

Caregiver Support Group



Caregivers' Reflections





Caregiver Support Group

SILVER STATION Caregiver Support Group

In April 2019, Silver Station was formed at REACH Senior Centre @ Bukit Gombak Vista.

Holding an anchor role in the Dementia-Friendly Community (DFC), Silver Station works closely with all other stakeholders in the community to move beyond social and health care services to community empowerment and enablement. Its objective is to support persons with dementia/mental health conditions and their caregivers.

Silver Station @ REACH Senior Service started the Caregiver Support Group to provide basic emotional support to caregivers of persons with dementia. The service also focuses on educating caregivers on managing dementia and increasing their coping resources. Coming together since September 2019, the group of caregivers meets regularly every month and has become mutual support for one another.

银站关护者小组

在 2019 年 4 月, 武吉甘柏景的援触乐龄康乐中心成立了银站。

银站作为失智友善社区的核心角色,与社区中的所有利益关方与社区伙 伴密切合作,跨过社会公益和医疗服务的范围,转向社区赋权和扶持。 其目标是支助患有失智症或精神健康状况的人及其关护者。

银站@援触乐龄服务启动了关护者小组,为照顾失智症者的关护者提供 基本的情感支持。该服务还着重于教育关护者管理失智症和应对失智症 所带来的变化和需求。自 2019 年 9 月以来,关护者小组每月定期聚会, 并成为彼此的互助。



FOREWORD

REACH Caregiver Support Group started in 2019 with its first meeting on 28 September 2019. The focus of this support group is on the caregivers, whose loved ones are suffering from dementia.

This publication was initiated during the COVID-19 circuit breaker period, and it represents the fruits of shared labour and love from the Caregiver Support Group workers and the caregivers. A collection of reflections by the caregivers in their caregiving journeys, it chronicles their real-life struggles as they provide unconditional care for their loved ones, even as the condition of their loved ones slowly deteriorate. It is heartbreaking yet equally uplifting in how the themes of hope and love persevere throughout their journeys.

It is my sincere hope for all who are reading this will find the stories of our caregivers inspiring as you understand them better through a glimpse into their lives. And for those readers who are caregivers, we hope this publication sends you a message of hope:

You are not alone.

We cannot take away all the pain and struggles, but we are here with you. Allow us to walk with you in your caregiving journey, as we have walked with others.

Yours Sincerely,

Gareth Huang Head, REACH Senior Service



前言

援触关护者小组于 2019 年开始, 首次聚会于 2019 年 9 月 28 日举行。 小组的焦点是扶持在照顾失智症亲人的关护者。

这份出版物是在冠状病毒 19 (COVID-19) 阻断期间发起的,代表了关护者和工作人员共同努力和付出的成果。它收集了关护者在照顾旅程中的反思,记录他们在现实生活中的挣扎。亲人的病况每日逐渐恶化,关护者却不离不弃细心照顾。希望和爱的主题在整个过程中坚持不懈,这既令人心碎,也令人振奋。

我真诚希望,从关护者们的分享您会更能够体恤他们也同时感到鼓舞。 如果您也是关护者,我们希望这份出版物给您传达希望的信息:

您不是独自一个人。

我们不能带走您所有的痛苦和挣扎,但我们能陪伴着您。请允许我们在 您的关怀之旅中与您同行,就如我们与其他关护者同行一样。

Yours Sincerely,

Gareth Huang Head, REACH Senior Service





Floral arrangement activity

Facilitated discussion group session – Being a Caregiver



Laughter Yoga exercise

Silver Station Outreach- Lasting Power of Attorney (LPA) Talk





CSG session

Silver Station Outreach at DVLA (Donor & Volunteer Lunch Appreciation)



Caregiver Support Group

The First Half of My Caregiving Journey

Caregiver: Mr Chua Koon Seng

At the beginning of 2012, my daughter told me that my wife was starting to become more forgetful and suspected she might have dementia. She requested that we bring her for a full-body check-up, but I just refused to believe that this could happen to my family!

By mid-2012, her temperament changed, and she started to become impatient and suspicious. She kept complaining to me that her clothes were stolen. Later that year, the doctor confirmed that my wife, Jessie, needed to take medication for dementia.

At first, life went on unchanged, without any major impact from the disease. Jessie could still travel to Clementi to visit our granddaughter. The only change we observed was that she was getting thinner by the day. In 2015, things took a turn for the worse. She got lost on her way home on two separate occasions. It took her more than three hours to get home one day. When I asked her what had happened, she was unable to give me an answer. Over the next three years, her condition continued to deteriorate. She started to have difficulty taking care of herself. She didn't know how to run basic errands such as withdrawing money from the ATM machine or make a telephone call. By 2018, she became incontinent and needed full-time care. She was unable to take care of her own personal hygiene and was even unable to recall our home address.

Now, she lives one day at a time. Occasionally, she would recall past events and insisted on visiting her childhood home and her mother, who had passed away many years ago. I try my best every day as her caregiver. From dawn to dusk, I am by her side – brushing her teeth, changing her clothes, caring for her personal hygiene, cooking and buying food for her. We stay happy together, listening to the music we

Caregiver Support Group

love, singing praise songs, praying together, and enjoying the limited good time left in our lives.

With our daughter's full support, Mayor Low's understanding and help, and the encouragement from friends and family, we are living lives more motivated than before.

This is me, a caregiver, describing the first half of my caregiving journey.

Wishing everyone well. **Koon Seng**

我前半段的路...

看护者: 蔡坤承

在 2012 初, 我女儿对我说, 我的太太有些健忘, 好像是患有失智症, 需要去做全身检查。我当时还不相信, 这怎么会发生在我的家呢!

但在 2012 年中, 她的性情变得比较急燥, 而且特别的多疑, 一直向我投诉, 说她的衣服常被人偷了。一直拖到 2012 年底, 经过医生的确定后, 丽星需 要吃失智症的药了。

在前三年里,生活还大致相同,没有什么大影响。丽星她本身还能自已搭 车去金文泰,女儿的家,看看孙女。只是身体一天比一天的消瘦了。

到了 2015 年,她的情况就改变了。她迷失了两次不懂得回家。有一次她 经过三小时后才回到家。 问她发生的情况,她也说得不清不楚。在接下 来的 3 年期间,她的病情慢慢的恶化了。不大能夠照顾自己,不能夠付钱 找钱,不会应用提款机,不会拨打电话,等等...



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到了 2018 年, 她失禁了。需要全天的陪伴照顾, 生活不能自理, 不知道自已的地址等等.

到今天,她就是一天过着一天,偶尔会想起旧事,偶尔想要回去40年前的老家,偶尔又要去找已逝世多年的母亲,等等...

我本身,做为一位看护者,尽量把她看好。从早到晚,刷牙换衣,洗澡,打 理各方面卫生,煮食买饭,共享音乐,同唱诗歌,一起祷告,一起享受我们有 限的美好时光。

我俩目前还是过着很快乐的生活。幸好有得到女儿的充足精神支援,刘市 长的谅解与帮忙,加上亲朋戚友的问暖,使得我们的生活更具有激发力。

这是我,看护者,的前半段路的略述经历。

祝大家,康安。

坤承





Short Daily Reflections

Caregiver: Mr Chua Koon Seng

30 April 2020

My sharing today...

This morning was busy yet unhurried.

Dust accumulated at the head of the bed, so I wiped it clean.

The standing fan was particularly dirty, so I dismantled it and gave it a good wash.

Made breakfast for two, but my wife spilled her cup of tea on the floor.

Had to clean up! Alas!

Then, it's time to cook again.

Like an old cow ploughing the fields,

The more I work, the stronger I get!

4月30日2020年

今日随笔,共享...

今早心情好轻松,

但特别的忙碌。

床头好多灰尘,洗洁一番。

风扇特脏,折开清洗。

弄个早餐,两人共享。

但是

老伴把一杯茶水,倒在地上。

又得抹地…无奈…

现又要煮饭啰。

老牛耕田

愈耕愈壯。



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Short Daily Reflections

Caregiver: Mr Chua Koon Seng

1 May 2020

It's Good to Have an Old Companion

Let me share what I wrote this morning to unwind and relieve my boredom.

We have a saying, "Living in blessing, must appreciate it."

An old companion... comes with many opinions,

She can argue with you, show displeasure, scold you and even control you.

Yet above all, she cleans, cooks, washes and does all the chores at home so capably.

Oh, how I cherish this....

My friends, please keep this word in your mind forever:

"Cherish"

5月1日2020年

有老伴真好

早上, 随笔一则。 舒松解闷, 与君共享。

身在福中要知福。 这句话,真的很切实。

老伴, 能与你商量, 讨论, 给意 见。

还能与你争吵,给脸色,甚至责骂 你,控制你。

最重要的是, 扫地, 煮饭, 买菜做菜, 洗衣晾衣, 家内琐事, 样样都行。

我多么的向往啊...

朋友们,请把以下这两字,永留在脑中...

"珍惜"



Short Daily Reflections

Caregiver: Mr Chua Koon Seng

5 May 2020

Overflowing Again

Following my usual routine these days, I woke my wife up at around 3 am and assisted her to the toilet. I touched the sheets and found out that it's wet. I rubbed my tired eyes helplessly, soon realising that I was going to be doing some hard work again.

After helping my wife wash up and change, I changed the bedsheets and tried to put her to bed again. After some urging and coaxing, Jessie began to fall asleep.

It was 4 am, and just when I was drifting off to sleep, Jessie suddenly opened her eyes and said, "thank you, brother". I patted her and said, "Sleep". My eyes welled up with tears, and all the tiredness left me. Thank God for giving me strength.



5月5日2020年

又是满溢了

凌晨3点出些,照着惯例,叫醒老 伴,扶着她起身,想上卫生间解 急。触摸一下,又湿透了。

稍愣了一下,意识到,这回又要 "干苦"了。果然不出所料,床单 湿了,床单保护层也"中标"了。

我揉着惺忪的眼睛, 意识的感到 无奈。但很快的又觉醒过来, 这 是我分内的责任啊!

把老伴清洗一番后,换了衣裳, 也换了床单,在半哄半催之下,丽 星又很快的入睡了...现已凌晨4 点了。

当我准备進入梦乡之际,她突然 睁开眼儿对我说:"阿兄,感谢。"

我拍着她说:"睡罢。"

此刻,我的眼晴湿润了。疲惫也 消了。

感谢主恩给于我的力量。

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Letting Go & Pressing On

Caregiver: Mdm Yap

Time passes quickly. My mother-in-law had lesser responsibilities and things to do at home when the grandchildren grew up. Meals with her daughter became more infrequent and had become simpler preparations. As my mother-in-law had more free time, she would often visit a second-hand goods store at Jurong East just to browse the products. Sometimes she would return home only after 9 pm, as there was no one at home to keep her company. When my husband found out, he discussed with me about inviting her home to stay with us, and that started our caregiving journey.

With less frequent trips out and lesser walking, my mother-in-law's legs became weaker, and she fell once or twice. There were no major repercussions back then. However, with her recent fall, she had to be hospitalised and was subsequently diagnosed with mild dementia.

During the earlier times when she lived with us, she would often come into our room in the middle of the night to see if my husband was asleep. She would also pull away the pillows that he used to cover his ears. Awakened in shock, my husband would sometimes react in a fit of anger, causing quite a lot of conflicts at home. Our sleep was often affected. To this day, my mother-in-law has a habit of unbuttoning her blouse when she sleeps, which may have resulted in cough due to the chilly temperature at night. When we told her not to do that, she would say that she was not feeling cold. She also stubbornly refused to use a walking aid. These issues bothered me but knowing her personality, my husband would simply accommodate.

My husband would often advise me not to take things personally with my mother-in-law, and to abide by her wishes as it would not be easy

to change her. I started to accept this reality in due time, in part due to my faith's teachings. We managed the caregiving routine ourselves till she was hospitalized one day. After her discharge, my husband decided that it was time to hire a domestic helper to look after her.

When I joined REACH *Silver Station* Caregiver Support Group, I realised my problems were really small compared to those faced by the caregivers here. They have so much love, patience and perseverance facing their daunting challenges. I thank the Caregiver Support Group In-Charge and fellow caregivers for sharing their experiences. I am grateful to all and wish that everyone will enjoy smoother times ahead.

放下+坚持 看护者:叶女十

时间过得很快,一向照顾的外孙已工作,很少在家吃。婆婆与她女儿也 吃很少,所以很容易准备。而且更多的时间往外走动。婆婆很喜欢拿东 西到裕廊东二手商店卖东西。有时去到晚上九点多才回来,因为家里无 人,所以随便到处走。丈夫发现便与我商量之后,决定接她过来和我们 同住。

因在家少走动,脚力也因此退化,所以在家有跌到一两次,应无大碍。 但最后一次跌倒后,便进院住,经医生看诊后,发现有轻微的失智症。

和我们同住的当中,婆婆半夜时常起来看丈夫是否在睡觉,或拉开丈夫 盖耳朵的枕头,惊吓到丈夫,便发生很多口角,也渐接影响到我们的睡 眠。婆婆在睡觉当中,很喜欢把上半身的衣服拉开来睡,造成胸部寒 冷,更引起咳嗽及吐痰,叫她不要这样,她却说不冷,喉咙痒没事。也



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不愿意拿拐杖,什么都不愿意听。丈夫因太了解母亲的性格,一般都顺 从她。

丈夫不断的开解我, 说长辈的坏脾气是无法改变的, 要学习去谅解, 顺 从她。再加上宗教信仰的教导, 我对人、事、物也慢慢开始看开不那么 的计较了。直到她住院, 丈夫决定找帮佣来帮忙。

当我来到 REACH *Silver Station* Caregiver Support Group(援触关护者 小组)时,我才发现自己所面对的都是小儿科,在这里的关护者照顾着 失智症的亲人都比我辛苦。他们都是多么有爱心、耐心和恒心。最后很 感谢 Caregiver Support Group 小组负责人,还有关护者的分享,让我 获益很多。在此感恩,并祝福大家日后一切都顺顺利利的。





Caregiver Support Group

A Pilgrim's Sharing

Caregiver: Patrick

As a secondary caregiver for my mum, the bulk of the work falls on Kareen, our foreign domestic helper, and I support her by giving her more space.

It is comforting that my mum can be kept out of the nursing home with a helper to take care of her needs. I think there is more dignity and quality of life for my mum to stay with her helper, than being in an alien environment with care staff who are most likely overworked and unable to readily attend to her. I am relieved that I can constantly oversee her welfare medically, financially and psychologically.

Disruption came unexpectedly with the intrusion of COVID-19. I cannot visit my mum regularly and have to rely on Kareen. My mum's services for occupational therapy, physiotherapy and elder-sitting also stopped abruptly leaving her with no one to talk to except Kareen.

But there is only so much Kareen can do. It pains me to see my mum deteriorate quite rapidly over the weeks and to discover that her eyesight is failing. I am stressed by it.

The only solace I have is that my mum still recognises me all this time and her feeble hand still reaches out for me whenever she sees me. A thought entered my mind, "everyone will have to go through old age frailty. And when we do, will there be someone to take care of us?"

I guess the turning point is when I realised that I have done what I needed to and even beyond to look after my mum. I believe when the time comes for her to go, there will be no regrets and 'what ifs'. I know I can carry on without guilt or remorse.

What I cannot do for my mum in her late-stage dementia, I now do with my clients at the eldercare centre where I work, cheering them up each day through various activities. I believe God has a purpose for us in whatever we go through in fulfilling His purpose.

My Sister-in-Law and I

Caregiver: Angie

My sister-in-law, May, has always been very caring to my family, often taking us out for meals and showering my children with gifts. After she retired, she would often travel all the way from Bedok to Jurong to visit us and stayed on for dinner. Things began to change after a few years. Unlike her usual self, I noticed that she was getting rather unkempt and her hair was tangled together. Visits became lesser, and she would call me to bring food for her and do her laundry. When I did, she would only meet me at the void deck. Her youngest sister also noticed the change when she came to visit and brought her for a check-up. May was diagnosed with early dementia.

One day, her nephew contacted me as May had not been answering his calls. We went to May's home, knocked on the door, but no one answered. However, I could hear a faint shuffling sound inside, so we decided to alert the police to force open the door. To our surprise, the whole living room was full of junk! May was in a dazed state, she looked weak and smelled bad too. One of her legs had been badly scalded.

After her discharge, she came to stay with me. However, what I thought would be a temporary living arrangement turned into a sixmonth stay. She insisted on sleeping on the living room sofa even though we had an extra bedroom. Our family life was disrupted, and it was also difficult for us to have guests over. Despite all, I tried my best to accommodate her as I respected her. She was an elder, and she had been good to my family. I felt that it was only right that I help her as much as I can.

One day, she wanted to go back to her house to get some belongings, but she would not allow me to go with her. The next day we received a

call from the police, informing us that May had fainted in a hawker centre and was admitted to Changi hospital due to dehydration.

After a few more months, her sister and I decided to place May in a nursing home. I thought May would be reluctant to stay there. However, after touring the facility, she happily bade farewell to us.

May was one of the healthiest residents there, always going around to serve others. But as the disease progressed, her physical health went downhill. Towards the last few months of May's life, she was in and out of the hospital. All her organs were failing her. She passed on peacefully last year, 20 years after her first diagnosis.

I believe that it is possible for persons with dementia to have a good quality of life with the community awareness and support we have now. I have been attending a Caregiver Support Group at REACH Silver Station @ Bukit Gombak Vista because I want to learn and be better equipped to help others in the future.



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Learning to Care

Caregiver: Magdalene

Since the sudden passing of my dad 23 years ago, I have committed myself to take care of my mum. But it has recently gotten more challenging after she fell twice last December and was also hospitalised due to severe diarrhea and vomiting. I became more anxious about her overall well-being. On top of that, at a recent memory test done at the hospital, the doctor told me that my mum had symptoms of early-stage Alzheimer's disease.

I observed some behavioural changes exacerbated by the COVID-19 circuit breaker. I was overwhelmed. We would argue almost every day, and it sometimes became rather heated. My mum was restless and upset that she was unable to go out for her usual morning exercises and routine. For me, I had to work from home and take over the additional role of going to the market.

My mum's memory seemed to be affected by her fall. Other than asking me the same questions over and over again, her mood swings were getting more frequent too. I was stressed because I was not able to find a balance between family commitments and work during this period. I was also worried about my financial situation and felt drained by this friction I was having with my mum. She seemed to have discouraging comments on whatever I did. I felt helpless and at the same time upset by my mum's behaviour. Often, I tried to remind myself that she might be lonely and needed someone to talk to. I tried to encourage her to chat with relatives and friends to keep herself occupied. At the same time, I also reminded my siblings to try to call our mum as and when they could. Even if it was just a short call, I knew it would brighten up her day.

Initially, I tried to encourage my mum to continue with her physiotherapy exercises given by the hospital therapist. However, she was resistant and we would end up in an argument over this issue. Eventually, I stopped reminding her. I felt guilty for not insisting on her to do the exercises as it would help her in her coordination. However, if I persisted, it would add unnecessary stress on both of us and further strain our relationship.

It was only in the past two days that we managed to have less friction with each other. I keep reminding myself to be more patient and to learn to let go of things that are beyond my control. I appreciate how Esther from REACH Silver Station would text me occasionally to check how I am coping. Our short chats not only helped to lift my mood, but it also helped me take my focus off mum. Thank you, Esther, for your moral support, I am very grateful!

AFTERWORD

Caring for someone with dementia not only requires patience, commitment, knowledge, and skill, it often involves a rollercoaster of emotions where you will feel angry, sad, discouraged, or helpless. It is therefore vital to find support.

- Ask for help when you need it
- Join a caregiver support group
- Be mindful of burnout and make time for self-care by arranging respite etc.
- Keep up with social activities e.g. meeting friends and relatives
- Eat healthily and exercise

When you have a spare moment – rest, reflect, and acknowledge your feelings. Pen down in a journal and share with others. It can be a great way to increase your self-appreciation and discover your personal growth in the journey of caregiving. The key is to understand that you do not have to face it alone. Contact us via the contact details provided on the back page.



REACH Community Services Society (RCSS) was founded in 1998 by Grace Assembly of God to help the hurting and needy in the community. Registered as a society separated from the Church in 1998, a charitable organisation in 1999 and a full member of National Council of Social Service (NCSS) in 2000, RCSS became and has been an approved Institution of Public Character (IPC) since 2009.

RCSS offers community and support services to individuals and families through various community projects in our current 6 touchpoints. We seek to reach out to the least, the lost and the lonely; regardless of race, language and religion.

