



**Little Steps Toward Letting the Legacy Live:  
Fine Traces of Life to Accompany Families Grieving the Death of a Child  
By Linda Moxley-Haegert and Carlin Moxley Haegert**

(Elements of this work have been previously published in both French and English. Moxley-Haegert, 2015; 2018. We have been given permission to translate the French into English)

Introduction

The objective in this paper is to describe narrative practices used in work with families who have had a child who died in palliative care at the Montreal Children's Hospital, Canada as well as describing how this work was received. We describe how 13 parents and two siblings responded to these practices. We hoped to better understand the perspectives of these families on how various narrative practice bereavement services helped them and in how parents responded to such practices as making meaning (without asking them to do so) and the identity projects that were promoted through narrative practices.

Narrative therapy has been described as a form of psychotherapy that seeks to help people identify their values, and the skills and particular knowledges they have which will help them to live those values, so they can effectively confront whatever problems they face. In this specific work the problems faced were managing when a child is very sick with a life-threatening condition and the child dies. During this difficult yet precious journey we sought to help each family member co-author new narratives about themselves.

According to David Epston narrative therapy involves:

“Listening to and telling or retelling stories about the challenges and problems people encounter in their lives. In the face of serious and sometimes potentially deadly problems, the idea of hearing or telling stories may seem a trivial pursuit. It is hard to believe that conversations can shape new realities and meanings of our lives. **But they do.**” (Narrative Approaches, n.d.)

This was found to be the case in our work that for many of these family members, they not only were able to shape new realities but appreciated finding new meanings. In this particular palliative care program, community was developed by the narrative practitioner to promote such ‘tellings and retellings’ and many narrative community practices, as well as individual narrative therapy, were used to promote such pursuits.

Additionally, we sought to challenge some dominant discourses regarding grieving that some parents had found not helpful (i.e. Kubler Ross, 1969 and her stages of grief; Freud, 1961 and Lindeman, 1994 who suggested detachment from the loved person who has died as a goal in



managing grief).

Ultimately, our hope is that this work will lead to the consideration of more uses of narrative practices in pediatric health care settings, in palliative care, and in bereavement care in particular. If too ambitious, we are optimistic that readers of this paper will begin, or continue, to deeply question and consider the role of narrative therapy in the lives of children and their families.

### Life (and Death) as an Identity Project

As a psychologist and narrative practitioner for a children's palliative team, the important question was how to be helpful to family members. How could one respectfully acknowledge their stories of pain and anguish while intervening in such a manner as to keep the presence of the child alive even after death? In response to these questions we shaped narrative practices to 'fit' this situation (Moxley-Haegert, 2009) in order to help the children and their families create their identity life projects so the children could leave a legacy and the parents could assure that this legacy would live on in the lives of the families the children left behind. Michael White (2001) stated that life is an identity project. He also stated that identity is a public and social achievement, not an individual achievement. Our work discussed in this paper is to demonstrate how narrative practices can be used to help families develop their new identity in a social and public way after the death of a child (i.e. Little Steps, 1). Identity can get confusing when there is a loss of a child.

'Am I still a mother when my only child has died?'

'Am I still a parent of two children when only one child is still alive?'

We have described this work using the stories of the people who consulted the narrative practitioner involved in this palliative care program. These stories are told from her (Linda's) perspective as well as using the parents' or siblings' own words<sup>1</sup>.

### How It All Began

Linda: *Pierluc was as adventuresome in the afterlife it would seem as in life itself. Three months after his death from a devastatingly fast growing tumour he paid me a visit in my dreams (speaking English perfectly even though in life he knew no other language than French). He stated that his mother needed help. I awoke, fresh with amazing memories of both Pierluc and of his mother, Sylvie. Both had such vivid personalities. I remembered Pierluc sailing down the hospital hallways using his intravenous pole on wheels as a semblance of a skateboard. He was very deft and ran into no one. Shortly after hearing that the treatment for his tumour was not working and would be stopped, I went to visit him in his hospital room. I had only known him for four and a half short*

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<sup>1</sup> Stories are written in italics for clarification for the reader





months and already I knew I would never forget him. He was playing a video game and his video character had just died. He reset and that character came alive again. I asked him, somewhat tentatively, 'Is that what happens to us when we die, we reset and come alive again?' He was scornful and very wise for a 7-year-old: 'No, silly, they become a flash of light and go up to the sky. I am going to ride a dolphin there'. Then softly, he said; 'That will be pretty soon'. Later I asked his dad, 'Has he been told what it means to stop treatment?' His dad said: 'No and we are not planning to tell him'. However, I let both parents know what Pierluc had told me and they wondered if he understood more than they had thought. Dolphin was a theme for him because he had been planning to go and swim with the dolphins for his Children's Wish (a program that supports children getting a dream wish when they are severely ill). Pierluc had been told that this trip could not happen until later. It was much later, and that is another beautiful story. Pierluc turned for the worst less than a week later. We found a storybook in French that told of a mother dolphin releasing her baby dolphin to fly to the sky after death. Sylvie read this to Pierluc and told him a story of his trip to swim with the dolphins, reading and talking of dolphins all night until Pierluc lost consciousness in the wee hours of the morning.

Sylvie was one of the parents who asked me to provide services to help, not only the children when they are sick, but the family members as well. Together with other parents, we created the COURAGE (Cancer as an Oppportunity to Unite and share Resources in an Amicable Group setting that provides Encouragement) group for parents and families in oncology which later turned into a COURAGE program using community narrative practices to provide support for parents, families and the sick children (Moxley-Haegert, 2012; 2015).

Pierluc's parents lived far from Montreal but I went to the Memorial service for him. I noticed that the dolphin theme continued as his parents had placed his ashes in a dolphin chamber. There were many parents from the COURAGE program there and Sylvie seemed to be surrounded by supportive friends. When she did not call me for the follow-up that I could have provided, I thought that she must have been managing all right. I had written her a narrative letter with many of my memories of Pierluc during his months in hospital and sent some questions to help in the re-membling of Pierluc. I received a lovely note of thank you and acknowledgment for the work we had done together.

### Narrative Practices Used in This Work

**Re-membling: Questions to Say 'Hullo' Again.** Michal White (2005; 2007) used the metaphor of life as a 'club' (to create a community) that includes significant members of the past, the present and the future. When someone dies, the relationship with the person one has loved is not lost. Hedtke (2000; 2012; 2014) and White (1989; 2007) taught the narrative practice of re-





remembering conversations and these conversations seemed useful before and after the death of a child (White, 2007, Chapter 3). Borrowing from ideas by Hedtke (2012), re-membering questions were added to certain narrative letters sent after the death of a child.<sup>2</sup> Such questions, as follows, could help parents to say 'Hullo' again.

**Getting to know you – again:** (Questions will use the male pronoun, as such questions were sent to Pierluc's parents in the narrative letter they received?)

- Could you please explain who your child was before his death, what kind of person was he, what did he like?
- What do you think he might have chosen as his profession? What were his passions? How did he like to spend his time?

### **Contributions and appreciations**

- What have you received from having known him? What contributions has he made to your life?
- What things about knowing him make you realise what is important to you?
- What have you appreciated in your relationship with him?
- What did he say that was important to you? (If the child died before talking)
- What things do you think he would have wanted to say to you that would have been important to you?
- What did he teach you?

### **Identity**

- If you could feel his presence now, how would it show itself?
- What difference would it make to your life if you were able to do just that?
- What possibilities would it bring to your life if you could feel his presence closer?

### **Re-membering**

- If he could hear what you are saying now, how would he respond? What would he be feeling about your relationship together?

Guided by the metaphor 'Saying Hullo Again' one can help parents to re-establish the relationship with their child that they might have lost when the child dies (White, 1989).

Linda: *I called Sylvie and it certainly was evident that she was having a very difficult time. She said that she had lost her community when Pierluc had died. Those friends from the COURAGE program whose children survived seemed to not know how to interact with*

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<sup>2</sup> See Moxley-Haegert, 2009 for an example of such a letter



*her now. Because she lived some distance from many services in Montreal, she did not know many other parents who had a child who died. She was feeling very alone and lost and I began to consider forming a narrative therapy bereavement group. I learned that some parents who had been involved with grief groups that followed some contemporary ideas of grief felt they were doing something wrong if they did not follow the stages of grief; if they did not feel they had learned from this experience; or did not believe that they needed this experience to gain certain knowledge; or felt that they did not want to disengage from the relationship.*

*However, meeting with Sylvie made me re-think the need for providing a group which followed narrative therapy ethics of re-engaging, keeping the loved one close, keeping stories alive, and bringing the best of the past into the future. Sylvie was interested in this idea as she was such a social person and was willing to travel far for such a group.*

*I also heard what David Epston, Kay Ingamells and Tom Carlson call a counter-story during this conversation (using double story listening). Antoine (not his real name as I have not permission to use it) went on a swim with the dolphins' trip for his children's dream wish. He had been a friend of Pierluc's in the hospital and his mother was Sylvie's friend in the COURAGE group. When Sylvie heard that Antoine was going to swim with the dolphins, she asked if they would bring a picture of Pierluc on a toy dolphin so he could also swim with the dolphins. The dolphins took a particular liking to Pierluc and played with the toy dolphin for a long time. Sylvie was able to bring Pierluc closer to her heart and soul. When I pointed out this story to her, she began to realize that her stories were not only of loss and sadness. She had a counterstory of this new ability to be able now to seek out joy and appreciation'.*

*Translated from the French 'Little Steps' book 1, Sylvie wrote: Pierluc cherished one dream, that of swimming with the dolphins. The Wish Foundation helps children have a wish, but the cancer progressed so quickly that he left us a few days before the planned trip. When the doctors told us that he only had a few hours to live, I slept at his side and told him to close his eyes and I told him of the dream trip he was supposed to have taken. Pierluc smiled and saw very well in his imagination.'*

**The 'Double or Counter Story'.** Narrative practices in search of the 'double story' helps people to distance themselves from the realities of the problems and to focus on other realities that are also present, but relatively unavailable (White & Epston, 1990). David Epston, Kay Ingamells and Tom Carlson have recently further developed the theme of listening for subordinate stories into what they call a counter-story<sup>3</sup>. Counter stories are actions and are identity focussed. The

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<sup>3</sup> Please refer to Ingamells, 2016 for more information on counter-storying ideas



'Little Steps' document<sup>4</sup>, was produced under these conditions and inspired by the narrative practice of always listening for the hidden and subordinate stories (White, 2007). Such listening recognizes not only the stories of these parents' challenges to survive the death of a child but also the stories of the competences, the special abilities and the special knowledges that can be specifically discovered on this occasion.

Linda: *During our group meetings that we later called the Little Steps group, Sylvie remembered Pierluc's high action, courage and vibrancy. She talked to others in the group asking, 'What might I be doing with Pierluc if he had lived? She realized that one thing he would have loved would have been to learn to ride a motorcycle. She decided that her learning to drive a large motorcycle would be a way to celebrate Pierluc's life, and to take such road trips as he would have wanted to take. Her husband turned in his four-wheeler that he had bought to play with Pierluc for another motorcycle. The two parents then had an interest in common.*

Sylvie: *Two years after the death of Pierluc I enrolled in the Huma Ecuador Challenge with Leucan – an organization for the well-being and recovery of cancer stricken children. This challenge tested me in every imaginable way, and that is where I realized I still had a taste for life.*

**The Definitional Ceremony.** To accompany this project of identity reconstruction of the parents involved in the production of the souvenir album "Petits Pas/Little Steps", we proceeded to the 're-narration' of the history of the parents in written and artistic form, to make a definitional ceremony. A re-narration of stories promotes the development of rich stories that recognize and value life. The objective was to help parents renegotiate their earlier conclusions about life identity that may be weakened with the loss of a child<sup>5</sup>.

Linda: *Pierluc and his mother helped me to think of collective ways of practice as a means of helping with this challenging time. Prior to this, my bereavement work had not used ideas of group work. This was in part because other parents had told me of grief support groups that they felt were harmful. I did not want to replicate this harm. I invited Pierluc's mum and several other parents to participate in a project that aimed at determining knowledges and understandings recognized after the death of a child and letting the legacy of their children live.*

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<sup>4</sup> This document can be accessed through the Montreal Children's Hospital [Here](#)

<sup>5</sup> Definitional ceremonies were also used with children to re-value life (Moore, Talwar & Moxley-Haegert, 2015)





**Collective/Community Practices.** Through various collective practices<sup>6</sup>, the narrative therapist works to assist families to find stories of hope that would help them better manage these tragedies. We used narrative practices with the intent of finding a way that the child's presences might remain. To this end the children were encouraged to use narrative collective ideas (e.g. Denborough, 2010; Ncube, 2006) to make legacies. Narrative collective practices allowed for subordinate stories to emerge which could leave a legacy. We began to use collective and community practices so the legacies of these children could continue to live on in the hearts of their families and friends.

### The Little Steps Programme

Community was developed with our Little Steps Program. This form of community engagement is characterised by a criss-crossing exchange of stories and messages. These are stories and messages that contain hard-won knowledges about ways of responding to tough times. They are stories and messages that describe family initiatives, skills, values and dreams that are implicit in these stories or messages. Our particular community was bilingual, both French and English, the two official languages in Canada. The project Little Steps was designed to be a living document (Newman, 2008) so that stories could be continually added to the album that was the result of this project. It is our hope that such a community approach described here can be replicated by practitioners in many different contexts.

When beginning this project parents were presented the following in both verbal and written form:

*When such a catastrophe as the death of a child occurs, we can ask ourselves many questions regarding how to make sense of all this?*

*Humans use language universally to tell their story. Narrative Practice focuses on the narrative process of the story in order to cope with strong emotions. In this group, we will share our stories and it is the hope that we can then create together a collective document that will demonstrate what we are doing to survive this life challenge. Questions have been prepared that may lead you to share your thoughts and achievements. The purpose of these questions is to guide you through the experience of your story, which we perhaps can write together and pass on to other families.*

### Questions for the realization of our project

We started the project with questions developed with the help of other therapists practicing the narrative approach (David Denborough, 2010; personal communication, 2009). The categories of questions arose from the many previous conversations with parents consulting

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<sup>6</sup> For more ideas of collective narrative practices see David Epston's Anti-Anorexia Leagues [Here](#), and Dulwich Centre's Collective Narrative Practices [Here](#)







the narrative therapist in individual narrative therapy within this palliative care program. Many of these categories seemed important to parents as ways to bring the child who had died closer to their hearts.

**The physical - the place:**

- Are there particular places you frequent that provides a sense of comfort to you after the death of your child? Why are these places special? Could you tell a story of one of these comfort areas? What are you doing in this location?

**Memory - your memories:**

- Are there particular memories that you revisit and that bring you comfort? If so, can you share a story about some of them?

**Your own story:**

- Were there other moments in your life where you had to deal with loss or grief? If so, how did you do it? Would you like to tell us a story of these moments? What were the most difficult steps? Did you get help or support on these occasions from any person or particular community? If so, how did this help you? And what would these people do or say if they were with you now?

**Missing/lamenting:**

- What are the things you miss most in relationship to your child who died? Why are these things so important right now? Have they always been important to you? How did they take on this importance? Who else knows what matters most to you in life?

**The spiritual:**

- How do you approach the issues of pain and loss? Are you spiritually engaged in one way or another? If so, what kind of "spiritual conversation" do you have at the moment? With God, with yourself, with others? What do you think of these spiritual conversations? Are they important to you? Have these values always been important to you in life? Who transmitted these spiritual values to you?

**Culture:**

- Are there specific ways in your culture to respond to the pain and loss that is important to you? Why are they important? How do you participate? Are there aspects or ways of your culture to respond to the pain and loss that do not fit very well for you? If so, how do you find ways to grieve in your own way?





**Different areas of expression:**

- At this moment of loss, are there certain odours, sounds, songs, textures, tastes, dances, etc. that are particularly important to you? If so, could you explain why they matter? Are there rituals that you find useful? These can be rituals that celebrate a person's life or rituals that increase the memories of your child or other forms of rituals.

What was at least one of the results of these conversations? A memory album to help other parents that is now available to consultation on line, on the website of the Montreal Children's Hospital, Montreal, Canada.

The Little Steps memory album

To help with this identity project created through what became the 'Little Steps' album, we planned 'a 'telling' of the stories in written and artistic form. These are stories of survival about how these parents are in the process of managing their lives after the death of a child. Re-telling stories of survival can thicken the story, making a re-grading (in a strength direction) of earlier conclusions about identity of life which can be weakened by the loss of a child. It was hoped, as well, that these parents could help themselves while helping other parents.

The 'Little Steps' project also followed the narrative practice of searching for 'double stories', including hope stories and perhaps new identity knowledges that could be discovered (White, 2007). The hope was that identity knowledges could become social and public.

*A group of mothers used 'scrapbooking' as a form of narrative therapy for grief. Each child has its proper story. 'Little Steps' is a memory album of all the stories accompanied by words of comfort, words of hope and counsel developed by these parents in grief to help and support other parents who have had a child die. Written and created by a group of mothers whose child was treated at the Montreal Children's Hospital for children (Montreal, Quebec, Canada), and edited by Linda Moxley-Haegert and Marie-Claude Proulx, this album 'Little Steps' is an amazing work of love. (Petits Pas 1)*

The goal was to unite parents living the death of a child with the aim of sharing their special knowledges and creating tools to help other parents living this experience. In this way, we implemented the knowledge of what parents had not found helpful with support groups and the knowledge of what was felt could be helpful from narrative practice. This was a different identity project.

Two excerpts from the Preface of Little Steps Album

*Never in their wildest dreams could parents think they would have a child diagnosed with a life-threatening condition. Then, when it happens, it seems like their greatest nightmare. However, when that nightmare turns into knowing a child will die, the reality of this wild dream seems like*





*a living hell. Yet these parents must live on. While working with these families, the aim was to have conversations that can be healing. We often wondered how to have such conversations and not end up only with stories of suffering. How can one respect their very difficult story, and yet find stories of mastery and coping? How could we together find ways that achievements, knowledges, and resources can be voiced?*

*Identity is built through stories. We contain multiple identity stories. Many people contribute to one's identity. Through re-membering we can incorporate stories of a child who has died into our identity'. It was the hope and dream of Linda and Marie-Claude that a new identity could be built through the creation of this document, Little Steps.*

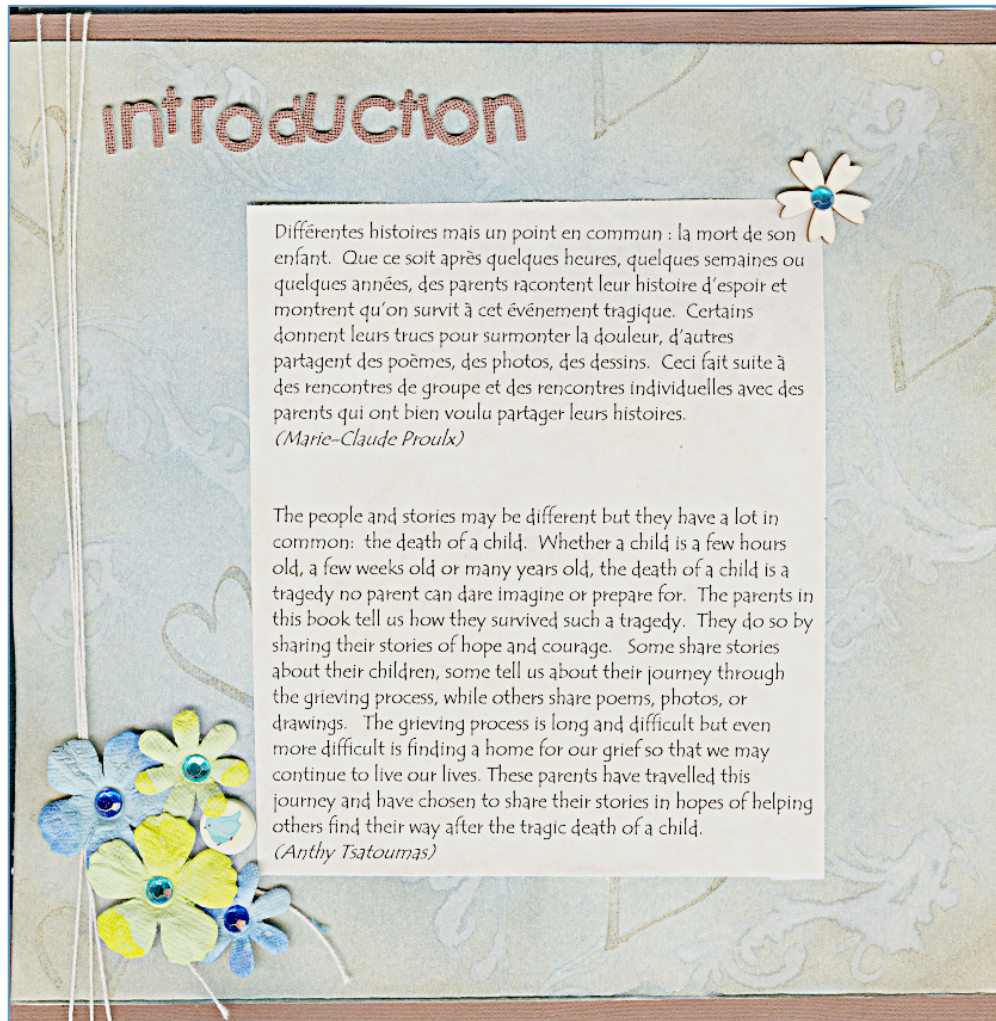
### The 'Little Steps' project

Each chapter contains different elements: text, scrapbooking, drawings, lists, thoughts, poems, witnessing, etc. We wanted the project to be flexible and thus to permit parents to express themselves and share with other parents in any manner they wished. Every item in the book was edited in order to follow narrative practice ethics of practice. That is, nothing is presented as a must or should, but what was found to be helpful to the person.

A picture of the introduction [Figure 1] is included to demonstrate their work. Individual stories are French for the francophones and English for the anglophone. All introductions were bilingual.



[Figure 1]



### Chapter 1, Portraits:

This chapter allows you to get to know us, the parents, and our children. You will read about our journey and learn about our struggles. We share our story with you.

### Chapter 2, The how to's:

Hope is what helped us to find our way through the stormy times of our grief. Our grief surrounded us with many struggles before and after the death of our child. We hoped for less pain and more happiness to come our way. We did not know how to find that happiness. Here we tell you how we found our way out of the storm and began to live again, albeit in a different light.

### Chapter 3, Pastimes:



The grief a parent faces when a child is sick or when a child dies is all consuming. It disables you and every day life becomes difficult and overwhelming. An escape from the emotions, anxieties and pain faced each day was a necessity. The ways we chose to escape from our daily turmoil are shared in this chapter. These moments of escape were priceless for our well-being. Some of these activities still play a prominent part in our lives.

#### **Chapter 4, Creations:**

Creativity seemed to be an activity many of us chose as a means of escape. Many creative avenues were chosen. Scrapbooking, card making, crafting, drawing, writing, reading, music and poetry are a few examples. Why did so many of us reach out to our artistic side? I once read that “art requires the ability to surrender to the unanticipated possibilities of the work as it unfolds”. Our hope for a brighter tomorrow provided us with the ability and willingness to surrender to our ‘art’. In doing so, creativity provided us with a great peace and a means to release our pain. It was a therapeutic escape.

#### **Chapter 5, Words and writings:**

Understanding a parent’s grief is very difficult if you have not traveled the same road. However, acknowledgement of the grief a parent is enduring is priceless. Kind words, simple acts, listening, and a hug are all simple gestures that provide enormous comfort to a grieving parent. Comfort can also be found in books, poems, support groups or music. This chapter lets you know some of these that brought us comfort.

#### **Chapter 6, Family and those around us:**

The illness and death of a child does not only affect the parents. They say “it takes a village to raise a child”. That same village is there when a child is ill and the parents are left with empty arms. The people in this village help us to live day to day, they support and comfort us and they grieve with us. Brothers, sisters, parents, aunts and uncles, friends and colleagues also suffer the loss of this child. How they helped us and how they grieved for the loss of our child is found here.

#### **Chapter 7, What we did not find helpful:**

The death of a child is difficult. No one wants to think of such tragedy. Many people are not comfortable talking to a grieving parent and often speak and act inappropriately. Their words and actions are hurtful, although with good intentions, and do not help us. This chapter shares some of the words and actions that have not been helpful to us.

#### **Chapter 8, Rituals, symbols and souvenirs:**

Our pain is forever present, but so are our children. You are invited to think about what it might mean to children and families who have suffered this trauma to know that their legacies are shared with you. What would it mean to them to acknowledge that they can leave a legacy rather than a loss? What would it mean to the parents and siblings to know that they are ‘Letting the Legacies Live’? What new ideas for legacy do you have?





### In Helping Others, We Helped Ourselves

Two mothers were overheard to say: "In aiding others I realized that I was helped myself". They were asked if they would be willing to explain in more detail what they meant by this statement, and Martine wrote the following:

*Thank you for directing our project with such dedication and organization and compassion. When Linda asked me to be part of this project, I felt privileged to be part of something that joined my interest in creating and my desire to help others. At first it was hard and then I realized we were being led by hope. I hope with this project I will lead others to want to help themselves while helping others.*

*While participating in Little Steps with Linda, psychologist and Marie-Claude, nurse specialist in palliative care, I was very pleased to work with two women who had such dedication. They led the project with great respect, plus I liked that the meetings were in a beautiful office far from the noises and atmosphere of the hospital.*

*At the first meetings each told their stories. This was hard to listen to. Each experience was different but also so close to mine. In fact, the pain of memories was intense for all. However, I realized that one of the things in common during this project was that we were all being guided by hope.*

*For me, listening without judging the behavior of other members, as we had been asked to do, was challenging. I felt grief harder to overcome. In addition, expressing oneself gently without hurting others sometimes became difficult because the emotions, spontaneity and sensitivity were palpable.*

*Through the dialogues I began to relive the beautiful moments with my child and appreciate even more all the delicacies of my family and my friends. We seemed to be encouraged to let the images speak and to express my way was a balm to my pain, because I shared my methods of relief and appeasement. I allowed myself to laugh, to be happy and to live fully the present moments.*

*When I think about the project "Little Steps" I feel that I had a chance to share my abilities with people around me who could understand me completely. I was helped to create something which was healing. Imagine a project that allows oneself to express one's emotions or share one's lived experiences, all in the goal of helping others. We were surrounded by people with a lot of imagination. I felt I was able to let go of these cowardly feelings of never recovering and I could then give birth to another baby in this creation.*

### Evaluation of this Work







In our practice we used many ideas developed by David Denborough (2008) and we adapted many of these ideas using our own creativity. Many parents discussed their feelings of loss of their previous community during the illness and death of their child. Thus, it seemed particularly appropriate to use community narrative ideas with these families. This paper describes an approach to collective work that required a development of a community in oncology (COURAGE programme, see Moxley-Haegert, 2012) and invited outsider witness practices as well as definitional ceremonies at all times (Moore, Talwar & Moxley-Haegert, 2015). In an earlier informal enquiry regarding the usefulness of the multiple narrative practices used in oncology, 50 parents responded to a questionnaire. The results demonstrated that two of the collective/community activities, Tree of Life and questions for finding hope<sup>7</sup>, were among the three practices they most appreciated (the third being the individual narrative therapy sessions). We wanted to do a more formal inquiry about this work in palliative care.

In this enquiry regarding how people in palliative care received this therapy and what they felt about its effectiveness, we were using the narrative principles of double-listening (White, 2004) as well as double-storied testimony (Denborough, 2006) as an approach to conducting an enquiry (Marlowe, 2010). There are certain ethics of practice that we followed both in the narrative practices provided and during this enquiry. These ethics relate to the belief that the insiders (those affected by the problem) are the experts in the knowledge of what is helpful to them. This follows David Epston's insider witnessing enquiry ideas shown in his work with anorexia nervosa (Maisel, Epston, & Borden, 2004; Epston, 2019). Although at the time the authors were unaware of Sasha Pilkington's (2014) narrative work, we noticed that we have both interpreted narrative therapy in palliative care in similar ways, as have we interpreted in similar ways the narrative work of Lorraine Hedke (2014).

There is also a growing body of quantitative and qualitative studies exploring the experiences of bereaved parents and their adaptation to the loss (Stevenson, 2014; Stevenson et. al., 2017). Much of the research findings of these researchers support the idea that parents might appreciate the use of such narrative practices to enhance meaning making and promote counter-story development, as well as create new self-identity. There is support that collective practices such as helping others, definitional ceremonies, re-membering conversations that bring the child closer to their hearts and souls, and of building community could also be seen as helpful.

### Co-research

To try to understand how families in this enquiry viewed narrative therapy, four parents and the therapist co-developed the following questions (Freedman & Combs, 1996; Gaddis, 2004):

- What would you say was important to you in the therapy provided to you during your time of grief? What did you most appreciate in the work?

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<sup>7</sup> Questions created by the authors and placed on pictures to be answered and coloured in by the children, see Moxley-Haegert, 2012 for examples



- How would you describe what was meaningful to you?
- Were any narrative methods used to help you in the process of managing grief useful, and if so how?
- Were any of the narrative methods used not so helpful, and if so how?
- What could have been done differently in this work?

Ideas from Lokken (2011) were also used to consult with parents who needed bereavement care in order to develop questions. These questions were chosen collectively from among questions used frequently in the narrative therapy conversations. Research ideas also came from readings by Thorne (2008).

A collective document presents the written collective responses of 15 family members to these questions<sup>8</sup>. The themes developed are narrative therapy terms which present some of the hopes and dreams of the described outcomes from narrative therapy conversations and community practices.

We present the collective document in bold type, with quoted comments in italics. These questions and responses are termed primary research in narrative communities, that is, questions for therapeutic purposes as well as research purposes.

#### Some Ways in Which this Work was Received

The Collective Document: "What sustains us through difficult times?"

A large number of us have confronted what could be called the greatest tempest of our lives: the death of a child. Sometimes these storms seemed like a hurricane and have produced such very hard times.

We are mothers and fathers and siblings with a family member, a child, who died and we worked hard to overcome this most difficult time in our lives.

It was not easy to survive the death of a child in our family, but we have worked to keep going during very difficult times. We have been thinking about all our special abilities and special knowledges that have helped us face so many problems and sustained us during these very tempestuous times. We have thought about all that has helped us keep hope alive during this greatest challenge of our lives. The questions in narrative therapy helped us find our ways of survival.

Some of us felt that we lost our identity when our child died. Am I a parent when my only child has died, am I am mother of two children when one has died?

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<sup>8</sup> For ideas regarding collective documentation please refer to Denborough, 2008.





### Life as an identity project

Sylvie: *For me, working on the French in Linda's manuscript for her chapter to go in a grief counselling book has really helped me to find closure and turn the page, as well as giving me a more concrete sense of our individual meetings and permit a new reflection. What really touched me in the text were the explanations of the need of humans for self-identity. It is certain that after the death of a child, we ask ourselves if we are still a parent. It has been hard to respond to the questions of who is in our family when we meet people. Often, we are questioned regarding how many children we have.*

*Do I respond, originally two but now only one child? In that case, we need to begin talking about the fact that one child has died, and our questioner is put in an embarrassing situation and offers condolence. In brief, I still have work to do but less now that Linda has given me the necessary tools to reconstruct my identity. Please thank her again for permitting me to help her with her text (Moxley-Haegert, 2018).*

Doris: *I really appreciate what I learned about myself while participating in the Little Steps project. I found my voice, literally and figuratively. I joined a choir and it has given me a new lease on life. Thanks for helping me find my voice.*

Some of us felt that the project Little Steps, a narrative collective document guided and edited by Linda and Marie-Claude Proulx, helped us find our identity again and refocused our direction in life. Others found identity in different narrative practices.

Some of us had difficulty in finding a meaning in these experiences.

### Meaning-making

Maude: *I attended a group for bereaved parents, and they wanted me to find meaning in the experience. I did not want to search for a positive meaning as they expected. I did not have to have my son die in order to understand that I was a strong person. No one involved with the Little Steps project seemed to expect or asked me to find meaning and yet in the process I learned so much about myself and what I want with life. I became brave enough to get pregnant again as I realized that I was always a parent even when my only child had died.*

Martine: *I want to thank Linda and Marie-Claude for directing our project. When Linda asked me to be part of this project (Little Steps), I began to make meaning of the whole experience. I wanted to help others living with the experience of the death of a child. I hope with this project I led others to want to help themselves while helping others.*





Sylvie: *I really appreciate that when Linda had a dream about my Pierluc and he told her to call his mother, she listened and called me. I was so down that I could not reach out but my Pierluc reached out 3 months after he had died and Linda listened. We made sense of even a dream.*

Nash: *What I really appreciated was the legacy [a collection of pictures and sayings that her daughter Iman used to give meaning to her life] that my daughter left us with her work with Linda and Kelsey. I learned more about her values, beliefs and wishes for her life than I had ever known. Some things we did not talk about together. It gave me more meaning about her life.*

Anthy: *Our pain is forever present, but so are our children. I wrote this in the Little Steps book and the creation of this book helped me understand and make more meaning of the experience.*

Nathalie: *Raphaël had special knowledges and a special story to tell. He told Linda of a dream that he had in which he was dying in a fire and his mother wouldn't save him. Linda has a special conversation with him about this dream and they decided that if it should happen that he was in such a situation and his mother didn't save him, it was that me, his mother couldn't save him. Later, when we went to Florida to see Disneyworld for his special wish, he managed one day before he became so sick we had to call emergency services. When the emergency responders arrive, they were firefighters. Raphael, using his dream, said to me, I am dying maman [mother], and you can't save me. I was so happy that he and Linda had had that dream conversation, so then we could speak about death that night so openly.*

Many of us realized that making meaning of this difficult time was important for us in our healing but it had to come from ourselves and not forced by others.

Some of us found that it greatly helped to have a supportive community around us. For some of us that was more difficult, but the narrative therapy we received helped us develop community when it was not there naturally.

Some of us found it so helpful to find ways to continue the memory of our child so our child will not be forgotten. For some of us remembering came through re-membering conversations with Linda. For others, it was through the creating The Little Steps book or the Tree of Life, and for others it was in the creation of legacies by our children. Linda also took pictures and filmed our projects and sent us every copy of them, as well as the questions of hope our child answered in that group project.

### Re-membering



*Jackie: What I really liked was the letter written by Linda and Kelsey and that they collected memories from the team to put in the letter. It reminded me of some of the good times in hospital with Liam. Thank you.*

*Maude: I would like to thank Linda so much for that re-membling conversation she had with me. And for filming it so that I have the conversation forever. Taric was always going to remain with me but he became so vivid after that conversations.*

*Nicki (sister age 14): I loved the memory box we made together. I could remember not only Harris Dean but my twin brother and sister who died right at birth. I still have it and look at it sometimes.*

Some of us began our healing by keeping our children close to our hearts which was keeping our relationship with them alive.

Some of us found help in finding another story other than just the story of our pain.

#### Double stories

We found that there was often more than just the hurt and pain.

*Harris-Dean's family: We appreciated the stories that some of the after-therapy questions helped develop. We found a lovely memory regarding Harris-Dean's only outing during which he wore a snowsuit for the first and only time. We remembered that it was a time of concern and worry because he was going to another hospital for an intervention. However, during the after-therapy conversation, we were able to remember his snowsuit and appreciate that he got a chance to wear a snowsuit and that there were other ways to remember that outing. We appreciate that remembering the happy part of that story is helpful even now to bring Harris Dean more into our lives.*

#### Community building

*Anthy and George: What we valued most was the encouragement of the creation of a community (we called it the Condo Boys) on the NICU [Neonatal Intensive Care Unit]. The families of four little boys in the neonatal intensive care unit asked to be placed together and our therapist helped us in this endeavor. These four families are still in touch today. Two of the boys survived and two did not. Our son Harris-Dean is still a condo boy with the one little friend who died. Our boys are buried in the same cemetery so that Harris-Dean and his friend can still be together.*

*Maude and Martine: By helping others in the creation of the Little Steps Book we were actually*





*helping ourselves. Also, we got a chance to develop our own community of parents who understood our experiences as others never could. Our new Little Steps community was very helpful in our healing process.*

*Sylvie: I lost my community when Pierluc died because I had been very active with the COURAGE group, a community that Linda developed for the oncology programme. When I told her how lonely I felt, she began thinking of the Petit Pas (Little Steps) project. At first, I felt that I would cry too much if I attended but then when I did I found so many loving families who completely understood. I really appreciated that even though it was hard at first.*

*Jimmy: I really appreciated Linda coming to our home to do the Tree of Life with my family. We would have preferred to do it with other families who were part of our community developed by Linda. Both my wife and my daughter, Megan (see \*2), were dying of cancer and could not easily leave home. My wife was so happy to strengthen our family togetherness while creating our Tree of Life as a family. Now I am so happy to have that legacy of our family when my wife and my daughter were alive.*

Some of us received considerable support from the community of other bereaved parents while others found community within the family.

#### What was appreciated about this work?

*Harris-Dean's father George: I appreciated the part of narrative therapy that allows the family to lead. I was never 'a talker'. I healed more by doing and sometimes I really did not want to talk so much. My wife was a talker and I appreciated that there were services so my wife could talk and that I did not feel pressure that I had to talk as well.*

*Laura (sister, age 13): I was ten at the time of my brother's death. I have kept the memory box that Linda and I made together. I really appreciated this memory box. I also appreciated it when my therapist went to my school and helped me explain to my class what it feels like to have a brother sick for many years of cancer, then die. Linda helped the teachers understand that it still is as hard to manage after a brother had died as to manage when a brother is sick. Also, she explained that everyone managed grief uniquely, that there is no should in how one manages it. I really appreciated that.*

*Anaya (A different name was given for this mother to respect privacy requested): What I really appreciated was the book that my daughter, A....., created with the psychologist. My daughter's name meant 'who knows what God has brought us through this child'. The book reminds us of the love and joy and intelligence that God brought us through our child.*





### What could be done differently?

Martine: *There is nothing I would have wanted done differently. I felt respected and never judged. I never felt pressured, disturbed or stressed by the process. I was given room to be creative in an intellectual way and I felt so much better after.*

### Evaluating the Ethics of This Practice

**On Bilingualism and Culture.** There is an ethical consideration relative to the particular environment in which this work was done, since the collective and community work was carried out in both of Canada's official languages, French and English. The psychologist and narrative therapist was an anglophone (English first-language speaker) born outside Quebec. This means that, as polanco and Epston (2009) have written, "considerations of bilingualism or multilinguality can influence our practice *within* language" (p.62). For this reason, the therapist frequently consulted francophones (French first-language speakers) on the accuracy and quality of the written language as well as on cultural interpretation (polanco, 2011; 2013). It was, in part, for this reason that Marie-Claude Proulx was invited to be part of the Little Steps group.

**On Accountability and Transparency.** As narrative therapists, we try to engage in practices of accountability and transparency: the openness of our work with parents and children and constant questioning of this work are more likely to provide those who consult us with what they want to receive. We must be alert to any form of discomfort and remove any issues that cause such feelings. Always, an attempt was made to lead with questions and respect the preferred wish of those consulting us, for example, George who stated in the collective document that he preferred not to talk very much, but was able to participate in creating a Tree of Life with his family. Children and parents seem to appreciate when the therapist is inspired by their answers and uses these answers to guide the rest of the conversation, and when the therapist frequently confirms with them that the topics are the ones they wish to address. The practices of accountability in relation to this dilemma involve continually asking questions such as those used in this co-research. These accountability practices can also be put in place by asking frequently, "Am I addressing the subject that you want me to ask about?" We tried to watch for discomfort and to pull back when necessary. As we learned from George's comments, this was greatly appreciated.

**On the co-research:** In this co-research, the parent or sibling was asked to intimately describe what was helpful and unhelpful in the therapeutic approach. Co-development of questions to be posed to parents and families was also part of the ethics of this narrative practice.

**On the Circle Giving and Receiving:** Each family received a written narrative summarizing their particular responses to these questions after our interview conversations<sup>9</sup>. Martine, one of the parents who responded to the questions and who was a great admirer of narrative practices, reminded us of what the Just Therapy group taught us (Tamasese et al., 1995, p. 109). Martine

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<sup>9</sup> An example of such narratives can be found in Moxley-Haegert, 2009





recommended two new resources for more creative ideas. We used this book and website in our work (Corneau, 2014; Jobin, 2014). This narrative practice is certainly a circle of giving and receiving.

### Conclusions

In summary, in palliative care work with children and parents, we used narrative therapy and community practice to create songs, poems, films, art, documents to consolidate values, beliefs and special knowledges in a medium that not only preserves these values, beliefs and special knowledges, but also communicates them and makes them known to family and friends. This work was named, 'Leaving a Legacy'. We helped these legacies develop through the use of many Tree of Life workshops (Denborough, 2010; Ncube, 2006), a monthly 'Journey Group' (McPhie and Chaffey, 1998), weekly group projects which we called 'Questions to Find Hope' all which produced words of wisdom to be shared with friends, family members and other families participating in the COURAGE program. Legacies were also created through individual narrative therapy conversations (Moxley-Haegert, 2012; 2015).

We had many re-membling conversations to help parents keep the memory of the deceased child alive in their hearts. But in this article we mostly discussed the collective work with parents after the death of the child. Collective community work included archiving stories in a document called "Little Steps" and community development between parents who already knew each other and newly mourning parents. This development was supported through sharing letters, stories and support. This particular narrative practice was named "Letting the Legacy Live." We are honoured to have been able to participate in a therapeutic exploration in which many of the participants considered themselves to have benefited from the process.

For us, this therapeutic exploration is the result of a communication in the respect of the ethics of the Just Therapy group who taught that "the values of humility, sacredness, respect, justice and love, trust and cooperation are essential to the accountability process" (Tamasese, et. al., 1995, p. 109). We believe that these values were part of our responsibility for this work. The responses of the participants in the follow-up enquiry reminded us what the Just Therapy group taught us.

### Appreciation

These conversations were lovely and rewarding experiences. We hope was they were just as rewarding for the families. The co-research enquiry suggests this was so. It was an honour to be part of a therapeutic journey which could produce such a response from so many who told us they benefitted greatly from the process.

We would like to express our appreciation to all these family members for their many conversations with us both in the narrative therapy process and in the enquiry process.



1. To read more of Pierluc's story and those of other children refer to the Little Steps publication: [Access it here](#) (français) and [Access it here](#) (in English) 2014
2. We shared photos, stories, documents and names in this article with the permission of the families and individuals involved. We worked together on how to share these ideas of resources and specific knowledge. This work could not have been done without the input of the community. We want to pay tribute to all the families and children we worked with who shared their stories and feelings of loss, pain, and fears, while finding their own hopes and dreams, values and the beliefs, and the particular knowledge they have treasured. Special thanks to the outstanding oncology staff and members of the palliative care team who participated in this work. We want to thank particularly Sylvie Séquin and Martine Bélair (two of the nine authors of Little Steps) who helped us so much with this article (particularly in French).
3. We wish to thank the parents who spent so many hours in the creation of this book and who decided to take control of their nightmares and to try to find transformation into what could become a dreams of survival.
4. We would like to express appreciation to the McGill University Health Centre for giving us permission to interview these parents.
5. Recently, We carefully considered polanco's (2011; 2013) ideas in terms of "foreignising" narrative therapy for French speakers, even if it is of European-American type. polanco & Epston (2009) suggested that translation studies and bilingualism offer interesting contributions to the development of narrative therapy. They say that narrative ideas migrate with cultures, and these passages can enrich and diversify narrative practices. Linda considered this view in the past and their statement is corroborated by our experiences (Moxley-Haegert, 2009).

#### Notes:

1. Spirituality and religion are implicated in helping the bereaved cope with their grief. These family members did not mention either as helpful although the children did (Moore et. al., 2017)
2. All parents except Anaya wanted their real first names used and those of their children.
3. Megan's voice can be heard reading a children's collective document in oncology in a Dulwich Centre Friday afternoon presentation (Moxley-Haegert, 2012).

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Carlin Moxley Haegert has a master's degree in applied psychology and is becoming a registered psychologist in Ontario where he also studies analytical (Jungian) therapy. He learned narrative



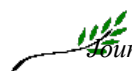




therapy with his mother, Linda, and has participated in narrative therapy workshops in Vancouver, Winnipeg and Dublin, Ireland. You may contact him at [carlinhaegert@hotmail.com](mailto:carlinhaegert@hotmail.com).

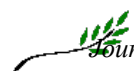
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