Welcome to the October Newsletter of the Family Bereavement Support Programme. We hope that in reading this Newsletter you will find connection with other parents and gain strength and support as you grieve for your child.

“Remembering the Past, Living the Present, Shaping the Future: Finding Meaning in Loss”.

Carol and Maree (filling in for Jane Sullivan who is on leave) warmly welcomed parents to the October Group. Carol acknowledged the strength and courage of the parents who were joining the group for the first time and conveyed our hope that they would find the group a safe space to share their thoughts and feelings. We reminded the group that they may choose to talk or just listen and they may have a break from the group at any time if they need to.

Our guest speaker for the night was Irene Renzenbrink. Irene is a Social Worker who has worked at the Hospital in the 1970s in the Oncology Unit and again in the early 1990s when she had some involvement with this group. Irene has also worked in the funeral industry. She currently works in a palliative care service and provides a consultancy service both locally and internationally. Irene is a member of the International Workgroup for Death Dying and Bereavement.

Irene began the evening by expressing her hope parents would feel safe in the group and able to remove the masks that they might have to wear in other areas of their life. She acknowledged the challenges parents face in making sense of what’s happened and finding the right people to support them, “the ones that listen and don’t give unwanted advice”. Throughout the evening Irene utilised images and quotes to explore the experience of grief and offer some thoughts about what might be helpful in remembering the past, living the present and shaping the future.

We began with a painting by a refugee who came to Australia by boat. It was a striking image of a tiny boat being tossed around on stormy seas. Irene spoke of the ‘storm of grief’. How we might feel like we are being battered by the elements and tossed around on stormy seas without control. This experience is captured in the words of Anna Bardsley, a mother Irene met through the Compassionate Friends Organisation. Who has written,

“I have heard grief described as a process, heard the words phases and stages but my grief is anything but orderly…more like the storm raging outside my window, a storm which buffets me at its will. Winds that rage then subside, only to rage again. Rain that drenches me or drizzles until I am wet through. Sometimes I can hold up an umbrella or take shelter. Other times there is no shelter and the umbrella is torn inside out and ripped from my hands.”

Irene went on to discuss the finding of shelter and showed us a photo of a broken umbrella left by a canal in her place of birth, Amsterdam. She asked the group “who is it that provides us with shelter?” She spoke of how people in their grief often find the ones closest to them cannot be there for them as they are too involved in
their own pain. There are new friends that are made, those who can listen. The expectations of others for grief to follow a certain course or just disappear over time can also leave you weathering the storm alone. It can be hard when people tell you what you are feeling without asking. There is no absolute course to grief and often we find there are triggers that take us back to experience the floods of emotion again. It might be a song that played on your child’s toy or an image, a smell. Anna once told her that people have asked, ‘Are you still grieving for your daughter’ and she replies ‘well my daughter is still dead!’

Irene encouraged the group to investigate other groups such as The Compassionate Friends, a bereaved parent organisation where like this group there are others who understand. She displayed the symbol of a butterfly which is used by The Compassionate Friends and spoke of it as a representation of transformation and hope.

There were more images of uprooted trees and a tiny chick depicting the chaos, confusion and vulnerability of the grief experience. Irene read out a quote from Charles Dickens which said:

“and can it be in a world so busy, that the loss of one creature makes a void in the heart so wide and deep that nothing but vast eternity can fill it up”

She described hearing many parents say they feel like their heart has been ripped out, that the loss is so great it feels like there will be a chasm inside forever.

As Irene showed more slides of sculptures and paintings, she talked of the many creative expressions of grief and the power of creativity to be “transformative”. As Patch Adams, the famous clowning doctor said, “Creativity is one of the greatest medicines ever…creativity is essential nourishment….it is the very soul of our self worth”.

The act of creating together, such as the quilt project sometimes provides us with new understandings and a sense of healing. Irene acknowledged that no amount of creativity and healing would change the knowledge that life would never be the same again.

The theme of transformation continued and Irene spoke of story telling as another way of making sense of our experiences. She read a quote by Connie Goldman, “This is the magical, mystical power of stories: they tell us not only about others but about ourselves”, and wondered if this might be the experience of parents in the group as they tell and listen to each other’s stories. Experiencing others listening to our story can have a powerful impact. There is a quote from Rachel Naomi Remen in the book “Kitchen Table Wisdom” that states:

“Listening is the oldest and most powerful tool of healing. It is often through the quality of our listening and not the wisdom of our words that we are able to effect the most profound changes in the people around us.”

Irene reflected on how this sort of listening can be hard to find. It involves being open to another’s experience of pain, not waiting to tell our own story and not competing for air space or a better story.
Within the stories of loss there is some hope. For some, this comes from the gifts their child has given them. It might be a particular quality that their child had or that their child brought alive in them. Irene illustrated this thought with a quote from Linda, Jamie’s mother in Elizabeth Kubler Ross (ed), ‘To Live until we say Goodbye’.

“No feeling of having left my child there. She was with me as she has been many times since her death. In the midst of anguish are so many beautiful memories. Jamie’s courage, her joy, her love will always be with me. She was truly a very precious gift.”

Irene described how parents have told her that through their experience of grief, they have grown and changed. Some have referred to developing a deeper awareness of what it is to love and live; of what is truly important and what is trivial. Some have felt compelled to help others through volunteer work. She gave several examples of this including the involvement of parents in developing services and facilities for parents who are bereaved at hospitals. Irene showed us a slide of the viewing or bereavement room in an Irish Hospice. She explained how the stained glass screen was added because parents did not want those entering the room to be immediately confronted with their child who had died. It gives people entering and people inside the room some time to prepare themselves. She spoke of a women who helped to plan and decorate the venue for the annual memorial service every year for 16 years. Some staff had asked, “isn’t she over it yet?” They couldn’t see the value in her very positive way of honouring her child.

The search for meaning within the experience of great pain has been written about by Viktor Frankl in relation to his time as a prisoner at Auschwitz. He observed how people could survive and continue to say ‘yes’ to life in the midst of severe deprivation and despair. He stated;

“We cannot judge a biography by its length or by the number of pages in it; we must judge by the riches of the contents. Sometimes the ‘unfinished’ are among the most beautiful of symphonies.”

Irene noted that the search for meaning is itself a journey and there may be many questions left unanswered. She referred to a quote by the late, Dame Cicely Saunders who founded the hospice movement that states:

“The search for meaning is not only a challenge for patients and families. As individuals and as a caring team many workers feel compelled to seek answers or more often to develop a readiness to live with the questions.”

Irene encouraged the group to give themselves time to explore the questions and see what arises. She stated that in a world where everyone seems to be pushed for time the challenge is to not hurry your grieving.

The image of a tree depicting the four seasons was displayed as Irene discussed the hope that is present with the changing of the seasons.

The planting of a tree can be a way of commemorating a child’s life and death. Irene read the following quote to illustrate this:

“I planted a tree honouring my daughter. As her tree grew tall and healthy I feel connected to her. I call it Marion’s tree. And even though her little hand will never touch that tree, I know it has been touched by her heart. And that is enough for me.”

Alice Rademacher, in memory of her daughter Marion Maree. In Remembering with Love, by Elizabeth Levang and Sherokee Ilse. Fairview Press, Minneapolis, 1992
Nature can offer a special place for reflection and rejuvenation. Irene shared with us some slides of nature. We reflected on the beauty of a waterfall and the vast and ongoing nature of the sea with its waves always crashing in to shore. Irene suggested that we may all have special places where we gain strength. These may provide us with a sense of spirituality and hope. She read a quote by John O’ Donahue, an Irish theologian which speaks of this hope;

“A spiritual outlook helps with transfiguration of the darkness. You are more than what has happened to you. Dignity is creative hope.”

Irene returned to the theme of creativity in grief. Stating how creativity can offer a way of expressing something that it is too hard to find the words for. It is also a way of connecting with your child and the child within. It has the potential to remind them of what their children were able to do and what they taught them. Some parents have told Irene that thinking about how their child would have coped if it was they who died first has helped them in some way.

The idea of the inner bereaved child has been written about by Beverly Raphael who states, “The inner bereaved child…that part of us that is reawakened when we lose someone we love or when we share someone else’s loss and attempt to comfort and console him. It is part of our empathy yet is difficult to bear.”

Irene suggested that when we are grieving we regress and become very childlike in our need for much support, comfort and security. Like children we need to find our own security blankets, the things that are familiar and loved that we can hold on to.

Irene summed up her presentation by acknowledging the many different ways we may find strength, support and meaning. They may include, connecting with others who can listen and understand, connecting with the vastness and beauty of nature, exploring our spiritual beliefs and connections with religion and gaining strength from what your child has brought to you. Irene finished her presentation with a quote from Helen Keller

“What we have once enjoyed we can never lose, all that we have loved deeply becomes a part of us”

She then asked the parents to reflect and join in discussion on the following three questions:

What is lost?
What is left?
What is possible?

The immediate response from one couple to the many losses associated with the death of their son was their incapacity to enjoy their current pregnancy. The father described how people ask if they are excited and all they can say is they’re “terrified”. They have “lost the opportunity to be pregnant and carefree and normal”. A mother responded, “You have lost your innocence in a way”. The couple agreed and added, it is not just what has happened to us before but we are now aware of what has happened to all the others around us here. They spoke further about the events surrounding their son’s birth including problems with the delivery and the discovery that they are carriers of a genetic disease. For them it is too frightening to think ahead. The planning for this baby has involved being confronted with triggers to the deep feelings of grief for their first child. They described pulling the string of a toy in Baby Bunting that played the same song that their first child had listened to and bursting into tears.

Even the thought of the new baby being healthy brings with it a fear that everyone will say “Oh they’re OK now – and they will become socially acceptable but it doesn’t mean that our child didn’t die”. The loss of “social niceness” was recognised by many parents. Irene stated she had heard parents say, “they dread small talk and meeting people for the first time”. There were many nods around the room as one mother stated, “people are so distant from me now”. She described seeing people at her workplace purposefully change direction to avoid her. She tries to tell them she would prefer to talk about her son. One mother suggested she could wear a T-Shirt saying ‘you can’t upset me, I’m already upset’.
A Grandmother who had joined the group with her daughter told how she is surrounded by new grandmothers and constantly struggles with listening to how wonderful it is. She described being happy for them but wishing they would show more consideration of her feelings and not talk about it all the time. A father in the group also related to the experience of births being all around him and found it particularly hard when he was asked by a family member about a newly arrived baby, “Isn’t he the most beautiful boy you ever saw”? “That’s crap - That was my son!”

For one father the response to what has been lost was “everything”. He spoke of how he had changed as a person. He no longer had the social ability to have fun and said, “I don’t like what I am or who I am at the moment but I can’t do anything about it”. He described the difficulties many parents have talked about when each partner has their own way of grieving and each one thinks their way is the ‘right’ way. This makes it difficult to share with each other. A mother in the group also related to the loneliness of her and her partner “travelling down different paths” with their grief. Irene acknowledged how isolating grief can be but also reinforced that “there is no right or wrong way to grieve just your way”.

Another loss related by a father was that of being in control and believing he could protect his family from harm. This had been a very important part of his identity at home and at work. A sense of losing control is often described by people in the midst of grief. For many it can be the first experience of not being able to effect a desired outcome in their lives. Despite this father’s sense of isolation and despair, he found the group a safe place to share with others, a place separate enough from the rest of his life, where he was not going to receive unwanted advice or have people ‘scatter’ from him.

The parents moved on to talk about their fears and difficulties trusting the medical profession. A number of them were questioning why things went wrong. Why weren’t problems identified on the scans?; Why didn’t the Doctors recognise I was dilating? and so on. As one mother said, “Doctors are only human and yet you put all your hope and trust in them, you have to.”

For those contemplating another pregnancy this was a serious consideration. They imagined seeking second opinions and being very anxious and assertive with the medical staff. The fear of it happening again was ever present.

The question of what is left was easy to answer for one mother who has two surviving daughters aged 6 and 2 years. She described how the youngest one regularly talks about her sister being sick on the floor (a common occurrence due to her treatment). Her current challenges are working out how to interpret her childrens’ behaviour and misbehaviour. She is trying to understand if it is a response to the loss of their sister or simply normal testing of their boundaries.

The question of how do we make sense of what has happened was grappled with throughout the night. Whilst some parents recognised there may be positive changes, these could never compensate for the loss of their child. As one father said, “Maybe it makes you appreciate things more and see beauty where you didn’t but I would rather have had my son and him tell me at 50, he didn’t know me because I was too busy than to have had him die.” This couple had come up with theory for their experience referred to as the, a ‘Random Acts of Crap Theory’. They have found the recognition that there is no rhyme or reason to who experiences terrible things, in some way comforting. It is a recognition that they were not singled out in any way. It doesn’t matter who you are or how good you are, terrible things can happen to you.

Others had utilised their religious beliefs in trying to come to some sense of peace or meaning. One mother agreed that bad things happen to all sorts of people and this was indiscriminate. This however raised questions for her about how to incorporate her experiences with her belief in a God who is good. She has come to a belief that whilst bad things happen maybe good can come from it. She is looking for this good and has found a little in the changed attitude of people around her who are appreciating their children a bit more. She continues to search for the good in herself and others but acknowledges it will never change the fact that a horrible thing has happened.
Another mother found peace in the belief that her son is in heaven. She described reading lots of books including some that help her form a mental picture of heaven. She has found her Christian faith a source of strength.

Irene asked the group if they draw strength from their child who has died? One mother responded immediately. She stated, “he was so beautiful and changed our lives in so many ways we need to go on to do something good to honour him”. She described how her son’s love was so special and unexpected. “To allow our lives to turn into a tragedy forever would take away what he gave us”. Other parents agreed that they had an obligation to keep their child’s memory alive. The grandmother in the group was doing this by making a quilt and shedding many a tear as she sewed. Other parents had given a particular sort of rose to all their family members to plant and name after their son. Others were looking for those moments of good they could connect with their child’s life and death. Many recognised gifts of love, courage and perhaps other things too precious to put into words given to them by their child.

As the evening drew to a close, Irene thanked the parents for listening to her and sharing their stories. We thanked Irene for her many images, quotes, stories and thoughts about ‘remembering the past, living the present and shaping the future’. The discussions continued over a cup of tea and biscuits.
My Brother, Sumith

You were the gift from god,
Loved by all family and friends.
Mum was the most happiest,
When the nurse said it’s a boy.
You grew up cheeky and naughty,
You loved schooling and playing with friends.
You were the brightest,
Your name stands for:

S – sensational
U – understandable
M – marvelous
I – intelligent
T – terrific
H – hero!

Footy, music and watching car racing were your hobbies,
You also loved visiting places.
You helped dad in gardening and washing car,
Remember fun with Jiji, Vandana.
Even at 9 years you forced into mums laps,
We all miss you but will be in our hearts forever.
You are an angel for us now.

Your Little Sister
Joyce
Contributions such as poems, letters, songs, quotations from parents, grandparents and friends are most welcome in the Newsletters. Share your thoughts, experiences and questions with others who are bereaved.

Please forward them to:

The Editor
Parents’ Bereavement Support Group
Social Work Department
Royal Children’s Hospital
Flemington Road
PARKVILLE VIC 3052

Please fill our mailbox.

The next meeting of the Parents’ Bereavement Support Group will be held on:

Thursday 17th November
7:30 pm – 9:30 pm
Seminar Room 2, 4th Floor
Front Entry Building
Royal Children’s Hospital

Our guest for the evening will be Geraldine Paine, a Nurse, Grief Counsellor and Family Therapist. Geraldine presented to the group in February of this year and is returning to further explore strategies for expressing our grief and ways we can care for ourselves.

The theme for the evening will be “Finding a balance in the chaos of grief”

Please join us for the November group.

The newsletter is a team effort. Thank you to the parents of the Parents' Bereavement Support Group, Irene, Carol, Jane Miller (Chief Social Worker), Maree, Jodi and Aleisha for their enormous assistance with the creation of the newsletters and to the Social Work Department for its ongoing support.

Maree O’Toole
Author & Editor