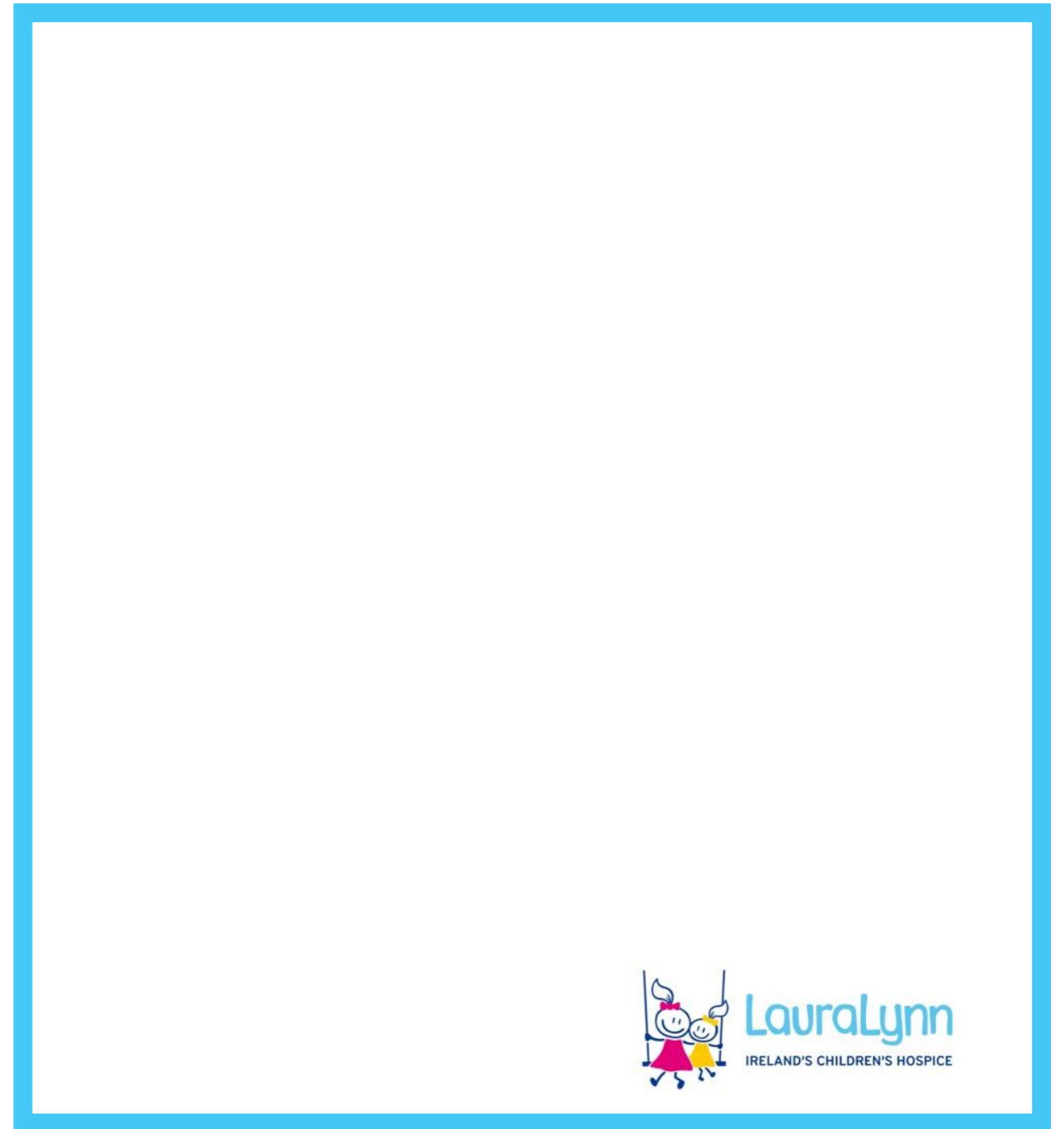


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# Memory Making at End of Life

Fiona Woods  
6<sup>th</sup> Nov 2019



# Acknowledgements

- Terrie Clarke
- Families who shared their  
‘memories’
- LauraLynn Staff who  
facilitate memory-making



# WHAT IS MEMORY MAKING ?

Memory making, also described as 'legacy making' is a family centered activity offered for children with life threatening/ life-limiting illness.

It is described as a process of doing or saying things in order to be remembered, either intentionally or unintentionally

(Foster et al., 2009)

# EXAMPLES OF PRECIOUS KEEPSAKES

Hand moulds, photographs, creative art  
and song (*Foster et al., 2012*)

Fingerprint pendant project (*Miller et al.  
2014*)

Memory boxes and the retention of a lock  
of hair (*Carlson 2012*)

Digital Storytelling (*Akard et al. 2015*)

# LauraLynn Research

To explore the lived experiences of parents who participated in memory-making with their child close to or at end of life

## Objectives

- 1.to explore the impact on parents/families
- 2.to gain an insight into the participants experiences
- 3.how this could be further expanded

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# WHY CREATE MEMORIES?

- **Helps prepare for the death**
- **Supports anticipatory grief**
- **Increases QOL (children with cancer)**
  - **Fun**
  - **Express ideas & feelings**
  - **Cope with illness**
- **Family involvement**
- **Last meaningful activity**
- **Being remembered**

**Meaningful Memories & making sense experience fewer symptoms of complicated grief**

# Preparing for the death of a child

Physical remembrances and items associated with the child demonstrate tangible evidence of the child's life (Tan et al., 2012)

The sense of connection to objects as well as the process to create them creates a bond with the child, and to acquire and strengthen memories of a positive nature (O' Leary et al., 2011; Tan et al., 2012)

Supporting anticipatory grief , Time spent and opportunity hugely significant (Tan et al., 2012)

Can provide the opportunity for the ill child to express their concerns or fears about death (Foster et al., 2012)



# Family participation

Many children suffering from cancer showed an awareness of their own impending death, and demonstrated death awareness with actions rather than conversation (Foster et al. 2009).

The opportunity to involve siblings and grandparents in the process of creating memories has also been identified as beneficial (Carlson 2012).

Option of family participation and individualised activities and projects being important (Foster et al. 2012).



# Digital Storytelling - Legacy Making Intervention

Quality of life was increased as a result of partaking benefiting the child.

Fun and enjoyable activity

79% of parents felt their child was able to openly express their feelings by participating.

Promising and feasible strategy for children with cancer to adjust and cope with their illness

(Akard et al. 2015).



# Theoretical underpinnings

## **Continuing Bonds (Klass)**

- **Importance of keeping a connection**
- **Meaning making & staying connected**
- **Recognises the individuality of loss**
- **Evolve over time**

# Challenges

Professional's unsure how to broach or discuss

Time

- Sudden or short illness
- Antenatal death
- Life-threatening illness

Distressed parents

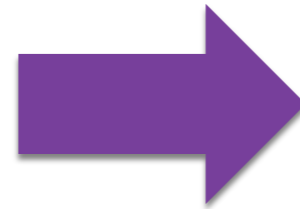
Preconception that memories already made



# THEMES FROM RESEARCH

## Making the memories

- Introducing the concept
- Choice, guidance & support
- Activity of memory making
- Individuality of creation
- Sibling participation



## Impact of the memory making

- Readiness to receive the memory making
- impact of participating
- Future impact
- Impact on grieving the loss

## End of Life Care Journey

- Choice at EOL
- Alleviating the fear
- Early referral
- Gratitude

# What our parents say .....



“ Even in the awful circumstances we were facing we felt like a normal family for that time”

“When we saw the artwork after Daniel passed away we realised just how important and valuable this activity was”

“We will be forever grateful for this priceless gift....when you lose a child...you grasp onto each and every memory for dear life”

“To be so caringly guided through the process when you cant think straight yourself is something we will treasure forever”



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# What our parents say .....



“We painted handprints, our family ....myself and my husband painting each others feet in the middle of our darkest days still makes me smile”

“We get to look at it every day, and it is priceless”

“I take the moulds out regularly, I touch them, I feel them, ....It is just a piece of her I never knew I needed but I really really do”

“Memory making has meant the world to me...It gave us time together...allowed us to be together as a family of four and create something meaningful”

“It is invaluable and we are forever grateful”

A pink rectangular box containing a white circular logo with the text 'GROWING A COMMUNITY OF CARE' inside.

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