



# Blue Sky

PAEDIATRIC END OF LIFE PROGRAM  
CATA

End of Year Report  
November 2019

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## Informed Practice

Creative Art Therapy Australia (CATA) 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 (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. Art opens the doors to those unspoken moments and images support in a different and safe way. 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. Other beneficiaries of the program are children of the same age group who are being treated for chronic life-threatening illness, under the Victorian Paediatric Palliative Care Program. CATA are referred these children and are visited by Art Therapists in their homes. 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 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
- Working with siblings, parents, extended family
- Unlimited time frame spent with our team based on need
- All consumables including canvases, paint supplies and brushes
- Fully framed legacy artwork and drop-off to family or hospice
- Evaluations of outcomes
- Work conducted at children's hospice in Malvern.
- Outreach work throughout greater Melbourne area.

## 2019 Summary

CATA have worked with a total of 15 children/adolescents, including siblings, for the 2019 year to date. 3 of the children/adolescents, have been at the hospice for end of life while the remaining 10 were at home with disease progression. One of these individuals we have been working with for almost a year and is still working with us.

CATA have also been working closely with 3 bereaved siblings who have been needing extra support. Children/adolescents frequently have conflicted feelings related to their loss, and the use of Creative Art Therapy can help them identify and manage these feelings. Art making creates the space where the child/adolescent can openly explore and integrate their grief. These interventions promote emotional regulation as well as relaxation and helps the child/adolescent develop language around intense emotions they may be experiencing. (Edgar-Bailey & Kress, 2010; Hartley & Payne, 2008; Malchiodi, 2014).

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

### **Bridgette Age 16 – outreach [VSK Referral]**

- Osteosarcoma (bone cancer)
- Had right leg amputated from knee and now has prosthetic
- CATA has facilitated 39 sessions with Bridgette and will continue until her death.
- CATA worked with her to create mural – street art combined with art processes that help develop self-awareness, self-reflection and empowerment
- Connected with 2 street artists to custom design art her prosthetic
- Bridgette is the ambassador of the ART-i-ficial Limb Project and making this her legacy
- CATA has been the only therapeutic team that has been accepted by Bridgette. Through the connection we have made has allowed for a hospice support worker to also step in to help assist the family
- Relationships between family members has improved
- Bridgette has made the decision to stop any more treatment and is at the stage of acceptance – this has allowed her the freedom to let go and live
- Bridgette is more present and positive in day to day life

### **Angus Age 8 - outreach(deceased) [VSK Referral]**

- Relapsed Ependymoma (brain tumour)
- Created legacy family tree - large canvas with family members handprints around a simple painted tree
- Weekly art therapy at family home
- Supporting Angus's psychological transition of his condition through the safety of creativity
- Conversation around space and super heroes. Angus's statement that he is going to space on his own and art therapist acknowledging his brave and super hero-like qualities
- The art making was also used as a way to support self-regulation

### **Heather Age 12 – outreach (deceased)[VSK Referral]**

- Diffuse Intrinsic pontine glioma (brain tumour)
- Heather was unresponsive to receiving any kind of counselling or support and art therapy was introduced as “art sessions”
- Heather needed to be coaxed out of her room on the first session and this was a behaviour toward any new person. Mum told me it took her physio 7 weeks before Heather came out to see her
- By 2<sup>nd</sup> session Heather was no longer needing to be coaxed out of her room
- Worked with Heather for 9 weeks and during this time she became more confident and was more open to seeing support workers coming to the house
- She no longer locked herself in her room

### **Mitchell Age 11 months – hospice (deceased)[VSK Referral]**

- WWOX chromosome deletion - carcinogenesis
- Came into hospice for legacy art
- Worked together with parents for a beautiful connecting session
- Created legacy piece that included favourites of Mitchell's – music, fish and rocket ships

### **Lucas Age 8 – outreach (deceased)[VPPCP & VSK Referral]**

- Progressive brain tumour & autistic
- Siblings aged 4 & 18 months
- Created family legacy tree and handprints on canvas
- Weekly art therapy sessions with Lucas

- Focusing on his feelings of sadness and allowing expression for that through art would often leave Lucas in a more settled/content frame of mind – body mapping the feelings helped release anxiety or tension from the body
- Focusing on his body which was failing him and finding new ways to work creatively – using his left hand instead of his right; using our toes instead of our hands – this supported empowerment for him as he could achieve in a different way

### **Nadia Age 5 – outreach [VSK Referral]**

- Leigh’s Disease (a rare inherited neurometabolic disorder that affects the central nervous system)
- Siblings aged 7 & 1
- One sibling 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. The prints were taken at RCH and given to parents

### **Mike Age 14 – hospice (deceased) [VSK Hospice]**

- Lissencephaly (rare brain disorder)
- Siblings aged 13 & newborn
- Creating legacy piece sitting with extended family and hearing his story – his favourite things and what he loved
- This created the artistic vision for his personalised art piece
- Created a space for reminiscence and connection between family members – and Mike smiling throughout this process

### **Matthew Age 18 – hospice (deceased) [VSK Hospice]**

- Glioblastoma multiforme (fast growing brain tumour)
- Siblings aged 15 & 22
- Worked with Matthew at the hospice – one on one sessions when he was feeling strong enough
- These sessions served as some distraction for the head pain Matthew was experiencing – he felt the art making helped him relax
- Created a “superhero” canvas that family and friends added to on his 18<sup>th</sup> birthday.
- Created handprints with family members

- Framed both legacy pieces and gifted back to his family after his death

### **Max Age 9 – outreach [NDIS private]**

- Batten Disease (fatal inherited disorder of the nervous system)
- Sibling aged 13
- Max is also blind
- Weekly sessions with Max that improve his quality of life as he is bedridden and is difficult to get out of the house
- Creating relationship and interaction with Max
- Max's condition means that he has a lot of involuntary movements.
- During art therapy sessions these movements are noticeably less as he appears more relaxed and focused during art making
- Creating legacy pieces for the family – including one large canvas with the whole family's handprints which was framed

### **John Age 14 months – outreach [VSK Referral]**

- Pompe Disease (genetic disorder)
- Initially worked with John at the hospice
- John has poor body tone and is unable to hold anything or hold his head up so often worked with him as he was lying down on the couch.
- Although John has poor muscle tone, when he comes in contact with the paint, he is able to move his fingers and on occasion lift his hand as he paints
- Creating legacy piece of 3 small canvases
- Framed legacy piece

### **Tom Age 10 – hospice (deceased) [VSK Hospice]**

- Lysosomal storage disease (rare inherited metabolic disorder)
- Siblings aged 8 & 15
- Younger sibling has same condition
- Created legacy pieces with brother while both were in hospice. Individual and collaborative pieces
- Tom is bedridden and is unable to paint without assistance
- Together he is able to make micro movement with his finger or his toes
- Improve quality of his life as he is able in some capacity to paint
- Noticeable relaxation in Tom's body, often accompanied by smiles

### **Billy Age 8 – outreach (deceased) [VSK Referral]**

- Brain Tumour
- Twin brother aged 8 (Nigel – refer below)
- Mostly worked with sibling as Billy was unconscious
- Created family legacy piece of hands on tree – Billy’s brother was in charge of this process. Empowering him to choose the colours, make choices and also paint his
- Continuing to work with Billy’s twin brother Nigel, after his death

### **Nigel Age 8 – outreach (bereaved sibling) [VSK Referral]**

- Continuing work with Billy’s bereaved twin Nigel
- Creating a safe space to creatively express emotions, such as grief, loss, anger and survivor guilt
- Nigel created a “one of a kind” whale which he protected with layers of green tape. His whale does not die and it also helps people
- Nigel’s whale did not have any defining features until the end of the session, where he named it, put colourful fingerprint dots all over, gave it eyes and a smile – the Jelly Bean Whale was complete

### **Emma & Lucy - outreach (bereaved siblings) [VSK Referral & FFS]**

- Working with the sisters of Geena who died last year (part of Blue Sky 2018)
- Continuing on working with body/emotion focusing – checking in with feelings bear cards
- Using the art making as a way to express and connect with their emotions
- Working toward creating butterfly wings from fabric – starting in the cocoon of brown paper then tearing through to be butterflies
- Working with symbol and metaphor and incorporating movement and play
- Supporting and continuing to build their resilience

## Program Outcome 2019

CATA is now accessing even more children through outreach and as funding continues, we will be able to broaden this reach even further. The demand is there and the only obstacle preventing more outreach is funding.

- Worked with 15 families, where children/adolescents were end of life or bereaved siblings
- Framed art works gifted back to the families
- Completed an average of 104 contact hours with outreach families
- Completed 65 hours non-contact hours for children staying at hospice
- Completed an average of 168 hours for case notes and evaluations
  - 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, and in the homes of families

### Staff and Collaborators:

- Three registered and qualified CATA Art Therapists
- Four assistant art therapy students
- Collaboration exist between doctors, nurses, social workers, family support practitioners, families, siblings, and allied health
- All sessions facilitated by CATA 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

## Testimonials

Angela Flood (VSK family support practitioner)

*"I have been a witness to the beauty that art therapy and memory making can create. The CATA art therapists have a beautiful gentle ability to encourage a family to tell their story and that of their child and to help them create an artwork which is beautiful and so meaningful. In their bereavement, families have been in awe when their legacy piece has arrived and have spoken of just how much the piece speaks of their child and of the joy that creating the art gave them in the final weeks, days or hours of their child's life."*

Adriana (Bereaved mother)

*"It was such a relief and a joy to see him achieve and create unique art pieces with a big grin on his face. He was much more focused, calm and he was totally proud of the colourful marks he made on the canvas."*

Tammy (Mother of child with terminal condition)

*"Wow, what an amazing morning we had! CATA had arranged some 'art therapy' for us as our eldest daughter had expressed that she'd love to do some hand & foot prints with her unwell sister. CATA visited our home this morning with paint & canvas in hand! My girls had a really fun time, and our canvases will now be finished off, framed ready to be hung on our wall. Such a beautiful idea & we are feeling very blessed. Thanks so much CATA."*

Jenny (Mother of adolescent with prosthetic and EOL)

*"You have put a spark in her eyes again. We haven't seen her smile like this for the last 5 years. CATA, you have been heaven sent. Thank you."*

## Annual Program Cost 2019

Canvases Mixed	\$1,415.38
All Art Materials	\$1,012.65
Framing	\$3,500.00
Art Therapists	\$20,215.00 (including non-contact hours at hospice) **
Supervision for Art Therapist	\$1,250.00
Total	\$27,393.03

\*\*This is based on an average of 5 sessions x 14 families, including one child with whom we have had 39 sessions.

## References

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