

**Perinatal & Infant Loss Bereavement  
Support and Information: Training for  
Professionals and Volunteers in the USA &  
UK**

**Report on Winston Churchill Memorial  
Trust Fellowship**

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## **Acknowledgements**

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Barb Himes and Laura Reno, First Candle

Joni Cutshall, St Francis Hospital, Indianapolis

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Cherie Golant

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Cheryl Titherly, Sands UK

Ruth Bender Atik, Miscarriage Association

Helen Tourle, Cruse Bereavement Care

Mel Scott, Towards Tomorrow Together & Baby Loss STAR

Dr Ann Rowland and Elizabeth Morgan, Child Bereavement UK

Francine Bates, The Lullaby Trust

Jane Fisher, Antenatal Results and Choices (ARC)

## **Introduction**

Perinatal and infant loss (also referred to as pregnancy, baby and infant loss) is a topic that has been shrouded in silence and stigma for much of the twentieth century and into the twenty-first century. Ironically, baby loss was not such a taboo topic in the nineteenth century because infant mortality was so prevalent; families expected to have a baby, or babies, die around birth or in infancy. It was in the twentieth century, as birth and death were medicalised that the landscape changed. And now, with the twenty-first century's promise of technology, the persistence of myths and a general silence around the death of a baby, families have an expectation that pregnancy is typically safe and successful (Broderick & Cochrane 2013, Davis 2016, Layne 2003, Malacrida 1998, Stanbridge & Woolley 1993).

With expectations of pregnancy as safe and predictable, families are often traumatised by the death of a much loved and much wanted baby. Often their baby's death is the first time they have been confronted with the death of a close family member, and it is foreign and uncharted territory for them. They are frequently led by their healthcare provider as to what they are able to do in wake of such tragedy.

The need for training on the topic of baby loss for health and caring professionals is essential. Additionally, as voluntary organisations have grown in our communities, providing support and memory-making services, the need for training their numbers has also grown.

Here in New Zealand, like other high-income and developed countries, we have seen a change in practice in relation to baby loss – at both the healthcare and societal levels. Hospital care has changed dramatically; whereas bereaved parents might never have seen, held, named or buried their baby, parents in contemporary New Zealand are encouraged to spend time with their baby, parent them and take them home before a funeral or farewell service. Post mortems are routinely offered and we have a national committee dedicated to the reduction of maternal and perinatal morbidity and mortality (the Perinatal and Maternal Mortality Review Committee or PMMRC).

We also have organisations in our communities provided by volunteers, often bereaved parents, who want to ensure that families are offered support and services to assist them in their grief. They run support meetings, organise awareness events and stock hospitals with memory and clothing items for deceased babies.

What we haven't seen alongside these developments is consistent and professional perinatal and infant loss training in New Zealand. This is an important element of providing quality perinatal bereavement care. With that in mind, it seemed logical to look to what other countries have done in their development of training for professionals and volunteers in the area of perinatal and infant loss.

In October 2015, I was fortunate to be awarded a Winston Churchill Memorial Trust Fellowship and was able to travel to the United States and the United Kingdom in 2016 to meet with baby loss support organisations to discuss their training programmes for health and caring professionals, and for their volunteers.

My particular interest in this area of training in perinatal and infant loss support and information derives from my experiences as a bereaved parent, as a volunteer with Sands New Zealand for fifteen years, and my business, Vicki Culling Associates, which specialises in training for volunteers and professionals in this field ([www.vca.co.nz](http://www.vca.co.nz)).

I travelled from New Zealand to the United States and met with two organisations, visited a hospital and met with one individual working in the area of perinatal and infant loss support and research.

I then travelled to the United Kingdom and met with seven organisations that work in the area of perinatal and infant loss support and resources.

This report begins with my reflections of the learning I derived from the trip I undertook. I came away with different outcomes than those I was expecting. Learning about the initiatives in the UK around accreditation, standards and collaboration was interesting and thought provoking.

I then go on to describe each of the organisations and/or individuals with whom I met in the USA and the UK.

## **Reflections and Learning**

I started my Winston Churchill Memorial Trust Fellowship with expectations that I would learn about training of professionals and volunteers and return to New Zealand to consider how I might incorporate that learning into the work I do and how I might effectively disseminate and share it with others.

Of course, I did learn much about training content and processes and there are many different concepts and/or content that I am intending to expand upon. For example, First Candle's inclusion of the grieving single parent in their volunteer training; Joni Cutshall's use of aromatherapy for grieving parents and support groups; Share's training topic of Perinatal Grief and Complicating Factors which includes secondary losses, complicated grief and the impact of loss on the wider family; developing specific support groups for subsequent pregnancy after loss; Sands UK's focus on active and interactive learning; the Miscarriage Association's high calibre videos that can be used as training tools; Cruse Bereavement's 'Bereavement At Work' topic; the recognition of health professionals through Baby Loss STAR's Butterfly Awards; Child Bereavement UK's pre-course learning provided on an easy accessible CD; the Lullaby Trust's approach to Befriender training and maintaining their levels of knowledge and professionalism; and ARC's training content around decision-making in pregnancy.

But I also came away with new learning and some concepts that I feel are relevant and important to New Zealand. They are – accreditation, bereavement care standards, and a collaborative approach to providing professional and consistent training.

### **Accreditation**

The organisations I met with in the UK all talked of having their training accredited through a national organisation. They have a number of organisations that can provide accreditation for baby loss support organisations and their training:

Accreditation UK - <https://www.britishcouncil.org/education/accreditation>

Mentoring and Befriending Foundation - <http://www.mandbf.org.uk/>

CPD Certification Service - [www.cpduk.co.uk](http://www.cpduk.co.uk)

The Open College Network - [www.opencollnet.org.nz](http://www.opencollnet.org.nz)

This is an area I would like to explore further. I believe an accreditation process, especially for volunteer training, would provide both an auditing component and a benefit to the person undergoing the training in the form of a qualification or recognised training profile.

There are existing bodies which provide accreditation to professional training – specialist colleges such as the College of GPs or the Royal College of Physicians, the Midwifery Council, and The Funeral Services Training Trust. But volunteer training remains unaccredited

This was an area I became increasingly interested in throughout my trip. A result of this learning is my plan to look into our New Zealand frameworks and identify organisations that can provide accreditation for the training that baby loss support organisation undertake.

### **Bereavement Care Standards**

Another theme that emerged from my trip was the Bereavement Care Service Standards, developed by Cruse Bereavement Care and the Bereavement Services Association with the goal of improving bereavement care services nationally.

The standards define a set of criteria that represent what professionals, patients and families have identified is important in bereavement care. They came about because of the increasing recognition that the manner in which services, professionals and volunteers respond to the bereaved can have a long-term impact on how they grieve, their health and their memories of the individual who has died (Bereavement Care Service Standards, 2014).

The Standards are designed to ‘bridge the gap’ between the experience of bereaved people and the services delivered to them in the statutory and voluntary sectors.

An online search indicates New Zealand has Palliative Care Bereavement Support Guidelines (<http://www.arohanuihospice.org.nz/wp-content/themes/arohanui/images/Bereavement-Support-Guidelines-2232-Links.pdf>) but no general bereavement care service standards.

Would having some bereavement care service standards make a difference to the experiences of bereaved parents following the death of a baby? Of course, there can be no assurance that such a move would make a difference. But it would provide those agencies, both statutory and voluntary, with a template or guideline of what is expected in the care they provide.

Again, it is an area I would like to further discuss with New Zealand agencies. Additionally, it may be more realistic that we look at developing specific pregnancy and baby loss bereavement care guidelines as a project with all baby loss support organisations in New Zealand. This leads to my final learning point.

## **Collaboration**

Talking to the many baby loss support organisations about their training for professionals and volunteers was inspiring and illuminating. There were many aspects of the different training I learned about and observed, that I found overlapped with training I have seen, and provided myself, here in New Zealand.

Perhaps the most important theme that came though was the need to have structured and professional training. New Zealand is a small country with a small number of organisations providing support for bereaved parents and also providing training for health professionals. Reflecting on my learning, I see the possibility of a central training provider for these organisations which are primarily voluntary and therefore want to spend their time on their core services which is the provision of support and memory making services. One training provider would relieve many of these small organisations of the pressure to find the funds and organise the training of their volunteers.

It would also assist in ensuring consistency and, like Sands UK has done with its professionals' training, ensure that learning objectives are met and bereavement care practice around the country is improved.

In order to undertake these such a project, as well as investigate the development of baby loss bereavement care standards, it is apparent that we need an organisation like the UK's Bereaved Parents Support Organisations Network (BPSO) <http://bpson.org.uk/> or a more general organisation like The Bereaved Services Association <http://www.bsauk.org/>.

A collaborative endeavour might relieve our small organisations of the pressure to be many things – a provider of bereavement support, raising awareness of baby loss, an advocacy organisation, a political voice, a training provider for both professionals and volunteers and a fundraiser.

Historically, New Zealand did have an organisation that might have met the criteria I am suggesting - the National Association of Loss and Grief (NALAG) - but it disbanded a few years ago.

I believe that bringing all of our organisations together under one umbrella to develop training opportunities, standards, consider accreditation and provide updated information and resources would be an effective use of time, funding and resources.

As it happens, I received funding in 2007 from the Ministry of Social Development's Community Development fund to investigate setting up an umbrella organisation for baby loss organisations (it was called Cherish). My focus at that time was on information provision and I was looking at setting up a clearinghouse website. There was interest from the many organisations around the country and I was able to secure external funds for a national meeting which saw the beginning of a network.

Unfortunately, the funding was for 12 months only and when the funding ran out, so too did my ability to maintain the momentum. Ten years later, I find myself in a similar position – looking at how we might bring baby loss support organisations together but this time to provide much more than information.

A network or structured approach could ensure baby loss bereavement care standards, provide training for volunteers and professionals, investigate accreditation and be a central point for liaison, information and resources.

This then is the outcome of my Winston Churchill Memorial Trust Fellowship. I hope to investigate this possibility further and ultimately contribute to the changing landscape of baby loss information, support, training and education in Aotearoa New Zealand

## **First Candle | now CJ First Candle [www.cjfirstcandle.org](http://www.cjfirstcandle.org)**

**Barb Himes, Director of Training & Education and Laura Reno, Director of Bereavement, | Monday 1 August 2016**

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First Candle began in the 1960s as the National SIDS Foundation, focusing on supporting families who had experienced the death of a baby from SIDS. In the late 1980s, following mergers with several national and regional SIDS groups, it became the SIDS Alliance. In 2002, the focus of the organisation expanded to include stillbirth and SUID/SUDI (Sudden Unexpected Infant death or Death of an Infant). Alongside this development, the name was changed to First Candle, reflecting its broader mission and hope for the future. In early 2017, First Candle merged with CJ Foundation for SIDS, another organisation focused on research, support, education and awareness of infant death. The new organisation is now called CJ First Candle.

I was fortunate to spend the day with Barb Himes, Director of Education and Training, and Laura Reno, Director of Bereavement, in Indianapolis. Barb had organised a day's online training for volunteers and I was welcomed along to participate. The morning was spent on Peer Support Provider Training and the afternoon on Self-Care Training.

The Peer Support Provider Training was hosted on the Zoom platform and lead by Barb Himes with a presentation on PowerPoint. First Candle has volunteers in different parts of the United States providing support to newly bereaved parents, often by phone or in person. Training enables First Candle to ensure the support being given is safe, appropriate and meets the needs of the bereaved parents in their communities who access their services.

Barb started with some introductory information including an explanation of what peer support can offer grieving families. Volunteers are provided with current and accurate information, they provide a non-judgemental listening ear and offer coping skills at a time they are very much needed. She then went on to discuss the characteristics of a good peer supporter and offered definitions of grief, bereavement, mourning and traumatic grief.

The next section covered was the phases of grief, and Barb explored different aspects (shock and numbness, searching and yearning, disorientation, hope and healing). She then went on to talk about common grief responses, the experience of a single bereaved parent and explored complicated grief in some more detail.

The last section was on being a peer supporter – how to be and what to say and not say. Barb also talked about sibling grief and finished with a section on self-care and resources.

The afternoon session, Taking Care of Yourself While Caring for Others, was presented by Sue Morris, PsyD, Director of Bereavement Services, Dana-Farber/Brigham & Women’s Cancer Center, Boston, Massachusetts. The presentation was virtual, through the Zoom platform as well.

Dr Morris talked about the importance of self-care and the importance of building our own self-care tool box. After defining self-care, Dr Morris invited everyone to participate in an activity which focused on the barriers to self-care. She then discussed the challenges and opportunities of supporting bereaved parents and outlined what good self-care looks like.

Dr Morris presented three important aspects to consider when building one’s self-care toolbox – our emotional, physical and spiritual wellness. She suggested that peer supporters incorporate tools that tackle each aspect, and both individual and team strategies. Some time was spent on defining strategies and an activity on exploring what is already in our toolbox and what we might add to it, ended this topic.

Dr Morris recommended an app called Simply Being (a meditation app) to the participants at the end of the presentation.



Above: Laura Reno (left) and Barb Himes (right)

## St Francis Hospital, Indianapolis | [www.franciscanhealth.org/Indy](http://www.franciscanhealth.org/Indy)

Joni Cutshall, Bereavement Coordinator | Tuesday 2 August 2016

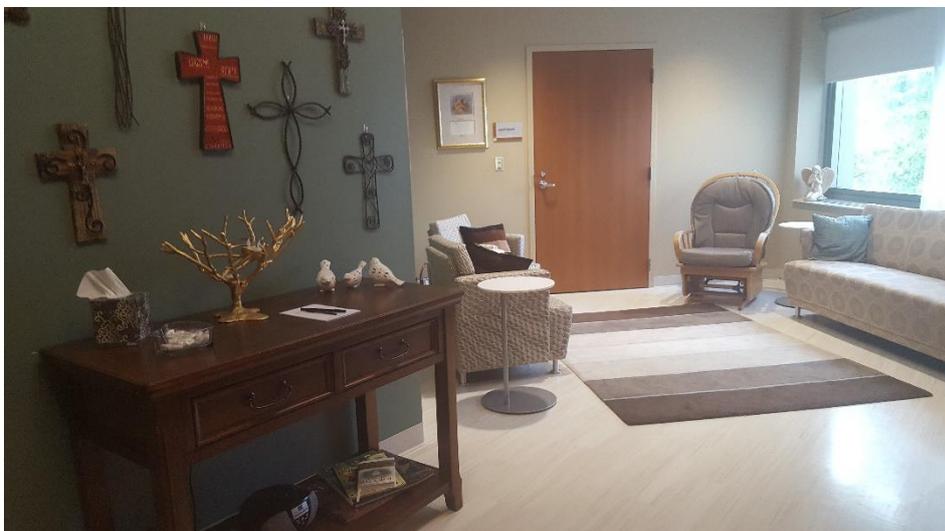
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I was very fortunate to visit with Joni Cutshall, Bereavement Coordinator at one of the Catholic/Franciscan hospitals in Indianapolis, providing faith-based, integrated healthcare.

Joni has an office which adjoins the dedicated perinatal loss room. The room consists of a hospital room, an adjoining family room, and a supplies room which Joni's office is connected to. Joni showed me the various clothing and memory items they provide families in the hospital following the death of a baby. Many of the items were similar to those provided in New Zealand.



The perinatal loss hospital room at St Francis Hospital.



The adjoining family room at St Francis Hospital (the door goes through to the supplies room).

Of particular interest were the items made by volunteers for parents and families, either as clothing, to hold their babies or as memory items. Just as in New Zealand, Joni noted that having tangible items was important to families as it helped validate their loss and provide them with articles or items they may not otherwise have because their baby was so small or premature.



A small pouch or cradle made from material and felt for babies of around 14-20 weeks



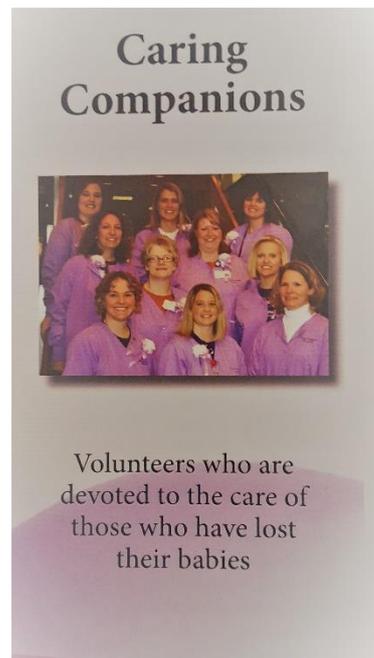
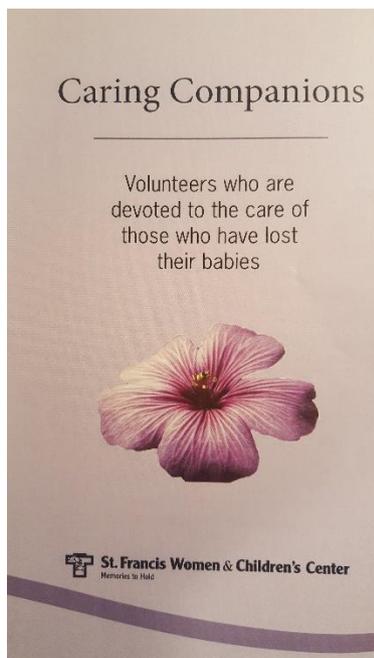
A piece of remembrance jewellery – the smaller heart is placed in the casket with the baby and the parents/s keep the larger piece of jewellery with the 'missing heart'.



A memory box made of material for parents to place special remembrance items in and take home.

Joni also talked about the hospital's Caring Companions program. This program was set up by a group of bereaved mothers who had spent time at St Francis Hospital when their baby or babies died, and who wanted to provide support to both bereaved parents and to the staff at the hospital.

The Caring Companions program is voluntary and participants are required to undergo volunteer training as well as specialised perinatal bereavement training (Resolve Through Sharing or RTS training). There are ten bereaved mothers who make up the Caring Companions program; they provide bedside support, antepartum support, organise awareness events, raise funds, provide follow up for parents once they have left the hospital and also provide some office support. The program is clear that the Caring Companions provide non-clinical or non-nursing support and they specialise in creating remembrance keepsakes for parents and families (photos, hand and footprints, hand and foot imprints and casts).



Further information on the Caring Companion program can be found at this link...

<https://www.franciscanhealth.org/health-care-services/caring-companions-program-92>

I talked with Joni about the work she does as a Bereavement Coordinator. Joni is called to meet with families who have experienced the death of a baby in any part of the hospital and also in the community. She organises all aspects of memory making and sometimes creates

the items such as castings and prints. They have a local *Now I Lay Me Down To Sleep* photographer who comes in to do professional photographs.



One of the memory items provided by the hospital to parents who know their baby's death is imminent, is a teddy bear with a recording of their baby's heartbeat inserted inside.

Joni will often provide the families with two copies of their baby's heartbeat – one which is inserted in the bear and one which is given as a back-up or copy of the recording.

Finally, I talked to Joni about her use of Clinical Aromatherapy as part of her work. Joni is qualified in aromatherapy and she talked about the impact it has on parents. One interesting aspect was Joni's practice of creating a special mix, or Bereavement Blend, for families which she would then spray on items worn by the baby. Joni uses mixtures of aromas not usually present in everyday life. The family is given a bottle of the special mixture so they are able to remember their baby through the sense of smell. The sense of smell is believed to have more power than any other sense in recreating memories and Joni is harnessing this for the benefit of bereaved parents and families. Joni noted that frankincense, rose and jasmine provide great support during grief.

Joni also talked of using aromatherapy in support meetings. She will spray a room prior to participants arriving to promote calm and peace.

## Share: Pregnancy & Infant Loss Support, St Charles,

Missouri | <http://nationalshare.org/>

Rose Carlson, Program Coordinator | Thursday 4 August 2016

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The Share office is located a block away from the St Joseph Hospital-St Charles, the largest hospital in the St Charles area.



I met with Rose Carlson, Program Director, Patti Budnik, Bereavement Care Manager and Debbie Cochran, Executive Director at Share Pregnancy and Infant Loss Support in St Charles, Missouri. I spent most of the day at the Share office, learning about their training with professionals, with volunteers and about the running of their organisation.

Share began in 1977 when Sister Jane Marie Lamb started a support group at the insistence of a newly bereaved family in Springfield, Illinois. Share's mission is to serve those whose lives are touched by the death of a baby through pregnancy loss, stillbirth or in the first few months of life. Share's national network of services includes over 75 Share Chapters in 29 states. The National share office has 11 staff, a Board of Directors and an Advisory Board; they are funded predominantly through fundraising and donations.

Share offers a number of different training programs aimed at both professionals and volunteers. Their professional training consists of three training options :

**Sharing & Caring** – this is a two and a half day or 20-hour training program that provides professionals with information and tools to work with families who have experienced the loss of a baby either early in pregnancy, as a stillbirth or in the first few months of life. This training has 18.25 continued education credits for nurses and social workers and takes place over two days, starting at 7:30am and ending at 5:30pm. Pre- and post-training surveys are distributed in order to evaluate the effectiveness of the training for participants.

This training begins with reflection on perinatal loss – looking at Share and its history, examining the changing practices in perinatal loss and the increased support for families in the 21<sup>st</sup> century. The next topic is Perinatal Grief and Complicating Factors. This section covers the unique grief of perinatal loss, secondary losses, complicated grieving, subsequent pregnancy and the impact of perinatal loss on couples, partners, grandparents, siblings and the wider family.

The training then goes on to look at Difficult Decisions which addresses the many different situations parents face after receiving a prenatal diagnosis. This includes disposal of frozen embryos, selective reduction in pregnancy, ending a pregnancy due to congenital abnormality, a life-threatening diagnosis or maternal health, continuing a pregnancy after a life-limiting diagnosis, and decisions in the NICU around life support and life-saving measures.

The next topic is the Rights of Parents, which includes standards of care for bereaved parents, the difference between choices and mandates, and the evolution of choices offered to parents. And the last topic for the day is Cultural and Social diversity in which culture is defined, cultural influences are explored, and the notion of cultural competence is introduced. The topic ends with a discussion of cultural proficiency.

The second day of the Sharing & Caring training begins with Establishing a Share Bereavement program. Professionals are encouraged to consider establishing a facility-based program and are given direction and resources to do so. The next topic is Data Collection in which the importance of gathering facts to summarise and define the mission of a program is emphasised. This brief section also discusses the use of data in describing a program's activities to a Board, to families, to the media and the community at large.

The training then goes on to discuss Memory Making, suggesting ways to provide unique memory making opportunities for families at their time of loss. Many creative examples are provided of how staff and families can preserve lasting memories when a baby is not

expected to survive or has died. The inclusion of other family members in making memories is presented also – grandparents, siblings, the wider family. This section concludes with a discussion on memory making in a group setting, particularly including memory making in group/support meetings.

The Sharing & Caring training also includes the important topic of Caring for Yourself. In this section participants look at the ‘cost of caring’ or the impact of caring for others on one’s own life. This section includes the effects of stress, signs of burnout, compassion fatigue, explores individual coping styles, and offers practical suggestions for self-care.

The last topic in this training is Establishing and Maintaining an Effective Aftercare Support Program. In this section participants discuss the importance of ongoing support for the supporters, support group management (starting and running a support group), making use of online support, and evaluating and expanding your program. This topic also includes a section called Addressing Challenges which discusses the specific challenges in running a support group as well as challenges with individuals such as the threat of suicide. The training ends with a Closing Ritual.

This Sharing & Caring training usually costs \$500 per person to attend, but Share secured a grant that funded training across the state of Missouri so it has been able to be delivered in a number of locations.

Share also offers training for volunteers, called **Caring Companion** training. This is a two-day, 16-hour seminar designed to educate and prepare parent volunteers who are providing peer support to families experiencing the loss of a baby. A Companion is a bereaved parent who is supporting newly bereaved parents. They might meet them in the hospital setting and remain as their support for some time. They might take photos and assist in creating memories whilst the family is in the hospital, then provide support with follow up by phone or in person. The Caring companion workshop provides education and hands-on skills so volunteers can confidently work with bereaved families.

Share also provides two other training workshops – Compassionate Caregiving and Power of Presence: Providing Support After the Loss of a Baby.

The **Compassionate Caregiving** training is a four-hour workshop that provides an overview of the grief process and explores how perinatal loss affects parents and families. The training

also looks at the provision of family-centred care and aims to increase attendees' comfort level in talking to parents and families experiencing a loss.

The **Power of Presence: Providing Support After the Loss of a Baby** training is a two-and-a-half-hour seminar which aims to enhance an understanding of perinatal bereavement and its impact on families. The training is aimed at caregivers, focusing on the caregiver roles in various patient care settings and the importance of caring for the caregiver. This training has 2.5 nursing continuing education hours attached to it.

Share also offers a variety of **Online Support** options for bereaved families. Share maintains an active presence on Facebook, and offers three closed (or private) pages and one public page. The private pages are Share Bereaved Families Peer Support, Share Subsequent Pregnancy Peer Support, and Share group for Spanish Speaking Families. The public group is Share's national Facebook page.

Share also has a Pinterest page (<http://pinterest.com/nationalshare>), a blog (<http://nationalshare.blogspot.com>), a You Tube Channel (<https://www.youtube.com/user/NationalShare>) and offers a bimonthly e-magazine called *Sharing*.

Share does not receive government funding, it relies on two major fundraising events – an annual ball and the Share Walk for Remembrance and Hope. The 2015 Walk for Remembrance and Hope attracted 2,500 attendees (compared to around 300 people in 2007). Attendees pay for registration and pay for the annual walk t-shirt. This is the biggest fundraiser for the organisation.

## **Cherie Golant**

**Facilitator, Pregnancy After Loss Support group | Saturday 6 August 2016**

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Cherie Golant runs a monthly Pregnancy After Loss support group in San Francisco. I met Cherie at a MISS Foundation conference in 2006 in Phoenix, Arizona and wanted to take the opportunity to ask her about the support group while I was in the area.

Cherie experienced the death of her daughter in 2003 and attended a local support group called SAND (Support After Neonatal Death) for a few months. In her subsequent pregnancy, Cherie found she was not emotionally prepared and found a Pregnancy After Loss support group but it was 25 miles away. She and her husband drove the 50-mile round trip once a month and found it very helpful to meet others who were dealing with the consequences of loss in their subsequent pregnancy. Cherie noted that she was also receiving support through the MISS Foundation online forums which were incredibly helpful.

Following conversations with her local pregnancy education office about the lack of support for subsequent pregnancy after loss, and the opportunity to attend a national conference on patient-centred care, a plan was formed. Cherie attended training run by another pregnancy loss group, HAND (Helping After Neonatal Death). HAND runs a 40 -hour training program once a year for local volunteers interested in providing direct support over the phone or at support group meetings.



Vicki Culling and  
Cherie Golant in  
San Francisco.

The group Cherie facilitates is a drop-in, unstructured support group (they don't have a schedule for each month with structured topics etc). They often start with attendees sharing a brief re-cap of their loss and a check-in with where they are now (trying to conceive, pregnant, have experienced a loss after loss). Then the discussion is open and attendees ask questions of each other and share their experiences, thoughts and challenges. Cherie noted that the group works best when there are parents at different stages of gestation with their subsequent pregnancy.

It is the practice of the group to invite parents back who have recently safely delivered their subsequent baby. This helps if the group facilitator's experience of a subsequent pregnancy was many years ago and the immediacy of the grief and anxiety is dulled. Time is also spent on discussion of birth plans, potential triggers and specific anxieties that individuals are experiencing.

Like any support group, Cherie noted that time is spent on guidelines at the beginning and finds that clear and strong facilitation makes a difference to how the group functions. Cherie is paid by the hospital to run the meetings which reinforces the notion that the hospital sees value in providing such community support.

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**Lesley Dewar, Befriender Training Coordinator | Tuesday 9 August 2016**

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On Tuesday 9<sup>th</sup> August, I met with Lesley Dewar at the Sands UK offices in Belgrave Road, London. Sands UK has a network of groups throughout the country, with seven Network Coordinators covering geographic regions (North West, North East, West, East, South West, South East, London) and three Network Coordinators covering Scotland, Wales and Northern Ireland. The Network Coordinator role is a paid position. They oversee the activities in their region and provide information and support to the Sands volunteers, or Befrienders. (A Befriender is a volunteer peer-support role which may include personal one-to-one support and/or support group facilitation).

The Network Coordinators link up with monthly calls to ensure consistency and clarity in the work undertaken under the Sands umbrella in their region. They also organise and attend Network Days – a training day in the region to which local groups are invited and representatives from Sands head office and London also attend.

Befrienders undertake specific training that is run by a team of facilitators throughout the country, all with close links to Sands groups, and all who have been Befrienders themselves. The initial training takes place over two days and runs with a minimum of six participants and a maximum of twelve.



Spending the day with Lesley Dewar, Befriender Training Coordinator at Sands UK head office, London.

Participants are charged a fee of £25 for the initial two-day Part-One Befriender training and £15 for the one-day Part-Two Befriender training.

The Sands UK Befriender Training has been designed to meet the accreditation criteria of the Mentoring & Befriending Association [www.mandbf.org.uk](http://www.mandbf.org.uk). Sands UK has not yet gone through the accreditation process for this training.

### **Befriender Training (Part One)**

This training takes place over two consecutive days and runs from 10:00am to 4:30pm.

Prior to the training, participants are sent the Befriender workbook which contains information and notes in preparation for their two-day training. There is also an expectation that participants will have attended support meetings run by their local Sands UK group. The local group is consulted on whether a participant is ready to support others.

The two-day training is focused on active participation. Participants are presented with a number of activities to ensure effective learning. They are also provided with a Learning Journal to actively note their learning over the two days.

On the first day, participants spend time examining their own story and considering the change in role from seeking support to offering support. They are encouraged to tell a short version of their story, answering questions that may arise from bereaved parents they are supporting and encouraged to be aware of aspects that may 'push their buttons' or remind them of a personal and emotional experience they also had.

Another area of focus is interpretation. Participants are invited to take part in an activity which requires instructions being given on how to draw a bird. The aim is to reflect on how the instructions were presented, and for participants to identify open questions and clear instructions.

Participants also cover email and written support, looking at how to effectively communicate through different mediums. Another area of focus is dealing with difficult people and situations. This may be in a support meeting situation or in a one to one scenario. Sands UK Befrienders tend not to do home visits or personal one-to-one meetings. If a bereaved parent wishes to meet with a Befriender individually, a time is set up prior to the support meeting, perhaps an hour to half an hour earlier so they are able to have some personal one-to-one time for conversation and support.

Day Two of the training begins with a reminder activity on open questions. The next topic covered is boundaries, a vital component in any bereavement support training.

Participants then go on to take part in a telephone contact activity. They listen to a call and make comments on how they felt it went. They then listen to a second call with a script and are invited to comment on that. In this activity, participants get a sense of what good support sounds like, how silence is fine, and are guided in the use of language they use.

Another activity that takes place on the second day is skills practice – participants break into groups of twos and threes and practice being a Befriender. They are presented with scenarios and role play their responses.

Further topics on Day Two are how to access support as a Befriender (self-care), information about the Helpline that is run by Sands UK, and some information on communication theory.

### **Befriender Training Part Two**

The one-day training is for Befrienders who have experience in supporting bereaved parents and running support meetings. There is an expectation that Befrienders will have completed the initial Part One training and will have been Befriending for at least six months to one year.

The one day training covers facilitation skills, how to run a support meeting, revisits the topic of boundaries and invites participants to again reflect on their own personal journey.

Whilst participants complete pre- and post-workshop assessments, they are also being assessed through the course of the training as well. Facilitators also complete a ‘Readiness to Befriend’ form for each participant. If someone is deemed unready for Befriending, they have a minimum of a year before being able to apply and attend a training again. Sands will provide support for them throughout this process.

**Cheryl Titherly, Bereavement Care Coordinator | Wednesday 10 August 2016**

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Sands UK has been offering training for health professionals for around eight years. In 1991 Sands UK produced its first *Pregnancy Loss and the Death of a Baby: Guidelines for Professionals*, a comprehensive compilation of research findings, guidance and feedback on the principles of good practice when a baby dies. The fourth edition of the guidelines is currently being released, both in hard copy and online.

Previously to 2014, the guidelines authors wrote the Sands UK training called the ‘Guidelines Training’ which was then sent out to Sands groups who would then deliver the training on demand within hospitals or to centres. In 2014 Sands UK reviewed their training for professionals using an external contractor. They looked at the content of the training, its impact, and facilitators. The review found that Sands UK needed to recruit trained facilitators and re-look at the training content. Through evaluations and conversations with attendees, they found that whilst attendees thought the day was very good and they appreciated the parents experience as part of the training, they didn’t feel they were coming away any more confident in their communication and in their practice.

Feedback also noted that whilst it was a rich and valuable component having a bereaved parent present to tell their story, there wasn’t a time in the training when attendees had the space to speak openly about what they had seen or done without the fear of upsetting someone or being judged.



With Cheryl Titherly, Bereavement Care Coordinator, Sands UK head office, London

Sands UK took this all onboard and a new suite of training was written. They recruited new trainers who were skilled and professional and restructured the training days to have a bereaved parent present in the first session of the training to tell their story and/or talk about their local group. The bereaved parent now leaves after the first break and the rest of the day is run by the professional trainer. A bereaved parent is present for 97% of their training days and when a bereaved parent is not available, Sands UK has a recorded story they can show. Sands also provides guidance to the bereaved parent about their talk (for example, not naming the hospital or professionals by name, and framing their negative experiences with suggestions of how it may have been done more positively).

Sands UK offers a number of days for professionals:

Sands Training for Midwives

Sands Training for Multi-Disciplinary Groups

Sands Training for Student Midwives

Sands Training for Doulas<sup>1</sup>

Sands Training for Health Visitors

A half-day course is also offered:

Pregnancy Loss and the Death of a Baby: Sands Half-Day In-house Course for Professionals

The training is structured so that it is experiential and not a passive experience. Participants often comment that the day has been ‘hard work’ but rewarding. The experiential aspects are Skills Practice exercises covering topics such as Reactions to Bad News, Enabling Informed Choice, Best Practice Points, and Setting Personal Objectives.

Sands also works with maternity units to review practice points within the service and checks back in with the service after six months to review any changes.

The professional trainers have a set of slides, audio and film, quotes and exercises, transcripts of audio, trainer’s notes (transcript of day) and notes for local points. The training is written to suit a national overview, but also includes local information. In 2015, Sands UK delivered

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<sup>1</sup> A doula is a trained layperson (often a woman), separate from the medical system, but with knowledge and experience in pregnancy, birth, and the postnatal period. A doula has good knowledge and awareness of female physiology, but are not medically trained and cannot perform medical procedures. From [www.ohbaby.co.nz](http://www.ohbaby.co.nz).

73 sessions across the UK, six were hosted by Sands, the rest were in units or different charities. A total of 1500 professionals were trained, up from 900 the year before.

Evaluation forms are given out on the day, the trainer also completes an evaluation of the day, a summary is written up by Sands UK and is sent to the trainer, the parents speaker, the Sands group speaker, the organiser and any external funder. The administrative side of the training is a challenge – coordinating the training days, briefing the bereaved parents on their talk and also on the content they will hear in that first session, doing the evaluations, and follow up with units on their practice points review.

Attendees are sent an impact survey six months after attending a training. It is brief and in Survey Monkey format and asks if the attendees have used the skills they learned since attending the training.

The cost of the professional training depends on whether it is being run at a hospital or through a Sands group. An individual unit or hospital will pay £840 for a full day and £650 for a half-day. Sands groups are charged £600 for a full day and £540 for a half-day. Sands UK always pays the trainer and all expenses incurred and the cost includes workbooks, attendance certificates, post-training handouts, and units or hospitals receive copies of all sands products/literature.

Groups will often host a training day through their networks. The Network Coordinators will identify or organise the training, which is funded through the network. The network is funded through groups in its area. This arrangement has been successful in organising training in areas where there are no Sands groups.

Sands UK has been developing e-learning modules with other baby loss support groups for the Royal College of Midwives. One module is called ‘One Chance to Get it Right: Bereavement Care’ which was co-authored by Sands UK and Child Bereavement UK, and funded by Abigail’s Footsteps. Other e-learning modules are being developed – ‘Bereavement Care’ with Child Bereavement UK for the Royal College of General Practitioners, and ‘Communicating Difficult or Unexpected News’ for the Royal College of Midwives with Antenatal Results and Choices (ARC).

## The Miscarriage Association, Wakefield, UK

<http://www.miscarriageassociation.org.uk/>

**Ruth Bender-Atik, National Director | Thursday 11 August 2016**

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I met with Ruth Bender Atik, Director of the Miscarriage Association on Thursday 11<sup>th</sup> August in Wakefield. The Miscarriage Association is a UK wide charity providing support and information for women and families, and professionals on pregnancy loss, and works to change the perception of pregnancy loss so that nobody affected feels their loss should be hidden.

The Miscarriage Association has a fulltime director, Ruth Bender Atik; a fulltime Communications Manager; a fulltime Support Worker; and two part-time Support Workers. They also have a volunteer webmaster, a volunteer newsletter editor and two freelance project workers.

The Board of Trustees is made up of 11 parents who have experienced early pregnancy loss but also bring a variety of skills to the Board (for example, GP, nurse, marketing, HR employment).



Vicki Culling and  
Ruth Bender Atik,  
Director, Miscarriage  
Association.

The Miscarriage Association has a pool of volunteers who provide phone support and run support meetings. In our discussion, Ruth Bender Atik noted that the numbers have changed a lot over the years, and indeed the demand for services has changed. This could be attributed to the digital age, and people finding the support they need online. As a result, the Miscarriage Association reviewed the numbers of volunteers and now have around 40

volunteers throughout the country providing phone support and 15 support meetings taking place each month. They also run a public Facebook page, and groups, both public and private, in which support and information is provided.

The training for telephone supports has varied over the years. The Miscarriage Association had a Volunteers Manager for around nine years and she developed a training programme for existing and new volunteers. Because the volunteers were spread throughout the country, they found it impossible to make the training mandatory as it was not feasible to demand people travel to a central location for training. Instead the manager put together a distance learning package that consisted of tapes, reading materials and DVDs. These were distributed to the Miscarriage Association volunteers throughout the country. A few years later, a handbook was developed which outlined aspects of the organisation and explained what was expected of volunteers.

The same process has been followed for setting up support groups. A handbook is provided with information and guidance on how to go about setting up a group in one's community.

### Professional Training

The Miscarriage Association used to run study days and conferences for a number of years, but decided a couple of years ago to provide training or resources online. They have six short films available for professionals via their website that cover a variety of topics.

Four of the short films are around four minutes each and are a result of surveys undertaken with patients and health professionals. Scenarios have been developed from those surveys and professional actors are used. The four videos cover interaction with a GP, experience in Accident and Emergency (A&E), a visit to the sonographer, and interactions with an ambulance crew. In each of the videos, the patient offers a suggestion of how the professionals might have handled their role and communication with the patient in a more caring and compassionate way. The videos also have practice guidelines that can be downloaded as well.

The other two videos are slightly longer at 10 minutes and cover two very specific topics – talking to patients about options for management of miscarriage, and talking to patients about the disposal of pregnancy remains.

We ended our discussions talking about fundraising. It was very evident whilst in the UK that there is a culture of fundraising and awareness that we do not see in New Zealand. Like some

of the other organisations, the Miscarriage Association receives a sizeable amount of its funding from community fundraising (around  $\frac{1}{4}$  to a  $\frac{1}{3}$  of the Miscarriage Association's overall funding).

Ruth Bender Atik talked of the benefits of community fundraising – a grant for £1,000 will pay for a number of resources; but £1,000 coming from someone who has run a marathon has meant that around 50 people have been told about the Miscarriage Association when they have been asked to sponsor the individual, there is an online presence for the fundraising, they wear a t-shirt that has Miscarriage Association on it and perhaps a number of people now know where to go for information and resources when they experience an early pregnancy loss due to the exposure. That is why fundraising can be so much more effective than simply receiving a grant.

Ruth also spoke of the importance of nurturing the relationship with the fundraisers, writing to thank them for their efforts, wishing them luck in their endeavour, featuring their efforts on social media, and sending a free running singlet and t-shirt. All of these efforts contribute to raising awareness.

## **Cruse Bereavement Care UK** <http://www.cruse.org.uk/>

**Helen Tourle, Service & Development Manager - Training | Tuesday 9**

**August 2016**

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I met with Helen Tourle, Training Coordinator for Cruse Bereavement Care, in Sheffield on Tuesday 9<sup>th</sup> August 2016. (Unfortunately, we forgot to take a photo).

Cruse Bereavement Care is the UK's largest provider of bereavement care for all ages (in England, Wales and Northern Ireland specifically). The organisation was founded in 1959 and its name comes from a passage in the old testament about a widow's *cruse*, or jar of oil, that never ran out. This represents the care and support provided by Cruse that is ongoing and given as long as it is needed. Although the name is derived from the Bible, Cruse Bereavement Care is a secular organisation.

Cruse Bereavement Care offer support to anyone who has experienced a loss, this includes miscarriage, stillbirth, neonatal and infant loss. They have a network of 6000 volunteers, so they have volunteers who specialise in certain areas like neonatal loss or suicide.

Cruse Bereavement Care is a voluntary -led organisation with a very small staff team. They have around 30 full time equivalent staff, a management team, and a Board of Trustees. They are set apart from other non-profit groups in that their decision making is done by committees of volunteers and a council of volunteers.

Cruse has a diverse income generation – funding comes from trusts and legacies, project funding, for example working with families of homicide and BEAD (Bereaved Through Alcohol and Drugs), donations, the sale of training products and services and some fundraising. It is interesting to note that Cruse Bereavement Care's clients tend to be older, so there is less engagement with social media. Helen noted that they are still the 'collection tin' type of organisation. Whilst Cruse Bereavement Care has central funding, local areas also undertake their own income generation.

### Training

Cruse Bereavement Care offers different training options. One of their main training products is the Loss and Bereavement Awareness Workshop. This is offered externally to the public in cities throughout the UK every year and is also offered to organisations in-house. The

training is then tailored to the organisation's needs. This training is normally held over one day, that is the time frame for which there is the most demand.

The topics covered in the Loss and Bereavement Awareness training include:

- How to support bereaved clients and colleagues

- Understanding bereavement issues

- Factors affecting the grieving process

- Different cultural views of grief

- Communication and inter personal skills

Cruse Bereavement Care offers different packages for professionals. One of their central training workshops is the Bereavement at Work workshop. This is also offered as a one-day public workshop or as a tailored in-house training for organisations.

They also offer workshops in bereavement for schools, teachers and education providers; the funeral industry; customer care roles; banking sector; HR and line managers; healthcare and hospices; and housing associations.

With regards to accreditation, Cruse Bereavement Care is in the process of shifting their accreditation body. Many of their courses are now accredited by the National Counselling Society, not as counselling qualification but as CPD for counsellors.

### Volunteer Training

The volunteer training consists of a much longer time frame. The introductory course, Awareness of Bereavement Care (ABC) takes place over a number of weeks (one day a week over five to ten weeks) with portfolio work expected in between. The training days are Saturdays and the training is run from 9:00am to 4:00pm. Cruse Bereavement Care also offers add on modules to this training which are completed in their first year. The core course is an in-depth training delivered as a series of modules covering grief and bereavement, core counselling skills (paraphrasing, reflecting, clarifying, summarising, goal setting), establishing a relationship, boundaries, good endings, how Cruse Bereavement Care works, and supervision. This core training is highly regarded, with counsellors attending for their own continuing professional development (CPD) and not necessarily for the role of Cruse Bereavement Care volunteer.

The training is delivered in person, with around 16 or so in each group. Local areas organise and administer their own training, with approved trainers and co-trainers in most areas facilitating the training days.

One of Helen's roles as the National Training Coordinator is to centrally moderate the portfolios sent in by attendees, to ensure that training is consistent and to provide quality assurance.

The add-on modules are not moderated, but they are written by the national committee and approved to ensure consistency. A register is maintained of all the volunteers and the training they have completed. This is maintained on an electronic database, the Cruse Information System. Every volunteer is recorded and their status, skills, hours and training is recorded.

Cruse works to maintain professional standards, which can be challenging when the majority of participants are volunteers. Cruse Bereavement Care was also instrumental in developing Bereavement Care Service Standards. This project was funded by the Department of Health and aimed to address gaps in bereavement care provided within the statutory and voluntary sectors. The Standards set out what needs to be addressed in order for services to be both safe and effective in meeting the needs of all bereaved people. Cruse Bereavement Care worked with other groups as well as standards authorities to develop the Bereavement Care Service Standards <http://www.cruse.org.uk/news/BCSS>

Currently Cruse Bereavement Care does not offer online training but it is being considered for CPD provision. Evaluation for the professional and volunteer training is done online.

Cruse Bereavement Care also offers annual conferences for volunteers, usually one day conferences, and masterclasses which will involve the keynote speaker from the conference offering focused training on their particular topic.

## **Towards Tomorrow Together/Baby Loss STAR, Bridgwater, Somerset** <http://www.towards-tomorrow.com/> &

<https://babylossstar.co.uk/>

**Mel Scott, Founder | Wednesday 17 August 2016**

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Wednesday 17<sup>th</sup> August was a free day with no meetings planned, so with my Brit Rail Pass in hand, I took the opportunity to travel to Bridgwater, Somerset to meet with Mel Scott of Towards Tomorrow Together and Finlay's Footprints.

Mel is a trained Occupational Therapist who experienced the loss of her son, Finley, in 2009. He died in full term labour (an antepartum death). After Finley's death, Mel set up Finley's Footprints to provide support and information to bereaved families. In 2013 Mel set up Towards Tomorrow Together, a registered charity focusing on providing support and resources for bereaved parents in her local Somerset area. The charity provides memory boxes (or Butterfly Boxes) to families who have experienced an early pregnancy loss, a stillbirth or newborn loss. Mel currently supplies eight hospital in her area with Butterfly Boxes.

Mel has also written two books – *After Finley*, an account of experience of baby loss and her life after the loss of her precious boy, and *The Fairy Caretaker*, a children's book that explains the death of a sibling.

Mel also runs training days – she has two one-day workshops for professionals. The first, Baby Loss – A Parent's Perspective, is an overview of supporting families who are experiencing the loss of a baby, incorporating breaking bad news, the environment, types of loss, terminology, fathers and baby loss, making memories, birth plans, and self-care.

The second day, Pregnancy After Loss – A Parent's Perspective, covers pregnancy after loss, the impact of grief, complicated grief, support, making the parents' journey easier, and parents' stories of loss.

Mel also started the Butterfly Awards, an awards ceremony that recognises both professionals and parents advocates who work in the area of baby loss awareness and support. The awards have been running for four years.

Since meeting with Mel in 2016, she has merged her services and created Baby Loss STAR (Support, Training and Resources). The charity provides services for both professional and parents.

This new organisation offers Bereavement Doula services (both in person and distance), HOPE Coaching (a blend of Occupational Therapy and Life Coaching – HOPE stands for Hold On, Pain Ends), and Bereavement Training.



With Mel  
Scott in  
Bridgwater,  
Somerset.

## Child Bereavement UK, Buckinghamshire |

<http://childbereavementuk.org/>

**Dr Ann Rowland, Director of Bereavement Support & Education, and  
Elizabeth Morgan, Policy & Research Coordinator | Thursday 18 August  
2016**

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On Thursday 18<sup>th</sup> August, I met with Ann Rowland, Director of Bereavement Support and Education and Elizabeth Morgan, Policy and Research Coordinator, of Child Bereavement UK.

Child Bereavement UK is located in the Clare Charity Centre, Saunderton, Buckinghamshire. The building is situated on the site of the Wycombe Union Workhouse (a building to provide work for the poor and unemployed) which was demolished in the mid-1950s. The current building was built for Ortho Pharmaceuticals Ltd between 1955 and 1958. In 2009, the building was purchased for the purpose of developing a hub for local charities offering subsidised accommodation, shared resources, and meeting and conference facilities (pictured below).



Child Bereavement UK was established 22 years ago as The Child Bereavement Trust, and rebranded as Child Bereavement Trust UK in 2012. The charity has two central roles –

educating professionals and supporting families, both of which have equal weight and merit. It started with a focus on education, aiming to ensure that families who experienced the death of a baby or child had professionals round them with some understanding of the impact of that loss.

They have 70 staff (48 full time) located in offices throughout the country; 40 staff are located at the Clare Charity Centre.

Child Bereavement UK focuses training and support on two distinct areas – the first is families who have experienced the loss of a baby or child at any age, from failed IVF to the loss of an adult child. While most of their work tends to be with families who have experienced the loss from pre-birth to 18 years, they do still support families whose older children have died. The second area is support and training around the needs of bereaved children who have experienced the loss of anyone important to them. This support extends to 25 years of age, it was previously 18-19 but Child Bereavement UK has found that there is a need for extending the age limit. Child Bereavement UK is currently developing training with colleges and universities in the area of supporting bereaved youth.

Child Bereavement UK delivers their training around the loss of a child in a number of ways. Traditionally it has been the day long workshop for professionals, a six-hour multidisciplinary workshop. They have a number of workshops covering a wide variety of topics:

- Managing bereavement in the workplace

- Volunteer training: working in a service for bereaved children and young people

- Understanding loss, grief and bereavement

- Working with bereaved children and young people (an accredited two-day training)

- Grief and bereavement in schools

- Children and young people – loss, death and grief

- Children and young people with special education Needs, including Autism Spectrum Disorders – supporting them through grief

- Creative ways of helping children and families

- Teenagers and bereavement

Working with bereaved children and young people in fractured families

Supporting forces' children and families in loss and bereavement

Understanding traumatic bereavement

Suicide – the impact on families

Supporting families through pregnancy loss and death of a baby

The challenges of supporting parents through the neonatal experience

When a child dies – supporting parents and family members

Communicating with families when children have life-limiting conditions and complex needs

Paediatric post mortem – communicating with bereaved families

Supporting parents and children in end of life care and following bereavement – paediatricians' bereavement training days

Facilitating groups – two-day course, non-residential

Advanced facilitation skills

The training for paediatricians is accredited by the Royal College of Paediatrics. It is a full day's training for senior registrars who are about to become consultants. Whilst they will have had training on breaking bad news, this training is much more comprehensive. It runs three times a year, in different locations throughout the country. Pre-course learning is offered on a CD and the day is very interactive, including a session with a family speaker who has experienced the death of a baby or infant.

Child Bereavement UK trains about 7000 people a year. The people who deliver the training are a mix of CBUK staff and freelance facilitators across the country, for example, they use bereavement midwives for midwife training days. They use Child Bereavement UK materials and are paid a daily fee. A two day facilitator course is offered as part of the freelance training. They firstly attend as a delegate, then co-facilitate a training event before they are ready to lead a training day or course themselves. Child Bereavement UK also holds an annual facilitators conference day, in which they will be updated with current research and have the chance to connect with each other.

Training course charges vary depending on what is being delivered and where it is being held. Courses at the Child Bereavement UK centre have an average charge of £120, and when they go out to an organisation which constitutes 2/3 of their training, it is a sliding scale. The charge depends on whether they are a charity or a statutory organisation.

Child Bereavement UK also provides tailor made training for organisations who may want elements of the different workshops that meet their needs. They have provided training to hospices, hospital trusts, and health visitors for example. They have a good relationship with the NHS Newborn and Maternity Network, which includes attending their conferences and providing guest speakers when needed. Child Bereavement UK also organises annual conferences (one on neonatal death, a schools' conference) and study days.

All of Child Bereavement UK's training has CPD accreditation through the CPD Certification Service ([www.cpduk.co.uk](http://www.cpduk.co.uk)) and The Open College Network ([www.opencollnet.org.nz](http://www.opencollnet.org.nz)), both awarding bodies that offer qualifications or accreditation for training and courses.

Child Bereavement UK also works with other organisations in the provision of services. They provide some Sands groups in the UK with supervision, both individual and group supervision. They have worked a lot with the Scottish organisation SiMBA (an organisation providing support and resources for bereaved families following baby loss), training all of their Befrienders and providing supervision for them as well.

### Online learning

Child Bereavement UK offers limited online learning. The central training offered in this format is the course for schools which consists of four modules:

1. Introduction – how to use the online learning platform, 5 minutes;
2. Responding to a Death – explores bereavement from a pupil's perspective, providing support to the pupil and their family, 35 minutes
3. Ongoing support – explores how a school can provide ongoing support to a pupil and their family, 35 minutes

4. Supporting You – looks at self-care and looking after yourself while you support others, 5 minutes.

The organisation recently worked with Sands UK and the support organisation Abigail's Footsteps, to develop online learning for the Royal College of Nursing as well.

Child Bereavement UK is one of the founding organisations of BPSON (Bereaved Parents Support Organisations Network [www.bpson.org.uk](http://www.bpson.org.uk)) and the slightly larger network Childhood Bereavement Network <http://www.childhoodbereavementnetwork.org.uk/>. The aim of both networks is to provide support to member organisations and assist them in improving the standard of care, reduce unnecessary duplication of resources and to promote the sharing of best practice. The networks are a hub for those working with bereaved children and their families.



Elizabeth Morgan,  
Vicki Culling and Ann  
Rowland, Child  
Bereavement UK

## **Lullaby Trust, London** | <https://www.lullabytrust.org.uk/>

**Francine Bates, Chief Executive | Friday 19 August 2016**

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I met with Francine Bates, Chief Executive of the Lullaby Trust, on Friday 19 August 2016. Francine was appointed to the role in April 2011 and was instrumental in the rebrand of the charity in April 2013.

The Lullaby Trust began in 1971 as The Foundation for the Study of Infant Deaths. At that time, the number of babies dying suddenly and unexpectedly was abnormally high across the western world, and in fact New Zealand had one of the highest rates of deaths in the world.

A family motivated by personal experience started the charity with a focus on research and trying to understand why this was happening. At that point, there were theories as to why babies were dying but no strategic approach to research. The Foundation gathered people together to identify research priorities and after some publicity found they were inundated with letters from families who had experienced a SIDS death and were deeply traumatised by the experience. The foundation set up a welfare arm which is now called the support arm of the organisation.

The first 20 years of the foundation's existence focused on raising money for research and support for parents and families. At that point, there were support groups all over the country through which parents provided support to other parents – a result of the development of the self-help movement which was taking place in many areas of health such as disability and caregiving.

Substantial amounts of money were raised over the years and the Foundation was quickly funding key research projects. The breakthrough in preventing the deaths of babies occurred simultaneously in Britain, New Zealand and the Netherlands. It was apparent that Dr Spock's advice in the 1950s to sleep babies on their tummies was probably the worst piece of parenting advice ever given.

It was recognised that placing babies on their backs was the best way to sleep babies and so began the Back to Sleep campaign. Countries that adopted the campaign started to see a big drop in the numbers of babies dying and the results were replicated wherever the campaign was featured.

Evidence was then able to be gathered and it was clear that smoking in pregnancy, overheating babies, and sleeping with babies whilst under the influence of alcohol or drugs were all risk factors. And it was clear that placing a baby flat on their back in a cot or crib that was free of toys and paraphernalia was also recommended. Through the research, good public health messages were able to be developed and disseminated.

The charity changed its name in 2013 to The Lullaby Trust. One of the reasons was to target the hard-to-reach families for whom the name Foundation for the Study of Infant Death was foreign and unrelated to their experience. The organisation had been able to amass a lot of good advice through research and front line work over the years but there were still the population who were difficult to reach and connect with, families who don't necessarily engage with health visitors or their midwives. The name change was about making the charity more appealing to those groups; the original name being fine for 1971 but not so relevant for 2013.



Vicki Culling and Francine Bates, Chief Executive of The Lullaby Trust.

The Lullaby Trust has a team of 30 staff – 6 are part-time and work from home and there are 24 in the London head office. The Trust has a team of around 50 Befrienders who provide the Lullaby Trust's bereavement service. Funding for the staff and all services comes from a team of eight fundraisers who all focus on various aspects of fundraising – for example, major donors, events, community fundraising, and individual giving. Francine noted that the fundraising aspect of the charity has become quite technical as fundraising is now a huge industry.

With over 160,000 charities in England and Wales, there are many organisations and individuals asking for money, and at a time of austerity. There has been a big increase in

fundraising through challenge events, fitness and sport and there now exists a real culture around that aspect of fundraising. In the last London Marathon, The Lullaby Trust had a team of 70 runners who raised £200,000 for the charity.

The Lullaby Trust receives no government funding at all, apart from specified project work. Like all charities, the Lullaby Trust is dependent on its supporter base, Francine noted that some families, whose baby may have died over 40 years ago, will still donate to the charity.

The Trust does receive some funding from corporate sponsors, as there is a strong tradition of giving back to the community in Britain. They also receive some funding through charitable trusts grants and donations.

### Training

While the charity does not have a specific training function, it is incorporated into aspects of their support and information functions. All Lullaby trust staff are trained and the Befrienders, the network of bereaved parents providing support in the community, also receive training. The Trust has a team of six staff called Regional Development Officers who provide information and training throughout the country, including the Channel Islands. They do not cover Scotland as they have their own charity, the Scottish Cot Death Trust (<http://www.scottishcotdeathtrust.org/>).

The Regional Development Officers make themselves available to any group of professionals who want to know about safe sleep. They are paid staff so the training can be offered at a very low cost or for free. The RDOs have a training package that they deliver, ensuring consistency and quality. Francine discussed the importance of maintaining the safe sleep messages in a crowded channel. New parents have messages coming at them from a variety of sources who proclaim themselves as experts. The Lullaby Trust works hard to ensure their information which is evidence-based, ratified by clinicians and derived from research is available to professionals and parents alike. The SIDS rate is at its lowest in the UK but in order to keep the rate low, people need to be informed and educated. The messages have to be maintained.

The Trust's Befriender network also receives training. All Befrienders are inducted, receive regular training and are accredited. They are appraised every three years and the Trust's paid staff provide support. The Befrienders provide one-to-one support, mainly by telephone and sometimes by email. They do not run support groups any longer. They are expected to

provide notes from conversations with bereaved parents and attend meetings three times a year in which they are updated, receive training and can connect with other Befrienders. The Befrienders are all volunteers but The Lullaby Trust covers all their expenses.

The Befriender network consists of around 60, and at any one time a team of about 20 Befrienders will be active. The Lullaby Trust also runs an Information Helpline and a Support Helpline. The support Helpline runs from 10:00am to 5:00pm, and from 6:00pm to 10:00pm on weekends and public holidays. The Helpline is open 365 days of the year and Befrienders help to manage it.

We finished our discussion talking about the CONI programme (Care of Next Infant <https://www.lullabytrust.org.uk/professionals/care-of-next-infant-coni/>). This service has been running for 30 years by The Lullaby Trust in conjunction with the NHS and Health Visitors. The CONI programme offers additional support through Health Visitors, recognising that a subsequent baby will mean heightened anxiety for parents and families. The programme consists of frequent visits from specially trained health Visitors, apnoea monitors for the new baby, resuscitation skills training, a room thermometer and guidance on bedding and clothing, and frequent monitoring. The programme is available in 85% of the country.

Some areas offer CONI PLUS, a programme for families who may be anxious because close relatives have experienced the loss of a baby, whose baby has experienced a life-threatening event, or have experienced the loss of a baby due to a cause other than SIDS.

## Antenatal Results and Choices (ARC) | [www.arc-uk.org](http://www.arc-uk.org)

Jane Fisher, Director | Friday 19 August 2016

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I met with Jane Fisher, Director of Antenatal Results and Choices (ARC) on Friday 19<sup>th</sup> August 2016. Jane has been with ARC for 15 years, starting as their Support Coordinator.

ARC is a small organisation providing support and information on antenatal screening and its consequences. It was set up in 1988 by bereaved parents and health professionals in partnership, and was originally called Support After Termination For Abnormality (SATFA). In 1998 the name was changed to Antenatal Results and Choices (ARC) to reflect the growing number of parents wanting information on all aspects of antenatal screening.

ARC has a Board of Trustees and seven staff, three of whom are fulltime. ARC offers non-directive information and support to parents prior to and after antenatal screening, when they are making a decision about their pregnancy/baby, and after their decision which may include bereavement support. Their core services are support work (by phone and face to face). ARC doesn't have groups around the country like Sands.



With Jane Fisher of ARC at their London office.

ARC runs training for professionals, they have three separate days that are offered both in London (around 8 days a year) and around the country. They also tailor training to suit an organisation if requested.

Their training days are:

Day One – Communication Skills and Delivering Difficult News: The Implications of Antenatal Screening and Diagnosis

Day Two – Supporting Parents' Decision

Day Three – When a Prenatal Diagnosis is Made: Providing Best Care

Day One is ARC's most popular. It covers communication skills, communication around uncertainty, delivering difficult news, grief and bereavement and is attended predominantly by doctors, sonographers, genetic counsellors, health care assistance, midwives and student midwives.

Day Two covers decision-making by parents, the testing that is available, individual values clarification, debunking of common myths and principles of good practice.

Day Three is their newest workshop. It is more advanced and deals with more complicated aspects of antenatal screening and decision-making process. It is aimed at experienced professionals – midwives, genetic counsellors, doctors. The content is based on case studies and the complexities that arise in this area. It also looks at the latest antenatal testing technologies.

ARC doesn't involve parents in their training (for example having a parent come in to tell their story), preferring to use quotes from many parents rather than have one parent feature their one story.

ARC's training is accredited through the Royal College of Midwives.

ARC also runs training for volunteers, most of it through distance learning. The ARC staff also receive training and external supervision. Because the staff take the helpline calls during office hours, it's important that they receive training and support as the nature of the calls is relentless. Every call has an element of distress, whether it is someone who has just had an abnormal screening to someone who has made a decision. The helpline is open for professionals to use as well, but it is very rare that professionals will take up the option.

## Funding

The ethical and sensitive nature of ARC's work tends to limit the potential fundraising opportunities. ARC relies on grants, donations, membership fundraising, the sales of their publications to hospitals and their training days.

ARC is a member of an informal network of baby loss charities with Sands, The Lullaby Trust, Miscarriage Association, Ectopic Pregnancy Trust, Bliss, Best Beginnings and Twins & Multiple Birth Association (TAMBA). They have worked on a multi-organisation online bereavement care package for midwives recently.

## Appendix: Full Itinerary

Date	Travel/Meeting
30 July 2016	Travel from Wellington to San Francisco
31 July 2016	Travel from San Francisco to Indianapolis
1 August 2016	Indianapolis, Indiana. First Candle –Barb Himes, Director of Training & Education, First Candle & Laura Reno, Director of Bereavement
2 August 2016	Joni Cutshall, Bereavement Coordinator, St Francis Hospital, Southport, Indianapolis
3 August 2016	Travel from Indianapolis, Indiana to St Charles, Missouri
4 August 2016	Rose Carlson, National Share Office, St Charles, Missouri
5 August 2016	Travelled from St Charles, Missouri to San Francisco
6 August 2016	Cherie Golant, Pregnancy After Loss Support Group Facilitator, San Francisco
7 August 2016	Travel from San Francisco to London
9 August 2016	Lesley Dewar, Befriender Training Coordinator, Sands UK
10 August 2016	Cheryl Titherly, Bereavement Care Manager, Sands UK
11 August 2016	Ruth Bender-Atik, National Director, The Miscarriage Association, Wakefield

12 August 2016	Helen Tourle, Service & Development Manager – Training, Cruse Bereavement, Sheffield
15 August 2016	Travel to London
17 August 2016	Mel Scott, Towards Tomorrow Together/Babyloss STAR, Somerset
18 August 2016	Dr Ann Rowland, Director of Bereavement Services & Elizabeth Morgan, Policy & Research Coordinator, Child Bereavement UK
19 August 2016	Francine Bates, Lullaby Trust
	Jane Fisher, Antenatal Results & Choices (ARC)
21 August 2016	Travel London to Wellington

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