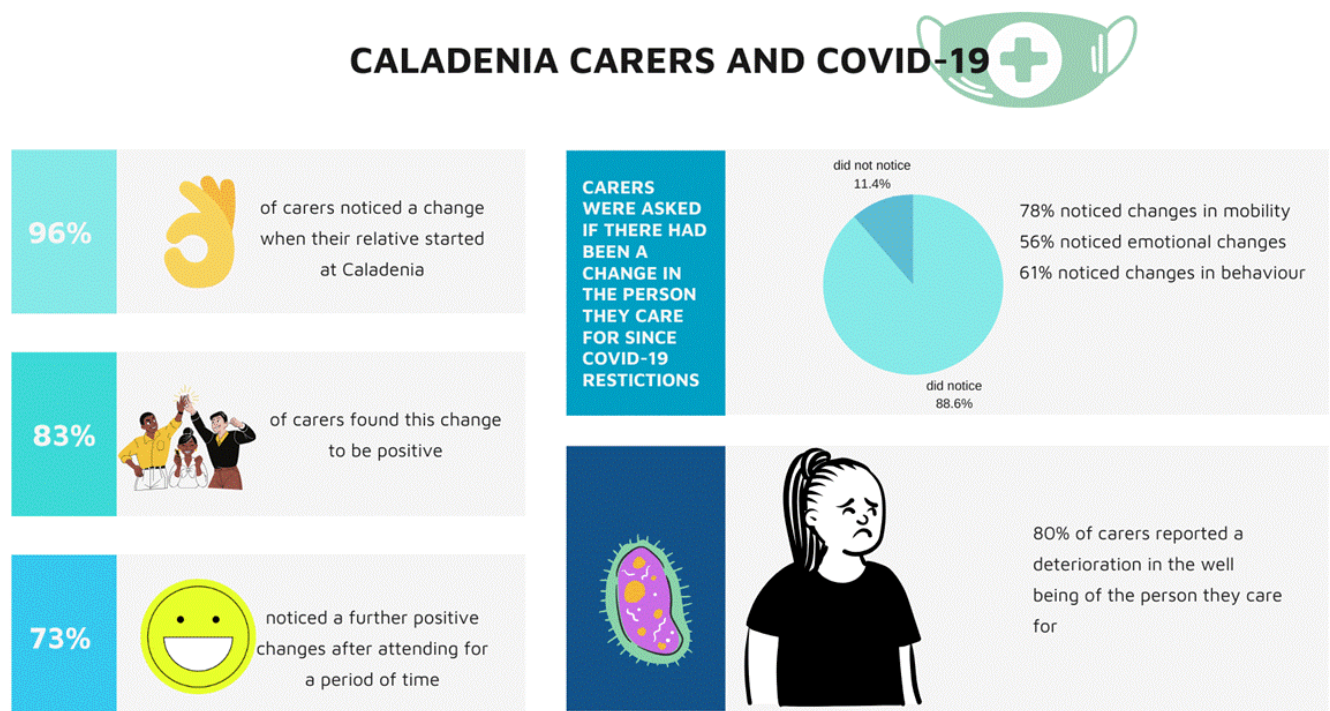
Another partnership that was formed during the pandemic was supported by both Caladenia and VMCH (Villa Maria Catholic Homes). The Dementia Knowledge Network sprang from a mutual desire to break down some of the artificial barriers to referral and access to support services that are brought about by such factors as diverse funding streams, differing government departments, public vs. Private sector, age and geographic region.

The Knowledge Network met fortnightly during the latter half of 2020 and had speakers from Innovative Aged Care Start ups, Occupational Therapists, Social Support Providers, and people living with dementia. All spoke of achievements and best practice programming, and the Network is attracting people who are passionate about improving the outcomes for people living with Dementia. The Network is held virtually, and is now attracting practitioners and providers from further afield than just the East, which is a plus. The network is planned to continue now for as long as participants are willing to attend and share their work.



Dementia Knowledge Network
sharing best practice across the Outer East

How Covid affected Family Carers



The social isolation during Covid-19, and the lack of respite options for carers of people living with dementia has meant that many more people have gone into residential care than we would have expected under "normal" conditions, and many carers that staff were talking to were reporting changes in the health and demeanour of the person they were caring for.

Caladenia sent out a survey (paper based) to all 75 carers on the current client list, we received 23 returns. A 30% return rate which is about average for our clientele. The carers were asked a range of questions but the ones I will discuss are the following:

- Did you notice changes when your relative first attended Caladenia? If "Yes" Were they positive or negative?
- Did your relative gain benefits from attending Caladenia regularly?
- Has Covid-19 had a negative impact on your ability to care for your relative at home?

96% of carers noticed a change when their relative began attending Caladenia, and for 86% of carers this was a positive change.

88.6% of carers noticed a negative change after the programs were suspended due to Covid-19.

80% of carers reported a deterioration in the well-being of the person they care for after programs were suspended.

It was the free responses that really reflected what was going on for people living with dementia during the pandemic.

"I have noticed a deterioration in my mother since Covid-19 restrictions. Her walking is slower and more cautious; she has developed a familial tremor and is often very emotional. Strange behaviour has also increased. Nevertheless, this may all have occurred regardless of the restrictions."

"She is more "Tired". Has more flat days, more withdrawn"

"Nothing for him to look forward to - No going to Caladenia, no going to the movies, no going out for a meal."

"Agitation and Mood swings"

"Lack of motivation to move/exercise, forgetting to drink, won't eat with just me home, generally lack of motivation"

"Cannot get up and go out. Sometimes gets annoyed as he doesn't understand the Covid laws. When I said yes to physical [changes] it was only when I said we couldn't do something then he threw the paper down in frustration. That's all. Just have to cope with it all. Upset when he couldn't see the new grandson"

"Bored and Irritated, Lethargic, Misses the outings and interaction with the other people at Caladenia"

"Considerably less walking, with that his walking has deteriorated"

"He is more unsettled and fidgety. His misses his chats (even if he does talk much more these days)"

"Not wanting to do anything. Trouble walking very far, constant complaining about lockdown. Cranky, lack of interest in things"

"I believe since virus lockdown he has deteriorated in his mind, lost interest in most things. I keep trying to get him involved in everyday life but find it very hard to cope at times."

"Unsure if any of the changes are a result of the Covid-19 restrictions or just the gradual deterioration of his dementia. He seems to be more depressed and prone to outbursts of frustration and anger."

"Unable to settle to anything, less communicative, uncooperative at times"

"Yes, he has gone downhill a bit since not going on his outings."

"She is not as settled as before. She is having problems with her eyes which means she doesn't read much, but yet is ok with TV. However, I've noticed she hardly ever finishes a full program."

People living with dementia and their carers have experienced noticeable changes in both their own well-being and the well-being of the person living with dementia. Isolation and lack of opportunities to socialise are the main reasons stated.

The value of social support programs has been proven unfortunately by their cessation.

Positive changes after starting at Caladenia



Negative impact of Covid-19 and Caladenia's suspension of programs

The word cloud visualizes the negative impacts of Covid-19 and Caladenia's program suspension. The most prominent words are "Covid-19", "frustration", "deterioration", "lost", "lockdown", "virus", "interest", "restrictions", "family-tremor", "walking-slower", "dementia-depressed", "cope", "lack-of-motivation", "uncooperative", "Agitation", "withdrawn", "Cranky", "Mood-swings", "Irritated", "cautious", "won't-eat", "Bored", "emotional", "less-walking", "fidgetty", "problems", "forward", "Lethargic", "downhill", "constant-complaining", "hard-to-cope", "less-communicative", "Nothing", "Strange-behaviour", "doesn't-understand", "Upset", "Lack-of-motivation", "mother", "annoyed", "Unable-to-settle", "look", "deteriorated", "forgetting", "outbursts", "Unsure", "more-Tired", "changes", "quiet", "flat", "angry", "walking", "not-settled", "lost", "lockdown", "virus", "interest", "restrictions".

The Road to recovery

Currently Caladenia is back providing 5 programs for up to 10 people a day. This is in line with current Covid restrictions and Departmental Guidelines. We have reassessed all our clients and have only invited back those who can understand and comply with hand hygiene, social distancing, and do not need close personal contact or assistance. This leaves a section of our clientele still at home receiving remote activities and phone calls, some are also receiving home visits for one or two hours.

This is not optimal, but at present Caladenia is walking a fine line between providing a service to people living with dementia, and keeping frail and vulnerable people with complex care needs safe.

As day programs reopen, each organisation has assessed their own risks and their own clientele as there are no clear directions concerning social support groups. The departmental advice in Victoria has social support groups in a category with community support groups, with general instruction for distancing, masks and hygiene procedures.

Caladenia has chosen a quite cautious way forward, and is running smaller programs with 1.5 distancing at all times. We have not opened up any outing or community based programs at this stage. This decision is planned for review in mid-March.

There are still decisions to be made around seating in community venues like cafes – it is unclear whether clients of a social support program can sit together at a café to have lunch – and if this is permissible, then why are we continuing social distancing within our own venue at lunch time? Again we will look at this in mid-March and reassess.

Our remote programs will continue. There has been a huge interest by many organisations to implement technology education and provision into homes, partly so people can take part in the extra activities available, but also partly to future proof out clients against another episode of lockdown or voluntary isolation.

The activity packs that were distributed to all clients, as well as some members of the public and volunteers were also converted to pdf format and uploaded to our website. The link was shared across various social media platforms for anyone to download. It must be noted that in the period between December 23 and January 24 the activity pack page had 243 downloads, from the US, UK, Australia and South Africa. With no data apart from the website analytics, I am presuming that they were used by activity workers during their own various lock down or closure periods over Christmas and the New Year.

We are much better at communication now, and will pro-actively keep in touch with our clientele, their families, our volunteers and other Caladenia Community members. The feedback from the regular updates via Mailchimp was overwhelmingly positive, and we will continue with regular updates whether they are weekly or monthly rather than daily.

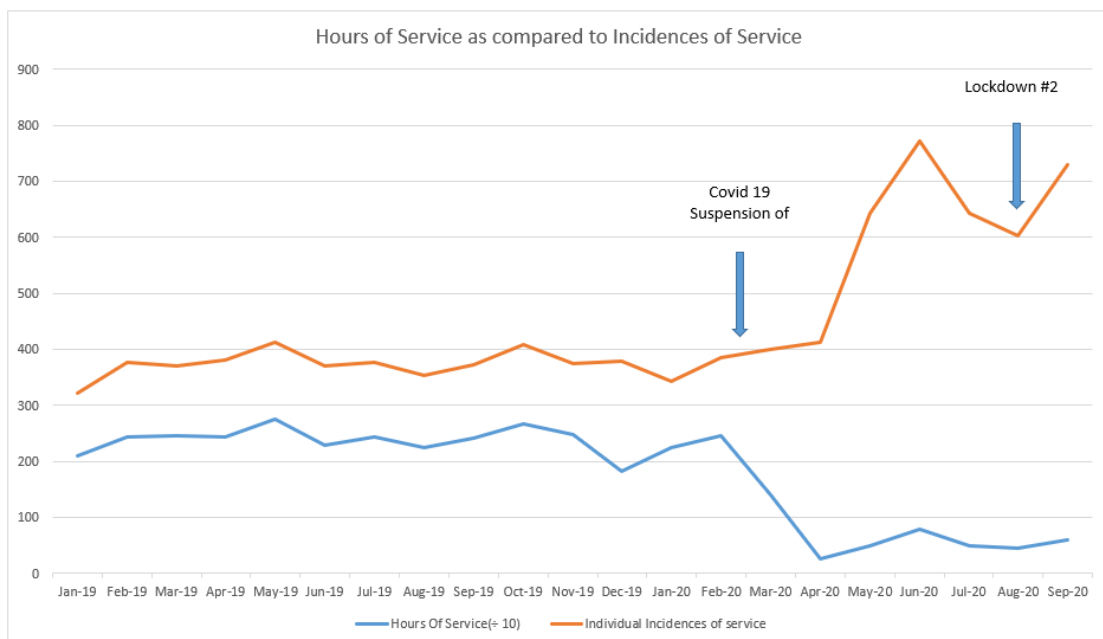
We learned that a carer support group online is a very different experience to a carer support group that runs face to face. Talking to a screen in one's own home, often with the person they care for either in the room, or in the house did not allow carers to share freely how they were going, or how they were coping. The online groups became a forum for a chat over a cuppa, and often a show and tell of various projects or achievements. Carer support groups that run face to face create their own "safe space" and encourage much more sharing of struggles and mutual support.

I hope the lessons learned in 2020 can assist programs and services in the future to plan for this kind of event when it next occurs.

Caladenia did not meet her service targets in 2020, but as the number of service hours dropped, the individual incidences of service increased.

We will not meet our targets in 2021, as we cautiously start to rebuild our programs and services. And we will continue to not meet service targets until there is no more threat of covid 19 community transmission in our community.

Our hours of service alone do not adequately reflect the efforts that the team went to, the time and creativity expended, the support offered remotely or the outcomes for the clients and their carers.



Sarah Yeates and the Team at Caladenia
10/02/2021