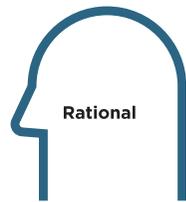


# EXPERIENCE 101

20 MILLION BITS | 5 SENSES | 6 SECONDS



ANTICIPATION

ENGAGEMENT

RECOLLECTION



Research is a story that supports change + innovation.

—Dreambox



# The Inquiry + Observer Effect



Once you measure something, it changes.

– *Goodhart's Law*



Once you observe something, it changes.

– *Margaret Mead*



Once you hear these stories, it'll change you.

– *Teri Kwant*





Objectivity is overrated.



The intent of these Experience Reflection Interviews was to deeply understand the current experience of our key users, and to lift out the key metaphors that represent the experiences.



How would you / did you feel best supported and cared-for on your journey of caring, change and loss with your family and child?



**Spiritually**

**Physically**

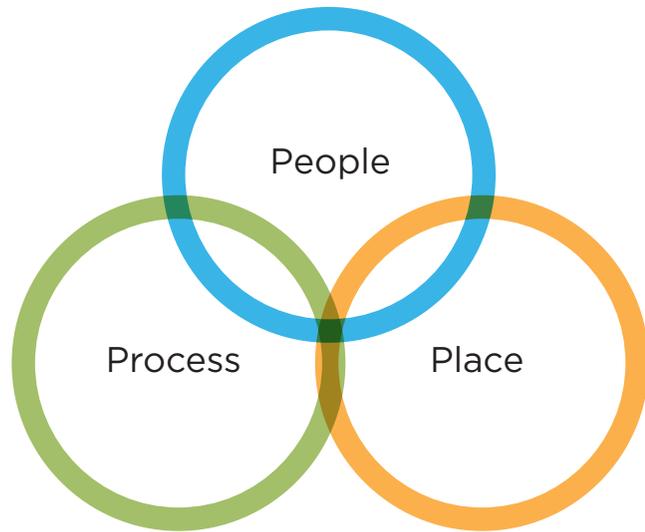
**Mentally**

**Emotionally**

**Financially**

**Socially**

# The Hypothesis + Assumptions



Families who go through the experience of caring for a medically fragile child or loss of a child have a journey with distinct stages and corresponding needs. We can address these needs by designing intentional experiences that will be delivered by people, process + programs, and place: site + architecture.

It's not a journey, it's an emotional minefield.

There is no norm. There is no consistent path.

It is a highly stressful and exhausting experience full of change and unexpected twists and turns.



Journey? Journey!? A journey suggests we knew where we were headed. We had no idea where we would end up.



— A MOM  
WITH A MEDICALLY FRAGILE CHILD

# Our Users

There are two primary user groups and three primary scenarios bringing families to Crescent Cove: respite users and hospice users, and among them, families who come for a first visit, those who come for ongoing visits, and for an only or last visit.

## RESPITE

FIRST VISIT  
"FAMILY MOVE-IN"

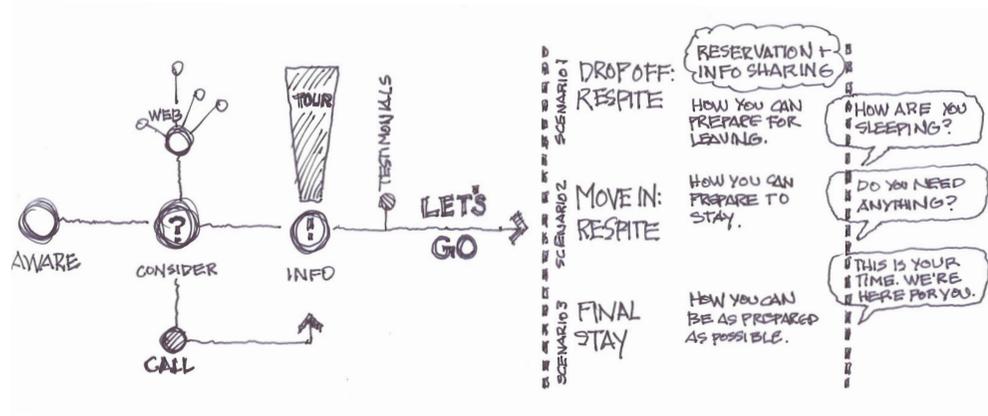
ONGOING VISITS  
"DROP OFF + RETURN"

## HOSPICE

FIRST VISIT OR RETURN VISIT  
"END OF LIFE STAY"

# The Pathways: Gaps in Information

DIAGNOSIS



IT WENT WELL WE HOPE RYAN COMES BACK SOON.

NEW SHARED MEMORIES AND A NEW COMMUNITY.

WE'LL CONTINUE TO SUPPORT YOU AFTER THIS LOSS.



Kids + Siblings

Staff + Volunteers

Allied Services

ANTICIPATION

ENGAGEMENT

RECOLLECTION

# The Findings: Themes



## **GUILT**

noun | \ˈgɪlt\

: a feeling of having done wrong or failed in an obligation

See Synonyms at blame.

Guilt was mentioned in every single interview. It is considered a secondary emotion meaning that it probably stems from another primary emotion, like fear, anger or sadness.

# Guilt



Culturally, we don't value rest, and we don't talk about grief.

— A RESPITE + HOSPICE MOM



Going to work

Not focused on other kids

It's my fault

Not on your watch

Stigma about needing rest

It's my job (hoping + fighting)

Exhaustion

Leaving them

No permission

(shouldn't need it)



The idea is foreign to seek help.

— A RESPITE MOM

There's never enough of me to go around.

— A RESPITE MOM

The kindest thing someone said to me was, "You're done now. You don't have to keep fighting. Just be a mom."

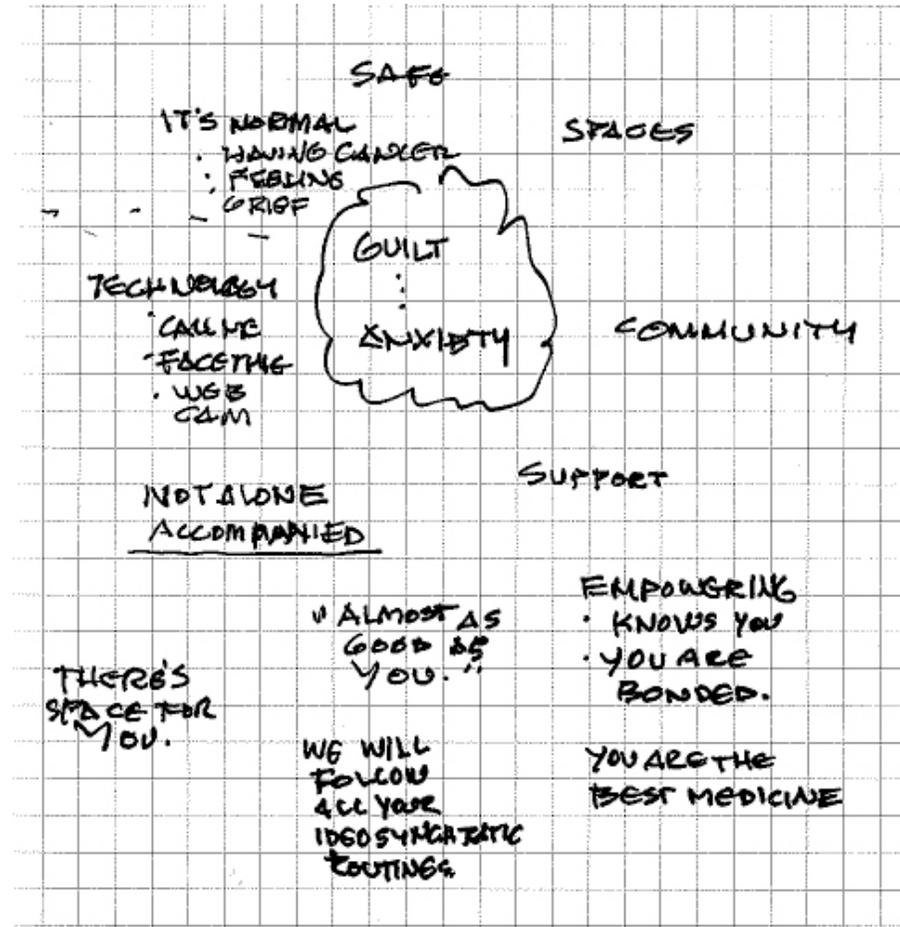
— A HOSPICE MOM



# Guilt

Guilt can sometimes be related to shame. Guilt might be mostly about anxiety and fear. eg. "I have a kid who is scary to others. **OR:** It's scary to take care of my kid."

Building an experience that alleviates guilt should address fears + anxiety.



# Isolation

**Social**

**Emotional**

**Can't go out: too hard**

**Within family: separate schedules**

**Health protection: Flu season**

**Financial: embarrassment**



Years and years of lack of sleep. It broke us.

— RESPITE + HOSPICE PARENTS



The biggest challenge facing families is isolation.



— HOSPICE CARE PROVIDER



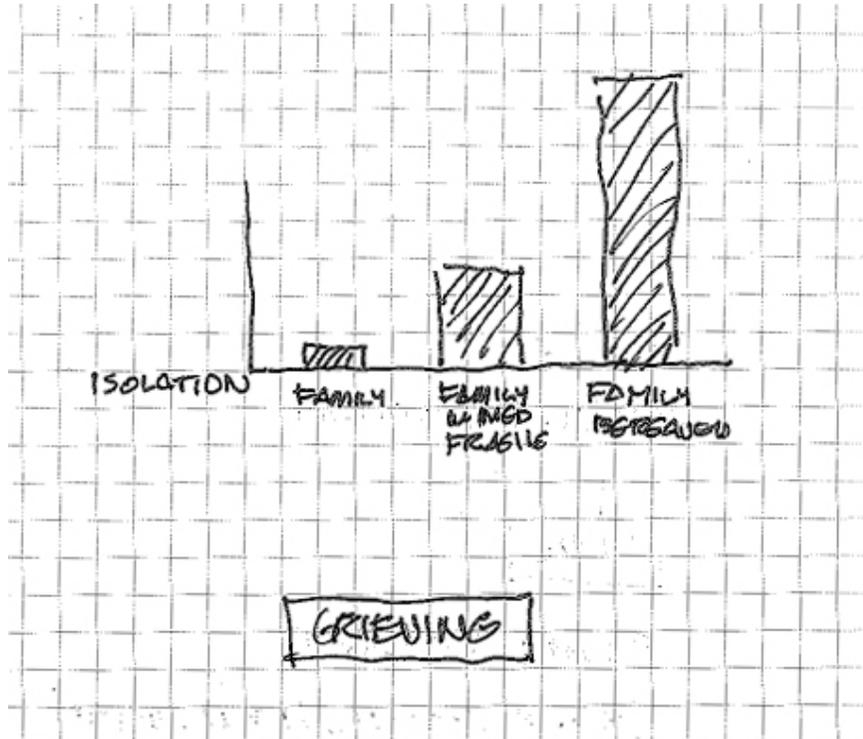
No matter what anyone says, only the immediate family really sees and understands the drain, the effects of caring for a [medically fragile] child. They just don't get it.

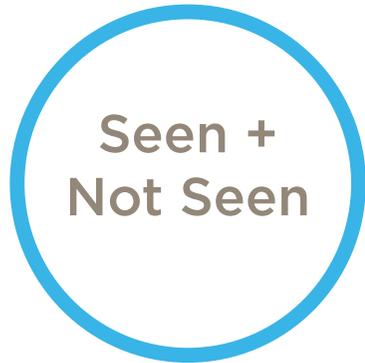


— A HOSPICE MOM

# Isolation

Isolation has a symbiotic relationship with grief, guilt and all the unknowns. Isolation makes families with loss or a child with special needs invisible.





Families in grief, or families with special needs, or medically fragile kids become invisible to the rest of our culture.

**Grief / Joy**

**Spirituality / Religion**

**Quiet space / Loud space**

**Private / Open**

**Present / Invisible**

**Entries / Exits**

**Technology / Distractions**

**Memorials / Living + playing**

**Attentive / Alone**

**Families are not seen**



For staff, we talk about if it's ok to cry with the family.



— HOSPICE CARE PROVIDER



One of my greatest fears is he wouldn't be loved and would be rejected. When I felt he would be loved there then I thought, it'll be okay.



— A RESPITE MOM



## Transitions

Physical (to site)

Entries + exits

Allow others to provide care

Role changes

1st diagnosis

Highly personal/private

Equipment to + from

Caregiver/parent to bereaved

Conversation changes (EOL)

Hoping to releasing

“

It has to be meaningful and peaceful.

”

— A HOSPICE MOM

“

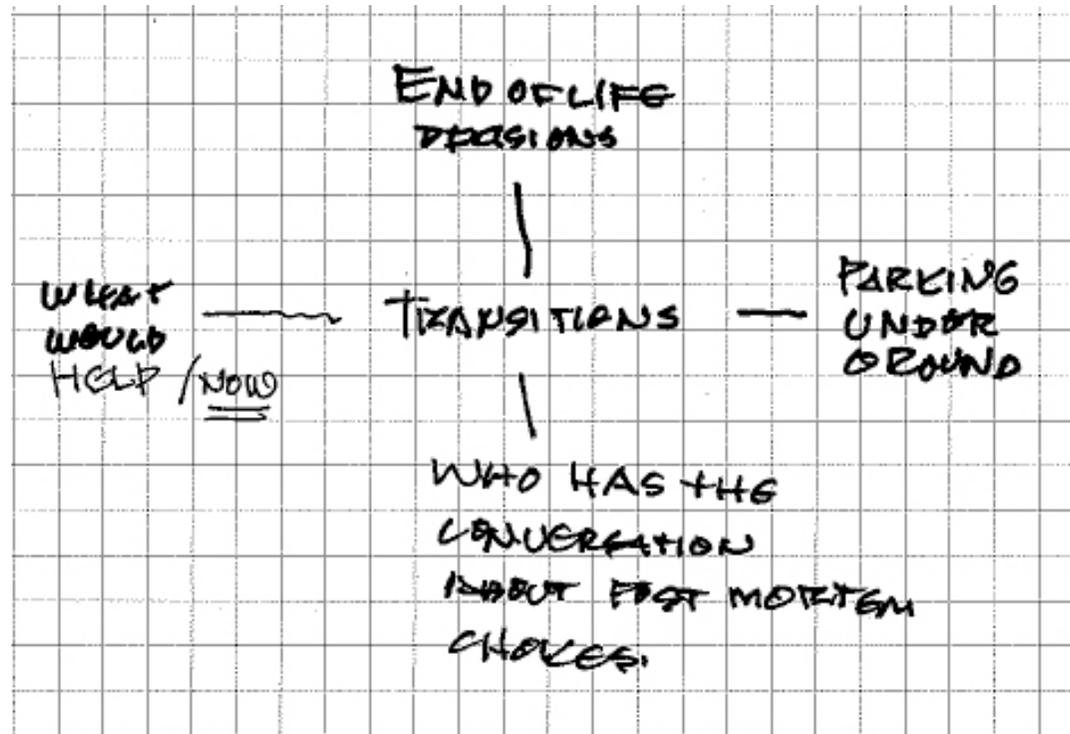
Will staff meet the needs of my child? No one knows her like I do. When I think about leaving her my stress goes through the roof.

”

— A RESPITE MOM

# Transitions

All transitions matter— in unique and different ways. There are mental, physical, emotional, metaphysical transitions, transitions of roles. Physical transitions should be covered or underground.



## Dealing with the Unknown



My kid's health can turn on a dime. One minute she's fine, and the next we're on the way to the ER.

— RESPITE PARENT



### Orientation at every step:

What choices do we have?

Where do we turn?

What can we expect?

What's next?

What are we allowed to do?

### The right amount of information

Ambiguous options

Need for certainty

Logistics



After our son died we were asked to speak with another family who had a baby with the same syndrome. Our family asked do you really want to go there? Of course I do. We're still in contact today.



— HOSPICE MOM



I didn't know that was an option.

— PARENT TO HOSPICE COORDINATOR



# Tools: Changing the Game

## Everyday Grief

Isolating

The burden is on the bereaved

Cultural norms + language

## Making Meaning

A place to return to

Give back

Support / mentor others

Cultural change / advocacy



My Gift of Grace



**We're really, really  
bad at talking  
about death.**

# Create Tools: Self Awareness + Permission

## BURNOUT VS STRESS

### STRESS

- Characterized by over-engagement
- Emotions are over-reactive
- Produces urgency + hyperactivity
- Loss of energy

### BURNOUT

- Characterized by disengagement
- Emotions are blunted
- Produces helplessness + hopelessness
- Loss of motivation, ideals + hope
- Leads to detachment + depression
- Primary damage is emotional
- May make life seem not worth living



I need permission to \_\_\_\_\_.



# Experience Pathways: Defining the Experience Goals + Architectural Implications

## Hospice Family Path: End of Life Stay

### ANTICIPATION

Crescent Cove goes to where the family is  
Home/ hospital  
Prepares family for smooth transition  
Communication liaison with EMT or other  
Logistics help and support  
Orientation to equipment changes, etc.  
CC is bridge between Child Life team and hospice  
Do you have any wishes + hopes right now?

### ENGAGEMENT

Orientation to what is possible to do during hospice  
How can I help my child: massage, scent, sound  
Mini respite opportunities  
Conversations that matter  
Just the right amount of information  
Help with choreographing a 'good death' experience  
Who do you want us to call? Who can be here?  
How many people to want in the room?  
Adequate privacy + space for all the visitors: Nooks  
Mini-Respite recommendations

### RECOLLECTION

Bereavement planning  
Support network identification  
Opportunities to heal + contribute: mentorship and more  
Memorial on site / Book or story of kid  
Visits to CC's Light Path: twinkling, active memorial experience

## Respite Family Path: First visit

### ANTICIPATION

Family visit + equipment check  
Packing list + pizza (mini-respite)  
Video at home of care methods  
Family provide video of care  
Transportation service  
Interviews: favorite things  
Orientation: here's what it'll be like

### ENGAGEMENT

Credentials display: professionalism  
Activity options: I had no idea!  
Permission slips: others are like me  
What kid will be up to: I know he'll be accompanied  
Web cam (I can stop by)  
Motel like: I can come and go and not bump into other families  
Food trucks on site: there's a community here  
What did you do today? It matters that I take care of myself

### RECOLLECTION

My kid loved it!  
Text: Saw a butterfly and thought of my kid  
Links to mentors [video diaries]  
Tools + assessment  
Reminder of stay: significant

## Respite Family Path: Ongoing vis

### ANTICIPATION

Pr-registration call  
Where do you plan to go / what do you plan to do?  
Travel or stay-cation?  
Is there something we can help with?  
Will you drop off or should we provide transportation?  
How is it going generally?  
How are your other kids?  
Send self awareness / permission form

### ENGAGEMENT

My kid's excited to return.  
I might stay for the gathering that is happening...  
I see other families I know.

### RECOLLECTION

My kid loved it!  
They texted us again: Happy birthday, kid!  
Tools + assessment: take care of me  
Reminder of stay: significant  
Nudge for next respite paired with value of self care  
Mini Respite: Would you like a pizza delivered?



## ■ **Permission Slips**

Families need emotional and rational support for taking a break.

## ■ **Mini-Respite**

A small amount of help goes a long way, + reminds you to take care of you.

## ■ **Mentor Me/Mentoring**

A way for families to give back, that creates community + makes meaning.

**Proximity  
Matters**

**Location  
Matters**



What matters most about site + location depends on the user.



**Close to children's hospitals** [respice]

**Running distance!** [walkable distance from hospice]

**Living distance from facility** [staff + volunteers]

# Site Criteria: Discussion

- **Infrastructure exists** [all functions]
- **Proximity to children's hospitals** [respice]
- **“Running distance”** [hospice]
- **Living distance** [staff + volunteer base]
- **Supports memorial space** [hospice]
- **Adequate parking for end of life events** [hospice]
- **Supports space program** [hospice / respice / staff]
- **Close to restaurants + distractions** [mini-respites]
- **Accommodates multiple types of transitions** [respice + hospice]
- **Supports covered/underground drop off** [hospice + respice]

# Architectural Implications: Additional Spaces + Places



- **Mentor Space: Peer To Peer Hangouts** [Counseling + Services]
- **Nooks: Solo Space** [For staff and individual family members]
- **Loud Spaces + Quiet Spaces** [Not just for activities, but grieving]
- **Energy Efficient** [Part of our story / Sustainability matters]
- **Bereavement Rooms / Cold Room**
- **Ability to Create Privacy** [sliding walls]
- **Wellness ≠ Spiritual ≠ Non Religious** [building the seen and not seen]
- **Family Rooms** [Each with outdoor access]
- **Child's Room** [Flexible bedding/ king bed for whole family]
- **Technology** [Video Conference + Storytelling]
- **Sound Insulation** [Loud machines/ Loud moments]
- **Suction + O2** [Wall mounted]

# Architectural Implications: Additional Spaces + Places



- **Active Ceilings** [Technology infrastructure, web cams]
- **Family Suites** [Different needs for Hospice and Respite]  
[Glass partition to family gathering area with micro kitchen: Hospice only]
- **Locking Medication Areas** [Room or cabinet]
- **Staff Space** [Decompression]
- **Fresh Air** [Access from each kid room and family room]
- **Mini-Respite** [Out-building, just far away enough]
- **Hidden Machines** [Sliding walls to cover technology/equipment]
- **Teen Space** [Flexible + customizable: make it yours]
- **Cubbies** [Places to store belongings of returning kids]
- **Gated Outdoor Garden** [Semi-private bereavement space]
- **Sensitive Entries** [Honoring all who come and go]

# For Your Consideration



- There is a critical shortage of RN's and LPN's AND PCA's.
- Staff + volunteers make or break the experience.
- Living distance from facility matters to staff + volunteers.
- To avoid burnout we need to make sure staff + volunteers are fully supported and are practicing self care.



Make no mistake. It's a burnout job.

— PALLIATIVE CARE / HOSPICE NURSE



# Funding / Stories

## CULTURAL CHANGE

Change the conversation about grief and loss through advocacy and engaging events.

## EDUCATION ABOUT GRIEF

Partner with children's book authors to write kid's stories, buy the chapters of the book. Creates children's books that discuss grief, change, loss, joy, in new ways.

## RX FOR FAMILY WELL-BEING

Alleviate suffering using the Gallup Well-being Scale through self assessment tools and metrics.

## CREATING QUALITY OF LIFE

Engage well known children's book illustrators for ceiling murals: auction the art and buy a room.

## INNOVATE THE EXPERIENCE

Robert Woods Johnson Foundation: propose to measure the impact on families, health and economic impact of respite.

## LET'S KICKSTART IT!

Create a mechanism to serve mini-respites (perhaps meals) to families right now.

# Next Steps

## COMPLETE THE DISCOVERY PHASE

Coordinate additional experience research at Ryan House in Phoenix with Arizona office:

Respite + Hospice Families [ERI]

Kids + Siblings [ERI]

Staff [ERI/X Assessment]

## DEFINE THE EMOTIONAL TARGET

At Crescent Cove we want our families and staff to feel

\_\_\_\_\_

\_\_\_\_\_

and \_\_\_\_\_.

## BUILD FUNDRAISING STORIES

Create communication and implementation strategies: to serve families with mini-respites ASAP, to approach major funders.

**Let's talk.**