



Blue Sky

PAEDIATRIC END OF LIFE PROGRAM
CATA

Annual Report 2020

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Creative Art Therapy Australia COVID-19 Response

Abbreviations

CATA	Creative Art Therapy Australia
CAT	Creative Arts Therapy
EOL	End of Life
PPE	Personal Protective Equipment

Pivoting Services to Online

Physical burdens of restrictions and lockdowns gave CATA the opportunity to pivot services to Technology Enabled Health for online service delivery. This service opened on the 20th July 2020 enabling us to work with any Australian in need.

Since our service delivery moved to online, CATA upscaled with additional 8 qualified Arts Therapists to meet public demand. It was an opportune time to re-evaluate and expand all service delivery methods, processes, procedures and guidelines associated with CATA's service provision. Public interest and demand for our service was at its highest with 176 direct email requests to our website for assistance. 66% of service seekers engaged in Take a Brain Break. CATA actively worked on a solution-based program, enabling us to continue to provide trauma-informed CATs sessions.

EOL work continued both face to face and online with dying children, bereaved siblings and their families. CATA adopted COVID-19 safe guidelines issued by State Government and implemented new policies and procedures. PPE gear was issued and hand hygiene practice instilled with CATA Arts Therapists, ensuring safe and compliant interaction with clients.

Since inception in 2014, until today, CATA has supported 78 End of Life children/adolescents and conducted over 300 sessions in this program.

CATA Trauma Informed Practice

Creative Art Therapy Australia (CATA) adopts a trauma-informed and person-centred practice. The Blue Sky program is holistic and inclusive. CATA Arts Therapists utilize multiple creative resources, so that children/adolescents can tap into their unique strengths and abilities to thrive. Further, Creative Arts Therapies (CATs) are considered trauma-informed because of their ability to allow for processing of the trauma narrative through nonverbal expressions (Malchiodi, 2007; 2014). Incorporating CATs into treatment plans helps clarify emotional, physical and psychological difficulties encountered in progressive stages of illness.

Children and families in the palliative care setting often express powerful and difficult emotions concerning their condition, treatment and sometimes mortality. (Hartley & Payne, 2008). There are often high levels of distress that can be too much to find words for. CATA understands that access to art opens doors to unspoken moments and supports creative expression in an alternative, safe and ethical way. Art becomes the new language through which children and families can express their painful emotions.

CAT is simple to implement in hospital, hospice or home settings and is more often received positively by clients as calming, relaxing and sometimes a distracting process. There has been much research with cancer patients where the evidence for the efficacy of CAT in reducing a broad spectrum of symptoms has been discovered (Nainis, et. al., 2006). CATA understands the power of CAT and how it can assist supporting the child and families on many different levels.

Life and Love Through Creative Legacy

At the heart of Creative Arts Therapy is the belief that engaging in purposeful activity can enrich and add meaning to life, especially during treatment for a palliative illness. Children and adolescents involved in the Blue-Sky Program 2020 ranged from 3 weeks to 17 years of age and at various stages of their terminal illness. All EOL children and adolescents either resided at Very Special Kids (VSK) hospice, received outreach support online or worked face to face with CATA Arts Therapists. Other beneficiaries of the program were bereaved siblings.

CATA's Blue Sky Program often incorporates a legacy artwork that is created with the dying child and their family. Legacy-making has positive effects for chronically ill and dying children and their family members, as it gives opportunities for memory making. Legacy work is engaged both before and after the death, and offers tangible memories for families (Allen, 2009; Allen, et. al., 2008; Nainis, et. al., 2006). CATA Arts Therapists use this as a potential for children to express themselves and communicate about death, providing a coping strategy for not only themselves but also other family members.

CATA supports the dying child's ability to communicate their emotional situation, while providing a safe space to express other aspects that may be causing concern. Increased feelings of isolation and fear, especially for loved ones, have been addressed specifically with art processes aimed at strengthening a sense of connection and promoting grounding techniques (Allen, 2009; Walsh, Martin & Schmidt, 2004). The positive nature of art making gives a sense of control over a dying child's environment, and often leads to meaningful and unexpected interactions between their family and hospice staff. It also has physiological, psychosocial and psychological benefits, including decreased breathing difficulties, distraction from pain and negative thoughts, increased religious meaning, greater social interaction, reduction of anxiety and depression, preparation for end of life, greater appreciation for self, as well as improved family communication and decreased caregiver stress. (Malchiodi, 2013; Nainis et. al.2006).

The intention of Blue Sky is to work alongside EOL children/adolescents to create a legacy piece that can influence others' lives and prepare for their own deaths, while inspiring and comforting family members. CATA understands how creative representation 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).

During 2020, CATA collaborated with Melbourne artist Tania Taranto to create Memories that Matter boxes for EOL children/adolescents. The intention was to give families another way of collecting keepsakes of their dying child, or a way for bereaved siblings to have a safe place to store photos or trinkets that hold meaning for them of their deceased sibling. These boxes were handcrafted with original resin artwork lid created by the artist.

Blue Sky program engages EOL child/adolescent, siblings, parents, and extended family. CATA Arts Therapists spend unlimited time with family based on the need. The service extends throughout the greater Melbourne area and includes evidence-based evaluations of outcomes.

Blue Sky Consumables

- Qualified Arts Therapist
- Moments that Matter boxes
- Three to nine smaller canvases [30.5 x 30.5 cm] or one large canvas [60 x 91.5 cm] for legacy art
- Balsa wood tree
- All consumables including extra canvases, paint supplies, brushes and cleaning utensils
- Fully framed legacy artwork and drop-off to family

2020 Summary

CATA worked with a total of 16 children/adolescents in 2020. 3 of the children were at the hospice for end of life; 1 was deceased; 3 were bereaved siblings; 6 attended the session with their dying sibling; while the remaining 3 were at home with disease progression.

CATA re-engaged with 3 bereaved siblings who were needing extra support during the COVID-19 lockdown. CATA facilitated free online sessions to help support the Mental Health and Wellbeing of these children, who were experiencing anxiety and heightened emotions due to the uncertainty and isolation the long period of lockdown instilled. CATA's re-engagement brought consistency, familiarity and support to these children.

Ronan Age 8- Outreach (sibling of EOL child)

- Struggling with low level anxiety and worry
- Hypervigilant
- His brother has a brain tumour and often has seizures which has had an effect on Ronan

Noah & Tayla Ages 13 & 15-outreach (bereaved siblings)

- Bereaved siblings of 1-month old brother
- Both siblings Involved in DHHS dues to substance abuse and mental health of mother
- Complex trauma/relational challenges
- Family home stabilised and they are living with father and step-mum

Brooke Age 18- (deceased)

- Osteosarcoma (bone cancer)
- Amputation from knee when 10 years old has left Brooke limb different
- CATA has facilitated 61 sessions with Brooke until her death in 2021

- No further sessions were engaged in 2021
- CATA has reinstated sessions (7 to date) with Brooke's family to complete the legacy videos and documentary that was initiated in early 2019

Kahleed Age 11 – Outreach (bereaved sibling)

- Kahleed's younger 4 year old brother died in 2020 and he has been struggling with the loss
- Khaleed dearly loved Jahleel and was a young carer
- Khaleed's father died when he was 8 years old and this new loss has been devastating for him. His grief is profound and he has become very sad, angry and anxious
- He has just started a new school but is finding this a challenge and at times refuses to go

Jana Age 5 – Outreach (life limiting condition)

- Leigh's Disease (a rare inherited neurometabolic disorder that affects the central nervous system)
- Siblings aged 9 & 3
- Jana's brother died of same condition at age 2 (before CATA became involved)
- Continuing fortnightly sessions and this is ongoing
- Spontaneous creative sessions that stimulate and engage and support self-expression
- Creating a family legacy piece that will also include deceased sibling's handprints.

Charlie Age 11 - Onsite Hospice (deceased)

- Niemann-Pick Disease(Type A)

Chelsea Age 9 - onsite Hospice (deceased)

- Niemann-Pick Disease(Type A)

Claire belling Garwood 17 - Onsite Hospice (deceased)

- Niemann-Pick Disease(Type A)

Charles Age 5- Onsite Hospice (deceased)

- Polymicrogyria, rare genetic condition unknown
- Worked with Charles at the hospice creating a number of art pieces

- Although his medical condition impacted his muscle control (atrophy) Charles was able to engage dynamically in all the art making to the surprise of the physiotherapist

Marley C - Onsite Hospice (deceased)

- Niemann-Pick Disease(Type A)

Jack Age 11 weeks – Onsite Hospice (deceased)

- Niemann-Pick Disease(Type A)
- Jack fought for life for 11 weeks and both his young parents commented on his determination, since the doctors didn't think he would survive the week
- Family asked for prints to be taken after he died
- Also assisted mum with painting moulds of Jacks hands and feet that were done while he was alive

Program Outcome 2021

Even with the limitations, CATA was able to design ways to work with EOL children, including online delivery.

- Worked with 9 families, inclusive of EOL child and their siblings or bereaved siblings
- Framed art works gifted to the families
- Completed 120 contact hours with outreach families
- Completed 38 non-contact hours for legacy, including post art work
- Completed clinical notes and evaluations

- It must be noted that children at EOL stage can continue to work with us for many months or years before death
- EOL families can continue working post death with CATA Arts Therapists
- Sibling work continued as required by families
- All engagements were executed onsite at the children’s hospice in Malvern, online or in the homes of families

01 January 2021 to 01 September 2021

Program	Sector	Number of Clients	End of Life Child	Suicidal Ideation	Bereaved Siblings	Total CAT sessions	Total Hours	Legacy Art
BLUE SKY	Paediatric Palliative Care	13	8	1	4	52	125	6

Staff and Collaborators:

- Three registered and qualified CATA Arts Therapists were engaged in program
- Collaboration between doctors, nurses, social workers, family support practitioners, families, siblings, and allied health
- All sessions facilitated by qualified CATA Arts Therapists

Program Components:

- 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
- Creating memory boxes with either bereaved sibling/s or dying child

Session Outcome:

- Safe expression of painful and difficult emotions
- Developing self-soothing techniques through creative processes to build resilience
- Creating memories through art process/recall of positive memories through the art process or making new memories
- Relieving tension and anxiety, harnessing sense of emotional regulation
- Reducing symptoms associated with life-limiting condition
- 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
- Framed art work presented to family as a visual memory/legacy
- 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

Lived Experience: (written by Principal Arts Therapist Svetlana Bykovec)

Transforming through ladybird hearts

Cassandra was admitted to the hospice for end of life and I was asked to facilitate a legacy piece for the family. After collecting Cassandra's handprints, I also did another canvas where she used her feet to explore and play with the paint. Cassandra's family stayed at the hospice and I had the opportunity to work with her brother AJ on two more occasions. Below are my impressions of our first session.

At first AJ did not engage at all – he did not make eye contact and was in a tight ball in his father's arms with his face hidden. I managed to get him to look at the paints and canvas but then he would hide his

face again. With some coaxing from dad, AJ managed to give me a nod when I asked if he wanted to paint. Dad helped him onto the chair and then I proceeded to pour paint into the palette as he watched. I asked him on a few occasions if he wanted to help but his posture was withdrawn, and he was hypo aroused – his hand would go limp when dad put a brush in his hand. Although he did nod to indicate he wanted to paint, he remained shy and withdrawn. Dad would show him what to do but AJ would just watch and not reach out or engage in the art making.

This went on for 10 minutes or so and then AJ tentatively took the sponge brush and began dipping it into the paint – often looking to dad for guidance and still avoiding eye contact with me. I sat between AJ and another child – not too close to AJ and averting my gaze, checking-in every now and then making comments on what I observed he was doing – or what colour he was adding etc. This is a deliberate and non-intrusive way of building rapport and trust– I let dad be the lead and I busy myself with something else but always holding the space with my intention, peripherally.

As AJ painted, I observed he began to become more animated and engaged in the painting. He was very careful making sure he painted the entire canvas. Methodically dabbing each corner and then pointing to where he had painted. He was intentional in making sure he covered the entire canvas and did not leave any white space at all. He began to warm up to me more and would make eye contact as I commented. At this stage I asked if he would like some stickers, I was informed that he loved stickers, and he was responsive to this suggestion and nodded yes. He used lady birds and put 3 together and one at a distance from the others. And although there were rows of these stickers, he did not use any more lady birds - he chose only four. There are four members in his family and one is very sick. I began getting a sense of something significant in process. It appeared to be a visual representation of his family.

As AJ used the stickers, I noticed his posture and energy changed – he sat up straighter, was more energized and made more eye contact – there was now a sense of connection and I moved closer to support his art making. AJ added glitter heart stickers to his painting – a big heart then a little heart. Again, there was a sense of structure in the placement and there was a pattern, so I offered a small purple heart (following his pattern) which he took but then handed back. He then used crystal stickers and once more made patterns and then broke the pattern. I noticed that one of the 3 lady birds was a large crystal – and this felt like it represented AJ in between mum and dad. There was structure and repetitions occurring, but there were also moments where this was missing –moments when things don't go to plan – moments that fell out of the pattern. It reminded me of how his life would be feeling right now – chaotic and changeable. I remained curious as to how

his art making was aligned to what he may be experiencing in his life with his sister dying and the daily uncertainty around this.

AJ then used the glitter paint and combined it with some yellow to create a boundary around his hearts and lady birds. His affect upon completing this circle had markedly changed and AJ was now happy, smiling, talkative and interactive – unlike his withdrawn state in the beginning. He had moved through a range of emotions and energy levels through the art making, the heaviness and unresponsiveness transformed into a light, playful and engaging AJ. Dad had slipped away to the accommodation during our creativity and AJ did not falter in his confidence with continuing the art making without him. What is significant to mention here is that AJ’s motivation and connection continued for the remainder of the day. Whatever he had been sitting with had been transformed through the art making and without having to verbalise or explain – the story was told and felt through images and actions.



Testimonials 2020

In May my wife and I received the news that no parent should ever hear. That their beautiful child had developed a brain tumour for which there was no treatment. Our darling boy was going to be taken from us far too young and we only had days if not weeks to try and cram a childhood of experiences into a precious few moments. We were connected with CATA and the art therapy program they provided was a fantastic way for all of us to interact as a “normal” family in an abnormal situation. The Art Therapist’s constant attention and pro-activeness to keep our son entertained and interested was amazing to see and that care was greatly appreciated by us, and still is to this day.

The painting that we created as a family now hangs on a wall in his bedroom. I often find myself staring at it and thinking about the good times we shared during such a dark time. While the pain of his loss will stay with us, so will the joyful memories that CATA helped to create.

- Bereaved Parents

My three girls; born within three years, have always being close; fiercely protective of each other, loyal and (mostly) kind with each other. The eldest two often mistaken for twins and the three looking like triplets when they are at the same ages! Our world was shattered when our eldest Grace was diagnosed with a terminal brain tumour and died 9 months later. She was 5 years old. Creative Art Therapy Australia have been a treasured support for our family during Gracie's illness, death and ongoing. The Art Therapist provided structure, consistency and safety amongst the chaos.

The weekly Art Therapy sessions in our home was the most exciting time of the week for the three girls during the most difficult moments of their and our lives. In a fun, calm, non - threatening, intuitive manner they brought the three of them back together after steroids and radiotherapy made Grace isolate herself.

This has given our now 3 and 4-year-old the skills to navigate the trauma of their big sister's death. They can articulate their anger, fear and love through their art and because of this are often more articulate when speaking about their grief than the adults around them.

Thank you will never be a big enough word for what CATA have provided our family.

- Jo (bereaved mother)

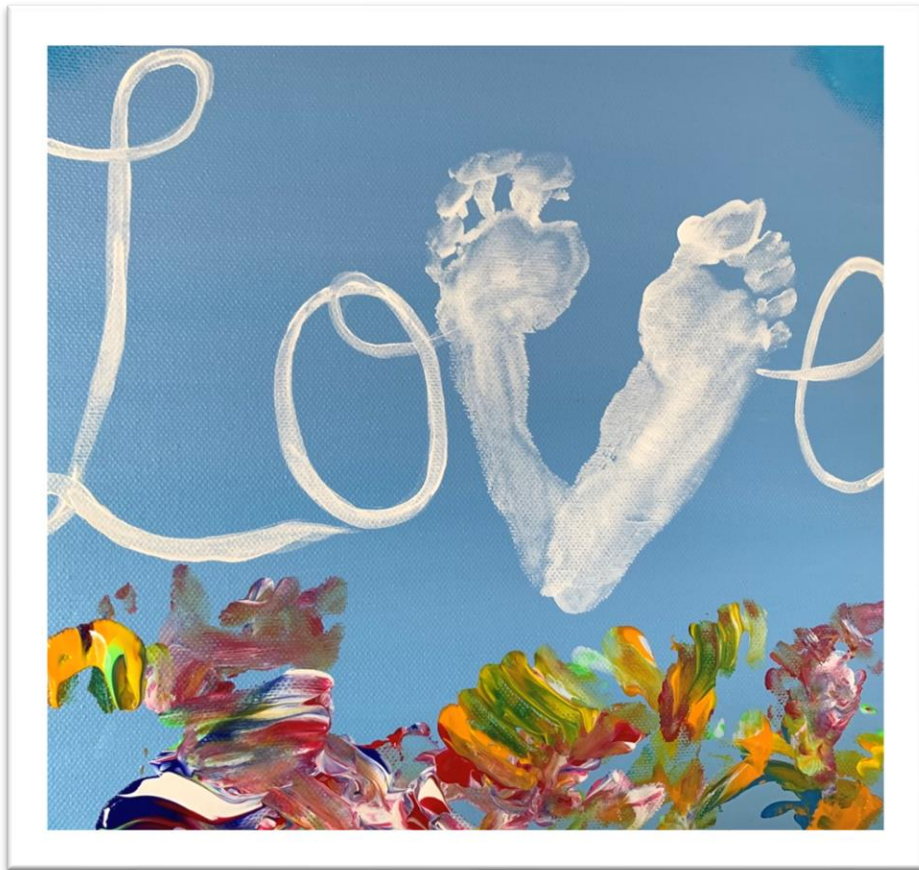
It is hard to believe that it has been 18 months since Gideon died. It feels very recent but far at the same time. We have lovely memories of all our art therapy sessions. I am still trying to work out the best way to display the special pieces. Not long before Gideon died, his occupational therapist who he knew for many years came to visit, and we showed her the shaving cream/paint activity you taught us, and she has taught it to some of her students and called it Gideon's game

- Rebecca (bereaved mother)

Annual Program Cost 2020

Canvases	\$1049.23
All Art Materials	\$607.59
Moments that Matter Boxes	\$600.00
Framing	\$600.00
Arts Therapists	\$8,690.00
Supervision for Arts Therapists	\$420.00
Total	\$11,966.82*

*Due to COVID-19 restrictions CATA's costing were affected by reduced hours and numbers of children CATA was able to work with. Funding will be rolled over into the Blue Sky Program for 2021



References

- Allen, R.S. (2009). *The legacy project intervention to enhance meaningful family interactions: Case examples*. Clin Gerontol. Vol 32(2):164–176.
- Allen, R.S., Hilgeman M.M. Ege MA. Shuster J.L. & Burgio L.D.(2008). *Legacy activities as interventions approaching the end of life*. Journal of Palliat Med. Vol 11(7):1029–1038
- Bertoia, J. (1993). *Drawings from a dying child*. New York, NY: Routledge.
- Edgar-Bailey, M. & Kress, V. E. (2010) Resolving child and adolescent traumatic grief: creative techniques and interventions, *Journal of Creativity in Mental Health*, 5(2), 158-176.
- Finn, C.A. (2003). Helping students cope with loss: incorporating art into group counseling. *Journal for specialists in group work*, 28(2), 155-165.

- Hartley, N. & Payne, M. (2008). *The creative arts in palliative care*. Jessica Kingsley Publishers: London & Philadelphia.
- Kubler-Ross, E. (1983). *On children and death*. New York, USA: McMillan.
- Malchiodi, C.A. (2007). *The art therapy sourcebook*. New York, USA: McGraw-Hill.
- Malchiodi, C.A. (2014). *Creative interventions with traumatised children* (2nd ed.) New York, USA: The Guildford Press.
- Malchiodi, C.A.(Ed) (2013). *Art therapy and health care*. New York, NY: Guilford Press, Inc.
- Nainis, N. Paice, J.A. Ratner, J. Wirth, J.H. Lai, J. & Shott, S. (2006). *Relieving symptoms in cancer: innovative use of art therapy*. *Journal of Pain and Symptom Management*. Vol 31 No. 2, 162- 169.
- Walsh, S.M., Martin, S.C. & Schmidt, L.A. (2004). *Testing the efficacy of a creative-arts intervention with family caregivers of patients with cancer*. *Journal Nurse Scholarsh*. 36(3):214–219.