

In This Together

Building Communities To Help
Young People Through Grief



APART
OF ME

Executive Summary

We are facing a grief pandemic.

Over three million children and young people have lost loved ones to Covid-19.¹

In this time of increased anxiety and social isolation, their grief threatens to transmute into serious, long-lasting mental health problems. 25% of under 20-year-olds who take their own life in the UK had experienced a childhood bereavement.²

The psychotherapist Darian Leader says that ‘mourning requires other people’. But what does that ‘other people’ look like in a time of extreme isolation, in a time when young people feel lonelier than the elderly, in a time where community is increasingly sought in a polarising, online world. A recent systematic review on loneliness and young people’s mental health concludes: “*Finding ways to give children and adolescents a sense of belonging...and to feel that they are part of a wider community should be a priority.*”³

The central question behind this report is:

How can we design better communities to help young people grieve?

The report is a summary of both primary and secondary research we have done over the last few months to seek answers to this central question. In our research we conducted a survey of young people across the UK and Europe, interviewed bereaved young people, child and community psychologists, experts in community-building and even had a conversation with a lesser spotted anthropologist of grief. (See Appendix for more details).

We looked at how much online communities help young people grieve, and in what ways they might hinder grief. We look at some of the barriers young people face today in accessing community. And we will share some design provocations to get you thinking about how you can facilitate better communities that can help young people to grieve. The novelist Cormac McCarthy writes that: “*The closest bonds we will ever know are bonds of grief. The deepest community one of sorrow.*”

In this Age of Aloneness, grief is a glue that can bind us back together.

1 <https://www.futurity.org/grief-covid-19-aftermath-families-2335962/>

2 <https://www.hqip.org.uk/wp-content/uploads/2018/02/8iQSVI.pdf>

3 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7267797/>

“I miss our community”

Jamie, 18

The Background

Hello. I am Louis, CEO of Apart of Me, a charity that helps young people transform their grief into compassion. We created the world's first therapeutic game to help young people grieve. We always knew that an app was a necessary stepping stone to help young digital natives build healing relationships in the real world. We built features into the app that have helped thousands of young people have difficult conversations with family members and friends, conversations about life, love, and loss.

But we also knew that - without anything to follow on from the game or our co-design process - its completion could feel like another ending to be mourned. Indeed, we had feedback along these lines from one of our young ambassadors, Jamie, who had helped build the game. The co-design workshops had given the young people the feeling of community. They enjoyed being part of something bigger than themselves, they explored new interests and talents, and they made connections with other young people who had experienced grief. But most importantly, having this deeper experience of connectedness, Jamie and the other young co-designers didn't want the community to come to an abrupt finish. This was our provocation to explore this theme of community for grieving young people.

I hope this report inspires you to design better, deeper, more transformative communities for the young people in your care.



Louis Weinstock,
CEO, Apart of Me

Louis

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The Landscape of Adolescent Grief

Humans are social creatures, so we naturally feel pain when a member of our tribe dies. Grief is a natural - albeit painful - part of human life. Over thousands of years and across many different cultures, collective structures have evolved to guide us through this pain. Yet, in modern secular societies, many people have become distanced from the language and practices which have historically guided them through the heartbreak of loss.

Young people feel the distance from these support structures more than any other group. In the UK, young people feel more alone than any other age group, including the elderly.⁴ We could imagine a topsy-turvy future where elderly people visit teenagers in their bedrooms, playing bingo with them to help them feel less alone.

"People don't talk to each other in London. I went to a talk about how to make friends.

It's basically either through a sport or volunteering. There are so many people in the city, it makes you feel bad about feeling lonely. Like...it shouldn't be hard to make friends."

Elliot, 21

A representation of an
Aboriginal women's grief circle



CC Baldwin Spencer and F. J. Gillen's *The Northern Tribes of Central Australia* (Macmillan & Co, England, 1904)

4 <https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/articles/childrensandyoungpeoplesexperiencesofloneliness/2018>

How can we understand this epidemic of loneliness amongst young people?

Adolescence is a unique developmental stage where the biological imperative is to detach from your family of origin and build new connections with peers. And young people are more connected with their peers than ever before - in almost constant communication - and yet they report feeling lonelier than ever.

As Technologist and Psychologist Sherry Turkle puts it succinctly, in this digital age we are 'Alone, Together'. In many ways, the connections we build online can not give us the deeper nourishment of real life connections that we are biologically wired to need. A virtual hug is never as good as a real hug.⁵



A virtual hug is never as good as a real hug.

Of the young people we surveyed:

40%

said they agreed or strongly agreed with the statement 'I feel a lack of community in my life'.

In research done by the Mental Health Foundation on young people and loneliness:⁶

25% said they "often" felt they lack companionship

25% also said that they often felt left out

27% felt isolated from others.

A survey of one thousand 13-25-year-olds in the U.S. found nearly

40%

feel as if no one knows them and nearly one third have no trusted adult in their lives.⁷

⁵ <https://journals.sagepub.com/doi/full/10.1177/1461444817707349>

⁶ The Mental Health Foundation (2019), State of a generation: Preventing mental health problems in children and young people, accessed at <http://tiny.cc/06vopz>

⁷ Springtide Research Institute (2020), Belonging: Reconnecting America's Loneliest Generation

Our 'flatline' culture pushes grief into lonely spaces

Grief can be potentially transformative – reminding us of our capacity for love, serving as an opportunity to learn about ourselves, find new strengths and discover what really matters most. Grief can be the glue that brings us closer together. But instead, in modern Western culture feelings like sadness and anger have been branded as 'negative' or 'problem' emotions.

In the latest edition of the International Classification of Diseases (the big book used by psychiatrists to diagnose mental health problems) a new diagnosis of Prolonged Grief Disorder is included for someone struggling with symptoms of grief in a way that *"clearly exceeds expected social, cultural or religious norms for the individual's culture and context."* Which begs the question:

What are the expected norms around grief in a modern secular society?

As Francis Weller puts it, we live in a "flat-line culture", where the parameters of the socially acceptable emotional range are incredibly narrow, we prioritise happiness above all else, and choose to numb or distract ourselves in the face of any feelings outside that narrow range.

"I feared emotions. I bottled up a lot. I was scared to add my sadness to the bigger sadness of my family. I didn't want to trigger my dad."

Elsa, 17

This flatline culture also means that big emotions like grief get pathologised, and this leaves young people feeling huge anxiety about their mental health. In our survey, the data showed clearly that young people's biggest concern was mental health. One third of respondents felt overwhelmed by this issue, nearly three times the number who felt the same about climate change (11%) and unemployment (12.5%). This suggests that they feel unable to handle or get support for big and 'difficult' emotions. This insight is supported by a recent OECD survey of young people's worries about the Covid-19 pandemic, where their biggest worry was the impact of the pandemic on their mental health.⁸

"My mum died in March. I felt guilty that I wasn't feeling bad enough. I was more angry than anything, not sad. I thought; is there something wrong with me? I had this heavy expectation around how I should feel when my mum dies. But I had a complicated relationship with her."

Elliot, 21

⁸ https://read.oecd-ilibrary.org/view/?ref=134_134356-ud5kox3g26&title=Youth-and-COVID-19-Response-Recovery-and-Resilience

And young people are finding it increasingly hard to detach themselves from these emotional storms. Over a third of 15-year-olds in the UK are 'extreme internet users', online for at least six hours a day at the weekend, whilst in the US 95 per-cent of teens have access to a smartphone, and 45 per-cent say that they are online 'almost constantly'.^{12 13} This means that young people - their developing brains and nervous systems - are constantly exposed to the harsh realities of the world, to the reality of death, and to the possibility of civilisational collapse, and it can all feel too much for them to bear.

We know from the research into people experiencing complicated grief, that their dopamine system is more highly activated. 'Complicated grief' is a term used by researchers and clinicians to describe grief that continues in a persistent, intense form long after the person has died. It can manifest in obsessive thoughts about the person who has died, intense anxiety, total lack of motivation, or a struggle to deal with day-to-day tasks. Complicated grief can develop into mental health problems, addictions and offending behaviour if it isn't treated with the right treatment and support.

Interesting Fact:

A medical version of dopamine is actually used to treat people who cry excessively, dopamine having the effect of reducing our capacity to shed tears.

In one study, when patients with complicated grief looked at pictures of their loved ones, the nucleus accumbens – the part of the brain associated with rewards or longing – lit up. It showed significantly less activity in people who experienced more normal patterns of grieving.¹⁴ Dr O Connor leading the study said:

"It's as if the brain were saying, 'Yes I'm anticipating seeing this person' and yet 'I am not getting to see this person,' 'The mismatch is very painful.'"

Given all we know about how social media and other digital worlds are designed to hook us by eliciting our dopamine-fuelled reward-seeking brain system, it is clear that for many young people it is more difficult to grieve in the digital age.



Part of Me guide - Charlie and his mum, Caroline

¹² <https://epi.org.uk/publications-and-research/social-media-childrens-mental-health-review-evidence/>

¹³ <https://www.pewresearch.org/internet/2018/05/31/teens-social-media-technology-2018/>

¹⁴ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2553561/>

And although a young person can feel supported emotionally on social media in an instant, there is an important question as to how quickly that support might die off as their online community moves on to the next thing. In her wonderful book on young people's use of social media called 'It's Complicated', technology scholar danah boyd notes that:

"the internet mirrors, magnifies, and makes more visible the good, bad, and ugly of everyday life."

We can see this internet magnification effect in support for the grieving - people of all ages can feel very supported online in the initial stage after a loss, but this support can quickly die down.

In real life,
there is
no respawning.

Author John Pavlovitz captures this reality perfectly:

"Just as the shock of grief begins to wear off and the haze is lifted and you start to feel the full gravity of the loss; just as you get a clear look at the massive crater in your heart—you find yourself alone. People don't leave you because they're callous or unconcerned; they're just unaware. Most people understand grief as an event, not as the permanent alteration to life that it is, and so they stay up until the funeral and imagine that when the service ends, that somehow you too can move ahead; that there is some finishing to your mourning, but you learn that grief has no shelf life."¹⁵

Finally, when someone we love dies, we now have access to terabytes of photos, videos, messages that help us to stay connected to them. But this can also make it harder to let go. 'Ambiguous Loss' is a term used to describe how the ongoing existence of the deceased's virtual self can make it more difficult to let go.¹⁶ In many modern video games, characters can die and get 'respawned' coming back to life an infinite number of times. But in real life, there is no respawning.



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¹⁵ Pavlovitz, John, The Grieving Need You Most After the Funeral.
¹⁶ <https://www.amazon.co.uk/Delete-Virtue-Forgetting-Digital-Age/dp/0691150362>

Why should we care?

The Covid-19 pandemic is increasing the risk of grieving young people developing 'complicated grief'. Sadly, we know how damaging unresolved complicated grief can be for adolescents: in the UK, 25% of under 20s who take their own life have experienced childhood bereavement, as have 41% of youth offenders (compared to 4% of the general population).¹⁷

There are several factors that increase the risk of experiencing complicated grief. These include social isolation, increased anxiety, and experiencing a loss that is sudden and inexplicable.¹⁸ Before the pandemic, young people in many parts of the world were already feeling increasingly anxious, and increasingly lonely.¹⁹

Sadly, all of the risk factors for complicated grief have been heightened during this pandemic. Young people are saying goodbye to loved ones via an iPad, funerals are either not happening or happening in a very restricted and distanced way, and traditional community support is just not accessible. A recent systematic review showed that prolonged periods of loneliness for young people were associated with mental health problems up to 9 years later.²⁰ This means that many young people around the world are going to experience complicated grief, unless they get the right support.

What's more, those from disadvantaged communities will be hit the hardest: they are more likely to lose a loved one to Covid-19, less likely to access support, and at greater risk of social isolation.

"It was shocking; she died so quickly. She was healthy, still went out camping. There were no signs. She died in 6 weeks. My grandmother looked after me and my sister a lot. As a result of that I developed bad anxiety, panic attacks. I had a big fear of strong emotions. I was scared of people being sad and that I wouldn't be able to do anything about it. When my grandmother died I was scared that I couldn't help my mum."

Anonymous, 17

Young people will also be affected by the fact that, as Nadia Bolz-Weber puts it, 'the normal turn-taking of who is grieving at any given time has been supplanted by grief as a universal experience'.²¹ Teachers and youth workers 'will be navigating their own loss while enduring the added stress of developing new ways to manage instruction, technology and classroom dynamics'. Healthcare providers will also be challenged by 'the level of uncertainty, quantity of suffering to be witnessed and often, an inability to "cure" which may be 'a source of moral injury and distress'.²²

17 A Survey of Some of the General and Specific Health Issues for Youth Offending Teams, Greater Manchester Youth Justice Trust, 2001

18 <https://www.tandfonline.com/doi/abs/10.1080/15524256.2020.1745726?af=R&journalCode=wswe20>

19 <https://www.weforum.org/agenda/2019/10/1-in-3-young-adults-are-lonely-and-it-affects-their-mental-health/>

20 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7267797/>

21 <https://nadiabolzweber.substack.com/p/your-grief-is-holy-to-god>

22 The Virtual Funeral Collective (2020) Death, Grief and Funerals in the Covid Age, [white paper], p.11-12, accessed at: <http://tiny.cc/obuopz>

Key Insights

The following are some of the key insights we gleaned from our research:

- A.** Young people turn to their friends when going through grief, even though this doesn't always feel safe to do.
- B.** Young people need a common framework to help them through grief.
- C.** New communities are growing around 'grief' and death, and we need young people-friendly versions of these.
- D.** Young people don't want to sit in a circle talking about grief.
- E.** Anonymity is important for grieving young people.
- F.** Co-designing solutions with young people creates community.

Young people turn to their friends when going through grief, even though this doesn't always feel safe to do.

To cope with feelings of grief, most of our survey respondents turned to their friends (57%). This ranked higher than speaking to family members (46%) and getting help from a counsellor (31%). Yet, only around a quarter (26.7%) young people said that it was 'totally fine' to feel and express difficult emotions like sadness, anger or fear with their friends. School certainly doesn't feel like a safe place for young people to explore these emotions – only 10% said it was 'totally fine' to express them there.

One of the young people we worked with during this research, Elliot, said: "I couldn't talk about my real feelings to my family. We're too close. They all had their own grief. I didn't want them to know that I didn't feel much. I was feeling like a bad son, but had no one to talk about it. I could have used an outlet – to have my feelings acknowledged." This sense that young people feel they don't have anywhere safe to go with their grief is mirrored by the research. According to research by the Mental Health Foundation, almost half of young adults in the UK (46%) feel they can't speak about their emotions with anyone.²³ The same study found

that only 55% of young people are confident that they know where they can go to find help if they were concerned about their mental health and wellbeing, and only 34% are sure that they would actually get the help they need.²⁴

"I couldn't talk to my family. There were always arguments going on. People were pointing fingers at my mum, saying it was her fault that my dad was ill. Then six months later, my grandparents passed away. It was like my whole family disappeared".

Jamie, 18

DESIGN CHALLENGE:

How could your community train young people as peer mentors, supporting each other through grief?

²³ The Mental Health Foundation (2019), State of a generation: Preventing mental health problems in children and young people, accessed at <http://tiny.cc/06vopz>

²⁴ *ibid.*

B

Young people need a common framework to help them through grief

“Death is medicalised in our society. If you are still grieving when you’re not ‘supposed to’ people will say: you should see the doctor! In some other cultures, there are tools easily available: everyone knows practices and words to help people who have lost someone to cope. We lost that shared framework in our society.”
(Aurélien Baroiller, Anthropologist of Grief).

A problem facing us in modern, liberal cultures, as, Aurélien Baroiller explains *“is that we have different beliefs about death. Some people are religious while others think there is nothing after death. There is no overall agreement in our culture”*. This means there are no commonly accepted practices or rituals around mourning.

People may fear causing conflict if they open up about their feelings and coping mechanisms with someone who holds different beliefs about death.

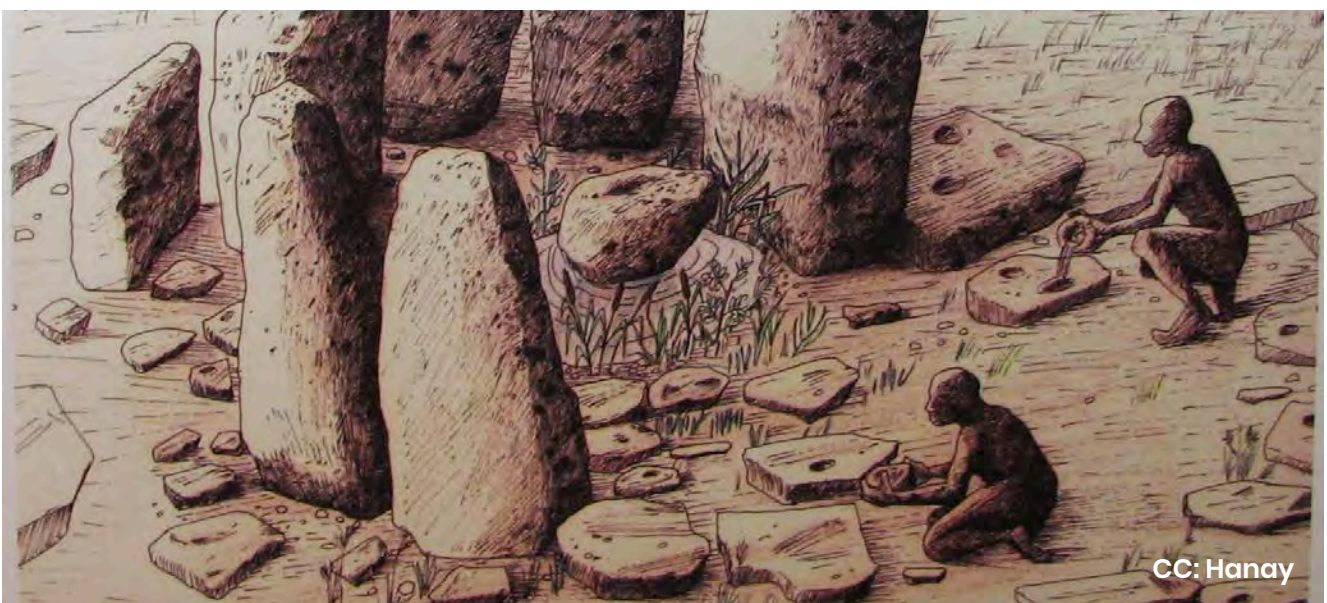
“Sometimes it feels it happens all over again. Certain times in the year, like anniversaries. It’s important to be aware of it. To know that it’s OK, it’s natural! You move forward, you don’t move on.”

Anonymous, 20

Building a sense of community takes time. We need regular interaction with others to create a space where we feel trusted and open to share. Establishing rituals also involves time and commitment. But they can make a community manifest and provide tools to help people through unexpected challenges and emotions. As grief comes at different times and in different ways, rituals provide a space to explore and accept those feelings.

DESIGN CHALLENGE:

How could your community provide a common framework for grief, a framework that can include individual differences in grief journey?



New communities are growing around 'grief' and death, and we can learn from these to build young-people friendly versions.

There are many examples now of new communities and subcultures emerging around grief and death, such as the Death Cafe movement, The Death Positive Movement and others, although few of them are young-people friendly. While grief is increasingly seen in the Western World as a fitting response to a variety of experiences and social issues including, for example, climate change, relationship breakdowns or infertility, the young people we surveyed associated feelings of grief overwhelmingly with bereavement. Only 34.6% felt one could feel grief for failing an exam, for instance, and 32.3% felt one could feel that way about moving house.

There is a need to rebrand grief as a subculture, a subversive community in which young people could feel a sense of empowerment

DESIGN CHALLENGE:

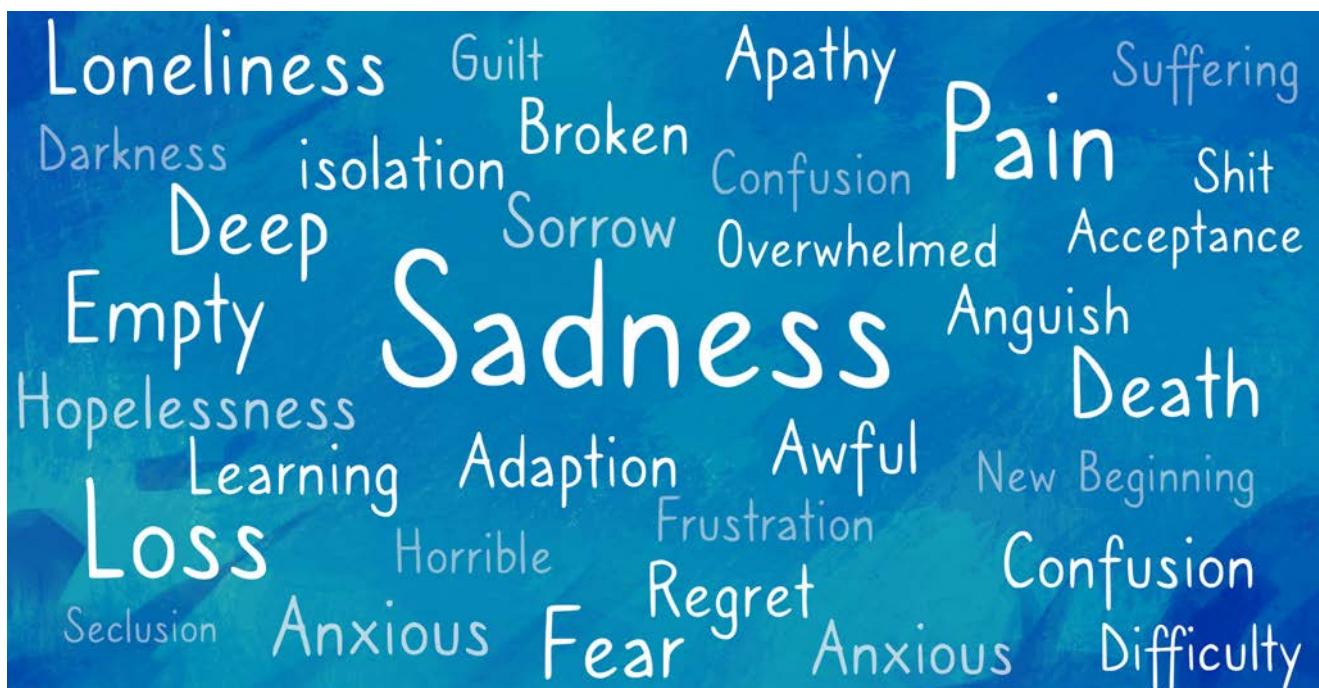
How could your community rebrand grief, showing its potentially radical, subversive, or transformative edges?

and belonging. As the psychotherapist Francis Weller says,

"Grief is subversive, undermining the quiet agreement to behave and be in control of our emotions. It is an act of protest that declares our refusal to live numb."

The words most young people we surveyed associated with grief were negative: 36% used the word 'sadness'; 29% mentioned 'emptiness and loneliness, and 17% described feelings of pain. Very few described grief as something natural or attached any positive connotations to grief.

We asked young people: "what 3 words do you think about when you think about grief?"



Young people don't want to sit in a circle talking about grief

We learned through the design workshops we led with young people that they would prefer connection to flow out of engaging in an activity or project which feels fun, meaningful or gives them a sense of purpose, rather than feeling forced to bond over their shared grief. Similarly, Community Psychologist Dunja Dunda observes that it may be beneficial for young people who have experienced bereavement to come together around at least one other factor which unifies them besides their shared grief - for example a social or political issue, fitness, meditation or sport.²⁵

In terms of the kinds of activities that young people gather around, we know that certain types of online groups are particularly popular among young people today. According to a big study done by Pew Research in 2018, 41 per-cent of young people take part in online communities based on hobbies such as gaming, and a similar proportion (40%) participate in communities with a focus on humor.

Interestingly, boys are roughly twice as likely as girls to hang out in online communities centered around hobbies, like gaming or sports, whereas girls are more likely than boys to hang out in online communities about fashion, health and wellness, as well as communities oriented toward people with specific characteristics (such as LGBT or people of color). Young people from lower-income backgrounds are about twice as likely as teens from higher-income families to say online groups play a major role in helping them through tough times.²⁶

Being involved in an activity or project can help people explore their gifts and strength, and give them an opportunity to re-define their story and identity. In a time of loss, it can give them a feeling of empowerment and sense of perspective.

"You need to create the right space for talking. I don't want to just sit in a circle and talk. It should be around something, around an activity, like learning a new skill. A place where everybody can be open about our joint confusion about grief. A place where we can start exploring what it means to us."

Elsa, 17

DESIGN CHALLENGE:

What activities could you build a community around that could teach grieving young people a new skill, giving them a sense of empowerment?

²⁵ <https://apartofme.app/research>

²⁶ <https://www.pewresearch.org/internet/2018/11/28/teens-friendships-and-online-groups/>

Anonymity is important for grieving young people

Despite the imperative to sharing things in public in this social media age, we found that grieving young people preferred to have some place to go where they wouldn't know anyone else. One of our young ambassadors told us that the only people he felt safe talking to about his dad's terminal cancer were the anonymous friends he was playing Call of Duty with.

Dr Gillian Sandstrom, a social psychologist who researches conversations with strangers, explained to us that when we want to have a difficult conversation with someone we know, we might fear putting that relationship at risk, so sometimes it is easier to open up to

strangers. This is why online communities can be beneficial as a stepping stone to real-life communities. As Professor of Communication Jessa Lingel observes, the online world is a space that is open and has less social and cultural obligations than does a traditional cemetery or funeral home. So, mourners don't have to follow instructions about what to do or what not to do and can take on different roles, giving them a greater sense of ownership, power and control over his or her grieving process.²⁷



DESIGN CHALLENGE:

How could your community help young people share their grief whilst protecting their anonymity?

"I like the AA system. The premise, the space of reflection on your own demons and trouble. It's completely anonymous. People have a lot of secrets. Especially around grief, people make personas around it. It's important to have the ability to go somewhere else to create a community that is separate from your own life. I'd want to talk to someone who is completely unconnected from my world."

Anonymous, 16

²⁷ Lingel, J. (2013). The digital remains: Social media and practices of online grief. *The Information Society*, 29(3), 190-195.

Co-designing solutions with young people creates community.

We worked with young people in the research, design, prototyping and evaluation stages of this community exploration project. While we expected a community for young bereaved people to be the end result, it in fact emerged along the way. We began the process by interviewing young people to find out what exactly the problems were surrounding community and grief, what resources and support networks they already had in place, and what they thought would benefit them.

We involved them in collaborative design by holding workshops where we presented what we had learned from our academic research and interviews in a condensed, comprehensible way and created ideation exercises so they could come up with possible solutions. They worked on these proposals in smaller teams so that the group was not intimidatingly large and they could feel a greater sense of ownership over their idea. These teams then presented

“It was exciting when people came to the workshops. It made me feel like I could actually do something, like I was a good person. As it got bigger it inspired me to do other courses, like business and entrepreneurship.”

Jamie, 18

their pitches in a Dragons’ Den style event and the whole group voted on which one to take forward. Through this, the young people felt part of something bigger, made new friends, and also gained experience which they felt opened up new avenues in their future.

DESIGN CHALLENGE:

How could your community use principles of co-design to build a sense of community?



Some of our young co-designers reviewing the Cornerstones

Cornerstones

Our co-design group came up with a set of 5 Cornerstones: principles they felt were important to consider when building better communities for grieving young people.



Cornerstone 1:
**Throw Out The
Rulebook**



Cornerstone 2:
**Redefine Your
Story**



Cornerstone 3:
**Look Up At The
Stars**



Cornerstone 4:
**Create Consistent
Rituals**

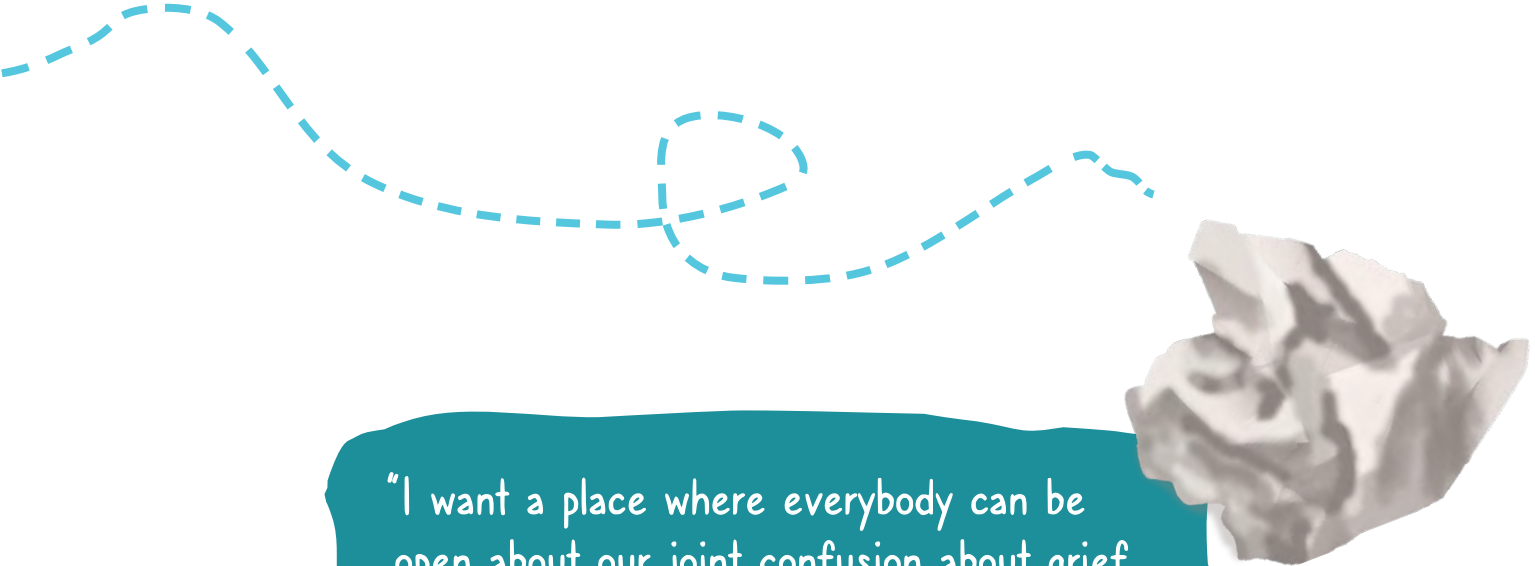


Cornerstone 5:
**Be Part of
Something Bigger**



Throw Out The Rulebook

We don't grieve by a rulebook. For many young people, the '5 stages of grief' don't fit onto their experience, and therefore they can feel like they're not doing it 'right'. But everyone has their own journey through grief, and it's time that we show that there are as many right ways to deal with loss as there are people in this world. Throw out the rule book and make your own.



"I want a place where everybody can be open about our joint confusion about grief. A place where we can start exploring what it means to us."

Anonymous, 17

DESIGN CHALLENGE:

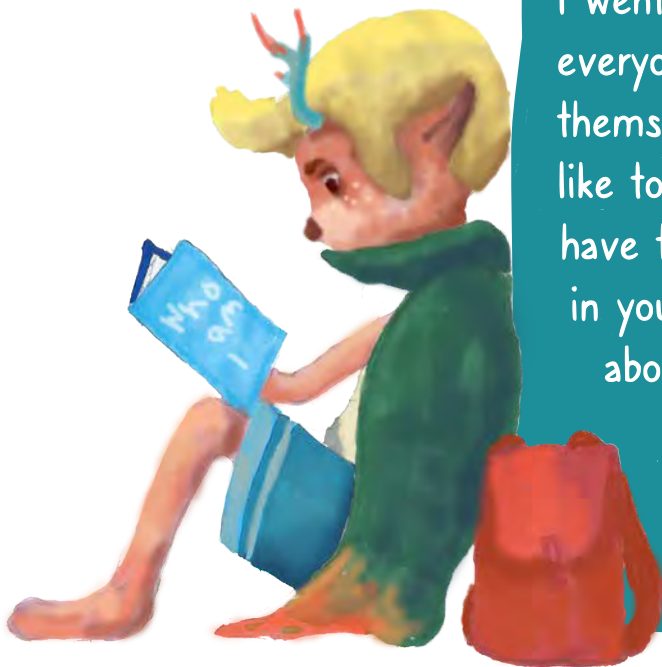
How could you embed some of the following Cornerstones into your service?

Redefine Your Story



cornerstone
2

When we go through an experience of loss, we also lose a part of the person we thought we were. Young people are figuring out their identity, and loss asks an even bigger question of their identity project. Who am I now? Who do I want to be? Loss creates a space for young people to step into and redefine their story.



"I managed to go from someone who doesn't like to talk about taboo subjects to someone addicted to big emotive feelings. I now love asking taboo questions I went from someone who wants to keep everyone happy, to someone who immerses themselves in difficult emotions. I would like to express the fact that you don't have to feel guilty about finding strength in your loss. A lot of the time it could be about how you can understand new parts of yourself, become a better person. It's OK that you learn through grief"
Elsa, 17



Look Up At The Stars

When we're in the middle of dark times, it's hard to find perspective or hope. When we look up at the stars, we can find peace and wisdom. Young people need communities that help them find this more spacious view.

"When my dad passed away, the worst communities found me. Eventually, my mum sent me away to stay with other people. This gave me time to acknowledge and think. Once my mum decided to send me to Thailand. I learnt how to scuba dive. When I was away I had to travel on this remote island and had to learn new skills, like how to ride a motorbike and meet new people. I would look up at the stars and have a deep think about what was going on. Being away from home really helped me. It's about having a safe communal space. It doesn't have to be far away, but should get you away from everything to get some perspective."

Jamie, 18



Create Consistent Rituals

Cornerstone 4



Building a sense of community takes time. We need regular interaction with others to create a space where we feel trusted and open to share. To do this, we need a sense of commitment and powerful rituals that give us the tools and grips to find our way through grief. As grief comes at different times and in different ways, it's important to know there's always a place we can go.

"It's important that it provides a routine – a service that people can go to on a regular basis, and gives them something to do when everything is crashing down around them, so they don't fall off their path."

Jamie, 18



Cornerstone 5

Be Part of Something Bigger

Experiencing loss can make you feel extremely isolated and powerless. A big part of your purpose in life has gone – as a daughter, a grandson, a student, a friend – and it can often seem impossible to find a reason to move on. Young people need to discover a new sense of meaning that shows there is a future beyond loss, that they're part of something bigger than themselves, something that's worth living for.

"I've been growing through the process of loss. The creative community of Apart of Me helped so much with this, the idea that I'm part of something bigger than myself."

Elliot, 21



Inspiration

The following are examples of community that our co-design group of young people (Elsa, Elliot, Matt, Jamie, and Alizah) said inspired them. Each example represents elements of the different cornerstones.

Video Games



Communities can emerge spontaneously in or around the subject of video games. For young people who might be reluctant to share on cue, especially in a face-to-face setting, the sort of groups which form in multiplayer games can be a helpful forum for them to share their feelings.

The community forms around a shared goal, while the skills and focus required mean that the young person doesn't feel defined by their grief. Similarly, the 'anonymity' can reduce the pressure felt by those who fear being seen to express their emotions, as can the fact that it is always an option to quit the game and walk away.

"I played Call of Duty with the same group of people for four years. I was the clan leader. We never met in person but we talked about what was going on at the time. I felt more comfortable talking about it there because no one would judge me"
Jamie, 18

DESIGN OPPORTUNITY

There are multiple ways which an 'online' community can go 'offline' and vice versa, including:

- Alternative Reality Games, in which the real world serves as a platform and players interact directly with characters in the game, solve challenges which have an impact on the game's narrative, and collaborate as a community to coordinate real-life and online activities.
- Augmented Reality Games, in which a game's visual and audio content is integrated with the user's environment in real time often by superimposing the game environment on top of a user's actual surroundings.
- RFID tags which connect real-world objects into the digital world.
- Voice chats in multiplayer games allowing players to call each other through the game.
- Audio walks are audio-guided routes through place which can either use geolocation data or be downloaded as an MP3.



K-Pop Random Play Dance



These pop-up events are an example of a spontaneously-forming one-off community. Following the rise of dance sequences as a preferred mode of expression for young people, in these gatherings people stand in a big circle and run to the middle to show off their k-pop dance skills. The atmosphere is non-competitive so newbies and veterans alike are able to join in.

The K-Pop Random Play Dance has become a global phenomenon, taking place in Times Square and many other public spaces all over the world. One of the reasons it is so popular is because it gives the opportunity to dance as a group, without the pressure of doing so in front of a huge audience. It allows for free expression, without having to talk, so language differences represent no barrier to connection. It is also easily replicable and can be set up in any environment. Additionally, as the playlist isn't pre-planned, the activity remains fresh and energising.

Death over Dinner



Death over Dinner attempts to bring the conversation about death back into mainstream culture and thus build greater comfort and literacy around the topic of death, so that ultimately more people can die in the way they wish (but daren't talk about).

Their interactive website helps people host a dinner over which they can talk about death. The visitor selects their intention for hosting the dinner, and a script is created with thoughtful questions for everyone present and some tips for how to go about it.

Since it was launched in 2013, there have been over a hundred thousand #deathdinners in 30 countries, and with a Jewish, Australian and forthcoming Doctors and Nurses editions, it is adaptable to several cultural traditions.

The project makes use of the ritual of the dinner table, which is shared by many religious and secular cultures, on the grounds that eating together creates warmth and connection, and puts us in touch with our humanity.



The Dinner Party



The Dinner Party is a regular gathering for people in their 20s and 30s who have experienced bereavement. Designed to help people who struggle to connect with their friends and family after they lose a loved one, it aims to build community and connection over time by having dinner tables meet every couple of months.

They screen and train peer hosts and connect them to 10 to 15 would-be diners nearby who are similar in age and experience of loss. They then provide ongoing coaching and support in order to sustain each group over the course of a year or more. Since January 2014, their network has grown to over 300 peer hosts and 3000 diners in over 100 cities and towns worldwide.

Like Death Over Dinner, the Dinner Party makes use of the ritual of a meal, but adds the element of repetition so that the support it provides is more long-lasting and people can gradually go deeper in what they share as they become more comfortable with the group. In contrast to the Dinner Party, it involves people from outside one's regular network of friends and family – which, as Dr Sandstrom observes, may make it easier to share intimate feelings and experiences.

Diners also feel like they are helping to create the experience and not just objects of support by bringing a dish and offering their own presence and counsel to people who have had similar experiences. This increases their sense of agency and empowerment.

The DINNER PARTY

Camerados



Camerados seek to encourage mutual aid for people going through tough times by setting up Public Living Rooms. Here, people can have agenda-free conversations with camerados, who do not try to fix the problem but simply come alongside and offer a non-judgmental presence.

These Public Living Rooms, set up and run by local people, have sprung up in community centres, schools, libraries, hospitals, universities, streets, and a prison. The guiding principles of the movement have been devised by listening to their users and are updated as the movement evolves. They actively encourage interactions across different backgrounds, and giving purpose to people who are struggling.

As a “camerado” is defined as “halfway between a stranger and a friend”, these communities make the most of our tendency to be able to share more freely with strangers, especially if we know they will treat us with kindness and respect, than with people we know. The person visiting the space is also in control of how much they share and to whom.

People who use Public Living Rooms do so on a regular, often weekly, basis. This gives them a ritual or pattern, which means they have a port-of-call when unexpected challenges arise. But, importantly, it is not a ritual to which they have to conform because of external pressure, but one which they set up and follow themselves.

Also, because Public Living Rooms are rooted in the belief that when we look out for others we are taken out of our own problems and given a strong purpose and a connection, they allow people to easily transition between the roles of supporter and supported, helping them realise their potential for positive change and their value to others.



ABandOfBrothers



ABandofBrothers exists to transform the lives of young men who have become entangled in the criminal justice system and had multiple Adverse Childhood Experiences. They do this by bringing young men and trained adult role models together for an intensive rite-of-passage programme (a 2-day residential) coupled with an accredited mentoring curriculum. This provides them with the foundation of a lasting community and a wider network of support. After the programme, they are able to attend a local circle, held every week, whenever they wish.

ABandofBrothers encourages young men to develop an appreciation for nature and humanity and channel their search for identity, meaning and purpose into their local communities.

The programme has an incredible impact on reducing re-offending among those they support. After the programme, there is an increase in the number in employment, education or training by 73%. 81% of participants show an improvement in levels of self-esteem and self-worth and the proportion of young men with severe addiction issues fell from 51% to 14%.

By incorporating a two-day residential programme, ABandofBrothers meets a need expressed in one of our user interviews: the chance to get away from normal life to better reflect upon it. The programme is built upon the recognition that rituals are important in structuring both our personal lives and our communities and that transformation requires long-term support rather than quick fixes.



Let's Talk About Loss



Let's Talk About Loss run peer-led meet-up groups in cities across the UK for young people aged 18 to 35 who have been bereaved at any stage.

They also host a Bereavement Book Club and a pen pal project called Share My Grief, where people are paired up with someone of a similar age, location or bereavement experience (they choose which criteria matters most to them).

People can also share their stories online and in 2019, young people were invited to submit creative submissions about their experiences and reflections on grief for an exhibition called When Words Hurt.

Let's Talk About Loss therefore provides regular support and a space to share with people with a similar experience, but also the option to access a one-to-one befriending service for those who don't like larger groups. Projects like their When Words Hurt exhibition give young people a creative means to express their emotions, and the opportunity to have their experiences seen and affirmed.





The Grief Network



Describing themselves as possibly “the shittiest network in the world”, the Grief Network is a community for bereaved young people, based in London. They host events with notable speakers, authors and creatives, and monthly meet-ups to “share our stories of love, loss and everything in between in an informal, no-pressure environment - usually over a drink or two.”

Their content on social media is well-designed, relatable and unflinchingly honest, referring to themselves as “grief grinchies” and hosting a Christmas gathering called “the shitmas party”. This approach is likely to appeal to young people as we heard time and again that what they most wanted from a community was a space to be honest, especially when they felt the older adults around them were being hypocritical or trying to make the complexity of grief too straightforward.



Conclusion

What we want to dream into being.

We dream of a world where young people who experience grief can easily find supportive communities that help them transform their pain into creativity and compassion. There are so many inspiring, creative initiatives that are helping people in their 20s and 30s navigate their grief. But as this report has shown, there is still a huge gap and sadly a growing need for projects which seek to build effective community specifically for bereaved young people

Many organisations feel young people can be 'harder to engage'. Another way of saying this is that 'engaging young people requires extra creativity'. There is so much potential for organisations out there to get creative in how they design communities to guide people through these difficult life events. And we have found that the young people we have worked with are very open to helping co-design these communities. In the brilliant Netflix series - I'm Not Okay With This - about grief and other things, anti-hero Sydney says: "I guess I have to make a choice: Either I lock myself away from the world and just disappear and let this stuff just destroy me, or I could make pancakes instead." Let's make pancakes.

For any questions about this report please contact us at hello@apartofme.app

Appendix

Stages of Co-Production

For those interested in co-designing and co-producing initiatives, the process we went through to research, design and prototype our community project may prove a helpful starting point.

1: RESEARCH AND ENGAGEMENT

- We did academic research into young people, grief and communities
- We held in-depth user interviews with four young adults, aged between 17 and 25, and five interviews with experts
- We conducted a survey of 131 young people based in the UK, Germany and Spain, looking at their experiences and perceptions of grief and the communities to which they belonged
- We did a horizon scan of inspiring case studies from around the world

2: BUILD A DESIGN TEAM

- We gathered together a team of young people, designers, therapists and a community manager to design and develop solutions

3: CO-DESIGN

- We ran 3 co-design workshops with young people who had experienced bereavement.
- We used user stories and inspirational case studies to come up with new ideas together.
- We split the larger group into three teams to further develop the best ideas.
- We held a pitch event where the teams presented their proposals we chose our favorite one to take forward.

4: PROTOTYPE

- We developed two light touch prototypes of our idea to test with a small group.
- The first was a WhatsApp challenge with bereaved young people to encourage them to build meaningful connections in the 'real world'.
- The second was a social media challenge, called Islands Apart, developed in response to the Coronavirus pandemic with the help of a game designer. The scope of this challenge was broader than that of the first prototype as it was intended to help young people during the lockdown to take care of their mental health while staying connected to others.
- We evaluated the success and learnings from both prototypes, which we will take forward in the future.

5: IMPLEMENTATION

- We are currently incorporating our prototyped solutions into our service, and into useable tools for other organisations to use

Thank you

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