

Personally Speaking

The Art of Caregiving

ABOUT

Personally Speaking is a visual arts project that explores the stories of caregiving for the elderly, and people with special needs and mental illness. Eight Singapore artists have been inspired by the personal joys and challenges of caregivers, shared with them by people of all walks of life, including parents, children, teachers, social workers and healthcare professionals.

PERSONALLY
SPEAKING:
THE ART OF
CAREGIVING

While each account is unique, they collectively reflect the anxieties and difficulties faced by many caregivers due to institutional gaps and the pressures of social stigma. Many of them harbour simple hopes and dreams of a better life for their wards. Through this exhibition, we hope to create a space that allows everyone to reflect on their own caregiving journey, and consider the kind of care that we would like our loved ones and ourselves to receive.

In addition to information about the artworks, this booklet contains interviews with the artists and caregivers that give insight into their creative and personal journeys. We are indebted to the generosity of those who have shared their stories with us.

Alecia Neo
ampulets
Deanna Ng
Gwee Li Sui
Joseph Chiang
Kray Chen
Mary Bernadette Lee
Sun Koh

FEATURING
WORKS BY

8–14 Oct Community Plaza, Oasis Terraces
15 Oct–18 Nov Jurong Regional Library
22 Nov–16 Dec Objectifs: Centre for Photography and Film

EXHIBITION
DATES

Panel Discussion
The Art of Caregiving
1 Dec, 3pm
Auditorium, National Design Centre
More information at www.objectifs.com.sg/personallyspeaking

Commissioned by



In partnership with



Produced by



01	About Personally Speaking
04	Foreword by Lien Foundation
06	Between Earth and Sky by Alecia Neo
08	Artist Interview - Alecia Neo
12	Caregiver Interview - Nur Hidayah
14	You Can Take A Break by ampulets
16	Artist Interview - ampulets
20	Yours Truly by Deanna Ng
22	Artist Interview - Deanna Ng
26	Caregiver Interview - Tan Ah Yaw
30	Old Heroes Solve Mystery by Gwee Li Sui
32	Artist Interview - Gwee Li Sui
36	Caregiver Interview - Frank
40	Say Yes To Inclusion by Joseph Chiang
42	Artist Interview - Joseph Chiang
44	3 Acts of Remembering by Kray Chen
46	Artist Interview - Kray Chen
48	Caregiver Interview - Janet Koh Hui Keng
52	I Carry You In My Heart by Mary Bernadette Lee
54	Artist Interview - Mary Bernadette Lee
58	Presence by Sun Koh
60	Artist Interview - Sun Koh
64	Resources for Caregivers

Personally Speaking – the Art of Caregiving -- is a visual arts exhibition that takes an unvarnished look at the grit, grace, challenges and rewards of caring for people who are physically or cognitively incapable of looking after themselves.

The Lien Foundation commissioned eight visual artists to spend time with different groups of caregivers and delineate their journeys through art. Many of the artists - ranging from graphic novelists and printmakers to photographers, film-makers and even someone who works with clay - are caregivers themselves and their visual essays are infused with personal experiences.

The phenomenon of families tending to their frail, elderly, mentally ill or disabled loved ones is as old as humankind itself. But falling fertility, rising life expectancy and rapid ageing --- the defining demographic trends of our time-- are set to change the face of caregiving. As family sizes shrink and more people need care, Singapore must embrace caregiving, not as the burden of a few, but as a responsibility for many.

In 2010, the National Health Survey¹ by the Ministry of Health showed that 8.1 per cent of Singapore residents aged between 18 and 69 were caregivers-- which means that, even after excluding caregivers who are elderly themselves, there were at least 236,000 people who provided regular care or assistance to family and friends as of 2017², up from around 220,000 in 2010.

The survey also showed that around two-thirds were looking after seniors, while the rest looked after children and younger adults with special needs or mental illness. Nearly six in 10 caregivers were in their 40s and 50s and 37 per cent had been tending to their loved ones for a decade or more. On average, they provided around seven hours of care a day, which was like having a second job.

As the title suggests, *Personally Speaking* melds personal observations and experiences of the participating artists with those of caregivers from all walks of life. In some of the projects, the caregivers are not just passive subjects, but committed co-creators of the works of art.

In Alecia Neo's photography and film project, *Between Earth and Sky*, for instance, caregivers of people with mental illnesses attend a series of workshops where they relieve stresses and articulate hopes and fears through movement, rather than words. Mary Bernadette Lee's offering, *I Carry You in My Heart*, documents pottery workshops where teenagers and adults with intellectual disabilities create clay vessels with their caregivers. Each vessel is a receptacle not just of their daily worries and frustrations, hopes and wishes, but also the fierce love that binds them together.

Deanna Ng's project is a series of double exposure photographs of parents and their children, all of whom have low-functioning autism and are unable to be independent. Embellished with paintings by the caregivers, it is a sombre yet realistic take on the fact that these children, who often grow up cloistered from an indifferent and occasionally unforgiving society, are always on their parents' minds. For the caregivers in each of these projects, the artistic process became a healing journey of self-discovery.

The remaining artists confront the issue of caregiving for seniors, something that may touch each of us someday. Artist James Teo, for instance, has drawn on his own experiences caring for aged parents and created an animated film and a book entitled *You Can Take a Break* on how caregivers, including domestic workers, need a break not just from their daily chores but also from the guilt that haunts them daily. Graphic novelist Gwee Li Sui, for his part, creates a world where three elderly men are not just passive recipients of care, but lively and fun folk who embark on an adventure to solve a neighbourhood mystery even as they look out for each other in their own informal network of care. Significantly, all four artists who explore the theme of ageing include stories of paid caregivers, such as domestic workers, home-help aides and nursing home staff, who will play an increasingly important role as family sizes dwindle and more people need care.

The Foundation would like to extend its heartfelt thanks to all the artists and caregivers who have journeyed together for the better part of a year to create these extraordinary portraits of hope, hard work, heartbreak and, above all, abiding love. A big thank you to our project partners too-- Objectifs and Ngee Ann Polytechnic.

The exhibition, we hope, will do more than just celebrate the everyday caregiver heroes in our midst. We hope it can inform, provoke thought and, above all, catalyse empathy and action in the form of more support services, be it by providers, companies or the community at large.

Collectively, we can care more--and should.

¹ www.singstat.gov.sg/-/media/files/publications/society/ssnsep11-pg12-14.pdf

² Calculations based on national population figures, 2017

BETWEEN EARTH AND SKY

BY ALECIA NEO

What does the weight of caregiving look like? Whose weight do we bear? Can we share it?

An intimate portrait of a community of caregivers and a performance project, *Between Earth and Sky* seeks to make visible the contributions and needs of caregivers who care for persons with mental illness. The lack of support and stigma towards mental health also affects caregivers who often bear the emotional and financial weight of caring for their loved ones.

After undergoing a series of movement workshops, the caregivers were invited to devise a performance which draws from their caregiving journeys to create narratives and expressive movements which symbolise new ways of being. These short performances were documented with photography and video for the installation.

Between Earth and Sky uses a kite as a symbol for both vulnerability and freedom. Each kite bears images of clothing from the caregivers and their loved ones, forming a collective body. In many ways, this project is about restoring faith in times of profound loss, within ourselves and in society.



From *Between Earth and Sky*. Image credit: Alecia Neo

Alecia's artistic practice questions the kinds of individuals who are valued by contemporary society by exploring the relationships between people, their identities and contexts. Working primarily with photography, video, installation and participatory workshops, she develops long-term projects involving a variety of individuals and collaborators, overlooked communities and their spaces. She is currently Artist Lead for Brack, an arts platform for socially-engaged artists and their projects.

ABOUT THE ARTIST

Thank you to the eight caregivers and their loved ones who made this work possible: Alvyna Han, Carol Ee, Frank M., Nur Hidayah, Sulis, Janet Koh Hui Kheng, Ng Sook Cheng, LM, Rita Minjoot

ACKNOWLEDGEMENTS

Movement Coaches: Sharda Harrison and Ajuntha Anwari
Camera: Khairul Amin
Editor: Armiliah Aripin and Alecia Neo
Additional footage: Gladys Ng
Sound Design and Music: Clarence Chung
Researcher: Gracie Teo
Design: Samuel Woo
Writer: Jill Tan

With special thanks to: Tim Lee, Karen Poh, Sharon Gan, Margaret Ong, Li Li Chung, John Clang, Melanie Chua

Supported by



Find out more:

Caregivers Alliance
www.cal.org.sg

Why did you choose to collaborate with caregivers from with Caregivers Alliance for this work?

A: Caregivers Alliance (CAL) is an NGO that provides services for caregivers who care for people with mental illnesses. It's a growing community. There is very little attention given to people with mental health issues, and hardly any services for caregivers. I had attended their workshops in a personal capacity, before embarking on this art project. When this opportunity came, I immediately felt that it was important for me to work with them. So the caregivers that I work with have all either attended CAL's workshops or have become CAL volunteers and advocates themselves.

Your participants created non-verbal movement pieces that were inspired by their own caregiving journeys. Why did you choose to work in a non-verbal medium?

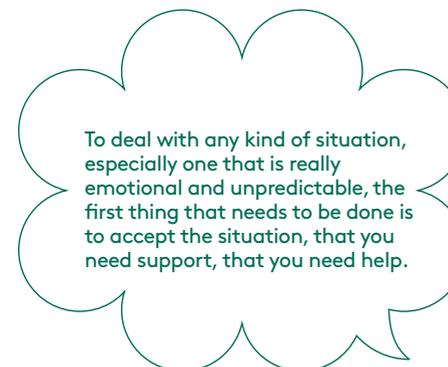
A: I think sometimes words can be very specific. And when you actually use your body, a lot of unconscious, latent sort of emotions and ideas can emerge. It can be a very powerful experience to embody it, to feel it.

How did the participants react to the movement workshops?

A: In the beginning, most of them were a little anxious, saying things like, "We don't know how to do this, we never do this art thing before." But they stayed curious, and when they started getting into it, even they were surprised at what they could do, so that was really wonderful to watch.

In the first session, one of the things we realised is that how very simple things are often overlooked in our lives. We were invited to find a partner, and look into each other's eyes. One of the participants was a mother-daughter pair, and almost immediately this exercise triggered very powerful emotions, because they both started crying, and she shared that it had been a long time since she had looked into her mother's eyes directly.

Over the course of the workshops, they discovered the joy of performing and sharing their stories in a different way. Some of them even suggested that movement workshops could be useful in caregiving training, or used as a non-direct, non-confrontational way of sharing their stories.



Alecia Neo

I also found that they discovered the beauty and joy of creating something, and while I can't speak on their behalf, I could also see that the process had some kind of therapeutic effect. I think the creation process is powerful. You might not feel its effects immediately, but a couple of months later it might trigger something. I enjoy that very much in my work. Sometimes you invite people into the process, and their expectations can be so different, depending on their exposure to and perception of art, and through the process, they begin to see things a little differently. That's a very exciting place to be for anyone.

The performances they created really went beyond my expectations for the project. I don't think devising your own movement piece is easy, especially if you have never done it before. I think they really tapped into something quite special.

Why do you think it's important for caregivers to be able to share their story?

A: To deal with any kind of situation, especially one that is really emotional and unpredictable, the first thing that needs to be done is to accept the situation, that you need support, that you need help. For you to seek help, you have to share what is going on, and that is really difficult to do.



From *Between Earth and Sky*. Image credit: Alecia Neo

In fact, even after the sessions at CAL, not everyone is able to speak to everyone within the group, even with the facilitation of a trained counsellor. I think everyone's journey is different; some people need more time because they have more barriers, maybe from society, maybe from their own expectations. There's a lot of shame and guilt involved, especially with parents whose children are ill, who worry about whether it is genetic, if it is something that comes from their side of the family.

So there is a need to overcome that, and then separate the illness from the person. There's also thinking about what we can do constructively, to actually think about what I can do to support my loved one, given what I have.

What did you learn about caregiving through this project?

A: To me caregiving is really about love. I think that without love it would be really hard. It's a practice, because it's often a very long, drawn out affair. In some ways it's also about courage, because it takes courage to confront not just the person that you are caring for, but also confront yourself, to deal with the emotions that come with it.

Another common thread amongst the caregivers I worked with is this spiritual connection. I think all of them go through this journey of rediscovering faith, religious or not. I think that's something that other people can learn from as well, how to connect with your spiritual side and how to then relate to the people around you.

This whole process, from attending the workshops at CAL to working with the participants, has taught me a lot about humility. They've become my pillars of support as well. It's a really formidable job for anyone to be the primary caregiver of another person. I think every caregiver needs to tap into their inner hero, because you really need to be the better version of yourself to be able to genuinely care for someone else.

For me, being able to witness that really taught me a lot about what it means to be human. To be vulnerable, to let your guard down, and to be okay with it.

I think every caregiver needs to tap into their inner hero, because you really need to be the better version of yourself to be able to genuinely care for someone else.

When did you start your caregiving journey?

H: I started caring for my brother in 2015, after graduating from Singapore Polytechnic. My brother has bipolar disorder, depression and IQ disability, and he was diagnosed when he was 17. Before that, my mother was his main caregiver. She wanted to protect me from these issues when I was growing up. But three years ago, when she said she was going to the Institute of Mental Health (IMH) with my brother, I actively came forward to help. It's been quite a struggle for her because she is Indonesian and only speaks basic English. At the hospital, they tend to use complex English terms, or just sideline you completely if you are a foreigner. To add on to that, a doctor can see up to 70 patients a day, so they only have maybe five minutes with you.

When I came into the picture, it was a totally different ball game, because I made sure that my brother's needs were met. There were a few doctors whom my brother absolutely hated seeing because they made him feel invalidated as a person. I mean, this is the worst thing that you can do to anyone, let alone a person with mental illness (PMI). So I made the decision to change doctors. Very often, doctors only associate themselves with the patients and not the caregivers, but it's very important for a doctor to listen to the caregivers' input because we are the ones at home with them and we know what the PMI goes through. My brother's new doctor understands us better, and I feel very grateful because the doctor really notices my brother's progress and tries to improve his treatment.

I am my brother's advocate, adviser and best friend. I help him with his work by sharing his schedule with his manager at work, I accompany him to his medical appointments, I'm his exercise buddy. I make sure he has goals and interests. I help him manage his anxieties and emotions at home. When he has racing thoughts in his head, it's important for someone to be there and listen to him, to give him an outlet. So I sit down with him, get him to calm down, do breathing exercises.

For my mum, she was diagnosed with depression last year when my parents were going through a separation. She had insomnia for a few nights, and actively went to seek help at the polyclinic. When she got a referral to IMH, she got a shock, and asked me to accompany her. I'm actually proud of her for being open with me, because I feel that it's not easy for mothers to show their children that they actually need help. It's not about pride, but wanting to protect your kids. Like my brother, I listen to my mom when she experiences anxiety. With her, I can be more logical and rational with my approach.

It's about adapting to their different needs. What might work for loved one A might not work for loved one B.

"I think all caregivers will ask themselves, why me? That was the first question I asked myself as a teenager. But I realised at the end of the day, if not me, then who else will care for them?"

What do you think people should know about caregiving?

H: It's important to realise that caregivers are hidden heroes. They straddle two worlds; caregivers have their own work struggles, career aspirations, personal goals, and then there is caregiving where they need to meet the needs of their loved ones.

What's the hardest part of caregiving?

H: I think all caregivers will ask themselves, why me? That was the first question I asked myself as a teenager. But I realised at the end of the day, if not me, then who else will care for them? It really boils down to that, so I try to let go of that mentality. It's a constant learning process, and you need to be really patient with your loved ones when they need you.

As a young adult, it's really difficult when I'm struggling with my own issues, like work, school and relationships. Another difficulty is that you have to be prepared for the unexpected, to quickly bounce back by reconnecting with your support system. I also need to affirm my mum's role as a parent in my life. At the end of the day, I still look up to my mother. We still need each other.

My mom and I also struggle with guilt. For my mom, she feels guilty about burdening me with such a huge responsibility, and for not being a better protector for my brother when he was younger. For me, I feel guilty for not being able to be there for my brother 100% of the time. One of my aspirations is to hire someone and train them to care for my brother full time. It's a long shot, but I believe anything can happen if you work hard.

What's the best part of caregiving?

H: My caregiving journey has also been one of personal development. I discovered that I have a really big heart for people. I've become much more empathetic because of my brother and mum. It's also helped chart my aspirations. For example, I want to study Sociology because it can help explain a lot about whatever is happening in my life, to see society in a better light.

To me, the reward is to see your loved ones communicating closely with each other, knowing that no matter what happens, that you are going to be there for each other at the end of the day. To forgive whatever grievances or mistakes. With caregiving, it's always important to forgive, forget and learn from your mistakes and be sure you won't repeat the same mistake again. After all, it is for everybody's good.

YOU CAN TAKE A BREAK

BY AMPULETS

My mom passed away 10 years ago after a stroke. I witnessed my dad's struggle to care for my mom and later, come to terms with her death. Since then, my dad has suffered a fracture in his vertebrae, severely affecting his mobility. Amidst a host of other ailments, he also has dementia. Caring for my parents has often left my siblings and I feeling stressed, anxious and tired. We hired a domestic worker to be Dad's primary caregiver, but her duties have also left their mark on her.

I saw how, despite all their efforts, caregivers are often guilty when they take time off to rest and relax. And so I wrote a story that drew on my experiences, featuring a fictional character – V8, a robot designed to be a caregiver. V8 is our help and our guilt. He works so that we can take a break! But is he indeed super-human? Does V8 not need a break too?

My hope is that caregivers can see themselves in V8, or that others can see in V8 the caregivers in their lives. If they do, perhaps they will be reminded of the message "You can take a break". Taking a break prepares you for the journey ahead.



From *You Can Take A Break*. Image credit: ampulets

ampulets 安普樂 is a creative design studio founded by James Teo in 2006. The studio creates visual and brand identities, publications and communications design for clients that range from museums to cafes. ampulets also produces independent art and design projects under the label Neighbourgoods. We believe that good design responds to and satisfies our human desire for both meaning and beauty.

You Can Take A Break is written, illustrated and designed by ampulets, with copy editing and English translation by Yeo Wei Wei.

The short film is directed by ampulets, animated by Khoo Siew May, with music by Victor Low.

ABOUT THE ARTIST

ACKNOWLEDGEMENTS

Find out more:

Care Where You Are –
Enabling Singaporeans to age well
in the community
<http://bit.ly/carewhereyouare>

Lien Foundation Long Term Care
Manpower Study
<http://bit.ly/lcmpstudy>

What's the inspiration behind this work?

A: I saw how my parents cared for each other, and also drew on my own experience caring for my father now. My mother passed away ten years ago, and my father was her main caregiver. It was very tough for him, and when she passed, he became depressed because they were very close. Now he is in his 80s, and has dementia and problems with walking. He still stays on his own, and we have a domestic worker to help care for him, but caring for him has gotten more difficult over the years.

While my siblings and I don't stay with him, we are still very involved in his care. There's a lot of heartache and guilt, and my siblings and the domestic worker sometimes feel that it's wrong to take a break. I visit the hospital a lot because of my father, and I see this happening with other caregivers too.

This issue has been on my mind, so we created this character, a caregiver robot called V8. In the film there are parallel stories. One is told through text and it is a more personal story of our struggle with caregiving, and how we hope V8 can help take better care of my father than the older V7 robot. The upgrade from an older version to a newer version is also a reflection of how some people think when they are changing domestic workers. Every time you get a new domestic worker you hope that the person will be able to help better with caregiving. In the parallel story told through the animated illustrations, we see V8 going around helping different people and getting damaged in the process. In the end, V8 receives help from an old man to recharge itself.

Could you share your experience of caregiving?

A: I think caring is definitely borne out of love, but caring is also borne out of responsibility. Maybe it's our Asian values that makes us feel like we need to care for our parents and our elders.

Also, seeing someone whom you love go from being very active and independent to needing help for basic things like going to the toilet and getting out of bed is very emotional. To me, to want to help is something that is ingrained. We are all human, and if we take love and responsibility away, then we might as well be animals.

Caregiving can be a sprint, or it can be a marathon. In the case of it being a long-term commitment, you need to know how to conserve your energy.



James Teo, founder of ampulets

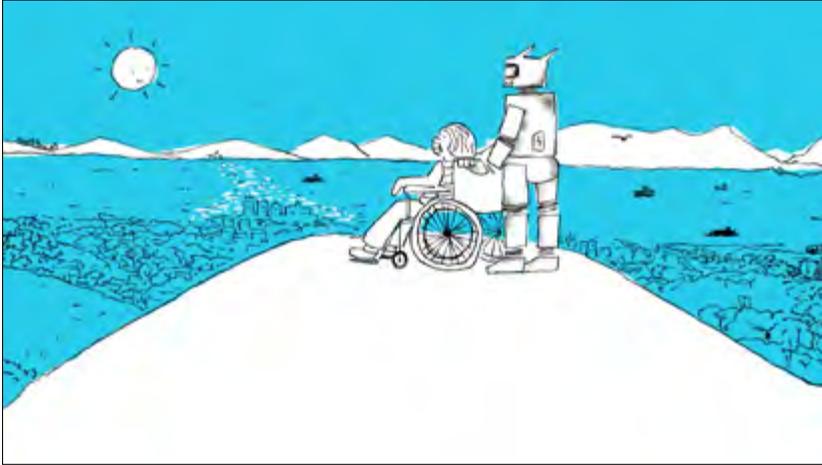
Sometimes I even see my domestic worker cry a little when my father has to be hospitalised again or if he has a bad fall. Yet we often neglect the feelings of domestic workers and forget that they are often the primary caregiver.

It's also somewhat ironic that it is a stranger whom we entrust with the responsibility to care for someone we are often closest to. When I go to the hospital with my father, the doctor will ask us what he is eating, if he pees well, if he has been eating well, if he has lost weight, stuff like that, and most of the time, we will reply "ask the domestic worker". While we take care of the medical and financial aspects, the domestic worker definitely knows more about his daily routine.

Which is why I chose to tell such a story; I wanted to reflect on the situation where the primary caregiver is a "stranger" to the family, and sometimes even treated as if they are a robot. At the same time I wanted to touch on the perspective of the children as well, that although we don't see my father and we are not the primary caregivers, there is also a lot of anxiety, stress, guilt and struggle.

Why do you think it's important for caregivers to take a break?

A: Caregiving can be a sprint, or it can be a marathon. In the case of it being a long-term commitment, you need to know how to conserve your energy. If not, I don't think that anyone can continue to care for someone over a long period of time without taking breaks in between. With helpers, they work almost non-stop, cooking, cleaning, taking care of children and old folks.



I think caring is definitely borne out of love, but caring is also borne out of responsibility.

As they say in Hokkien, “You are not made of metal.” Which is ironic because even V8 who is a robot, needs to take a break. It’s important to have a breather to recalibrate yourself.

This is something I try to remind myself as often as possible - to me, life is a series of obstacles, and how well we live our life depends on our approach to these obstacles. Try not to worry or dwell on them too much, because these challenges will pass, and life will go on. You still need to live life. That’s why taking a break is so important for caregivers.

What do you want people to take away from your work?

A: Some people might identify with V8, or see V8 in their friends or other caregivers they have encountered. I hope that this work, whether it is the film or the book, reminds them of the importance of taking a break or giving the caregiver in their family a break. It’s a very simple message – take a break, otherwise it’s very hard to carry on as a caregiver.



From *You Can Take A Break*. Image credit: ampulets

YOURS TRULY

BY DEANNA NG

I worked with a group of parents, mostly mothers. They are caregivers to their children, who are aged 18 and above and have moderate to severe autism. People with moderate to severe autism have fewer opportunities to find employment in our society. Most of them require round-the-clock care. Their parents constantly watch over them.

This series of artworks is a collaborative effort between the parents and myself. I photograph the parents and their children in a double exposed image. The idea of a double exposed image came about as caregiving is an endless task. These people with autism need constant attention from their parents. What happens when they are not together? Does the caregiving stop?

The parents were invited to paint and draw on the canvas printed with their image. This is to express their challenges, dreams and hopes for their children and themselves.



普案 / *It is what it is*. Painting by Tan Ah Yaw, photography by Deanna Ng

Deanna is an independent photographer, artist and educator. She was one of Asia's emerging talents profiled on Nikon's "Through Asian Eyes" campaign in 2011. In 2015, she was one of 60 artists included in the book *Singapore Eye – Contemporary Singapore Art*.

ABOUT THE
ARTIST

Thank you to the caregivers who made this work possible: Tonia Chan, Choo Kah Ying, Lily Chow, Koh Soek-Ying, Peng Wei Yan, Tan Ah Yaw, Tong Mei Leng

ACKNOWLEDGEMENTS

Special thanks to Chen Jing Jing, Carolyn Chew and Benedict Wang

Find out more:

St Andrew's Autism Centre
www.saac.org.sg/index.php

What made you decide to focus on caregiving for young adults with autism?

D: When deciding on the scope of my project, I spoke with the people around me who were caregivers for different groups of people, and I also drew on my own experience as a photography instructor to different communities, including children with chronic illnesses, the elderly, and children with special needs, particularly children with autism. This made me realise that caregiving has a very wide scope. Even within special needs there are different areas to look at, such as Down's Syndrome, cerebral palsy, dyslexia, ADHD, autism and many others.

I finally decided to focus on caregiving for people with moderate to low-functioning autism because of my own experience teaching kids with special needs. I noticed that some of the students were non-verbal, and they always have a domestic worker around or a therapist next to them. During a visit to Rainbow Centre, they also told us that their students have nowhere to go after the age of 18. There is no possibility of educational advancement for them. The responsibility for their care falls solely on the caregivers that they have at home.

Why did you decide to encourage your participants to paint on the photo prints?

D: I feel that there are some things that I cannot capture through photography, such as experiences they may have had in the past, their hopes and dreams for their child, or whatever mentality that they have when it comes to caregiving. So I chose to let them paint, to express their thoughts on caregiving.

I also try to pick out different things from my conversations with them to focus on in the painting itself, so that everybody has different voice or a unique perspective that they can express.

Many people who have children with low-functioning autism do not bring them out to public areas, and don't tell their family about their situation.



Deanna Ng

How did the participants react to the artmaking process?

D: There was a lot of initial resistance to painting, but when they actually started, they really enjoyed it. For many of them, it was a nice break from their daily routine. At first, we set aside two hours for the participants to create their pieces, but this quickly overran to three, even four hours. Everyone left feeling very happy and empowered, including Carolyn, the visual artist who helped with the painting sessions, and myself. Everyone felt they had accomplished something to get their message across.

What did you learn from your participants through this process?

D: My participants are really a mixed bag. Some are hopeful and optimistic, and some are brutally honest about the challenges of caring for people with autism. Some will tell you, "I wish I can be separated from them. If I had known my son had autism, I wouldn't have had him." All of them were concerned about how their children would fend when they passed away.

I also found out from caregivers that many people who have children with low-functioning autism do not bring them out to public areas, and don't tell their family about their situation. These are the cases that we don't see. Several of the participants came into this project because they feel that instances of people with low functioning autism are rarely seen in the media. Their children are non-verbal and go to a day-care centre. There's no way they can find a job and become independent. These participants want to others to know the challenges of caring for people like that.



When love means letting go. Painting by Choo Kah Ying, photography by Deanna Ng



Journey towards hope. Painting by Tonia Chan, photography by Deanna Ng

When we just celebrate these caregivers and all the sacrifices that they made, are we actually doing anything to help them?

One of the things that struck me during the research process, was that there are an overwhelming number of stories out there that talk about the sacrifices that caregivers make for their loved ones. Looking at all these stories actually made me feel quite helpless.

As Kah Ying, one of the participants, pointedly said, "When society celebrates caregiving, it absolves itself of its responsibilities." In a way it is true. When we just celebrate these caregivers and all the sacrifices that they made, are we actually doing anything to help them? What happens to the cases that are not doing so well? As a society, what can we do to help them?

What kind of impact would you like your work to have?

D: I think a work like this is able to open many points of conversation through different stories. On one hand, we have a very loving family who are all involved in caring for their daughter with special needs and mothers who hope for a bright future for their children. On the other hand, there are mothers who want to share the hardship and challenges of caring for someone with low-functioning autism. And almost in the centre, we have someone like Kah Yin, who is asking questions about the big picture, about society's role in caregiving.

Tell us about your caregiving journey

AY: My sister looked after my son till he was four years old, because I was having issues with my health. When I took over as his caregiver, his autism started to manifest. He started making a nuisance of himself by doing things like unrolling toilet paper. He still does that, which is why I need to watch him so closely.

I had a hard time with mainstream kindergartens, because he was very disruptive and the teachers didn't want him to mix with the other children. We had to keep changing schools, because he was always eventually asked to leave. When he was diagnosed with autism at the age of five, I became aware of our options through the Autism Association. Back then, there was very little information available on how to care for people with autism.

He started going to Rainbow Centre, but those times were still difficult. He refused to sleep at night and had a hard time waking up in the morning. Things got better when he started at MINDS. He learnt how to sit down quietly and to queue. The biggest improvement came when he started taking medication at the age of eight, which regulated his sleep patterns and stabilized his behaviour. That was a great relief to me.

I also preferred putting him in MINDS because he would be in school five days a week. It was very tiring to care for him all the time. If only he could have stayed in MINDS forever! But he had to leave when he turned 18. Now, he goes to SUN-DAC day activity centre five days a week, which gives me a break from caring for him. Holidays are tiring because I need to watch over him all the time.

He's very disruptive and noisy. It drives me crazy. He seldom has meltdowns but when he does, he is difficult to control. He only has a very basic command of language, so I invented my own system for communicating with him. I allocate different options to my fingers and ask him to make a choice.

"I've had to take care of him through my own illness and injuries. I try my best. I know that it's for a lifetime."

I use a numbered lock to secure the front door, because he might wander off and get lost. It's happened before. I also need to latch the kitchen in case he eats too much and makes a mess. I need to watch him constantly and clean up after him.

It's stressful bringing him out on public transport because I'm afraid he might disturb others, so I tend to hang out nearby. I won't go far unless I'm accompanied by people who can help manage him, like the other mothers from my support group.

I've been looking into more long-term care options for him, because I'm worried about his care if something happens to me. I hope that my son passes away before me, because I don't think anyone will look after him. Even my own family refuses to look after him. I've had to take care of him through my own illness and injuries. I try my best. I know that it's for a lifetime.

What would you tell someone who has a child with autism?

AY: I might sound pessimistic, but keep your expectations low. Just be grateful if they are obedient and aren't too disruptive.

My son also has epilepsy. Because of that, I can't travel overseas. I can't even go to Sentosa, because the light show triggers his fits. This is a great regret of mine. I resent my son for affecting my life this way. Even then, I do a lot for him; I massage his legs and clean his teeth everyday. I'm very protective and will not tolerate any ill treatment of him. But I definitely feel resentful and frustrated.

It's only the both of us at home. My husband and I are separated, and I only continue to see him in the hope that he will help look after my son eventually. If not for my son, I would have cut off relations long ago.

You're being very honest.

AY: There is resentment and there is love. When he behaves well, I feel proud of him. I'm a very frank person. What hope is there? It has been so many years and I know that he is only capable of so much.

How do you cope with caregiving?

AY: I used to share my frustrations with friends. I called them so often that they refused to answer my calls. That was when things were particularly bad – my marriage was falling apart, my son's diagnosis was fresh. I used to be so lonely.

Nowadays, I love looking at Facebook, reading the papers and watching TV. I also belong to a support group for mothers of people with autism, and that has really helped me. We go on outings together and share our experiences with each other.

“Not everyone who has autism has a special talent or is able to be independent.”

“The media should showcase people who are lower functioning, who require more care.”

What do you think society should know about caring for people with autism?

AY: My experiences in public have been fine. Even though my son has a tendency to snatch food and drink off random tables, people are usually understanding. Some even offer to help.

But I think that the media should portray people with autism more accurately. Not everyone who has autism has a special talent or is able to be independent. The ones in the limelight are all talented and capable. Because of these depictions, people sometimes tell me, “People with autism are so gifted!” That is true for some, but they need to know about the other side of things. My son doesn't have these abilities – I am grateful if he just obeys me and is docile.

The media should showcase people who are lower functioning, who require more care. They should share stories about the difficulties of caring for a person with severe autism, so that the public has a better understanding of what we go through.

OLD HEROES SOLVE MYSTERY

BY GWEE LI SUI

Old Heroes Solve Mystery is a mystery adventure comic involving three old men who live in the same neighbourhood. They are all care-receivers. The story follows their investigation into recent strange happenings around their area, during which we get a glimpse into their more mundane hours with their caregivers.

My project is modest in scope. I wish simply to depict the process of ageing and the routine of caring for another as normal. In passing, I also wish to point to the innate life of the elderly. The comic's vibrancy is meant to challenge and counteract the stigma often attached to giving and receiving care in ageing Singapore.

What I hope to affirm is a working, ordinary network of day-to-day support for the old. The story's three friends illustrate three main kinds of elderly dependency at home: on a domestic worker, on a spouse, and on a child. I have relied on direct experiences, private conversations, and casebooks to create this short work.



Illustrations by Gwee Lee Sui

Gwee Li Sui is a poet, a graphic artist, and a literary critic. He wrote Singapore's first long-form graphic novel in English, *Myth of the Stone*, in 1993 and has six volumes of poetry to date. He is also the author of the bestselling *Spikings English: A Companion to How Singaporeans Communicate*. A familiar name in Singapore's cultural scene, Gwee has edited several acclaimed literary anthologies and written and lectured on a range of subjects.

Special thanks to my family and relatives, friends Kumar, Ghawry, and Soo Lian, Dr Jacqueline Chin, NUS Centre for Biomedical Ethics, Jubilee Church, and Pekik Jalan Kukoh for varying forms of assistance.

ABOUT THE
ARTIST

ACKNOWLEDGEMENTS

Find out more:

The Bioethics Casebook: Caring for Older People in an Ageing Society, and Making Difficult Decisions with Patients and Families
www.bioethicscasebook.sg

How did the idea for your comic come about?

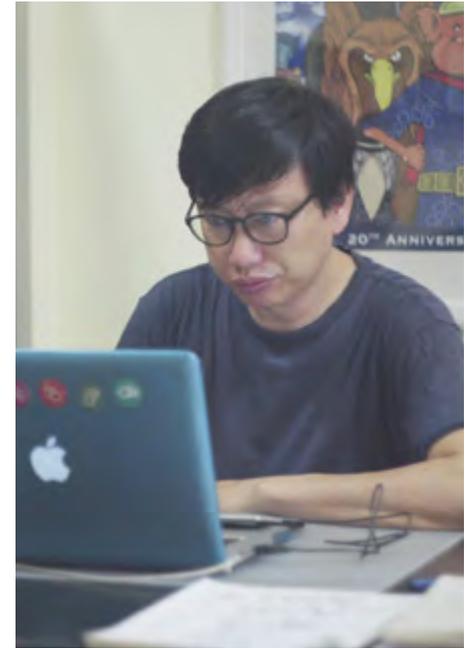
LS: I want to show that the elderly are still capable of going on adventures and to show the supportive role that is played by the caregivers. The point is to normalise the process of ageing and caring for the aged.

We currently still view people who receive care with a kind of stigma in that we don't really understand the kind of challenges associated with caregiving enough to help them on their journey. We see them around as our neighbours, our relatives, but we don't understand what growing old means and how it can affect a person's personality and routine. So we tend to view and treat them negatively because they tend to behave differently.

It's also a real thing for me. My parents are in their 80s and whether I like it or not, I am a caregiver. My father is also a caregiver for my mother. In fact, my extended family is overwhelmed with old people, and we have to find ways to support each other. It's the same for my friends.

What was your research process like?

LS: I wanted to observe different caregiving arrangements, and how they impact the relationship between the elderly and their caregivers. So I began by speaking to my relatives, my friends, and their parents, and looked at my own situation at home. I also joined a food distribution group in Jalan Kukoh and hung out in older estates to understand how the elderly interacted with each other. Lastly, a workshop organised by the NUS Centre for Biomedical Ethics helped me understand the psychological aspect of decision-making with regard to caregiving for the elderly.



Gwee Li Sui

I found that relationships definitely change once you start to take on a caregiving role. For example, parents are used to providing for their children, but now the roles are reversed. Not a lot of Asian parents are used to communicating their needs, anxieties, and worries clearly to their children, but they want their children to understand and respond accordingly. One lady I spoke to doesn't know how to tell her daughter that she wanted to know more about dementia, without the daughter worrying that she has dementia. Little things like these create communication issues.

As a caregiver, you're in a position where you lead a double life. Previously, you only had to worry about yourself, but, if you have an ageing parent or someone to look after, you have to find time for him or her within the day.

How did you come up with the different caregiving situations the three elderly characters have in your story?

LS: Through my research, I realise that the three situations are typical of what we encounter today. The most obvious one is probably the domestic worker. That is a growing reality; some families have two working adults, and they need someone to be at home. The domestic worker has to become part of the family and yet not presume too much. Their role is quite tricky; they have to be there to help the elderly person but then disappear enough for the person to feel independent. It's a difficult balance of how to empower and yet assist.

I guess family members ought to understand that as well, but at least they can talk it out. And this is something that I tried to deal with in my story for the relationship between husband and wife. That has a level of tenderness that a relationship between an elderly person and a domestic worker doesn't have. It's not so much one looking after the other, but both of them looking after each other.

The third one deals with people who have made the decision to move into a parent's life in order to look after him. The caregiver has to juggle a lot of things: their work and looking after their children and their parents.

Did working on this project change any preconceptions that you had about caregiving?

LS: One of the main preconceptions that I had going into the project was that it was going to be about responsibility and duty. But I realised increasingly that it's about the bond between caregiver and care-receiver. It came up a number of times during my interviews—a family caregiver does this or that for their charge out of love, and it is this love that makes the work worthwhile and necessary.



As a caregiver, you're in a position where you lead a double life. Previously, you only had to worry about yourself, but, if you have an ageing parent or someone to look after, you have to find time for him or her within the day.

This is something that I don't hear much about when people talk about caregiving. We take for granted the strength of emotional attachment. You must remember that, for caregivers, they don't really need to bother especially when they are not employed for that role. Why fit the needs of another person into your life? It's because of the special bond that they have.

What would you like people to take away from your work?

LS: For a young person, I hope that they will realise that they will be a caregiver or that they will need care one day. I hope that they will realise that this is not someone else's life, someone else's truth, but something that will hit them at one point. To learn to embrace this as their future.

For someone who is already in a similar situation, I hope they will understand that they are not alone. What they are going through is part of who we are and how Singapore will increasingly become. In general, I think that everyone should learn how to be comfortable with a Singapore where caregiving is an integral part of how we move on together.

Tell us about your caregiving journey.

F: It started in 2009, when my wife started to show signs of mental illness. She blew up one day, became violent, and had to be admitted to the Institute of Mental Health (IMH). It was a very bad incident; I had to call the police, and they handcuffed her. When they did that, I broke down, and it also made her hate me. She didn't allow me to see her in hospital, until she found out that I was the only person who could get her out.

We discovered that she had a hypothyroid problem, and that was contributing to her mood swings and psychosis. After she was discharged, she was quite disciplined about taking her medication and she got much better. She went back to doing her chores, got involved in church activities, and even did some part-time work. She was doing pretty well.

After some time had passed, she decided that she was well enough to stop taking her medication, and that caused a new set of problems. I couldn't monitor her because she refused to tell me anything. She stopped going to the doctor, and I had to go on her behalf to keep the appointments going. She was getting more violent at home; smashing kitchenware, damaging furniture, cutting up all our clothing. Once I put on a shirt to go to work and I realise that she had cut off all the buttons. It was crazy. It was a really tough challenge.

Nowadays I try to understand what she is going through by talking to her, holding her hands to calm her down. No more loud words, no more emotional outbursts and anger. I've begun to realise that she's got a lot of fear in her.

My biggest fear is that, if we don't treat her illness now, her problems will get worse if she gets dementia. So I'm praying that she will get better. I have been talking to her, trying to get her to take her medication and see the doctor, and it seems to be working. The doctor said that her recovery could take years. I am prepared to make that journey.

“What keeps me going is faith and trust. To me, if you don't have faith in a higher power, this kind of situation is impossible to deal with. My faith helps lift me up from this situation.”

How do you cope with the demands of caregiving?

F: I run marathons to deal with my stress. I make it a point to do every Standard Chartered Run and SAFRA Run. I run two to three times a week. I have two daughters so I have to make sure that I am healthy so that I can take care of everyone.

What keeps me going is faith and trust. To me, if you don't have faith in a higher power, this kind of situation is impossible to deal with. My faith helps lift me up from this situation.

Till today, I find it difficult to talk to others about my wife. I can't even count the number of people who know about my situation with one hand. My daughters tell me that I have to talk to someone. They have warned me many times not to bottle it up.

I don't know. I find it very difficult to talk about my wife. I love her so much that I dare not show the world what she has been through. She doesn't like to talk about it with others either. But I recently overheard her sharing with some friends, and I thought it was good that she was at least accepting her illness.

Actually I am praying that she will come back. I hope that we can go back to what we were before.

“Caregiving needs to be more easily available. We have an ageing population, and people still want to work, but have to take care of their parents, their family.

What are the positive aspects of caregiving?

F: I realise that I have been taking too many things for granted. My wife cooks every meal; she takes care of the house. Everything is done for us. I help out on the weekends, but I realised that there was a lot that she was doing quietly. It hit me especially hard when she was down. I didn't appreciate her until I had to take over.

There were other things I took for granted, like the time we used to spend together. We used to go on mountain climbing trips before we had children. Now, she is a bit more sensitive to me going out on my own, so I just try to manage it by staying at home and letting her go out more. I want her to have an outlet.

What do you think people need to know about mental illness?

F: There needs to be more education in schools to tell people that mental illness is just another illness. This stigma around mental illness is very hard to change. Even though things in Singapore are changing and there is a lot of advocacy going on, people with mental illness are still ostracised in the job market, in society. There is this fear of people with mental illness. That's why my wife was against going to IMH for treatment. She felt that if she went to IMH, people would know about her illness. I tried to get her treated at another hospital, but that didn't work out.

What do you think society needs to know about caregiving?

F: Caregiving needs to be more easily available. We have an ageing population, and people still want to work, but have to take care of their parents, their family. We need volunteers. The government needs to come in and pump in some money. Sometimes it's very painful to see my friends put their parents into nursing homes, but they have no choice. Parents would love to stay in their own homes, but who is going to care for them?

How did the Caregiver-to-Caregiver Education Programme (C2C) at Caregiver's Alliance help you?

F: It helped me understand the symptoms of certain illnesses, and to manage people with mental illness. For instance, when they are aggressive, don't be aggressive too. That helped change me from a very quick-tempered guy to someone very calm. I realised I had tone down, go slow, and not set my expectations too high. Also when caregivers share, it helps you make the connection with other people going through the same thing. We are all learning from each other, because there is no one cure for mental illness.

I am now a volunteer trainer at C2C. I feel that by doing so, I am doing my part to build a pool of caregivers and advocates.

SAY YES TO INCLUSION

BY JOSEPH CHIANG

Say Yes to Inclusion examines the importance of inclusion for children with special needs in early childhood education. As we aim to move towards an inclusive society where no one is left behind, there is no better time to introduce to our children, irrespective of their backgrounds or needs, the importance of difference and diversity. Through inclusion at a young age, children can grow up to embrace all individuals and be more accepting of people who are different from them, thereby building a more inclusive society.

Through a series of bold, two-colour linocut prints, hand-printed in the style of vintage political propaganda posters, the work serves to advocate as well as educate the public about inclusion. The posters are supplemented by an illustrated booklet to help everyone's understanding of inclusion, its importance and the issues related to it. Viewers can make their own mark on the blank pages of the booklets with rubber stamps that have been specially designed and adapted from the prints.

Joseph Chiang is a Singapore-based artist and printmaker. He is the founder of Monster Gallery, a creative print studio. He is also the founder of Young Printmakers League, a mentorship programme supported by Noise Singapore. He was commissioned by the National Arts Council to organise the Contemporary Printmaking Festival as part of Singapore Art Week 2017. He has exhibited internationally, and represented Singapore at the 10th World Triennale of Original Prints and Engravings in Chamalieres, France in 2017.

ABOUT THE ARTIST

Research assistant: Vanessa Leong
Co-illustrator (booklet): Darel Seow
Printing assistant: Yao Yu
Posters printed at the studio of TypsettingSG
Special thanks: Jean Loo

ACKNOWLEDGEMENTS



Illustrations by Joseph Chiang



Find out more:

Lien Foundation Inclusive Attitudes Survey
<https://bit.ly/2NY4Mip>

Kindle Garden
www.kindlegarden.com.sg

Inclusion values all individuals as members of society and ensures disabled individuals equal access and opportunity to flourish in a non-discriminatory, barrier-free environment. Why did you focus on promoting inclusion?

J: I enjoy working with kids, and I generally try to have a more optimistic view of life. My initial approach was to look at how the welfare of young children with special needs could be improved in the context of early childhood education. Factoring in inclusion was a big part of it. But as my research developed, I realised that we first need to change public attitudes towards inclusion, to get people to understand the value of providing opportunities to every child and that differences should be embraced.

What did you discover during the research process?

J: When I started on this project, I was totally new to this idea of inclusion. To help guide my research, I came up with a few questions. Basically, it's about asking what inclusion is, why inclusion, if it's important, why isn't it happening, and how we can go about making inclusion happen.

As part of my research, I visited Kindle Garden and Rainbow Centre, and this really helped to open my eyes, not just to the different possible environments for kids, but to the passion of the teachers. I realised that the teachers are there because they feel for it. It's not just a job.

It's really taught me about the intangible things; that it's not just about improving physical access for children with special needs, it's about breaking down attitudes, to encourage everyone to be more compassionate and welcoming to people of different needs.

Before this, I would say that most of my works are more personal, so this project is very different. After learning more about the challenges that people with special needs face, and about the importance of inclusion, I wanted to create work that would have a stronger impact.

I realised that we first need to change public attitudes towards inclusion, to get people to understand the value of providing opportunities to every child and that differences should be embraced.



Joseph Chiang

The posters have a very strong aesthetic. What made you choose this style?

J: When I started working on the sketches for the posters, I knew that they had to draw attention. I became inspired by posters made during the Chinese Cultural Revolution, because of their distinctive look and the impactful role they played in the propaganda campaigns during that period.

In terms of my work, it's about making a cheeky reference to political propaganda while using the aesthetic for a good cause, which is to educate people about the importance of inclusion. If I can change one person's attitude through the posters and the booklet, I think that this work will have made a difference.

3 ACTS OF REMEMBERING

BY KRAY CHEN

I conducted weekly visits with three different Persons with Dementia (PWD) and their immediate caregivers. During each visit, I tried to ask the same set of questions as a form of “memory experiment”, thinking that the similarities or differences in their responses would provide us glimpses into the conditions of dementia and therefore show the viewers the caregiver’s perspective.

This idea evolved quickly because in order to remain authentic in my engagement with them, I had to respond to their needs and moods more readily and empathetically. The three episodes document the process of friendship and discovery with these PWDs and their caregivers. Each episode is anchored by the question and an activity that became the node that revealed the stories and conditions that envelop their relationships.



From *3 Acts of Remembering*. Image credit: Kray Chen

Kray Chen is a video artist based in Singapore. He works primarily with video, performance and film to craft stories and situations that are angled to observe and comment on Singaporean issues. He has had several solo exhibitions, and has participated in group shows such as Art Stage Singapore 2014, Prudential Eye Awards Exhibition (SG), The Pleasure of Improbable Placements (Spain), Paradis Sans Promesse (France). In 2017, he received the Young Artist Award from the National Arts Council in Singapore.

ABOUT THE ARTIST

Special thanks to

Khoo Lih Yui
Tang Wan Xin
Vidhi Gupta
Ng Wu Gang
Megan Lam
Desiree Tham
Magdalen Chua
Cheong Kah Kit
Ko Shui Min
Wong Pei Ting

Jeffrey Linus Lee and Family
Daniel Lim and Family
Apex Harmony Lodge and staff
Mr Ridhuan
Benjamin Tan
Suraj Upadhiah
Danny Tan and Family
Alecia Neo
Geraldine Kang
Mdm Winnie

ACKNOWLEDGEMENTS

Find out more

St Joseph’s Home
Dusk till Dawn: An Overnight Respite Service for Caregivers of People with Dementia
www.stjh.org.sg

Alzheimer’s Disease Association
Caregivers Support Centre
www.alz.org.sg/csc

Forget Us Not
Initiative aimed at building dementia friendly communities
www.forgetusnot.sg/about.html

Why did you focus on this area of caregiving?

K: I used to live with a grandfather who has dementia, and in general I'm very interested in this idea of memory and how it ties in with one's identity. If you cannot remember who you are, then who are you? So that led me very naturally to thinking about dementia instead of other conditions.

You've interacted with family who are caregivers and professional caregivers through this work. Did you observe any differences?

K: Professional caregivers are in a sort of objective position, in that the care that is given is informed by a philosophy. When I talk to nurses who work in Apex Harmony Lodge for instance, they start their sentences with, "We believe in this, we believe that this is the way to approach a patient with dementia," so on and so forth.

For families, the care starts with loving that person and wanting them to be around. The families whom I spoke to will usually start with a complaint about conflicts and frustration that arise out of caring for someone with dementia, but you know that these complaints come from a position of love.

What impact did the art making process have on you?

K: I would say that it has been quite surprising. My approach as an artist has always been quite critical, in that I start by thinking about the overall topic from a very objective, analytical perspective. I'm aware that a project like this requires a lot of empathy as well, so I tried to take on the challenge of trying to harmonise these two different positions. At times, it was a real struggle for me to set aside my criticality and use a more empathetic approach.

For example, I would plan for a shoot, but when the shoot actually happens, the plan can't be executed, because I need to respond immediately to the mood of the person or his or her behaviour at the time. It becomes me reacting on the spot, having to respond not as a filmmaker but as a person.

This happened with the first family I engaged with, which was the family caring for a grandmother with dementia who loves to buy 4D. My initial plan was to visit her regularly, and ask her to give me a lucky number. But as the weeks went by, we still started off by talking about 4D, but the sessions evolved into friendly chitchat. At the later stages, she was even asking for us, like "how come these people never come this week?" On a personal level, it really is about building relationships with people.

One thing that the nurses at Apex Harmony Lodge said to me, with regard to people with dementia, is that their behaviour, whenever they are angry or moody, is actually a sign of an unfulfilled need.



Kray Chen

What did you learn about caregiving for people with dementia?

K: I learnt about the different degrees of dementia, and I think what I encountered is considered rather mild. In fact, the moments where I interact with them are the milder moments, and from the stories of the caregivers, there are moments that are much more difficult to deal with that perhaps outsiders like myself will never get to see.

I think different families adopt different strategies to deal with the patients. Some families are harsher, stricter. They will tell the person with dementia that they have to do this on their own so that it can help retain some skills and some memories, and they will try to live out their own lives and not over-support the person with dementia. Whereas there are families that take on a totally opposite approach where they provide care very readily and really give 100%. From talking to multiple families, not just the three that I engaged with for the video, I find that there is no one correct way to do it. It really depends on the family's dynamics and personality of the person with dementia. I don't think that anyone can judge the situation better than the families themselves.

One thing that the nurses at Apex Harmony Lodge said to me, with regard to people with dementia, is that their behaviour, whenever they are angry or moody, is actually a sign of an unfulfilled need. That sentence had a really huge impact on me. If I were to apply this concept to everyone in this world, when someone is angry or is behaving oddly, there is some kind of unfulfilled need. I suddenly start to see that, OK, I might have been a little bit too judgmental in the past.

CARES FOR HER MOTHER, 85, WHO HAS DEMENTIA, DYSPHAGIA, AND IS PARALYSED ON THE RIGHT SIDE OF HER BODY. SHE IS BED-RIDDEN.

Tell us about your caregiving journey.

J: I had to resign from my job as a secretary in 2010 to care for my mom, who had suffered a stroke. She had asked me to care for her, because she was uncomfortable with the idea of being cared for by a domestic worker. At the time, I had no knowledge of caregiving. I was in denial at that stage. I thought my mom would get well, and it would be fine. Unfortunately, she was diagnosed with dementia in 2014, and suffered a second stroke in 2017, which paralysed the right side of her body and plunged her into severe dementia. I had a fall that resulted in a hip injury in the same year, which made caring for her even more challenging. She was no longer mobile, and I was also recovering from my own surgery. It was my darkest hour. I had to care for her with stitches that were still raw, while making sure to take care of myself. I found amazing strength during that period.

She requires round-the-clock care. It's a tough job that is physically and emotionally draining. The hardest part is caring for her alone, 24/7. With her dementia, my mom is sometimes unable to sleep, and wakes up crying for her own mother, so I stay up to soothe her. I sleep when she sleeps.

I faithfully tap on the government's caregivers' grant every year to attend courses about caregiving. One thing I've learnt is that it's best to learn more about your loved one's condition when it is still mild. Don't wait till it's at a severe stage. In 2017, I had already anticipated that she would eventually get dysphagia as her dementia worsened, and had attended a course on how to prepare food for her by the time she had trouble swallowing. It's important to me that she receives a high level of care.

How has your mom's condition impacted your relationship with her?

J: Mom has been living with me since 2010. Before that we weren't very close, but since then, our experiences together and caring for her has made me treasure her more. Our bond has somehow grown, and has even intensified as her illness progressed. All these beautiful memories of my mom come into my mind each time I take care of her.

“Caring for a loved one can be a very solitary and long-drawn experience, but positivity and love is important.”

People with dementia sometimes experience brief periods of lucidity. To catch this is a wonderful thing, because that is the time where I can connect with her. She can recognise me, and she knows that I love her and that I am caring for her with love. Sometimes we look at old photographs, and she can tell me exactly what happened in the photo. Sometimes we play music and she can sing along too. She loves Taiwanese singer Teresa Teng. So my mom is still there, and I have just got to hang in there and make her very comfortable, very loved, very safe. This is very important in caregiving. Dementia can rob one's memory, but it cannot rob the love you have for your mom, because it resides in the heart and the soul.

What keeps you going?

J: Caring for a loved one can be a very solitary and long-drawn experience, but positivity and love is important. When my mom naps I surf the Internet and watch TV. I'm very active in my support groups and I catch up with fellow caregivers. I like to meet people and I like to share my experiences with others.

Before my hip fracture, I would go for a jog in the morning before my mom woke up. Now I am waiting for my hip to heal before I can start running again. Before her dementia set in, I used to take my mom to Care Corner¹ nearby for exercise sessions, and continued going there by myself when she decided to stop. Eventually I became an instructor for the group!

I also make sure I have fun. Laughter is the best medicine. Each day is a new experience, and somehow I just move on.

You've shared your caregiving story with many people. What has been their reaction, and what do you think people need to learn about caring for the elderly?

J: People have told me that they find my story inspiring, that I am resilient and courageous. I never expected to get an award for caring for my mom [Janet received the *Extraordinaire Caregiver Award* from Silver Caregivers Co-operative Limited in 2018].

I think that one of the gaps in caregiving is the need to take ownership to care for your loved ones. Even if you have a fantastic domestic worker, family members always must stay on top on things. If you are lucky, you have a domestic worker who knows about caregiving. If not, it's important to educate yourself or give your domestic worker the opportunity to learn. It makes your caregiving journey easier when you understand the disease, so that you know what to anticipate. Caring for the aged is complex. You have to understand their physical and psychological needs.

Mindsets also need to change. The way you think about people is going to affect the way you care for them. Always see the person for the person, and not the illness. They can feel your touch and your love.

"I think that one of the gaps in caregiving is the need to take ownership to care for your loved ones. Even if you have a fantastic domestic worker, family members always must stay on top on things."

"The way you think about people is going to affect the way you care for them. Always see the person for the person, and not the illness. They can feel your touch and your love."

What are your plans for the future?

J: My life has come full circle. I wanted to be a nurse growing up, but didn't have the means to become one. Now, I am learning so much about nursing. Caring for my mother has taught me so many things about health, about the elderly, about diseases, just to name a few. When my mom passes on, I would like to share my knowledge and experience from all these years of caregiving, from knowing zero to becoming a more effective caregiver. It's so important to spread awareness.

I would like to age gracefully by staying connected and giving back to the community. It's important to keep active, keep learning, and eat healthily. Mom has me to take care of her, but I am unmarried. My nephew told me, "Auntie I can foresee you selling this place and moving into a nursing home." Well, before that happens, I'm going to make sure to take good care of myself.

I CARRY YOU IN MY HEART

BY MARY
BERNADETTE LEE

I worked with 11 pairs of caregivers and their loved ones with intellectual disabilities from Rainbow Centre, MINDS and Y-STARS (YMCA Y Art Programme). Over the course of three months, I conducted a series of workshops where they learnt to create clay vessels that represented the relationship they share.

Working with clay teaches one to be patient, sensitive, gentle, firm and open-minded. Caring requires the same approach; it is important to understand each other in order to care effectively as everyone gives and receives love differently.

The process of making the vessels had many transitory and repetitive steps, which paralleled the highs and lows of caregiving; the joy and the pain, the frustration and determination, the pride and disappointment, the growth and the fear, and the giving and taking.

I used clay leftover from the workshops to create sculptural representations of my understanding of relationships in caregiving. Bulbous and stacked, the sculptures embody support and balance, the foundation of a strong relationship.



Kalwant Kour and Joanna Welikande.
From *I Carry You In My Heart*, behind-the-scenes film. Image credit: Mary Bernadette Lee

Mary Bernadette Lee (Mrydette) is an artist based in Singapore. She uses art as a medium to work with the community to encourage expression and creation. Her practice is a phenomenological approach to understanding the relationship between exterior topography of body, and the interior tapestry of psychological states which are expressed through her paintings and sculptures that foreground the architecture of her as a person and an artist.

ABOUT THE
ARTIST

Thank you to the caregivers and their care recipients who made this work possible: Wang Rosyniah, Noah Tan Kai, Marcia Lai Siew Chee, Galvin Tan Eng Huat, Biala Ginalyn Gamose, Filmer Tan Chin Wei, Tan Joo Geok, Kristin Tan Tze Yi, Ho Ai Leng Irene, Gabriel Tan Jun Jie, Nur Aida Sa'ad, Nur Aisha Sa'ad, Kalwant Kour, Joanna Welikande, Cindy Tan Soon Noi, Han Jia Le Joyce, Saw Eng Hock, Saw Yu Yaa Grace, Lim Ai Tee, Ang Zhen Jie, Hwee Hiang, Cui Yin, Doris Hui, Brandon Wong Ling Zheng.

Special thanks to Veronica Lim-Lowe, Ng Tian Hui, Julia, Regina Aun, Lun Wei Shi, and Jasmine Teo
Video by SPROUD, Music by Ferry

ACKNOWLEDGEMENTS



Clay vessels by participants,
illustrated by Mary Bernadette Lee

Find out more

MINDS: Caregivers Resource Package
www.minds.org.sg/Publications.html

Agape Village
Respite Care, Caregiver workshops
www.agape-village.caritas-singapore.org

MINDS Me Too Club!
Programme that enhances the social integration of people with intellectual disabilities (PWIDs) through leisure and befriending activities.
www.minds.org.sg/MeTooClub.html

Rainbow Centre:
Therapy and outreach services
Includes support services for caregivers of people with disabilities
www.rainbowcentre.org.sg/therapy-and-outreach-services

What drew you to working with caregivers of people with special needs?

M: When I was conceptualising this work, I was reminded of a time when I was a kindergarten teacher. There was a child with special needs in a class of 30, and she couldn't keep up with the pace of learning. It also brought me back to another project where I had worked with different communities such as youth-at-risk, people with intellectual disabilities and orphans. These experiences helped solidify my desire to work with people who have a special way of communicating. Most of the time, it's by touch. Touch is a very powerful communication tool.

That's why I embarked on these clay workshops. I hoped that it would bring out that magic in a caregiving relationship between two people. Clay is a very giving medium, and working with it can teach you things about yourself, relationships and people. Clay requires the participant to pay attention and understand its properties. Likewise, with caregiving, you also have to understand who you're caring for, because everyone has different love languages and everyone gives and responds differently.

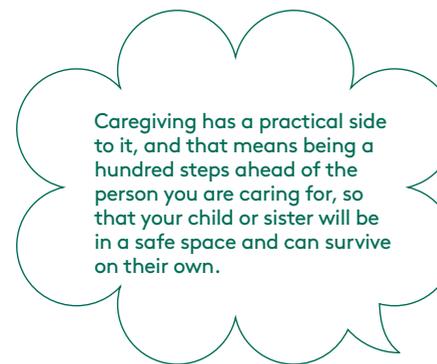
Why did you encourage your participants to create vessels?

M: I was inspired by the love poem, *i carry your heart with me (i carry it in)* by E. E. Cummings. Aside from the deep love and devotion that the poem describes, I was particularly drawn to the word "carry". In caregiving, you carry a lot of things: frustrations, worry, anxiety, but also love, patience and hope for the care recipient. So, a vessel is a representation of the bond that they share with each other.

I started by asking them about the first word that came to their minds when describing their relationship with their care recipients. We then used that as a springboard to creating the vessel that best represented their relationship.

How does your own work respond to the participants' vessels?

M: While I was conducting the workshops, I took my role as an instructor very seriously. If I was hungry or tired, I tried not to show it to give them confidence. I felt that the process was a little like caregiving; it's tiring, but you must still carry on and be strong for the person you are caring for. I applied it to my own work by collecting the leftover clay from the participants, and using it to create my own vessels, that expressed my own understanding of caregiving.



Mary Bernadette Lee

Did this project change any preconceptions you might have had?

M: Before I started the project, I was worried about my ability to deal with tantrums or meltdowns. It turned out that this was the least of my concerns. What I ended up focusing on is how to deliver my lessons in a way that the participants can understand and respond to me, by breaking it down step by step.

The whole process of learning about caregiving also really humbled me. After listening to the participants' stories, I learnt that caregiving has a practical side to it, and that means being a hundred steps ahead of the person you are caring for, so that your child or sister will be in a safe space and can survive on their own. That practical and very realistic, painful side must coexist with the wonderful part of the relationship. It made me understand that we are all in this world, just hoping to make connections, hoping to understand someone, hoping to make an impact on someone.

How did the artmaking process impact your participants?

M: Most of the participants shared that this project has encouraged them to speak up, to face certain fears and to express their love for their child or their sister more clearly. I think it's because we are brought up in a society where we don't typically talk about feelings. During the workshops, I emphasised that it was safe for everyone to share about how they felt about the workshop, about the process, and that we can work things out together. I think this has somewhat helped them realise that it's not difficult to speak up, not that difficult to be in touch with your emotions.

Over the course of the workshops, I noticed that the participants have grown in their own way. Joyce, for example, has an aversion to slimy textures and liquid, and her mother said to not have too many expectations. At the end of the project, she didn't react so negatively to clay anymore, and she really made an effort to do the work together with her mother. Grace started to show interest somewhere in the middle of the entire process. She began by playing with the clay, and when they started to glaze the artworks, she was painting the glaze on with her fingers with so much joy. Even her dad was really pleasantly surprised.

With Kristin, her mother had said, "I don't think my daughter can do this. She may not be interested and I don't want you to be disappointed." But she ended up making a lot of progress. Kristin doesn't really make any eye or physical contact, but she would put her hand on my arm or stand very close to me. She's not very audible but I could understand what she was saying. And that kind of progress is very encouraging to me, as well to her mom.

What do you hope viewers will take away from the artwork?

M: I hope that the audience will really think about the intention and the purpose behind the things that they do. I also hope to generate dialogue among professionals, among teachers, engineers, scientists, whoever, to talk about social issues that we have been evading or turning a blind eye to. Inclusion is a very trendy topic these days but what does it really mean? And that is something that the exhibition can help to work towards, to raise the bar about talking about what does it mean to be inclusive, what does it mean to show respect, what does it mean to care for people with intellectual disabilities or other needs.



Clay vessels by participants, illustrated by Mary Bernadette Lee



Top image, left to right: Gabriel Tan, Irene Ho, Noah Tan, Wang Rosyniah
Centre: Joyce Han and Cindy Tan
Bottom: Saw Eng Hock and Grace Saw

From *I Carry You In My Heart*, behind-the-scenes film. Image credit: Mary Bernadette Lee

PRESENCE (存在)

BY SUN KOH

Presence is a 360 film which places the viewer in the presence of a family that is witnessing the death of a loved one at home. The title also refers to the most important yet overlooked aspect of caring for a dying person. One can provide the best palliative care by hiring professionals and ensuring material comfort, but it is your presence that will make all the difference to a dying person.

Palliative care for the terminally ill is a nuanced profession which requires enormous empathy and people management skills. While caring and fighting for the rights and dignity of a dying patient, a palliative care worker has to meet the demands of the patient's family members who are often their employers. Family members are by default also caregivers. The difference lies in the latter's relationship with the dying patient and family dynamics, which can affect the welfare of the very person they are caring for.



Presence (存在). Image credit: Gin Lee

Sun Koh is an award-winning filmmaker whose films have competed and screened in more than 30 film festivals worldwide. She has worked in countries such as Singapore, China and Sweden, and her filmography is a diverse mix of format, genres and styles including short films, TV movies, omnibus features, documentary films and music videos both commissioned and independent. She received the National Arts Council's Young Artist Award in 2010.

Special thanks to the Singapore Hospice Council, Hospice Care Association, Nectar Care Services and the various individuals who stepped forward to offer their personal expertise and experience for the benefit of our production.

ABOUT THE
ARTIST

ACKNOWLEDGEMENTS

Find out more

Singapore Hospice Council
Caregiver support and services
www.singaporehospice.org.sg

Hospice Care Association
Caregiver support and training
www.hca.org.sg

Your film, *Presence*, enables us to be immersed in the last hours of a dying man's life. What inspired you to tell this story?

S: A few years ago, my father came very close to dying. He managed to bounce back and is healthy now, but ever since that encounter, I have been curious about caregiving for the dying. Also, dying is something that all of us will have to confront one day, but the taboos around death prevent us from finding out more. I think that we should have an open and healthy attitude towards dealing with death, as we do towards life.

What did you find out in the course of your research?

S: Before I started my research, I assumed that palliative care is about keeping the patient comfortable. This is basically true, but the process is very complex. I spoke to many people about caring for the dying — family members, social workers, palliative care workers, medical workers, and counsellors. The more I found out, the more vast I realised this area of care was.

One thing that really surprised me was how many palliative care services there are. It's mindboggling. I can imagine it being very overwhelming for a caregiver who needs to make decisions. But at the same time, I'm comforted that they are there. For example, there are organisations that befriend the elderly to prepare them for their own death. Most of us would probably not think of it as caregiving for the dying, but it's important spiritual support.

On the other end of the spectrum, there are agencies that provide live-in professional caregivers, who almost become a family member in the process of caring for your loved ones. And then there are medical workers who have very specialised knowledge, as well as counsellors and social workers.

After talking to a lot of caregivers, I realised that the most important quality in caregiving is empathy. Only when you have empathy can you start seeing the patient as a being deserving of equal care as yourself.



Sun Koh

What about the challenges that family members face?

S: According to health professionals I spoke to, the number one thing that affects family members is guilt. They ask themselves if they are doing enough. Guilt is behind a lot of the conflict and struggle that family members go through between themselves or with professional caregivers. Typically, everyone in the family has their own ideas on how to administer care, and it often stems from some sort of guilt. But the actions they perform might not be in the best interest of the patient. It is the job of a professional caregiver to fight for the wishes of the patient, as opposed to ceding to the wishes of the family.

I tried to bring this out in the film; the family keeps asking why Ah Gong isn't using the oxygen mask. They don't understand that forcing the oxygen mask on him at that point would make themselves feel better, but it would be pointless and very uncomfortable for Ah Gong.

Why did you choose to set the film at home?

S: To me, the most humane and dignified way to go is to die at home. People who are near death already have very little control over their environment and how death descends upon them. At home, at least things can be the way more or less that they want them to be.

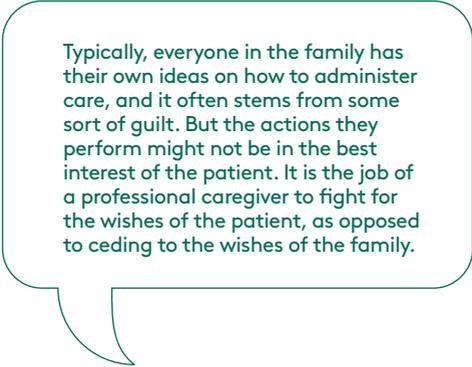
Family members can be with them more often. To this end, I wanted to show a home hospice, which might be unfamiliar to most of us. Your home has to be adapted in ways that disrupt your usual way of life, like having a hospital bed in the living room and medical equipment lying around.

My main resource in this project was the Hospice Care Association. They are an amazing organisation that strives to make palliative care accessible to everyone. One of their main services is to provide caregivers with the means to deliver palliative care at home, so that the patient can be surrounded by their loved ones in a familiar environment.

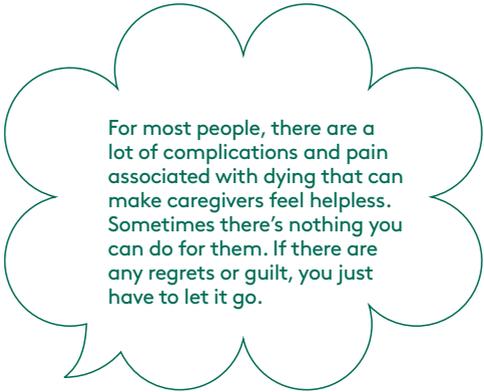
Why did you choose to make a 360 film?

S: After talking to a lot of caregivers, I realised that the most important quality in caregiving is empathy. Only when you have empathy can you start seeing the patient as a being deserving of equal care as yourself. I also realised that sometimes the best care is simply your presence.

That's why I chose 360 as a medium. It lets the viewer take on the perspective of a character that is present in the scene. For 12 minutes you are in someone else's reality. I think this is the closest I can bring someone to witness and empathise with this process of caring for the dying.



Typically, everyone in the family has their own ideas on how to administer care, and it often stems from some sort of guilt. But the actions they perform might not be in the best interest of the patient. It is the job of a professional caregiver to fight for the wishes of the patient, as opposed to ceding to the wishes of the family.



For most people, there are a lot of complications and pain associated with dying that can make caregivers feel helpless. Sometimes there's nothing you can do for them. If there are any regrets or guilt, you just have to let it go.

What were the difficulties you encountered in making a 360 film?

S: I was totally out of my comfort zone. In a conventional film, you direct *everything* that you want to appear or exclude, and then construct the rhythm, pacing, and even the performances to some extent through editing. These are very important creative decisions.

In 360 filmmaking, there's no such thing. The camera sees everything, and you have no control over what the viewer chooses to see. The only choice you have is where to place the camera, how the actors perform, and when a scene starts and ends. It is very hard to work in a medium where the rules have not been established.

One of the other difficulties was keeping it authentic. We consulted with a nurse who has decades of experience in caring for the dying. She was also on set to teach the actors what to do. In the end, we know that this is still not the real thing, but it's the closest we can bring the viewers to it given our current understanding and resources.

What do you want people to take away from the film?

S: In the film, we tried to portray some of the very common struggles that family members go through in caring for a dying person. If nothing else, I hope that viewers will feel a little bit less afraid of what is to come. That it will open up a little space in them to want to find out more about this process. For most people, there are a lot of complications and pain associated with dying that can make caregivers feel helpless. Sometimes there's nothing you can do for them. If there are any regrets or guilt, you just have to let it go.

RESOURCES FOR CAREGIVERS

For caregivers of the elderly

TOUCH Caregivers Support
www.caregivers.org.sg

Singapore Silver Pages
www.silverpages.sg/caregiving

For caregivers of people with mental illness

Caregivers Alliance
www.cal.org.sg

Alzheimer's Disease Association
www.alz.org.sg

For caregivers of the elderly and people with special needs

SG Enable
www.sgenable.sg

Family Caregiver Alliance
www.caregiver.org

AWWA Caregiver Service
www.awwa.org.sg

Caregivers Training Grant

For caregivers of people with special needs

MINDS Caregivers Support Services
www.minds.org/caresupportgroup.html

The Special Needs Trust Company
www.sntc.org.sg

Enabling Village
www.enablingvillage.sg

For caregivers of chronically ill children

Club Rainbow
www.clubrainbow.org

About the Lien Foundation

The Lien Foundation is a Singapore philanthropic house noted for its model of radical philanthropy. It breaks new ground by investing in innovative solutions, convening strategic partnerships and catalysing action on social and environmental challenges. The Foundation seeks to foster exemplary early childhood education, excellence in eldercare and effective environmental sustainability in water and sanitation.

www.lienfoundation.org

About Ngee Ann Polytechnic

Ngee Ann Polytechnic started in 1963 and is today one of Singapore's leading institutions of higher learning with 15,000 enrolled students in over 40 disciplines. It seeks to develop students with a passion for learning, values for life, and competencies to thrive in a global workplace.

www.np.edu.sg

About Objectifs Centre for Photography and Film

Objectifs is a non-profit arts space dedicated to film and photography. Our mission is to broaden perspectives and inspire through the power of images. We present exhibitions, screenings, workshops, talks and residencies, aimed at fostering dialogue, and advancing the practice and appreciation of photography and film.

www.objectifs.com.sg

