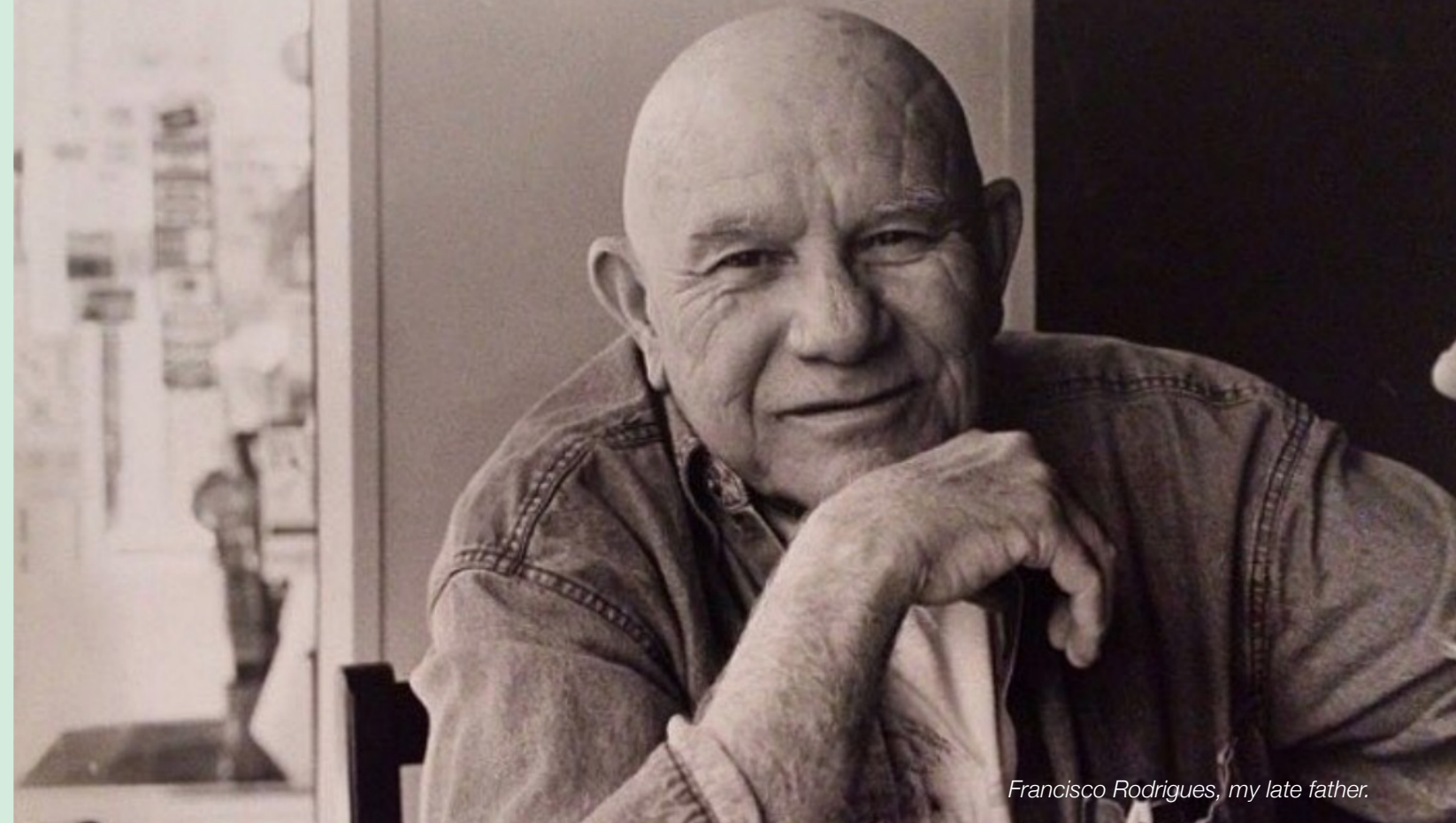


FWD

Friends with Death





Francisco Rodrigues, my late father.

Preface

When we're little, we look at our mom, dad, or whoever is raising us and often see them as superheroes. Invincible. As if nothing could ever hurt them. And many of us are lucky to be able to outgrow this view long before our parents and loved ones grow old and much more fragile. We are often well into our adult lives, with a clear understanding of how mortal the human body really is, before we are ever faced with our parents' mortality. This is the norm. But, every once in a while, we are struck with tragedy before we could ever even imagine. Tragedy, heartbreak, and death can and often do come with no warning, but if we knew, would it influence how we live each and every single day of our lives?

On August 29th, 2017, my father, Francisco P. Rodrigues was diagnosed with liver cancer. On April 20th, 2018 my best friend, biggest support, and greatest ally took his final few breaths after a tumultuous, exhausting, beautiful eight months. For these eight months I personally began to grapple with what losing a personal hero in my life would mean for me moving forward.

I also began to recognize the difficulties of being a 23-year old young woman who, as much as I would hesitate to admit it, needed her father. The support of a parent is something unmatched by anything else, and as grief slowly began to knock me down, like waves when the current is too strong, I began to see that the hurt of losing someone I love so deeply would exist within me for the rest of my life.

It was up to me, though, to move. Forward. To embrace the mortality of the human body. To live with grief, not as a weight, but as something that makes me who I am. To become so acquainted with death, that the unknowns that come from it would no longer scare me, but instead would push me to further become Friends with Death.

To moving forward. To living a life worth raising a glass to. To my new friend, Death. And to Cisco.

This one's for you.

Luciana Rodrigues

MFA Design for Social Innovation Thesis
School of Visual Arts
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“Friends with death may be pretty tough. But maybe what I more meant would have been to have some sort of relationship with it. Doesn’t need to be friendly at all. Just so that it’s less scary than this unknown thing in the closet that we never look at, never see, never touch.”

B.J. Miller, MD
Palliative Care Physician

Intro

Grief is often characterized as a monster, a seven-headed beast, an unknown. We hear of mourning rituals, sitting Shiva, specific bathing practices - but the lesser talked about element of losing a loved one, the grief that follows, can be so complicated, and yet so lingering.

Grief becomes much more complicated as we begin to factor in the realities of everyday life, the expectations to assimilate back into our “regular lives,” and the added stressors of handling a loved one’s affairs after they pass. Grief also becomes much more complicated with age. Young children who lose a parent often have very specific resources that exist catered specifically to them. Older folks who lose their parents, although unfortunate, have much more support around them from family, friends, and colleagues because as someone ages, it is unfortunately a natural part of the aging process to lose a parent.

But for those in the middle, the “not yet adults but not so much children anymore” people who lose a parent, this reality is not something many this age have experienced. So when the unfortunate does happen, these emerging adults can feel isolated and alone, as they potentially have very few peers and friends they can turn to who have experienced something similar.



Brianna C., a member of my Dinner Party table, pictured with her late aunt



Carolina, 26
Pictured as a child with her late father

Context

According to the last US Census done in 2010, there are approximately **18.4 million students enrolled in American colleges and universities**. There is anywhere between 35% to 48% of these 18 million college aged students grieving a loss that occurred within the previous 24 months of a close family or friend. **This means there are about 4 million college aged students grieving a loss of a close family or friend that occurred within the previous 24 months.**

There is research that indicates that a student's GPA will decrease during the semester of loss.¹ Further, there has been research that suggests that up to 15% of these grieving young adults will face long term psychological and physical health risks from prolonged, unaddressed grief.²

These numbers suggest that there is a significant need to further look into the unique complications that can emerge from young adults dealing with grief. From both personal experience as well as in depth research and conversations with other young adults who have lost a loved one, I learned that there was something severely missing from this space -- resources that feel relatable to this age group.



*Elia, 25
Pictured with her late father*

“I love talking about my dad - but no one knew what to say, so I’d find myself not talking about him to make other people more comfortable”

- Elia, 25

¹ Servaty-Seib & Hamilton, 2006
² Ott, 2003; Prigerson & Maciejewski, 2006

Process Snapshot

Arriving at the final intervention took months of research, stakeholder interviews, and co-creation sessions with end users to ensure that it is something young adults have an interest in and will use. Desk research was the first step to understanding the existing landscape of what already exists in this space, followed by various in-depth interviews with subject matter experts as well as end-users themselves. Finally, co-creation sessions brought the research findings back to end-users in the form of various ideas to be able to further develop and create a solution that addresses an actual need.

Secondary Research

Academic literature on the topic

21

Articles reviewed written on the general topic of loss and grief

2

Academic articles specific on bereavement in young adults

Primary Research

End user and subject matter expert interviews

26

Conversations with young adults who have lost a parent

4

Conversations with young adults who have lost a sibling

3

Conversations with grief and loss counselors

1

Conversation with a therapist who works at a university

Co-Creation Sessions

Workshops and sessions focused on bringing the end-users into the design of the final intervention

16

Young adults who have lost a parent participated in co-creation



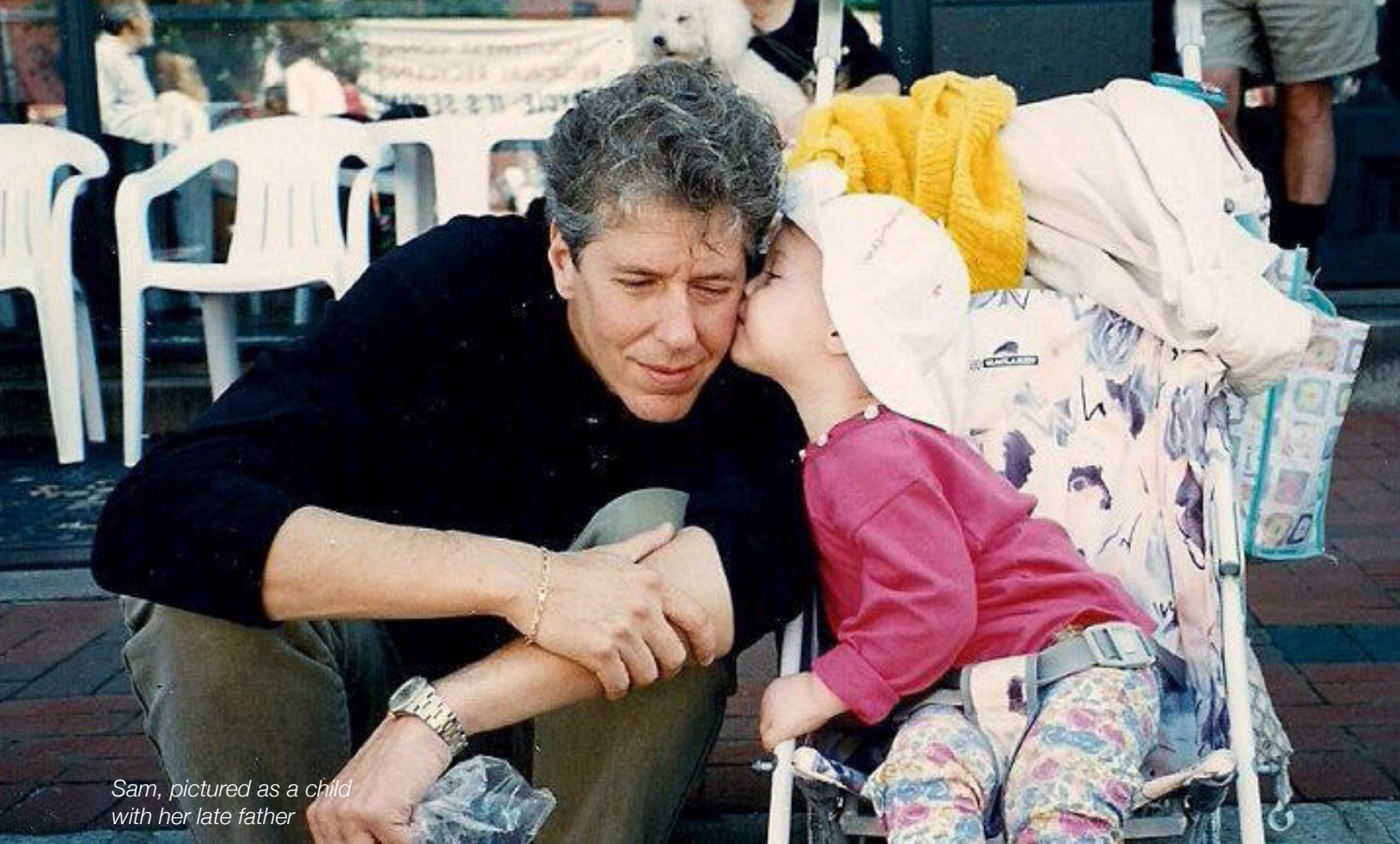
Ideas were narrowed down and further developed as a group



Story-slam nights were one of the ideas that took shape



Eventually, bookmaking took over as a group favorite



Sam, pictured as a child with her late father

Framing the Problem

Young adults, specifically those between the ages of 18 and 30 are facing a unique set of challenges at this point in their lives. Many young people in this age group are in college and living away from home for the first time. They are learning basic life skills, paying bills, managing money, and learning how to function in a world on their own. Many times, young people can slowly transition from living with and being supported by their parents to living alone and supporting themselves. It is during this period of a young person's life where they will often gain an education, learn to think critically on their own, and begin to follow a career path for themselves.

This time period is known for being extremely formative years, full of major life transitions. It is also during this period in one's life where they will develop relationships with friends and peers around them that will often carry them through difficult times that may follow ahead. But, if a young adult loses a parent during this already tumultuous time period of their life, an entirely new set of challenges will arise. What is unique though about this new set of challenges is that when looking around them, a young person may feel alone in this experience. It is not an expectation to lose one's parent while in their early/mid twenties, so it becomes easy to ignore. Up until we are faced with it.

Not having friends or peers to relate to can lead to feelings of isolation.

Not having an outlet for grief can make young adults feel weighed down.

Not having a use for these feelings can cause someone to feel at a standstill.

Insights

Giving grief more meaning

Through my initial interviews with young adults who have dealt with significant loss, I discovered that a sense ‘what now’ hung over people’s heads. Moving forward after a loss seemed to feel even more difficult among all the modern day expectations of being “okay.”

“The pressure to go back to work, to not break down in front of coworkers, to be strong for the rest of my family, to listen to all the unhelpful clichés -- it was just too much.”

- Brianna, 27

Not having an outlet

Not having an outlet for the grief that comes from losing a loved one, especially in the immediate months to year following the loss, caused young adults to feel extremely isolated. This feeling of isolation and not being able to relate to their friends around them gave many young adults this sense of being “stuck” in sadness and grief and further weighed down by it.

“I feel like my grief is a weight. It just sits in me, and I know it’ll be a part of me for the rest of my life, but I wish it didn’t feel like such a weight. I wish it felt more useful.”

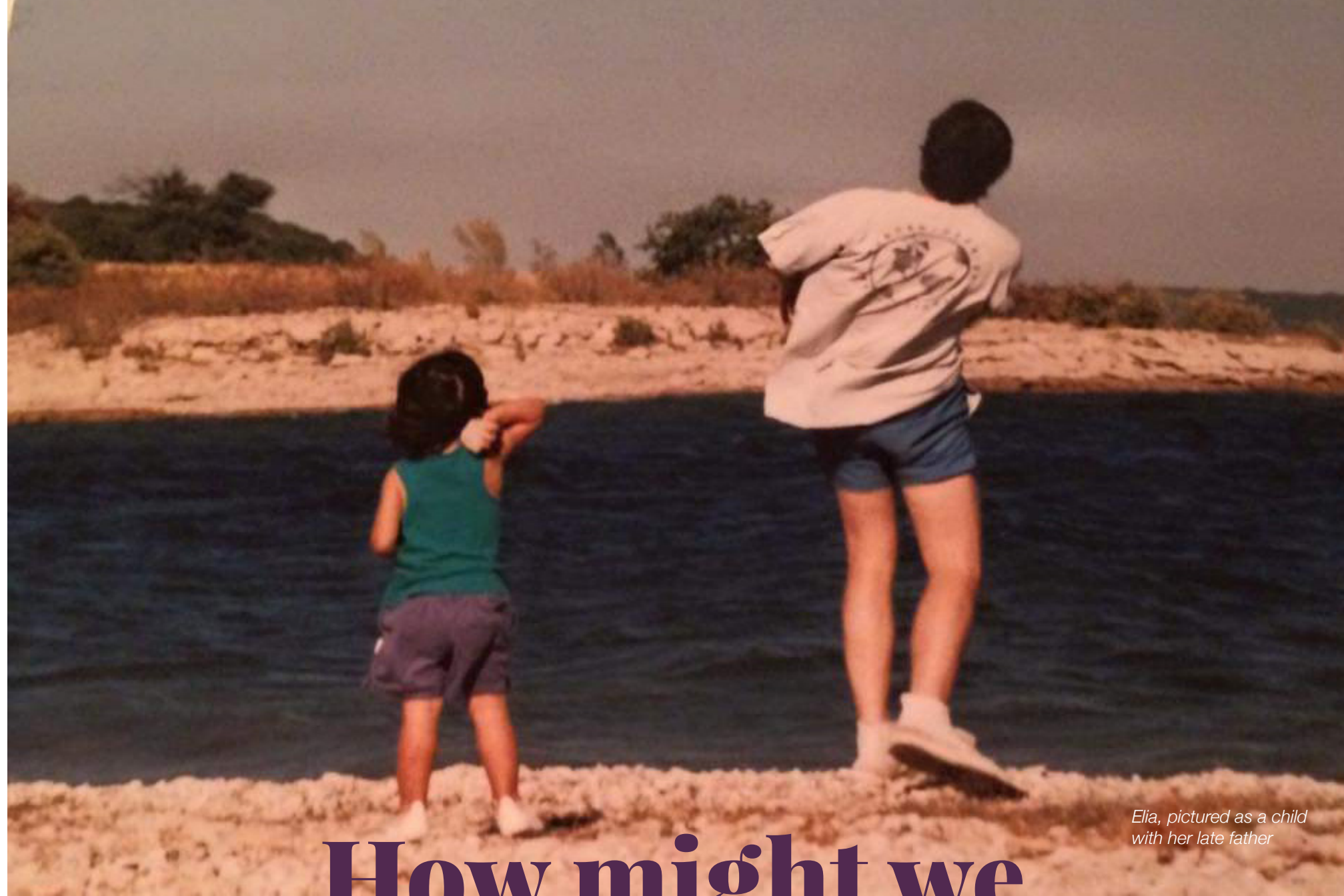
- Thandie, 28

Some key questions began to emerge:

How do we address the grief that comes from the loss of a parent?

How do we turn grief into something that doesn’t feel like a weight?

How do we, as young adults, feel most useful?



Elia, pictured as a child with her late father

How might we turn our grief into something that feels useful?

Key Learnings

From my initial research, problem framing, and stakeholder interviews, I started gathering insights that helped me define the direction of my intervention.

A key part of this process was starting to synthesize the primary needs of young people who have lost a parent and also starting to identify opportunity spaces in current efforts, to begin to establish design determinants.

Storytelling as Healing

Primary research and stakeholder interviews with grief and loss counselors made clear that **storytelling, sharing experiences,** and putting **action** behind grief are essential in healing. These are also often the most difficult things to do when dealing with a loss. Young adults need a space to externalize their stories, although simply asking for that or finding natural opportunities to share their stories were perhaps some of the hardest things to come by.

“I don’t consider myself a therapist or a counselor really. I’m more of a storyteller and a witness to other people’s stories. That’s where true healing happens.”

- Tom, 62, Grief Counselor

Relatability is Key

Young people want to **talk** about their loss but also don’t want to make others around them uncomfortable. Something my interviews with these young people made clear was that they were more comfortable talking to strangers that had experienced a loss than talking to their closest friends that had not yet experienced a significant loss.

“I feel like I’m so much more able to talk to you, since you lost your dad, and I just met you. I still can’t talk to my friends about this, they don’t get it. I mean one of my friends tried to relate to me losing my mom by bringing up her dog who was sick...”

- Anne, 29

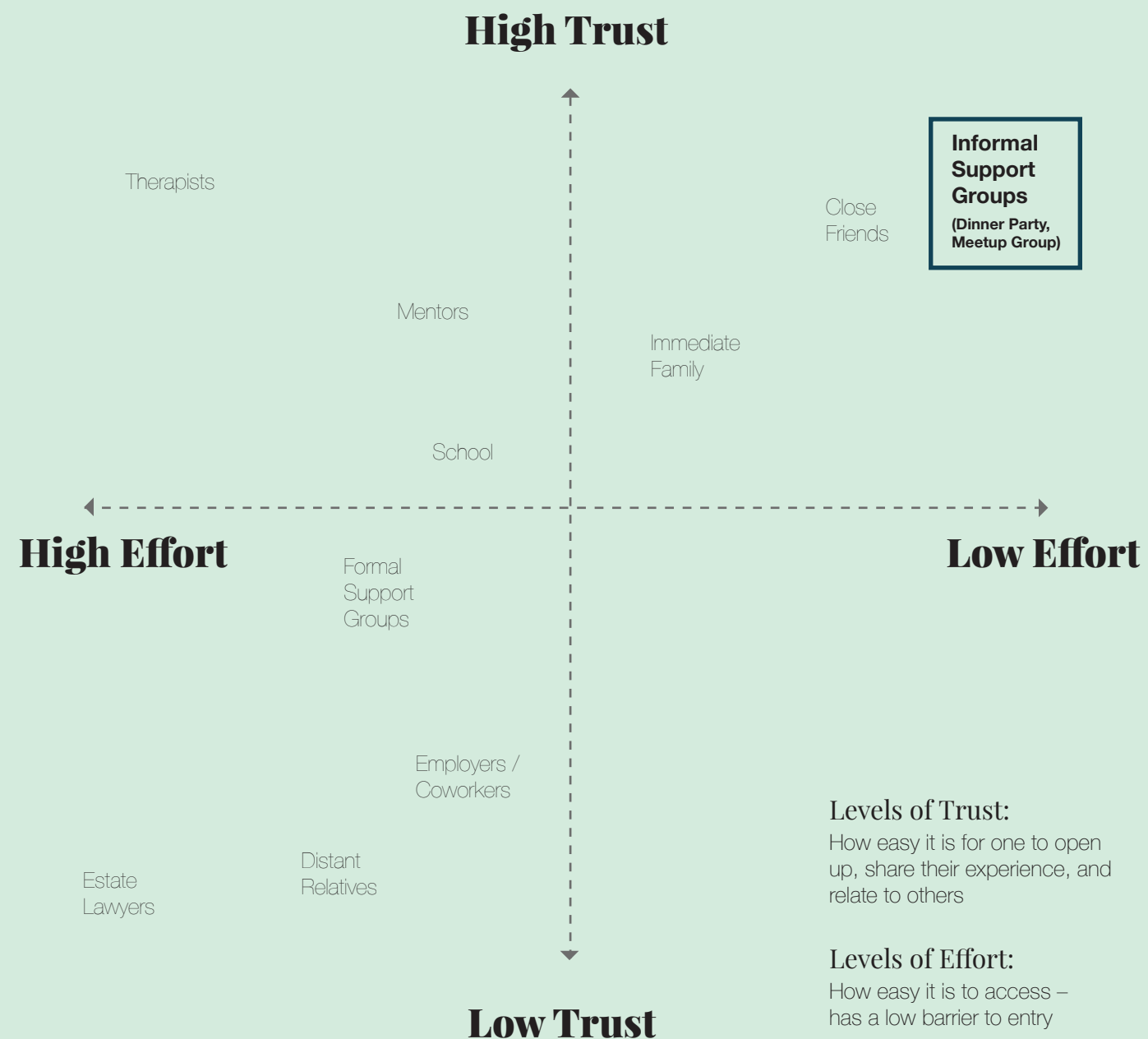
A Desire to Help Others

When given the opportunity to help or offer advice, 9 out of 10 young people I spoke to said they would **never hesitate** to be there for a friend going through a similar experience because they **know how alone and isolating** this experience of losing a parent can be.

“My grief is a private pain for me. It’s not something I like to share with people who haven’t experienced it, but if I had a friend going through the same thing I would never leave their side.”

- Valerie, 21

Finding the Opportunity



What Already Exists?

Creating something that was “low-stakes,” as one user put it, became the biggest opportunity area. After extensive research into what resources exist for bereaved young adults, the only informal spaces I could find, somewhat readily available, were a **Meetup group** and a program called **The Dinner Party**.

01/ The Dinner Party

The Dinner Party is a program specifically for 20 - 30 year olds who have experienced a significant loss of a close family member or friend. There is an application process to join a “dinner table” and it can (and did in my own experience) take up to 6 weeks to hear back from them. It is low-risk in the sense that other than showing up and being present, the commitment is still significantly low.

The Dinner Party addresses a significant need that young people who have dealt with a loss have in wanting to build community with others who have a shared experience. The Dinner Party also makes it easy to process grief because, as they put it, they employ the “**age old practice of breaking bread.**”

02/ The Meetup Group

The Meetup Group for Young Adults who have Lost a Parent(s) is created and entirely self-sustained by individuals who are passionate about the topic of grief and who have also, unfortunately, lost a parent while in the complicated, young adult stages of their life.

This Meetup Group is unique to the Greater New York City area and there is no standard or assurance that this sort of low-stakes meetup group exists elsewhere. The meetings are held once a month, in a set location in New York City, where anyone who has experienced the loss of a parent while young is welcome. It is an opportunity to have candid conversations and in almost every meetup are a few new faces.

Defining Insight

The biggest lesson that I was able to gain from these existing opportunity spaces, both from attending and from interviewing other attendees, was that neither one of them addressed the desire to **add purpose or usefulness** to grief. I saw this as a huge gap, and a space for me to design my intervention in.

How might we make grief feel useful & add purpose to pain for young adults who have experienced a significant loss?

Bookmaking

During early ideation sessions with my Meetup group, I presented several different directions – including a storytelling event and guided conversation cards. However, I sensed a much larger energy towards another idea: **Bookmaking**.

Let's Create

Bookmaking parties are opportunities for young adults with the shared experience of loss to bring purpose to their pain

1st Party

The first bookmaking party's main goal was to develop what kind of content would or should be included in books. Young adults were guided through various sticky-noting exercises and then finally given the opportunity to make their own books. In allowing them to create, it became clear that a strict structure on what should be included in these books is not always necessary. It also became clear that while a conversation was necessary in the beginning, the conversations that emerge naturally while books are being made gave more value to the session.

2nd Party

The second bookmaking party's main goal was to test if a loose structure would still work or if having less structure in regards to the content of the book made it more difficult. Elements such as how much time dedicated to conversation vs. actual bookmaking were also tested in this bookmaking party session. It became clear that a loose structure provided the most opportunity for organic conversation to emerge among participants as well as for more creative and unique books with little expectations.

3rd Party

The 3rd and final bookmaking party was led by a participant who had been involved in co-creation as well as in the first bookmaking party. The main goal of this bookmaking session was to see if it was something that could be done with as little structure as possible in regards to what content goes into each participants' book, with more time focused on making to allow for organic conversations, and all led by someone new. It became clear from this party that it was an easy structure to follow, making allowed for natural conversations, and it was possible to lead with only one's own experience with their own personal loss to guide them.

Final Design Determinants

With “bookmaking” as the main driving idea, the following design principles emerged as the most important to pay attention to when building the final intervention.

01/ Low-Stakes

It was important that the intervention felt natural, organic, and that it was not asking too much of the participants. Being so overwhelmed with grief and loss, asking too much of someone dealing with these complicated emotions became priority.

02/ Social

Although not completely necessary in the creation of a book, having the opportunity to share what someone includes in their book with someone else, whether that be other participants in the room or with a close friend who may have also just lost a parent, the opportunity to make this more of a social experience proved to be another essential element of a successful design.

03/ Practical - Grief into Purpose

Many young people expressed that it is difficult to deal with their feelings of grief and loss, but that they understand it's also an important part of the healing journey. Giving their grief more practicality in the sense that they are creating resource books for other people made it easier for these young people to face their grief and talk about it in a practical and purposeful way.

04/ Helpful To Others

Also in line with the need to feel practical, these books contributed significantly to young people's feelings of being useful. When asked how do you feel most useful, almost every young person I spoke to brought up themes of volunteering, helping others, offering advice, being a shoulder for those also dealing with loss, etc.



Cady, a member of my Dinner Party, pictured as a child with her late father.

Co-Creation Sessions

Through both an informal workshop and a more structured workshop, I set out to find if there was a shared or common understanding or theme of what young adults would want to include in books.

I was trying to gain insight into three key themes – what did young people already know about their experience? What did they wish they knew or had when they experienced their loss? What and also how would they share what they know now?

What do you know?

What do you wish you knew?

How would you share what you know?



“I love the idea of making something. I’ve had a few friends now who’ve lost their parents and it seems like every time I’m the person they turn to. I don’t mind, there’s just so much I want them to know, but I also don’t want to overwhelm them.”

Chloe, 23
Lost her dad in 2018

Pausing With Paper...

“A
blank
slate.”

“An
opportunity
to f*ck up.”

Something that was uncovered in the research and in talking to young people grieving a loss was the simple truth that taking a pause is essential to begin addressing ones' grief. But in the day-to-day reality of life, finding time to just “be” seemed nearly impossible. Being a young person in school or perhaps in the beginning stages of a career, learning how to be truly independent, and then all of a sudden dealing with the unfortunate realities of losing a loved one requires a pause that is rare to come by.

This is an opportunity to take a pause. In taking pause and in creating the opportunity for a blank slate, a young adult grieving the loss of a parent or loved one can then begin to open up and create a space to begin a new chapter. Paper is just a practical vehicle for this necessary pause to happen.

FWD


Friends with Death is a DIY bookmaking movement that offers young adults grieving the loss of a loved one an opportunity to create purpose and use for their grief.

“You know, I think the scary part is the unknown... And the lack of control.”

*Thekla Hammond
Palliative Care Patient*



Taylor, pictured as a child with her late aunt



“A personalized way to spend time with your grief without interference or judgment.”

- Tepper, 27
Participant at 2 Bookmaking Workshops
Lost his father in 2018

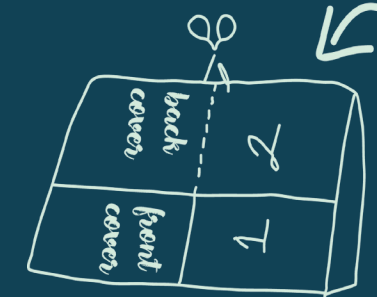
How it works



Step 1:
Find an 11x17 piece of paper. Fold the sheet of paper in half, three times.



Feel free to label 6 pages + front and back cover to help guide you!



Step 2:
Fold sheet in half and cut top half along the dotted line.

Step 3:
Push booklet together like so...



You're Done!
Easy! You're ready to make your first grief book!



It's a simple 11x17 paper, folded in half 3 times, given one simple cut, and then folded together to create a small six page booklet. From there on, it is a blank canvas, an opportunity for the bereaved to put pen, marker, pencil, or whatever to paper. It's an opportunity to write down lessons learned, anecdotes on sadness, or any advice.

Friends with Death books serve the four main determinants of this project, which are that it is **low-stakes, social, practical, and helpful.**

By creating these books, participants have the opportunity to then take their books and share them with someone who may also have just lost a parent and who may not know what to expect with grief.

There is also the opportunity to upload one's book to the Friends with Death website, so that if they don't have someone to immediately share their book with, they can still make use of their book by offering it as advice to other grieving young adults who may be strangers, looking for people like them to relate to.

Piloting the Bookmaking

Friends with Death bookmaking events were able to be piloted twice with a total of 16 young adults who have lost a parent. All these young adults found the event through the Meetup Group for Young Adults who have Lost a Parent(s).

The first bookmaking event was led by myself and supported by two additional designers. These were all hosted at a community workspace open to the public in Harlem. The workspace was able to be reserved so that the atmosphere of a safe space was able to be maintained.

The second bookmaking event was led by a participant who had been previously involved in co-creation sessions and had attended the first bookmaking workshop.

I was also able to pilot the idea of making these books to 3 other young adults who had lost a parent who do not live in the New York City area, by electronically sending them the basic directions.

The purpose of these pilots was to find out whether or not this solution could be (1) scalable (2) sustainable without my involvement and (3) able to grow into a movement.



Tepper, 27
Sharing his book at a bookmaking event
Lost his father in 2016

The ability to make books about one's experience with grief, in a safe and comfortable setting, with few restrictions on what actually goes into the books provided young adults with the opportunity to be creative, practical, and useful about their grief.

Learning One:

100% of the participants who responded to post-surveys said they would "highly recommend" this sort of bookmaking process to a friend in a similar position.

8 out of 10 participants who responded to the post survey question asking whether or not they would do this again said "absolutely"

60% of participants said that it put into perspective how important it was to address their grief, despite it being a difficult thing to process.

"It felt like a judgment free space to just get some relief"

- Chloe, 23

Learning Two:

Friends with Death creates an opportunity for anyone, anywhere to put action behind their grief while providing use for it. The second pilot of the bookmaking event proved this, as a participant was able to lead the event.

Making books in a "scrappy" and "low-fi" method, just folding up an 11x17 sheet of paper creates even lower stakes and a **much lower barrier to entry for anyone to be able to participate.**

"I keep coming to these things because it sort of forces me to deal with these messy, complicated feelings of grief, but in a way that doesn't feel like a waste - but more of a contribution to someone else."

- Tepper, 27

Learning Three:

These bookmaking events also seemed to be incredibly useful as a "first step" for bereaved young adults.

80% of participants had faced the loss of their loved one within just the past year. In fact, 5 participants had lost their parent(s) within the past 4 months.

"My mom died just a few weeks ago, I can't handle much, but this felt like a good place to start."

- Thandie, 28



Participants sharing the books they made at the final Bookmaking Pilot event

Pilot Learnings



www.friends with death.com

Friends with Death - A Bookmaking Movement is hosted online at www.friendswithdeath.com. This allows for anyone, anywhere to access the resource. Friends with Death is a movement, so in the true nature of a DIY movement, led by the people that it is for, how young adults find and continue to cultivate this movement will be completely community led. The stickers are made to guide people to the website which will serve as a resource to be able to equip young people to (1) create a book on their own and (2) host bookmaking events - if they feel inspired to.

The books, they are just vehicles to equip young people to better, and potentially sooner, begin to work through their grief. The true mission of Friends with Death will be accomplished when young people are able to address the grief that comes from losing a loved one in a useful way that also allows them to begin to move forward.

Friends with Death, when abbreviated is fwd. Forward. Which encapsulates the overall spirit of this project. Moving forward.

FWD
Young, Wild, and Grieving?
Join the Movement at
FriendsWithDeath.com



Reflections

You have to do the work.

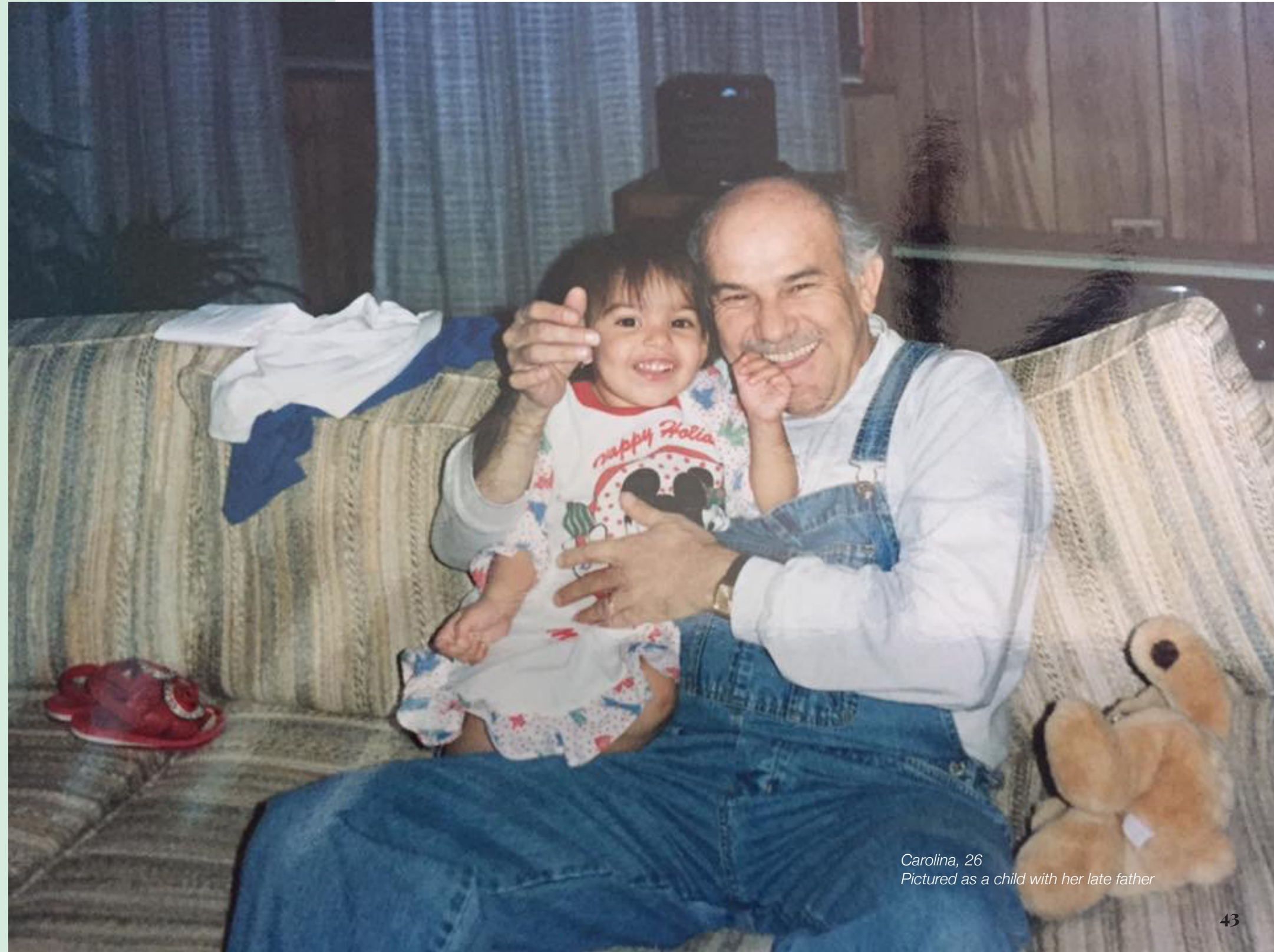
My biggest takeaway from this entire process of creating, learning, researching, scraping, starting all over again, and then again, is that in every single step, you have to do the work. You owe it, to yourself but most importantly to your end user.

If it's hard, you're probably on the right track.

I was having a hard time with how much everyone would advise me to stay away from a topic that was so close to me. I knew walking into this topic that it would be difficult. There were many, many times I would walk out of an interview with tears in my eyes and a heavy heart. There was a lot of hurt that inspired this project to grow, and in that a lot of internal growth as well.

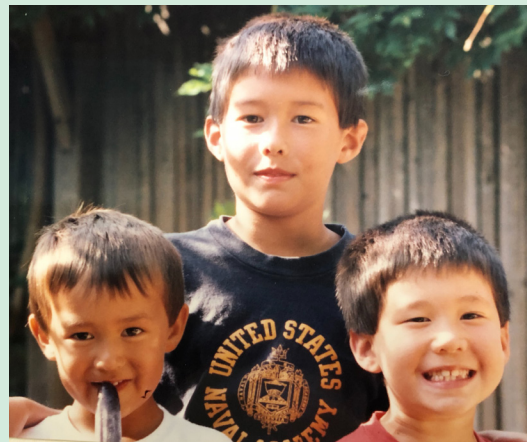
You have to ask for help.

From your end users, from your stakeholders, from your advisors, and from your friends. I know that had I not opened up to my advisor, Miya, about how difficult it was for me to return to school after losing my father, she would have never been able to offer me the support she did, and I would have not been able to finish this project. I know that if I did not have the help from my friends and classmates, so many incredible things would not have happened with this project. Asking for help is humbling, but necessary. No one gets through life alone. Same goes for thesis.



*Carolina, 26
Pictured as a child with her late father*

In Loving Memory Of



When You Meet Someone Deep In Grief

Slip off your needs
and set them by the door.

Enter barefoot
this darkened chapel

hollowed by loss
hollowed by sorrow

its gray stone walls
and floor.

You, congregation
of one

and here to listen
not to sing.

Kneel in the back pew,
Make no sound

Let the candles
speak.

Patricia McKernon Runkle

**...and all others
pictured throughout
this book.**

Thank You.

Acknowledgments

Friends with Death would not be possible without the love and support of so many people.

Seth Hoffman - Organizer of Young Adults Who Have Lost A Parent(s) Meetup Group

My Harlem POC Dinner Party Table

Nick Chan - DSI Alumni

Malé Sandoval - DSI Alumni

To **all those** who have shared their experiences and stories with me, your willingness to be vulnerable and honest about the loss of a loved one is what made this project what it is.

Rutvi Gupta, for never letting me give up, for holding my hand in the hospital, and for pushing me to get moving forward.

Danielle Hernandez, for being there through it all. I am so honored that you and my father were able to meet and I am so blessed to have you in my life to share in the memories I have of him.

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Matt Nuñez for always being my rock.

To the entire **DSI 2019 Cohort**, for being my rock the first year while my father was sick and never letting me feel alone.

Cheryl Heller, Chair, thank you for all the kindness, all of the support, the phone calls and meetings to check in on me. I never thought I would have found a masters program with a chair who has been so caring, and I feel truly lucky to have had you to support me through some of the hardest years of my life. Thank you.

Miya Osaki, Advisor, you were the most difficult thesis advisor and for that I am truly lucky. You pushed me to never stop asking important questions and inspired me to think of things in a bright, new way. You allowed me to rise to the challenges you set out for me and for that, I know I have grown so much through this journey. Thank you.

And finally, my mother **Ana Cristina** and my sister, **Carolina**. To the strongest women I know. And to raising me to be the strong woman I am today.



Friends with Death

MFA Design for Social Innovation
Graduate Thesis
School of Visual Arts
New York City
May 2019

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