

## **REPORT February 2015**

### **REST**

the celebration of life and the loss of a life still celebrated

conceived and led by artist Sofie Layton

Research and development for an arts collaboration with bereaved and pre-bereaved parents created in partnership with SLOW (Surviving the Loss of Your World); Graeae Theatre Company and Richard House Hospice, London.

sound: Jules Maxwell  
photography: Stephen King  
evaluation: Anna Ledgard

Supported with public funding from Arts Council England and The Blavatnik Family Foundation



## THANKS

Our thanks are due to all the mothers in the SLOW group who have given so generously to this work and also to the mothers group at Richard House Hospice and to Nic Whitworth, Sara Portnoy, Jenny Sealey and Carien Meijer for their mentoring and support to Sofie.

REST is dedicated to families everywhere who are facing or have faced the death of their children.



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Because of the sensitivity of the content of this project please contact Sofie Layton if you wish to listen to the soundscape or to reproduce content or images from this report:  
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Report written by Anna Ledgard, February 2015

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## 1. INTRODUCTION

REST was a research and development project to explore the role that creative artistic practices can play to enable bereaved and pre-bereaved parents to express memories and experiences. The project forged relationships between artist Sofie Layton, Graeae Theatre Company, SLOW (Surviving the Loss of Your World) group of bereaved mothers and parents and staff at Richard House and St Joseph's Hospices. A series of fifteen practical workshops with SLOW group parents and three workshops with parents at the hospices explored the arts of embossing, embroidery, screen-printing, story-telling and conversation. This research resulted in a public event in December 2014 followed by further consultation with project participants and a small invited audience of experts in end of life care and bereavement.

## 2. EVALUATION METHODS

This report, written by Anna Ledgard, Artsadmin associate producer, writer and end of life carer, draws on observations, conversations, interviews, written and email feedback from parents, audiences and key partners and reflects on the processes and potential for future development.



### 3. COLLABORATION & PARTNERSHIP

Sofie Layton managed and led this research and development. Jenny Sealey, artistic director of Graeae Theatre was involved as a theatre practitioner in a number of the workshops and in presenting and supporting the final sharing events. Evaluation and development support was provided by Anna Ledgard. Richard House and St Joseph's House Hospices were partners in the workshops.

### 4. DESCRIPTION OF PARTICIPATORY PROCESSES

Workshops with SLOW took place at Graeae Theatre's lounge weekly for ten weeks and included a screen-printing session at the Geffrye Museum print room. The SLOW group involved seven mothers and Sofie. The SLOW group's founder Nic Whitworth, a trained counsellor and bereavement specialist, was present at every session and played a critical role in communication and care of the emotional wellbeing of the group. Attendance was not always regular but all mothers were in contact with Sofie or Nic if they could not attend. Graeae's space was comfortable and discrete with no other users and the welcome and open hospitality from all at Graeae was greatly valued. Sofie's vision was to gather stories and language to explore how mothers could create rituals or activities to remember their children. Grief and loss are experienced differently by different people and Sofie's artistic process was sensitive to this. The content of the workshops was carefully planned to

provide a starting point for mothers which felt manageable both emotionally and practically. At the beginning the idea of working with images of their children was too hard for some mothers. Sofie's workshop framework was open enough to offer entry points for all, also enabling the group itself to support each other and, for those who were willing, to model the possibility of working with an image or memory, when for others at first this felt too enormous to attempt. In the end every mother made a screen print portrait of their child, an installation of precious objects associated with their children and a story which was part of a powerful soundscape created by composer Jules Maxwell.

Two taster workshops took place in association with Richard House Hospice and Sofie attended a social event for parents to meet them and test some of the practices in the context of pre-bereaved parents. For the one-off workshops Sofie devised a simple embossing process in which parents could make an image of their child's hand. Parents and families enjoyed the workshops and staff are keen to continue towards a more regular involvement with pre-bereaved families.

Jenny Sealey – artistic director of Graeae was involved in eight of the workshop sessions and played an important role in hosting the project at Graeae. As a theatre director Jenny's wish had been to explore the sign language of grief, and ultimately to explore the experience of children and siblings in families who are experiencing bereavement. Jenny's role in the research and development was to bring BSL (British Sign Language) into the artistic vocabulary, developing a signed interpretation of the mothers' stories, performed by Graeae's experienced signers Ali Potts and Jenni Draper. There was tension when deciding how the installations would be presented to an audience. Jenny, as a theatre practitioner, wished to explore the idea of bringing the mothers into their installations as performers. This was resisted strongly by the group, who did not want to be 'observed' as performers, but chose to sit with their families – which was acknowledged to be the right decision.

## 5. PARTICIPATION: KEY THEMES

### 5.1. Responsive approach by artist

Workshops were planned in response to individual needs and through continuing dialogue and reflection with the mothers at each session, and afterwards through communication with Nic Whitworth from SLOW. Meeting individual and group needs whilst moving the project forward required a careful balancing act at times:

*'as a group we lurched forward and backwards in our process, taking risks and then getting scared and stalling! Sofie handled this with amazing sensitivity and provided a seemingly infinite amount of patience and containment'.*

*'Sofie's amazing skill to go at the groups pace whilst helping us move forward – not an easy task!'*

### 5.2. Pace and Content of Workshops

Mothers expressed some difficulties with the pace of the workshops, pointing out that it takes time to be confident in a group to open up, and that there were a lot of new skills to take on, but also expressing satisfaction in the immersive possibilities of

the art making.

### 5.3. Story telling: Moving from Comfort to Challenge

At times the group found it difficult to move on to new art forms, particularly the storytelling. Mid-way through the project I arrived early to meet the group after the storytelling session and heard the mothers in the coffee area talking about how they had wanted to resist Sofie's request to find a way to write about their child through the form of story, but then reflecting on how beautiful the completed stories were.

*'The story telling and having to read and record it took me right out of my comfort zone, but having done it, I felt a real achievement! To go through the process of actually writing something down which was a vital part of Tom's life with us, and what he gave to us, was quite cathartic.'*

*'I found the story writing very difficult, but the finished piece felt cathartic and right for the time and has given me further ideas'*

*'The one that was difficult at the time was the story telling, having to share, record and then hear it back, but on hearing it over and over it became easier'.*

*'I find it painful to write about Kath. It was wonderful to hear it played back and the accompanying music. Hearing everyone's stories, with the music, was the highlight'.*

The power of storytelling and its capacity for catharsis is evidenced here. Although the mothers did not perceive themselves as storytellers the use of the fairy story form offered a non-literal route to explore memory. The soundscape revealed the mothers in fact to be remarkable storytellers. As one listener wrote: *'what other language could one use but the arts to give expression to such sweetness of love and loss?'*

### 5.4. New Opportunities provided by the arts

#### 5.4.1. A new language for grief

Mothers identified the value of the arts process in making their children more visible, offering them a reason to reflect on their children's lives in a creative way. This was: *'a chance to create something that used new language as my job is so verbal'.*

*'An important after-effect was that I found myself able to let go of some of my daughter's belongings....something about creating a 'fresh' representation of her (her silver boots stepping out of a forest of Christmas roses) enabled me to release some of my more dusty relics.'*

*'Something in the seeing and hearing, and distancing of the work created a quality that seemed unearthly, ethereal, transcendent, beautiful and incredibly powerful for parents and families/audience alike'.*

Nic Whitworth suggests that this has powerful implications for grief work and the impact of the creative process on bringing memory to the here and now.

#### 5.4.2. A community of peers

The work enabled mothers to meet and empathise with others whose children have

died. One of the very special things that emerged through the process was that a group of bereaved parents had a safe space to talk about their child. Parents have a need to share stories about living children but once a child has died it is as though the memories and associated stories have to be locked away as it is taboo to bring them up. When people ask how many children do you have a bereaved mother has to make a choice about sharing her history or not.

#### 5.4.3. Sewing and Embroidery - engrossing and timeless

The mothers commented on the engrossing nature of sewing providing an *'inner space and reflection'*. One mother commented that the shared process of embroidery was: *'rather similar to grief itself – slow – and allowing us to talk, bond, weep, laugh as we progressed our ideas and produced something which reflected our children'*.

#### 5.5. Partnership with SLOW

The project has cemented a strong partnership between artist Sofie Layton and Nic Whitworth, founder of SLOW. *'I have been wanting to do something like this for years - it is a gift to me to work with Sofie'*. Nic Whitworth played a critical role as project mentor, offering support to the SLOW group mothers and also recognising and helping Sofie in her judgements about when and how to introduce new artistic challenges to the group.

#### 5.6. Partnership with Graeae Theatre Company

The mothers valued Graeae's generous welcome and safe space which they recognised as vital to enabling them to share intimate and sometimes difficult thoughts. Jenny Sealey here reflects on the value of her role as an *'outsider'* who had not experienced the death of a child.

*'I was without doubt a clumsy clunky person in the room trying not to ask the wrong questions or put my foot in it, and of course I did. But that weirdly gave me the freedom to ask the questions that they wanted to answer. It opened up new discussions in and around cliches, thinking about stories and thinking about the role of death in theatre and the relation to this in terms of Graeae. I was and still am acutely aware that I was very privileged to be allowed to join their sessions and that it was not and will never be a club that I want to belong to. My role was also to support Sofie who was both the leader and a participant so I think my time in the room gave her space to just be and listen and took the pressure of having to have two hats on. I felt useful not only making teas, coffees, arms to hug but useful in my directness to be open and honest about my curiosity trying to understand such loss.'*

#### 5.7 Mothers' attitudes to the public presentation

Some of the mothers worried before the event because they were uncertain how the installation would be presented to a wider audience, but after the event they reflected on how important the day had been for them as a collective celebration.

*'The day of sharing was a very special memorable occasion. All the elements we had been working on coming together in a solemn and beautiful way to remember and celebrate our children. The hangings, our individual tributes, the bed with its cover, heart breaking but dignified, the music, the signing, the sight and scent of so many flowers'*.



*'The installation idea was hard to grasp at first, seemed confusing as I felt no-one really knew what it was 'supposed' to look like or be – and was very exposing. But the finished installation and, importantly, its audience, took all the work of the previous weeks to another, amazing level.'*

Jenny Sealey commented on the mothers' bravery in allowing their loss to be shared both *'to reach out to others and to dismantle the huge barriers that are mentioned each time they mention the loss of the child'*.

One mother encapsulated her doubts as to how the work might be received *'it's hard for me to judge what it is like for an audience, whether it is maudlin or beautiful'*.

## 6. PUBLIC PRESENTATION AND AUDIENCE RESPONSES

Two presentations of the installations made during the workshops took place in the Graeae Theatre Studio 14 and 15 December 2014, one for family and friends (attended by 35) and a second, for funders, potential partners and arts in health or end of life or bereavement professionals (attended by 25). The presentations were accompanied by the BSL signed interpretation of the soundscape of mothers' stories. There were seven installations and a bed with a quilt incorporating delicate screenprinted images of all the children. The room was filled with suspended embroideries, framed in wooden embroidery circles with unravelled treads. The childrens' images moved and floated in and out of view. The BSL signing was graceful, expressive and performative and provided a powerful symbolic vocabulary without dependence on words. A sung refrain *One day the child slipped away, slipped from time into timeless, time into timeless* punctuated the mothers' stories in Jules Maxwell's soundscape. Audience members were invited to reflect on postcards after the event, and by email describing an image which had remained in their memory.

### 6.1. Arts as a new language for grief and bereavement

6.1.1. The introduction of BSL as a language for grief was an innovation which surprised and delighted artists, audiences and mothers. Jenny Sealey articulates this very clearly:

*'The pre bereaved and bereaved mothers loved creating name signs for themselves and their child and the signing of the stories had an extraordinary impact on the bereaved mothers as it became a moving (in a literal and emotional sense) 3 dimensional memory which was brought to life by the sign names of the child , the smile, attitude of the child ( as depicted in the stories). I am always aware of the power of signing but this was a whole new level and was quite extraordinary.'*

The comments of audiences endorse the power of this language:

*'It's true that the addition of BSL allows for another way to express totally over-whelming emotion as movement and body is such a huge part of how we show what goes on inside.'*  
(audience)

*'At its heart it celebrates our children with our personal memories but it also, hopefully,*

*gives a wider picture of understanding grief”.*

*‘The articles of clothing affected me as much as the pictures. The signing – instead of people speaking on stage is very powerful. And the stillness. The soundtrack/music choice is perfect – I’ll be hearing in my head for some time. Thank you’.*

*‘I enjoyed at first visiting the installations. My first impressions were of the beauty of the whole and then I was drawn to the individual ‘shrines’ and the embroidery. I loved how they moved against the stillness. The sound-scape added to the experience and I was moved at times to tears. Listening and watching the stories added a whole layer. I am not familiar with sign language – it really helped me to ‘see’ the stories and feel them’.*



6.1.2. For some parents looking at an image of their child was, in the words of one mother, ‘a giant step’. Others had few images, and those they had were of low resolution. Digital photography and archiving of images is itself a transient and ever changing technology. The few images a parent has of a child can become corrupted or lost, thus echoing the nature of grief and loss. By transforming these images into screen prints the photographs become tangible, tactile objects, physical images with connection to the lost children.



## 6.2. Deepening Understanding of grief and Loss

*'I feel simultaneously like I want to leave this space and run for the hills....and like I want to stay here forever. It is overwhelming. I haven't lost a child, but I have known and lost some wonderful young people...and know some whom I know I will have to say goodbye too soon. I feel as though they are all in this piece, even if their individual stories aren't. There are many other parents who need this, I think....'* (Hospice staff)

*'Feels familiar, something about it feels like I know the space, the energy. Feels like if I was to be invited into the dream of grief, like a set/movie, to walk around gathering thoughts. My eye caught the embroidery on the ceiling, as they slowly turned around, like memories, sometimes close and other times far away. Inspiring piece of work, I want all bereaved families to experience the story of their loved one in this sense of eternity...living on...'*  
Shahina - Hospice Manager

*'Absolutely beautiful! Thank you so much to everyone involved for sharing this with us – it felt very special to be able to hear the stories, and see the artwork, a small-but amazing – glimpse of some special children'. Rachel, Hospice Manager*

*'The strength and love and knowing that fills this space could take on a new world.'*

*'The stories of such remembering, playfulness and loss all blended into memories of such treasured devotion – beautiful artistry, through journeys and memories never forgotten.'*

*'Thank you to all women who shared your memories, treasures and stories. They have been received with enormous respect, honour and warmth. Thank you.'*

*'Largely, I feel speechless. The experience I've had today will stay with me for a long time. And it felt like I entered each of these worlds – experiencing the pain of it all – even though I've never had a bereavement before. To me 'the gift of time' is what I take away with me – realising how precious it is'.*

*'Thanks for giving me a pen to write with because I don't think I could speak. This installation is beautiful and powerful and should be shared with a wide audience. Thank you for allowing me to be a small part of it.'*

*'We have all been incredibly moved by the project's strength and sensitive ambitions. The sharing of the material was utterly beautiful and full of warmth'. Graeae staff member*

*'I was struck by the wonderful variety of images and the exquisite construction of all the work. So many individual stories of relationship brought together. I was drawn back several times to the chicken wishbone mandala as an image of nourishment, care and love. An image of sustaining life in a very tangible way, and a striking image of the cycle or wheel of life' Hospice in the Community Manager*

6.3. One or two audience members expressed a sense of helplessness and unbearable grief.

*'The floor installations were devastating – like little graves exuding a child who had been and the unbearable grief that was in the room'.*

*'In many ways I feel lost for words- my throat feels like it is tightening as I am trying hard to swallow. Its in my throat and stomach that I feel the emotion of this piece'.*

*'Like songs of innocence and experience so unimaginable. In all the painful loss there was so much treasuring and preciousness, tenderness and attention to detail. Does the sharing with a wider public help? Is there some good in us knowing a tiny piece of the story of each child? For me in the audience I have been given a glimpse of another world'.*



## 7. REFLECTIONS & LEARNING ABOUT THE ARTS AT THE END OF LIFE

### 7.1. Sofie as artist and participant

Sofie's role in this project was complex and extremely demanding. Sofie's daughter Eva died 10 years ago. So in this project she was both artist and participant.

Sofie's experience as a peer was a critical factor in building trust with the mothers. They acknowledged how important it was to them that Sofie understood what it was to be a bereaved mother. It was because of this that the mothers responded to Sofie's urging them to push their artistic practice on to another stage. In their reflections the mothers used language like; *"I wouldn't have thought I could do this...."* So when the hurdle of making work based on images of their children had been overcome, Sofie wished to push the group further towards writing about their children in the form of fairy stories. The initial resistance to this was overcome when Sofie herself was able to read them a story she had written about her own child. Sofie was all too aware of striking the right balance between 'pushing' the art, and acknowledging the parents' need for safety within a process; between letting the parents work comfortably at their own pace and risking that they did not achieve the rewards of engaging more expressively with the emerging content – for example moving from a cosy sewing group, into an expressive story-telling genre. *'I go between artist mode holding it together and pushing to make a piece of work that hopefully has an integrity with out being sentimental and clichéd.....It does feel so important to make it however and it needs so much care and tenderness to make it appropriate and valid in the wider world in the future.'*

## 7.2. Public Presentation

Sofie was aware that six weeks is a very short time, and that as part of the research and development process she had committed to making a small public presentation in order to share outcomes and methods with an audience of families and professionals who might be involved in a future project. Her experience as artist also suggested that there were further rewards, pleasure and acknowledgement to be had in the public sharing of creative processes. However this was not easy for any of the group. *'There was a lot of uncertainty on the installation day and the group needed support and reassurance about the expectations. The installation itself was a massive success but I think we all got quite anxious about feeling vulnerable and exposed'*. Supporting and meeting the needs of the group in leading towards this reduced the amount of time Sofie had hoped for to develop her own reflective arts practice.

## 7.3. The Artist and a duty of Care

Sofie felt the responsibility to provide a duty of care to the mothers. Sofie had identified her own need for support as artist working with bereavement and met six times with psycho-therapist Sara Portnoy. This was extremely useful in assisting Sofie in processing the mothers' responses, reflecting on the artwork and planning. However, as Portnoy pointed out, running a group is not fundamentally any less time-consuming or energy-consuming than running eight individual sessions. So Portnoy's supervision prioritised support for Sofie in meeting the needs of the group but could not also fully address Sofie's personal needs as a bereaved mother going through her own artistic process. Portnoy pointed out how particularly demanding this was for Sofie – describing her role as artist as *'swimming with the crocodiles'* yet without the therapist's distance and supervision support. Any future development must take into account the dual nature of Sofie's role as artist and bereaved mother and provide sufficient professional support to her.

## 7.4. Is this Art or Art Therapy?

Sofie is an artist, and whilst she recognises the therapeutic benefits of working as artist, she is not a therapist and her way of working is not art therapy. However her approach as artist aligns with research which identifies factors which are known to help grieving families including: “open communication within the family and friends, expression of feelings and thoughts about grief .....[and] .....remembering the whole person who has died, meeting and talking with others who have been bereaved” (Stokes 2004).

Research on the role of remembering in bereavement has shown how working with symbols, photographs or imagery can enable the bereaved to connect positively to experiences, emotions and narratives of the relationship with the child who has died. Portnoy and Stubbs’ work (2012) acknowledges the important role of memory in “retaining a sense of the person they loved and have lost. Memories help to weave a strong, vibrant connection between the living and the child who has died”. Furthermore they emphasise that: “Remembering needs to be an active process. Bringing things to mind refreshes and secures the memory”. p. 8. Sofie’s approach to exploring memory and symbols and imagery was through the art forms of print-making, sewing and story-telling. It provided an ‘active’ process and when words were used, they were through the form of story-telling, enabling exploration of memories in a non-literal and extremely powerful way. Such activities can also enable parents to remember the essence of the person, rather than ‘how’ they died, which, when children have been ill for a long time, can dominate the memory of their lives. The peer group approach is also a distinctive feature of Sofie’s workshops, and recognises the importance of sharing feelings and experiences with others who have also been bereaved.

## 8. THE FUTURE

There was 100% support from the professionals working with bereavement or in hospices for involvement in a future project. Artsadmin and Anna Ledgard will support producing and developing future plans with Sofie leading the artistic process.

### Future involvement of Hospices

*We would definitely be interested in involvement in a future project if this was possible. It would be brilliant if Sofie could work with both our bereaved parents and our pre-bereaved parents (in two separate groups would probably work best). The same kind of project as this time would work well for us- but would need to look at different timings so that our parents could attend. The pre-bereaved parents who did a short one-off session with Sofie really enjoyed it and would I'm sure be interested in taking part in a longer, more focused project with her. (RF) Hospice Manager*

*I want all bereaved families to experience the story of their loved one in this sense of eternity...living on... Thank you for sharing this with us, it evokes all the right questions, and feelings and need. (Shahina) Hospice Manager*

And from Jenny Sealey at Graeae:

*This work is vital to continue. It is huge and necessary and we need to transcend class and ethnicity and make it available to women (and men) who might not necessarily be part of a*

*support group. I am interested in creating the quilt (one made of nails, metal, barbed wire etc) of cliches to capture the some of the many statements /cliches that I collected in my time with the women 'God wanted another angel' 'she was so disabled so it must be a relief'. I think the photos and tapestries and sound scape could/would make an extraordinary exhibition for Museum of Childhood and a few choice small galleries e.g. Staithes Gallery.*

Unravelled – a small collaboration with the V & A Museum of Childhood  
Sofie had applied for the REST R&D funding to develop her own artistic practice in conjunction with the participative group work as part of the small arts award. However the demands of the project meant that focus became heavily weighted on the participative process and sharing event. So in the short term Sofie wants to develop her own creative/reflective process around memory and loss with particular emphasis on clothing, fabric and texture. Rhian Harris director of V&A museum of childhood came to the event and is interested in supporting this conversation, enabling Sofie to access the children's clothing collection at the museum of childhood and developing a collaboration with the curators. Sofie is developing a new proposal "Unravelled" which will explore themes from REST as an studio artist lead project, and have a smaller participative element to enable artist development.



9. CONCLUSIONS & RECOMMENDATIONS FOR A FUTURE PROJECT  
REST: March 2016 - March 2017
- 9.1. Producing Framework held by Artsadmin  
Artsadmin can provide the producing framework with Anna Ledgard as Project Producer and Sofie as Lead Artist. Anna Ledgard is also a qualified end of life carer bringing together the realms of the arts and creativity, and end of life with her skills as producer.
- 9.2. Collaboration with Graeae Theatre Company  
The rationale for the collaboration with Graeae is central because many children with disabilities do not live long lives and they and their families often face the prospect of death and bereavement. Jenny's presence and the BSL interpretation meant that a central access strategy (BSL) is being developed as an artform itself. A close collaboration between Artsadmin and Graeae also strengthens the project's capacity to jointly raise funds for future work together.
- 9.3. Collaboration with Hospices  
Participation should be extended to include parents at both hospices and within the community of Newham through the hospice at home and community outreach of St Josephs and Richard House Hospice. Hospice provision focuses on respite care for parents as much as for the children. Any future project structure must be flexible to respond to the fluctuating attendance.
- 9.4. Cultural Diversity  
Collaboration with East London hospices will ensure inclusion of diverse communities so as to include different cultural attitudes and practices at the end of life.
- 9.5. SLOW Partnership  
The SLOW group wishes to continue its involvement and sees the project as an opportunity to fulfil its original aims of working with creativity and bereavement and to extend its remit to include partnership with artists.
- 9.6. Pastoral Support  
Resources should be allocated towards a pastoral role to work alongside the artist so that parents have sufficient psychological support. This was described as a 'safety-lane' person: *'to pick up people who may be struggling and work alongside them at a slower pace if necessary and provide listening support if needed.'* Supervision for the lead artist should also be provided.



- 9.7. Participatory process resulting in Public Art works  
The project should work towards producing a public installation/performance that can be available as a growing installation involving bereaved parents over a period of time and working with the hospices in East London to engage local families and communities at the heart of the project.
- 9.8. Artistic Innovation  
The future project will further artistic innovation with the evolution of non-verbal and highly visual artistic languages, creating collective art works and soundscapes and extending the use of sign-language and visual imagery as a uniquely expressive language of bereavement, grief and death.
- 9.9. Resources - Funding  
A fund-raising strategy will be devised to include: The Blavatnik Foundation; ACE; The Rayne Foundation and the Wellcome Trust. We will explore the capacity of hospice partners to be involved in raising partnership funds for a future project.

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