

# 'Place Bonding' at a children's hospice

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# Objectives

- To assess parents' perspectives of existing and potential children's hospice services.
- To identify barriers and facilitators for children and parents in accessing children's hospice services
- To define the types and characteristics of children's hospice services that parents and children wanted

# Study Design

**Qualitative study underpinned by constructivist grounded theory (Charmaz)**

**Phase 1** - invited parents who currently used the hospice to attend one of several focus groups held at various locations across the region.

**Phase 2** - invited parents, whose child was known to palliative care community services but do not currently access services at the hospice, to participate in in-depth interviews.

## Recruitment and participation

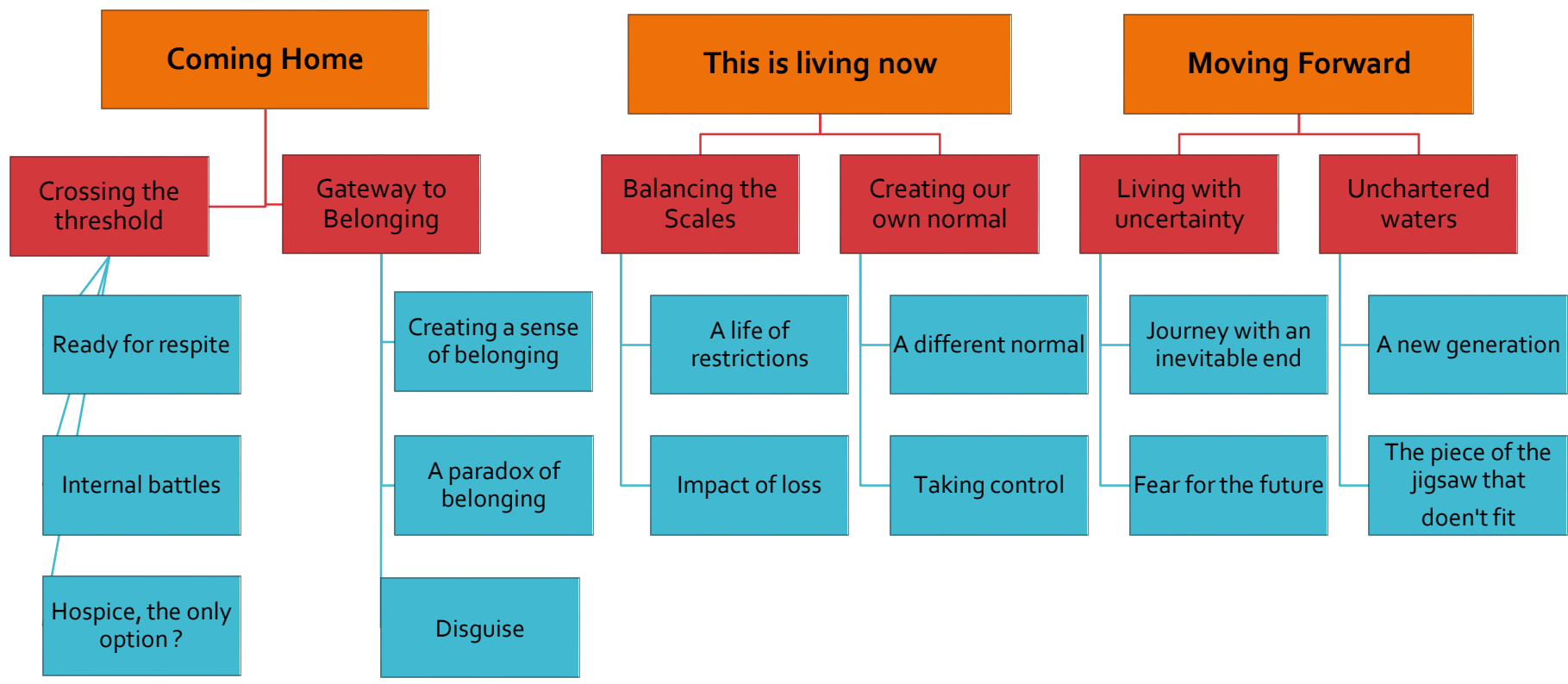
Children with a LLC as defined by ACT criteria

Phase 1 - 258 invited, 35 recruits, 24 attended focus groups (Hospice users)

Phase 2 - 48 invited from 7 teams across the region  
One to One interviews with 14 parents  
(Hospice aware and Non hospice users)

# Demographics

- 38 parents representing 36 children
- 8 dads
- 13 children were above the age of 16 years
- 6 groups other than white British
- 6 single parents
- Average length time hospice 8 years
- Travelling distance up to 58 miles to hospice



# Coming Home

```
graph TD; A[Coming Home] --- B[Crossing the Threshold]; A --- C[Gateway to Belonging];
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Crossing the  
Threshold

Gateway to  
Belonging

## Coming 'Home'

- The idea of coming 'home' depicts the desire, the sense of searching that parents have in seeking out a place, other than their actual home, where their child could access a caring environment and the parent/s receive some respite from caring.
- The idea of coming home reflects the sense of relief experienced by parents when they found that place. It was like 'home'



## Crossing the Threshold

Before parents are **ready for respite** they first have to move from a stage of coping to accepting help

**Internal battles** - External and internal factors influenced decision making.

**Hospice the only option** – lack of services available, by entry criteria, travel distance

Overriding factor for accepting the hospice as an option was the potential for rest

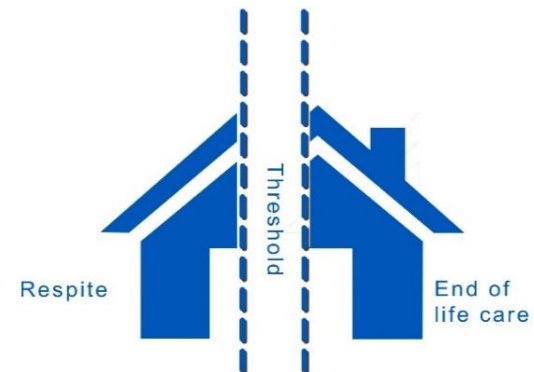


# Gateway to Belonging

**Creating a sense of belonging** –encompasses the characteristics that parents are looking for in creating a sense of the same experience as their place of home

**Paradox of Belonging** – the anomaly that a sense of belonging came with a diagnosis that ultimately child would die early

**Disguise** - different world, two sides of the hospice, a different place than expected, subtly hidden, masked identity



**This is living Now**

```
graph TD; A["This is living Now"] --- B["Balancing the Scales"]; A --- C["Creating our own normal"]
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Balancing the Scales

Creating our own normal

This is Living  
Now

Ultimately life was different from what parents had planned or hoped for.

Their life was a different normal than those around them, but they live to capture the best of everything.

# Balancing the Scales

Trying to maintain equilibrium in life, as parents they need to overcome **a life of restrictions** – timetabled, 24/7 care, intensity of everything, fight for resources

Having a child with a life-limiting illness meant that parents also had to cope with **the impact of loss in their lives** – their child, social, their identity, their future



## Creating our own normal

The idea of two separate parallel worlds, desire to have what parents with 'normal' children have

Their **different normal** – different from everyone else, siblings, Need to **take control** in order to create own normality – attitudes, routines, accepting respite, survival

The hospice gave parents a glimpse of normality – freedom to engage in normal family activities, spontaneity

# Moving Forward



Living with Uncertainty

Uncharted waters

# Moving Forward

Moving Forward' portrays the idea that living with a child with an LLC is akin to traveling a journey, although a journey of uncertainty, in terms of progression and path and obstacles.

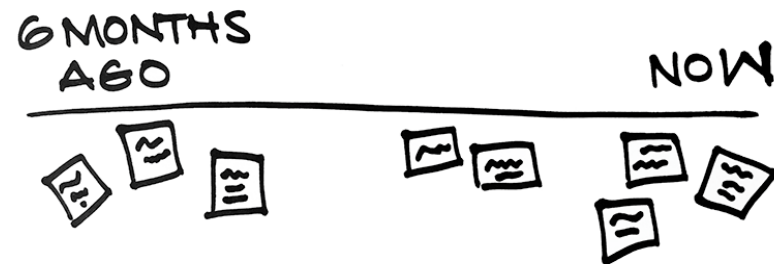
*"Sometimes times are hard and the pendulum doesn't swing quite so fast, and sometimes its all round the corner we are sat their like a ticking time bomb"*



# Living with uncertainty

There is a clear sense of direction of travel, life is like a journey, peaks and troughs, but the **journey is one with an inevitable end**, but unpredictable and uncertain

**Fear for the future** - longer journey than expected, transition fears



# Unchartered waters

Children living longer than anticipated, creating new challenges - **A new generation**, unpreparedness of parents and services for this

**Jigsaw that didn't fit** – cognitively aware young people with physical disabilities hospice is not the right place – But it's the only place they can go



## Conceptual thinking

**A theoretical understanding of the parents search for a place, the journey of complex decision making and the inter-relationships between the hospice and parents considering/receiving hospice care**

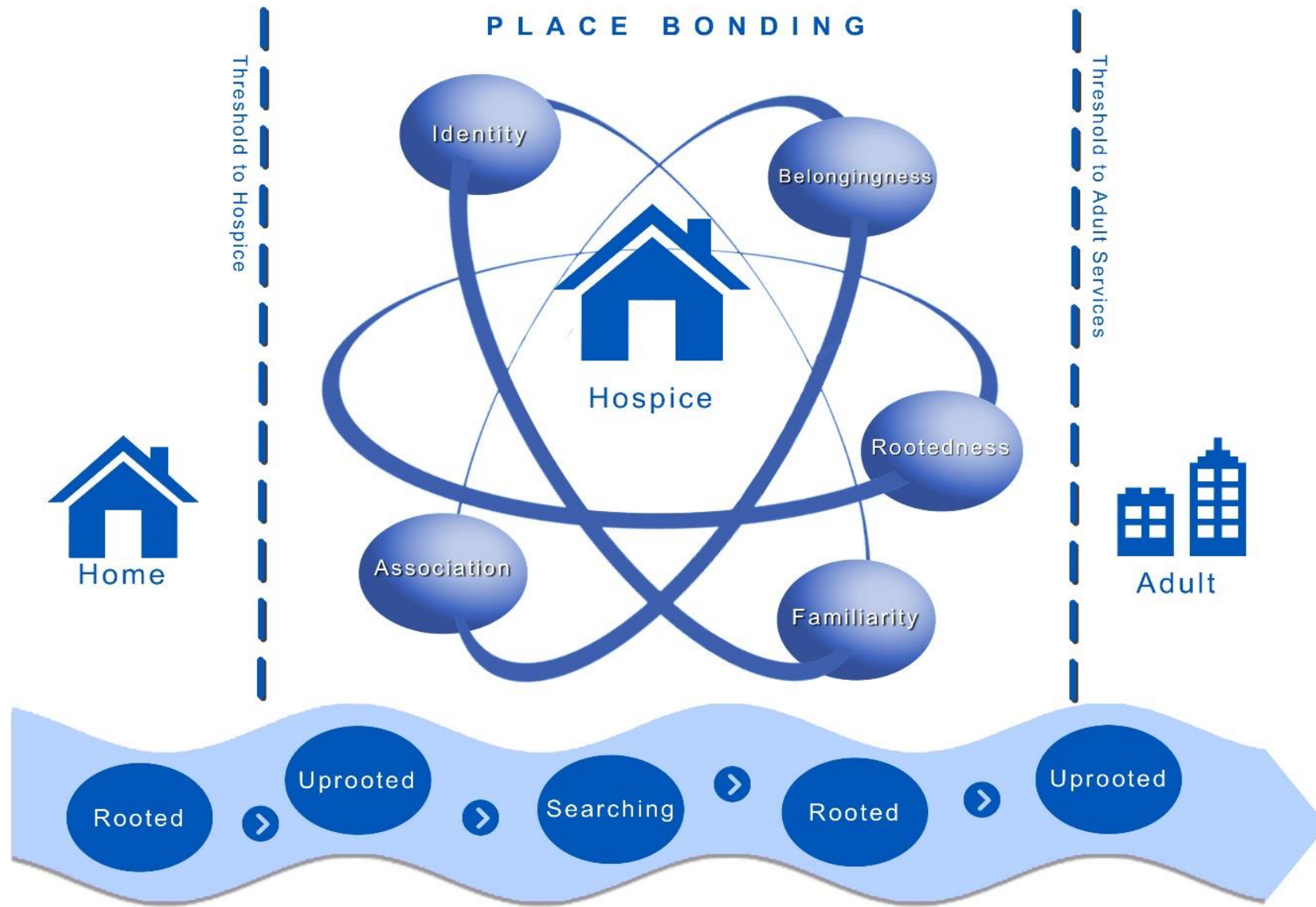
# Place attachment theory

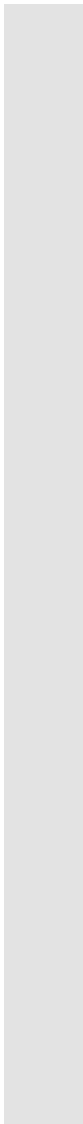

Growing interest in the concept of place and relationships.

Literature talks about concepts like place attachment, place identity, place belongingness.

Fundamentally it's about the affective bonds that develop between individuals and places

Place bonding (Hammitt et al, 2004, 2006).





There are five dimensions which when present foster a sense of belongingness and reassurance for parents that they made the right choice in coming to the hospice.

# Place Familiarity

- the importance of finding a place that parents felt secure and safe to be able to leave their child.
- Acknowledging that there were staff who knew their child
- Caring for their child in the same manner they would be at home
- Weighing up the benefits and the costs
- The more familiar with the place the stronger sense of insiderness parents felt
- Crossing the threshold – changing an individual's perception of a place

# Place Belonging

The characteristics described by parents as fundamental to achieving a sense of belongingness in the hospice.

- Safety and security
- Continuity
- Routines
- Forming healthy interpersonal relationships
- Trust
- Repetitive experiences with staff that are known to the family



# Place Identity

- The positive and negative connotations associated with the identity of the hospice .
- Allow identify as mum and dad to take precedent over a caring role
- There is a drawing in effect – creating a sense of home/shelter rather than a clinical environment - manipulation of space

# Place Association

- depicts the functionality of the hospice in providing quality care and therefore meeting the needs of the parents.
- Also about the external appearance of a building to offer reassurance there is nothing to fear
- Positive environments, enriched environment
- Enabling a sense of normality

## Place Rootedness

Repeated use and positive experiences helped develop in parents a sense that they had finally found a place where they belonged and where they truly felt at 'home'.

## Place bonding at the hospice

Feeling safe, having strong affective bonds, feeling comfortable and at home within the hospice

The paradox that a place where many parents initially dreaded entry, became a normal part of their world, a place of belonging, a family, somewhere where they missed when they did not have it.

Some parents remained safe in their own home, not ready to venture across the threshold, not at the point in their journey to envision it as somewhere they could put roots down.

## In summary

- *The theory of place bonding offers a new perspective of parents' journey to seeking and accepting hospice care for their children.*
- *Does bonding offer some reassurances for the time when end of life care is needed?*
- *Disguise?*

# Thanks

- To the parents who took time to talk to me
- To the hospice for sponsoring the PhD studentship
- Support for supervisors and all the staff at the hospice