

Informed Practice

The Art Cabriolet adopts a trauma-informed practice. The Blue Sky program is a holistic, supportive and inclusive approach. By applying multiple creative resources, individuals utilize their unique strengths and abilities to thrive and not merely survive. Further, Creative Arts Therapies are considered trauma-informed because of their ability to allow for processing of the trauma narrative through nonverbal expressions (Malchiodi, 2007; 2014). Incorporating Creative Arts Therapies into treatment plans helps clarify emotional, physical and psychological difficulties encountered in progressive stages of illness.

The act of being creative allows for children and families to express themselves where there are no words. Language does not get in the way of art making and when we are at our most vulnerable and grief stricken there are no words that can even come close to what we are experiencing. Art opens the doors to those unspoken moments and through image allows for healing. Art becomes the new language through which children and families can express their painful emotions.

Qualified art therapists who uphold a person-centered approach facilitate the Blue Sky program. Each session considers the suitability of the needs of the families and is structured for flexibility depending on the aptitude of the individuals. Blue Sky offers a safe expression of hard emotions, such as, fear, anger and grief, which surrounds death and dying. It aims to meet the broad range of these families' social, emotional, intellectual and creative needs.

Program rationale

The children involved in the Blue Sky Program ranged from 12 months to 18 years of age and at various stages of their terminal illness. All End of Life (EOL) children either resided at Very Special Kids (VSK) hospice or received outreach support in their homes. Other beneficiaries of the program are children of the same age group who are being treated for chronic life-threatening illness at the Children's Cancer Centre, Monash Pediatric Clayton. These collaborations have enabled families to be holistically supported and has given them an opportunity to create a lasting legacy of their dying child/adolescent. It also develops platforms create positive energy and memories to be harnessed in clinical settings.

Often parents do not talk to the child about death as they think it is better for the child or the child does not understand. Partly because parents want to protect their child from such knowledge, but mostly it

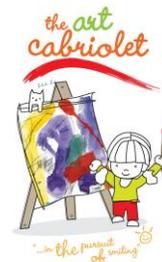


is that when death involves a child the discomfort is intensified. (Bertoia, 1993). But if no one talks to the child then how does the child fill in the blanks of frightening experiences they create in their imaginations? Experience indicates that at some point in their condition, children know they are dying. (Kubler-Ross, 1983). Kubler-Ross posits that children's understanding of their own death is expressed symbolically and non-verbally through art or play. Some were also able to verbalize, 'I know I'm going to die very soon and just have to talk to someone about it' (Kubler-Ross, 1983. pp. 21). Art becomes the tool connecting the dying child with not only the art therapist but their family as well.

The intention of Blue Sky is to provide a safe space for the dying child/adolescent or the chronically ill child enduring a life-threatening condition, where they can begin confronting painful emotions through engaging art processes. In many of the sessions, Blue Sky also allows for siblings and families to also express themselves creatively. The art sessions aim to build relationships through creative exploration and provide a space for positive memories and meaning making. Creative Art Therapy transcends words, allowing visual representation of an emotion/feeling where language limits expression. It bridges the gap in communicating tough emotions and when used within a bereavement support group, it becomes a powerful tool for healing. (Finn, 2003; Malchiodi, 2013).

Blue Sky Provisions

- Qualified Art Therapist, carefully screened art therapy students and volunteers
- Canvases 1000 x 1000 mm or 1000 mm high balsa wood tree, as required
- Canvases of various sizes and base materials
- Assistance in dealing with eminent death by communicating through the process of making art
- Work with siblings, parents, extended family
- Unlimited time frame spent with our team
- All consumables including canvases, paint supplies and brushes
- Evaluations of outcomes
- Work conducted at Monash Children's Cancer Centre, Clayton, Very Special Kids, Malvern as well as outreach work throughout greater Melbourne area.



Summary

2013 – The tender work begins

This was the first year that the Art Cabriolet became involved with end of life work. Our very first child was a patient in the Royal Children's Hospital and our team worked with him and his family around the clock until his death.

2014 – Number of children: 2

In 2014 we were invited to work with a child from home and visited her weekly for 5 weeks before she became too ill to participate. Her family was left with a large tree that she started and which her family completed after her death. Later that year the Art Cabriolet ran a pilot program at Very Special Kids Hospice, with a dying child and her family. It was from this pilot that the Art Cabriolet began a collaborative partnership with Very Special Kids which is still current today.

2015 – Number of children: 4

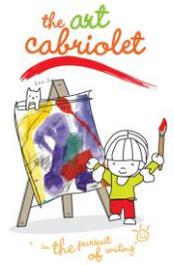
We began working for 3 hours 4 days a week at the Very Special Children Hospice with children who were staying for respite. During this time our team was asked to work with the 4 children who came into the hospice for end of life, or came in already deceased. This is common among families that after the death of their child they want something of their child to be captured on canvas. The Art Cabriolet have qualified compassionate art therapists that can hold this space with dignity and respect.

2016 – Number of children: 9

As funding increased the Art Cabriolet was able to reach out to more families. The demand was greater than the nine children we worked with but we were unable to do more due to monetary limitations. Two of these children were funded by the Victorian Paediatric Palliative Care Program, but unfortunately, this was not ongoing. We had to turn away 3 more requests to work from home because of lack of funding. The remaining children were children who came into the hospice.

2017 – Number of children: 11

This year we solely worked with children at the hospice as funding from Victorian Paediatric Palliative Care Program was not available. Two of these children came into the hospice deceased and the art therapists worked with siblings as well as gathering prints from the deceased child for the legacy art.



2018 –

So far this year, the Art Cabriolet have worked with 10 children/adolescents, who have been at the hospice for end of life or at home with disease progression. Some of these children may come into the hospice as they are closer to final stages of dying. The Art Cabriolet have also been working closely with one bereaved sibling who has been needing extra support. As the Art Cabriolet broadens it reach because of more funding, we are able to get involved with outreach work and we are now accessing more children who are at home.

There is so much more we could be doing to support these families and so many more families we could reach if we had a committed sponsor of this incredibly significant work.

Disclaimer: names have been changed to protect the privacy of individuals

Teresa Age 5 - (deceased)

- Hypoxic brain injury result of birth asphyxia.
- Teresa was a child I had worked with her for 2 years at VSK, so I knew her very well.
- Worked with her at the final hours of her death to create a legacy piece.
- Mum and step father were in room as I worked and although she was unconscious her body actually responded to the paint. Body memory?? She even smiled at the end of the session when I made a comment about her beautiful hand-prints and how they will transform into owls - her sister made hand-prints too
- Worked with her sister and family to create hand-prints together.

Jess Age 3 months - (deceased)

- Undiagnosed genetic condition
- Jess had not been to the hospice but family wanted hand and footprints
- Worked on legacy piece as family did not stay long at hospice
- There were 3 siblings and the family overall were highly erratic and distressed - would have been great to have had the opportunity to offer AT in their home

Merysa Age 8 - (deceased)

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Blue Sky Report

V1 September 11th 2018



- Dravet Syndrome
- We have worked with Merysa since 2015 and her death was sudden.
- She had a limited capacity to focus and understand instruction, but through art making she was able to develop a sense of intention and hand eye coordination.
- Her confidence with art making was apparent with each session.
- Merysa leaves many very *pink* art pieces that her family treasure.

Jakob Age 10 - (deceased)

- Cerebral Palsy; Global Developmental Delay & epilepsy
- We have worked with Jakob since 2014 and his death was due to his deteriorating condition and respiratory failure.
- Jakob had created many canvases that are hung up on the walls at home, including his infamous “Dinosaur Stomp” painting – he left a huge legacy.

Danniel Age 16 - (deceased)

- Malignant Glioma (brain cancer) that spread into his spine
- Danniel came into the hospice to specifically do an art legacy piece with his family.
- The art session was also a way to introduce the hospice to him and his family as a possible place for his EOL
- The Art Cabriolet facilitated 3 sessions with him and his family and also had a chance to work with him solely to create his own piece of art
- During his stay the art therapist would check in on him and chat to build rapport/relationship – build trust and safety
- If able to work at home with Danniel, there is potential to work more one on one with him and deepen the work we could do as Danniel is aware of his condition and is also been given the control of his treatment.
- Danniel is currently at home and stabilized. When he left the hospice, he was remaining more in bed and needing a wheelchair to get around. Pain has been managed at this stage. UPDATE: Danniel died at home peacefully

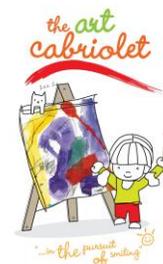


Calliem Age 3 - (deceased)

- Undiagnosed genetic condition; epilepsy; chronic lung disease; deaf; sever hypotonia; development delay
- The Art Cabriolet has worked with Calliem over the last 2 years
- He came to emergency respite at the hospice last week for EOL because his condition suddenly deteriorated in the last couple of months
- Working at the hospice, the Art Cabriolet is helping create a legacy piece for Calliem's family
- Calliem's 6-year-old sister, Rebecca, is staying at hospice accommodation with their mum and has been traumatised by a few incidents where Calliem stopped breathing.
- Rebecca was very quiet and subdued when the art therapist first met her. Her body posture was closed- head lowered; not much eye contact; not verbalising – just nodding/shaking head for yes or no.
- After initial art session where we worked outside on large sheet of paper, Rebecca's demeanour transformed. As she began using hands and feet and physically applying the paint she moved into a more open and engaged posture.
- Second art session with Rebecca occurred after Calliem died and saw her express her anger through "*angry elephants*" – where she used her hands to stamp out a paper full of handprints. Once the angry energy dispersed she began smoothing over the paint and then created an "C" for Calliem.
- Continuing working with Rebecca at the hospice during school holidays. Future sessions for Sept/Oct school holidays.

Hugh Age 17 – (deceased)

- Cerebral Palsy; uncontrolled epilepsy; died from complications arising from his condition.
- The Art Cabriolet has worked with Hugh over 3 years at the hospice.
- He had very little facial expression and total inability to move – but when he painted with the art therapist he became incredibly animated. Making art connected Hugh and the art therapist, and we would often get smiles as well as eye contact during art making.



Jayson Age 2 - (deceased)

- Brain tumour diffuse intrinsic pontine glioma. He has a right-sided hemiplegia.
- He came to hospice this week with father and brother, Rob staying in accommodation.
- The family lost mum to brain cancer (unrelated to Jayson's tumour) 8 months ago.
- The Art Cabriolet art therapist worked with his 6-year-old brother, Rob while Jayson was kept comfortable at hospice.
- Rob came in every day to create art and started a giant elephant sculpture.
- Rob was very clingy with dad and would need some time to warm up before dad could leave. The time it took for Rob to warm up lessened with each day. He grew more confident and open with each art session.
- After Jayson's death, the art therapist was requested to take his handprints and footprints for a legacy piece – father initially showed no interest in creating legacy piece.

Bridgette Age 15 - (home for EOL)

- Osteosarcoma (bone cancer)
- Had right leg amputated from knee and now has prosthetic
- The Art Cabriolet are working with her to create mural – street art; skateboard art as well as art processes that help develop self-awareness and self-reflection
- Connecting with street artist to custom design art her prosthetic
- Giving Bridgette autonomy with this project and making this her legacy
- The Art Cabriolet has been the only therapeutic team that has been accepted by Bridgette. Through the connection we have made has allowed for a VSK support worker to also step in to help assist the family.

Geena Age 5 - (home for EOL – possibly EOL at hospice)

- Diffuse Intrinsic pontine glioma (brain tumour)
- Siblings aged 3 and 2
- Will be creating legacy piece between the 3 sisters at the hospice – this helps make the hospice a familiar space. VSK and AC collaboration is so vital here because the child wants to come in to create art while at the same time it desensitises the child/children to hospice environment – making it a more inviting and familiar space, thus more likely that family will come to hospice for EOL.
- Continuing weekly art therapy as outreach in her home, until she comes into hospice for final stages of dying.



- Supporting the siblings through mindfulness and body focused processes. Helping to build their resiliency through these kinds of therapeutic processes.
- Supporting Geena in her transition and creating a safe secret box for her expression. Working with fear and pain – using art as a distraction when she is physically uncomfortable, or when there is any “scary” medical management by visiting nurse.
- Creating a picture book for Geena where she can create her own story and create a narrative of comfort and meaning.

Program Outcome 2018

- Worked with 10 families, where children/adolescents were end of life.
- Framed art works gifted back to the families
- Completed an average of 85 contact hours with families and 53 hours non-contact hours for VSK
- Completed an average of 30 contact hours with families from Monash CCC
- Completed an average of 21.5 hours for case notes and evaluations for VSK
 - It must be noted that children at EOL stage CAN and do continue to work with us for many months or years before death
 - EOL families do and can continue work post death
 - Sibling work continues as needed and as funding is available
 - All engagements were executed at the premises of VSK, Monash CCC and in the homes of VSK families.

Staff and Collaborators:

- One registered and qualified Art Cabriolet art therapist
- One assistant art therapy student
- Collaboration exist between doctors, nurses, and family support practitioners, families, siblings, allied health
- Sessions facilitated by the Art Cabriolet art therapist



Creative art processes:

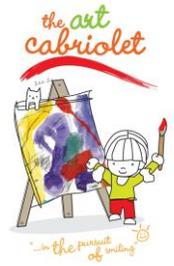
- Spontaneous art with dying child/adolescent – dependent on what the child/adolescent needs in the moment
- Spontaneous art with sibling/s and/or family as required
- Embodied work to help build resilience – working with emotions and finding ways to acknowledge and express through movement
- Creating a legacy piece with dying child/adolescent and their family
- Creating memory pieces for child with life threatening chronic illness

Outcome:

- Safe expression of painful emotions
- Teaching self-soothing through creative processes to build resilience
- Creating memories through art process / recall of positive memories
- Framing art work and presenting to family as their legacy
- Relieving tension and anxiety, harnessing sense of emotional regulation
- Promoting self-discovery and enhancing self-efficacy
- Encouraging the flow of communication in a clinical setting

Art Intention:

- To provide support, develop personal enrichment and meaning, to enhance self-expression and self-efficacy and to build family connection and belonging.
- Safe expression of powerful emotions
- Process intense emotions – to allow for physical, mental, emotional and spiritual health.
- Meaning making
- Emotional regulation for child and siblings experiencing survivor guilt
- Stress relief/relaxation
- Encouraging the process of building positive memories
- Increase in serotonin levels in the brain to reduce depression



Feedback

Mei Goh (VSK family support practitioner)

"I presented the legacy piece to the family. It brought some tears to the parents but in a positive way. I know they were going through a particularly challenging time and certainly seeing her hand print and foot print enmeshed with everyone in the family was bittersweet in so many ways and they fear they may have forgotten about her. The legacy piece was certainly presented timely to help them remember her."

Angela Flood (VSK family support practitioner)

"The mum has referred to the piece a few times in our sessions and it has certainly brought much comfort and memory for them to keep seeing his presence and art around the house. Being able to see and witness the legacy artwork has brought much comfort to the family."

Edwina Hargreaves (VSK family support practitioner)

"The siblings have been holding on to the canvas and taking turns having it in their room. The painting reminds them so much of their brother."

Svetlana Bykovec (Art Cabriolet art therapist)

"Many times, I have witnessed how a family that is disconnected in their grief come together through art and have a moment of just being a family again. The laughter, tears and affirmations of "I love you" flow as easily as the paint."

Rachelle aged 4 (bereaved sibling)

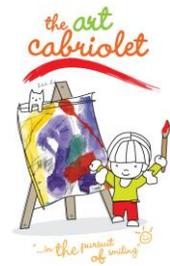
As art therapist painted alongside her, Rachelle began speaking of how her sister was sick again. The art therapist asked how this made her feel, she answered, *"I feel sad"*. She continued painting then said, *"no not sad, I feel scared"*. The art therapist asked Rachelle to paint something to help the *"scared"* feeling. She drew flowers and sprinkled glitter. She then stated, *"I don't feel as scared anymore but I am still a bit sad"*.

Anthony (bereaved father)

"This artwork is a real memory that her sister will always have. The butterfly hands will be a reminder of how much they loved the butterfly house at the zoo. This is her story."

Jenna (Parent of terminal child)

"My daughter is so excited and looks forward to the art sessions. It is so wonderful to see her engaged and motivated again."



Annual Program Cost

** This figure fluctuates annually based on number of EOL children and continuous work with nearing EOL children*

Very Special Kids and Monash CCC:

Balsa Trees \$1,5000.00
Canvases Mixed \$1,385.00
Specified High Grade Paint \$392.00
Misc. Art Materials \$250.00
Framing Glass and Exposed Framing \$2,100.00
Art Therapist \$22,080.00
Supervision and Counseling \$1,440.00

Total \$29,147.00

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