



# Dr Shelley Gilbert MBE

Insights into the  
emotional and  
psychological  
experiences of  
prematurely bereaved  
children and young  
people



# The Blue Satin Dress

Conspiracy of silence

Dance of complicity

See TEDx Talk Warwick

1 in 29 children under 16 will suffer the death of a parent in the UK. (CBN, 2014).

# Research

**Scarcity of qualitative and quantitative research around bereaved children & young people, most of which was conducted in the USA.**

**This has left bereaved children's position increasingly precarious. (Rolls,2008)**

# Why my research has been highlighted

- It researched an under-researched area
- It bridges research and practice at Doctoral level
- It is original work, where I was brave enough to challenge previously held theories and convictions

bacp

WILEY

New researcher of the year 2016/17

# Sample of the research influencers

- **Bowlby**
- **Winnicott**
- **Yalom** USA-highlighted existential issues for children facing death.
- **Worden (1996)** USA-highlighted fear and anxiety and also that symptoms may not be revealed for a year.
- **Silverman (2000)** USA-part of Harvard Study and highlighting children's issues
- **Tracey (2011)** conducted grounded theory research with motherless adults, which highlighted pervading loss of mother young which shattered childhoods.
- **Keenan (2014)** case study research-highlighted internal processes/identity loss.
- **Rolls (2014)** highlighting importance of rituals
- **Li (2014)** those bereaved young are likely to die young themselves.
- **Christ, G (2006)** be at risk of adverse psychosocial consequences
- **Fauth et al. (2009)** analysed ONS data of 5-15yr olds in UK found bereaved children more likely than other children to be diagnosed with a mental disorder.
- **Atherman and Statham (2014)** early parental death is the cause of a wide range of mental health problems
- **Penny & Stubbs (2014)** Helpful in the sense of encouraging that there is growth in the subject; growing research in to the efficacy of services in UK/USA.

**What had not been done was the lived experience of young people.**

- Abbreviated in the interests of brevity and time. For more detail, please contact the researcher Dr Gilbert shelley@griefencounter.org.uk

# Method & Methodology

- Charmaz's (2006) constructivist version of Grounded Theory
- The methodological framework of this study was Charmaz's (2006) constructivist version of Grounded Theory, based on the epistemological stance that would capture the essence of being, yet allow for the researcher's immersion and interaction with the data whilst retaining objectivity but recognizing that the researcher can never be totally objective.

# Data Collection

Purposeful sampling (Morse, 2007) was used in a comprehensive mixed gender North London secondary school, with an ethnically diverse population.

Seven girls and four boys 11 to 16 years old, of mixed race (principally white, African, Indian and Malaysian backgrounds) were identified by the school. They were interviewed using an hour-long, semi-structured questionnaire, CORE-YP (which included a question regarding self-harm, for a final safety check) and a creative tool (Feelings Figure).

All interviews were face to face, in English, digitally recorded, transcribed verbatim and stored as password protected word documents to make them easily accessible for coding, scrutiny and available for validity checks. A focus group with the participants to consider the results (recorded and transcribed) resulted in a wholehearted consensus, witnessed by the school representative, that this had articulated their lived experiences as told in the interviews.

**Abbreviated in the interests of brevity and time. For more detail, please contact the researcher [Dr Gilbert shelley@griefencounter.org.uk](mailto:DrGilbertshelley@griefencounter.org.uk)**

# Ethical considerations

Well-being of young person was primary:

- Recruitment
- Safe space
- Confidentiality
- Informed consent
- Right to withdraw
- Safeguarding procedures in place
- Information sheets
- Support offered at start and end

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# Data Analysis

**Data was analysed thematically, based on appropriate use of grounded theory procedures.**

The transcripts were analysed thematically, based on appropriate use of grounded theory procedures. Data was *in vivo* coded line by line, in order to stay close to the text and preserve participants' meaning to create "a frame" Charmaz (2006: 45). The data was then sorted by comparing code with code and code with category discerning some general themes. Second-level coding elicited the provisional headings for the subordinate themes and superordinate themes. The information was collated as purported by Orona (1997), such as the use of memos to begin the conceptualisation, using a processing method of introspection, intuition, rumination and analysis over a period of a year. Intervening conditions were identified using Strauss and Corbin's (1990) general paradigm model eliciting actions, strategies and consequences. Diagrams helped to show the process, the lines of action and integrate the concepts (Orona, 1997). The literature reviews and theoretical frameworks were updated, a final validity check carried out, and all work and findings were written up in the final thesis.

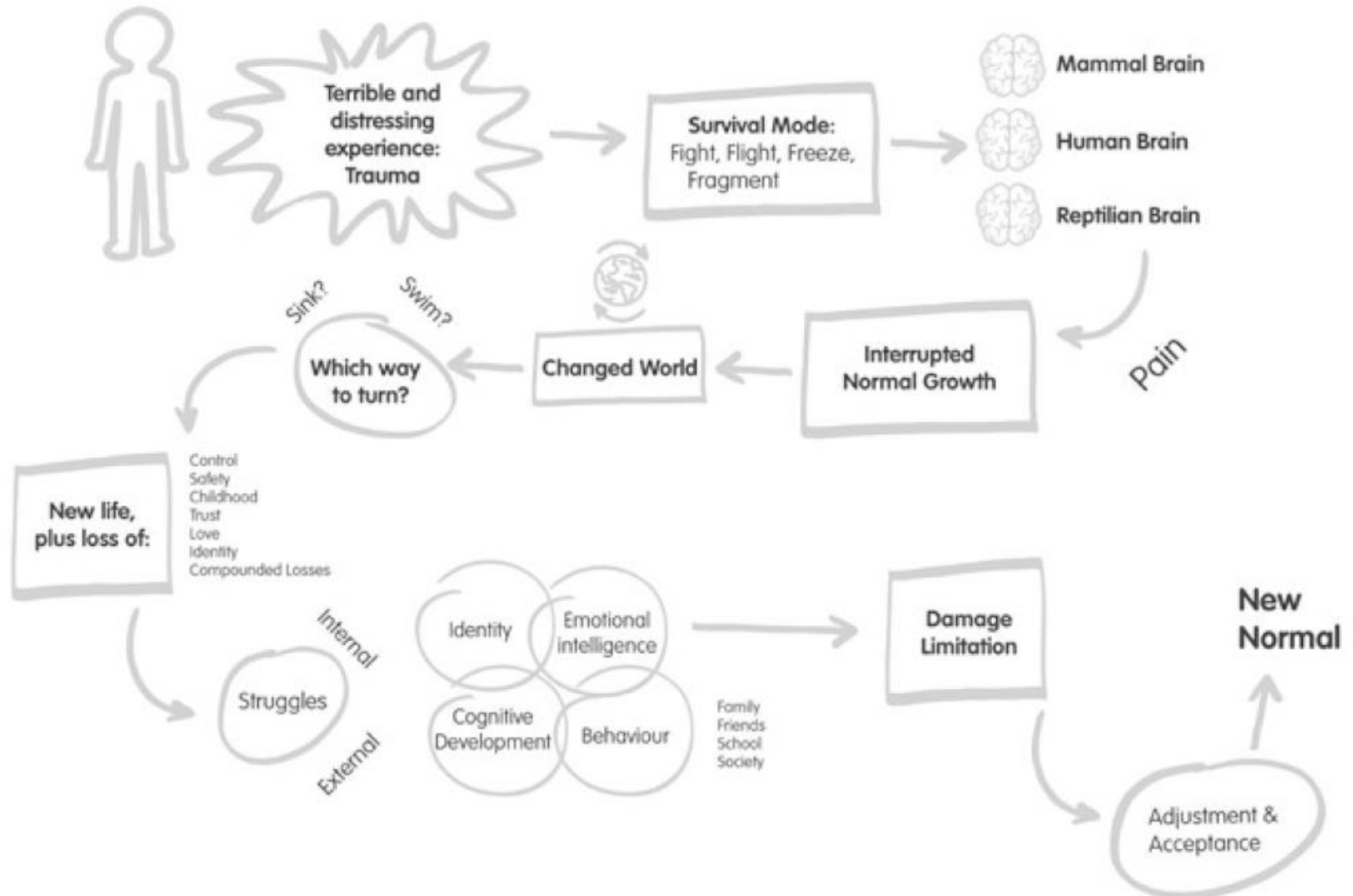
# Collaboration

- Academic Consultant
  - Consultant Group
  - Academic Adviser
  - School
  - Childhood Bereavement Network
- 
- As a practitioner-researcher, steps were taken throughout the research to limit any bias as far as possible. Validity and bias was addressed by the formation of a consultant group of three researchers, removing institutional bias, reflexive use of supervision with my Academic Adviser at Metanoia and an Academic Consultant, a reflexive journal and Metanoia study groups.

# Research questions

- What were the actions and strategies used by the participants to make sense of the bereavement?
- What were the intervening conditions that influenced the participant?
- What were the consequences of these actions and strategies?
- What were the implications for supporting the bereaved?
- What was the emotional and psychological impact of the death on the participants' lives?

# Grief's trajectory



# Findings

- Twelve themes were identified and organised under five primary superordinate themes.

*Losses; Disrupted identities; Struggling to make sense of grief; Role of others; and Finding a new kind of normal.*

- *Time* and *Ambivalence* were positioned as overarching themes, as they overlapped and intertwined, as with the warp and weft of a carpet.

# Research highlighted four key focus areas

**Identity**

**Extreme fear and safety**

**Isolation**

**Existential challenges**



**New understandings identified by research**

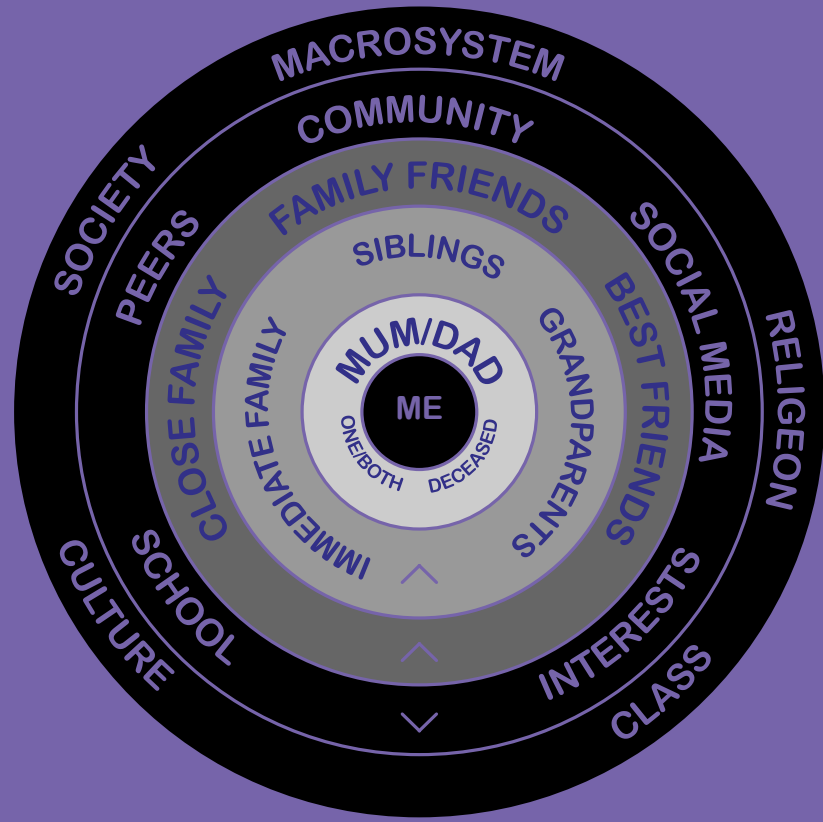
# Disrupted Identity

My ecological environment system

Following my parent's premature death,  
how have I changed internally?

How does that impact my environment?

And how does the changed environment  
impact me?



**ME:**

MY IDENTITY

MY FEELINGS

MY DEFENCES

The death of a significant other changes how a  
young person sees themselves fitting into their world

# Managing the trauma

Freeze

Flight

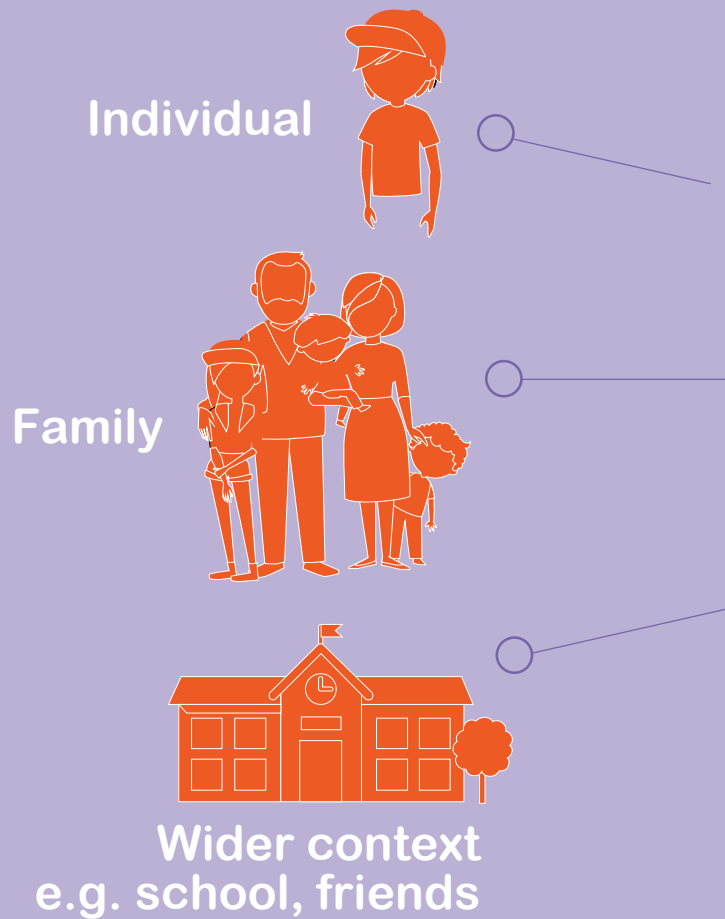
Fight

Fragment

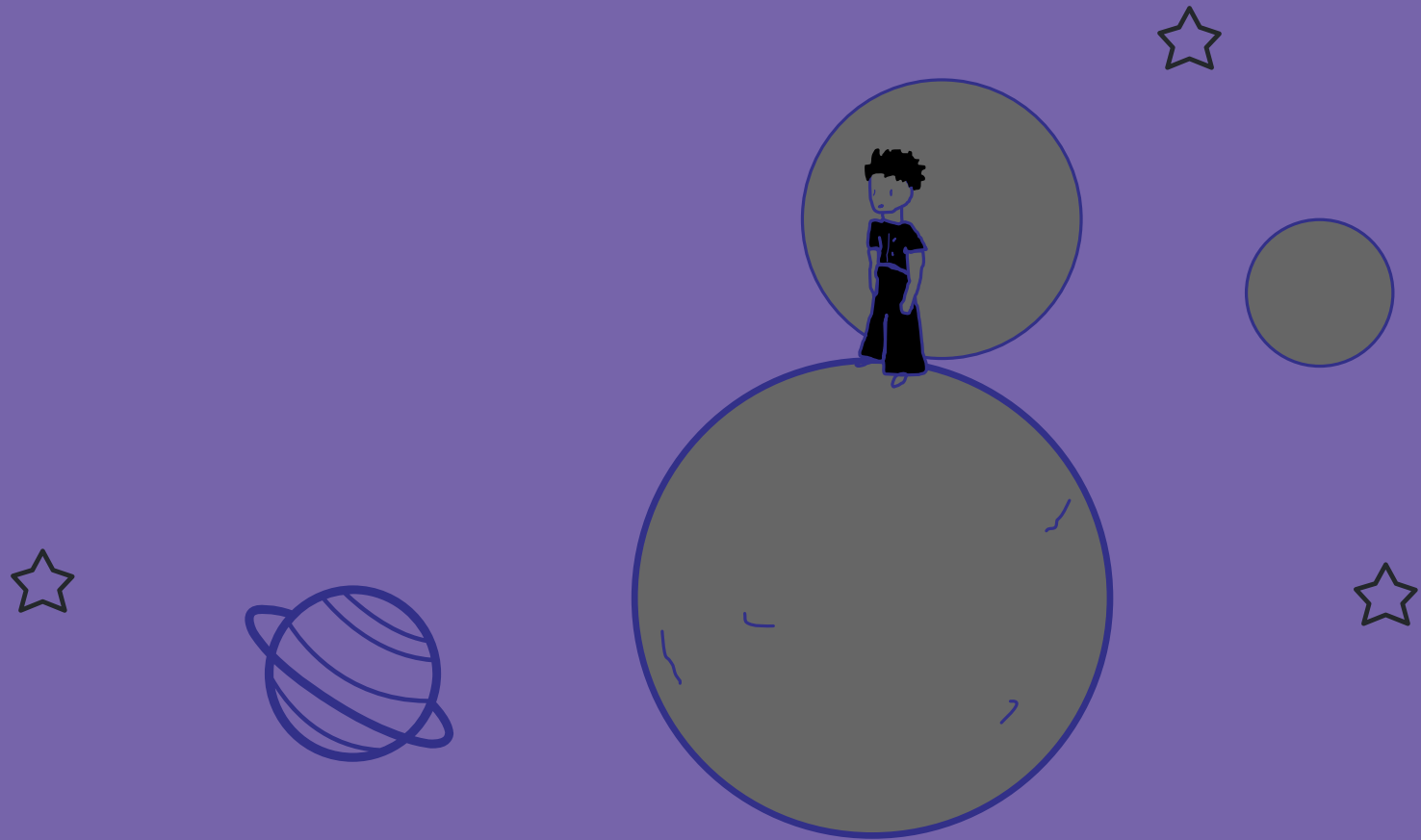
Flock







**Role of others; Struggles to make sense of grief and resultant isolation.**



Existential challenges: Experiencing premature death takes someone into a completely new world, challenging previously held paradigms, values and knowledge

# Focus areas for support identified by study

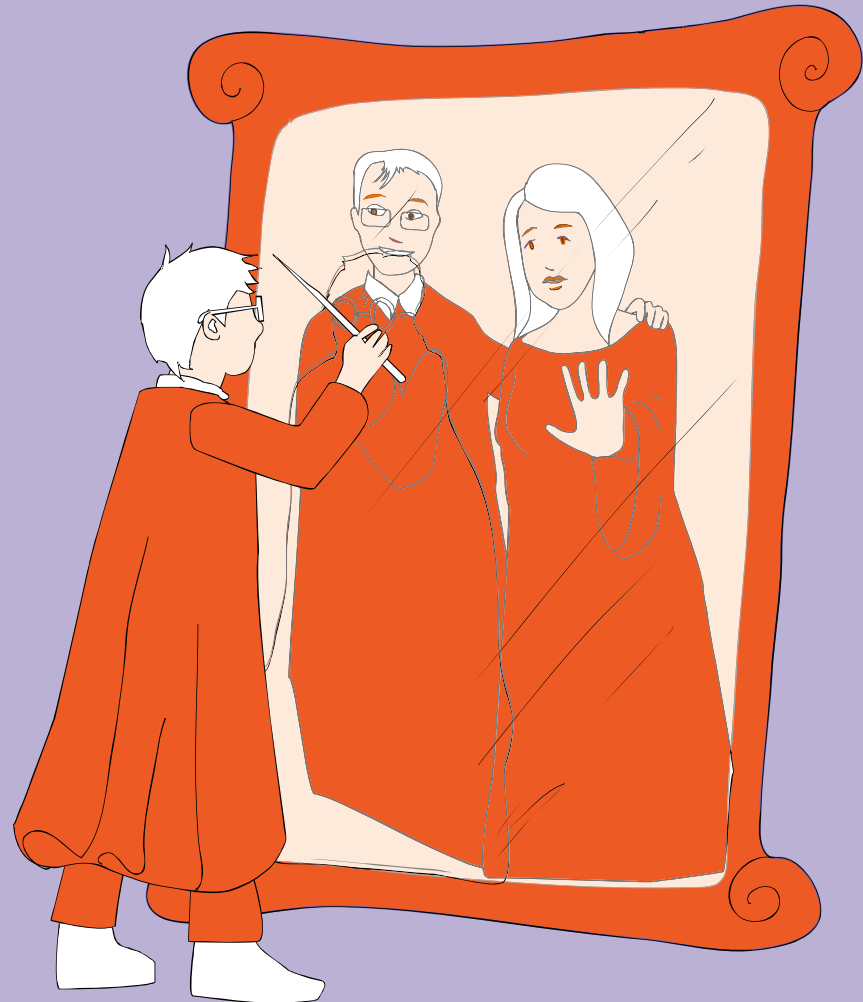
Quality support  
for the bereaved: public  
v private

Rituals and  
memory making: past,  
present and future

Change the language of  
grief & use death word

Different measures & a  
new Model of Grief

Gone Forever

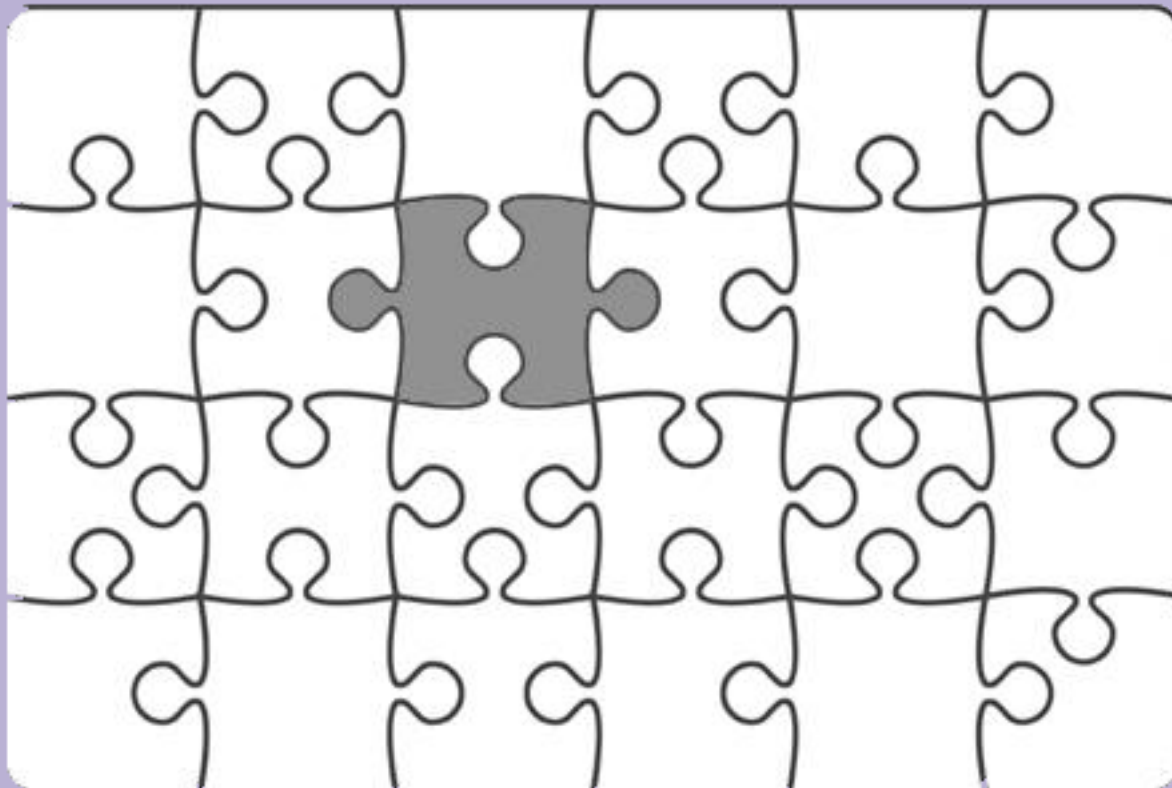


# Limitations

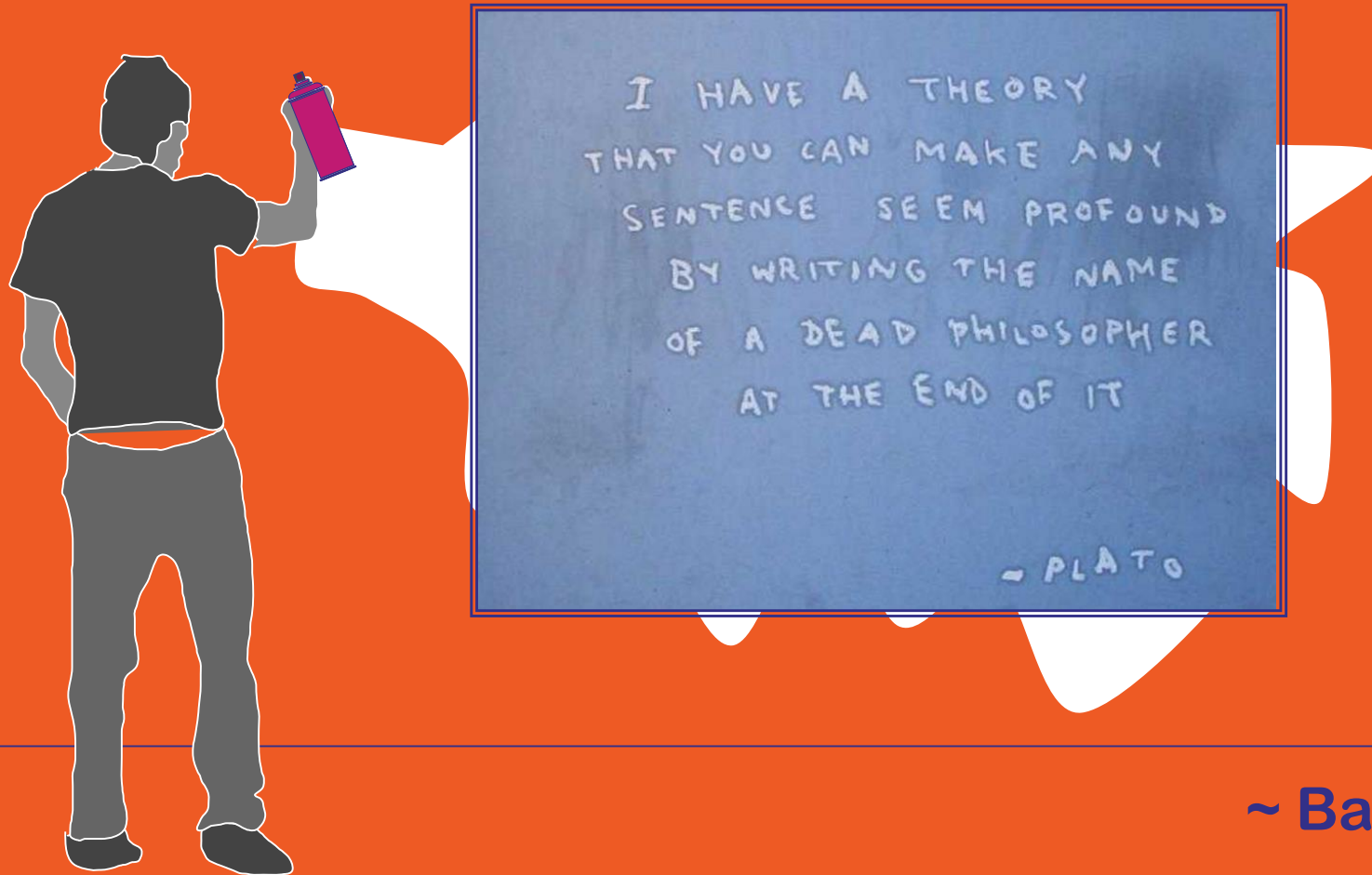
- Qualitative not quantitative
- Small scale
- Individually focused: not directly focused on the wider contexts of the family such as their financial, class, cultural or religious status and beliefs
- Interviews were not a naturally occurring situation
- The process of analysis: Stuck close to the participants words. Theme headings may not have conveyed deeper content or unconscious motivations
- Inherent bias

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# Bridging Research and Practice



# The Upward Spiral of Grief Model



~ Banksy

## grief's journey: a spiral of grief

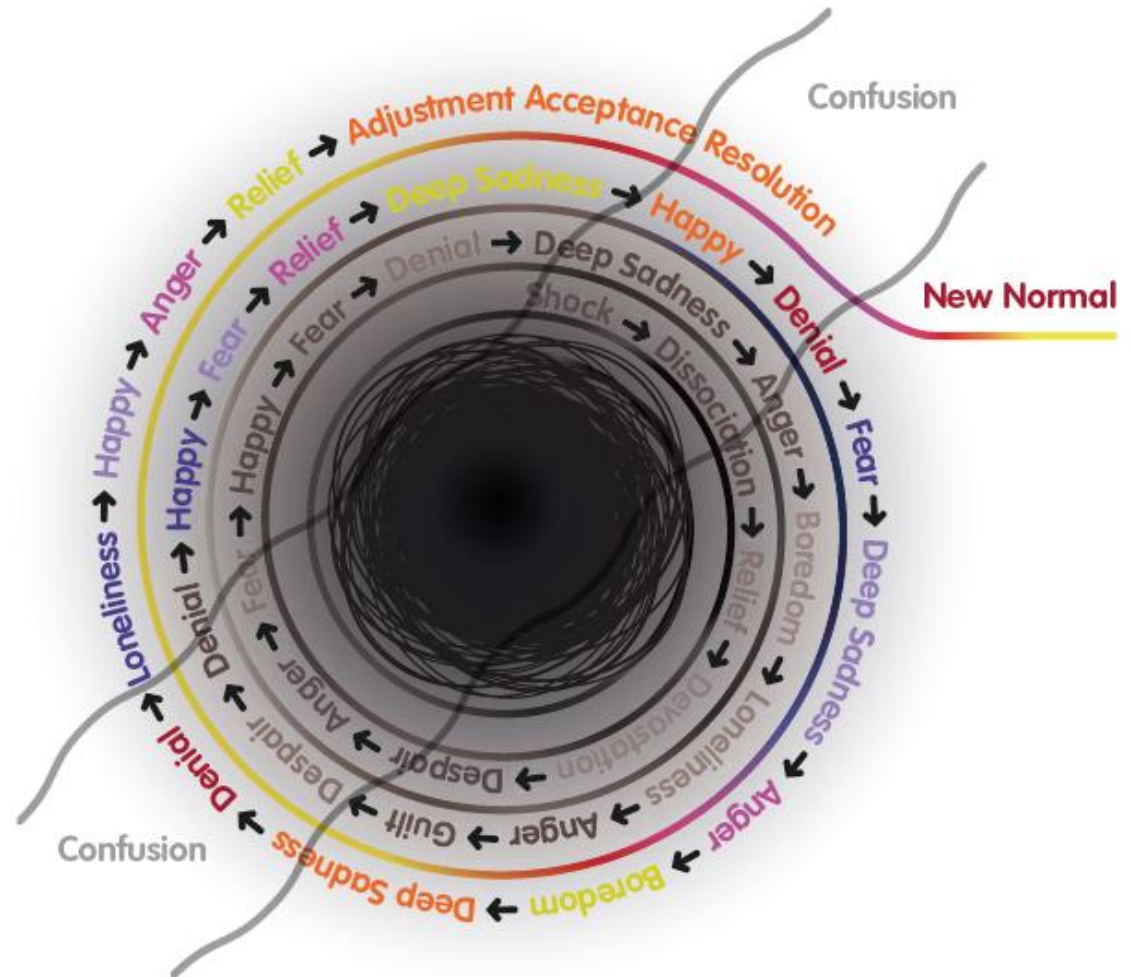
We like the picture of a spiral, which shows moving around the spiral to the next part of your different life, your new normal. Feelings and thoughts are still there, just less intense and painful over time.

Grieving is not over in a day,  
week or month.

People, including children,  
need permission  
to grieve in their own way.

We like the word Adjustment rather than just Acceptance.

**Our warning signs  
are STUCKNESS  
OR EXTREMES.**





## **grief's journey: a spiral of grief**

## Phase I of the journey

Children and young people tell us about feeling traumatised after someone special dies. Traumatized is like being shocked, feeling numb, running away, fighting, falling apart, even trying to pretend nothing much has happened. This is the black hole in the middle.

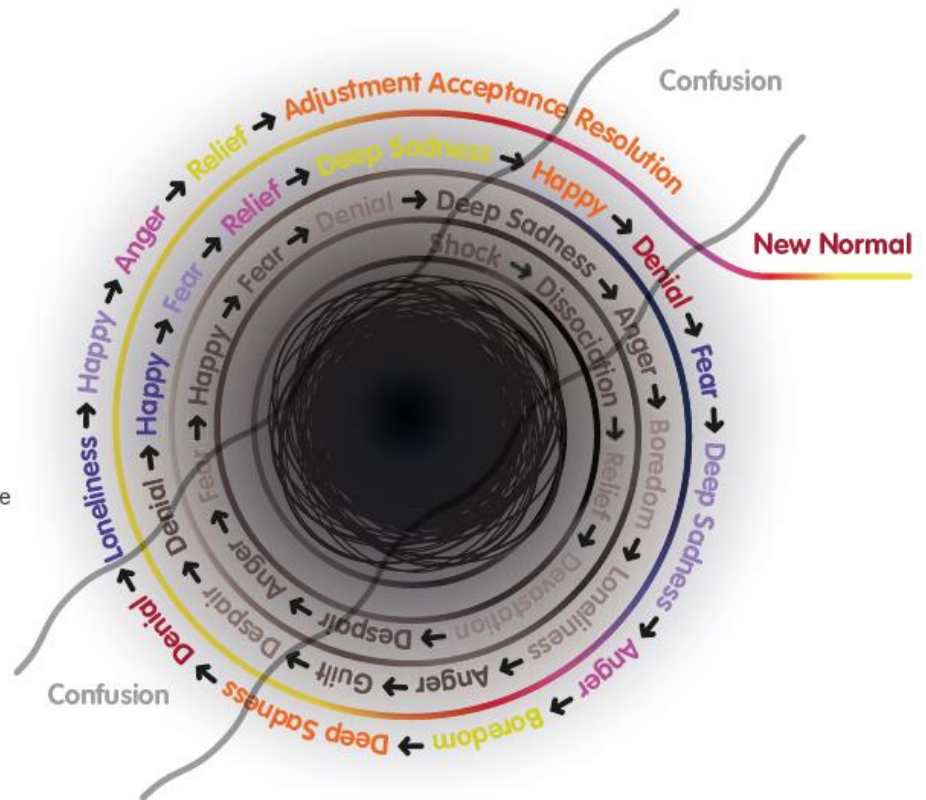
## Phase 2 of the journey

Bereaved kids and young people are often still left feeling constantly in **DANGER**, hyper-vigilant, hyper-aroused, on the edge, unsafe, cut off/zoned out....

It's usually later on when you can really think about and **feel** your feelings. You may feel all these feelings in one day, they come back like waves, they may be intense or not. It's **VERY CONFUSING** and **hard** to explain.

Use the spiral picture to show where you are (then & now).

All is OK, as long as you are not **stuck** or feel you're going backwards.





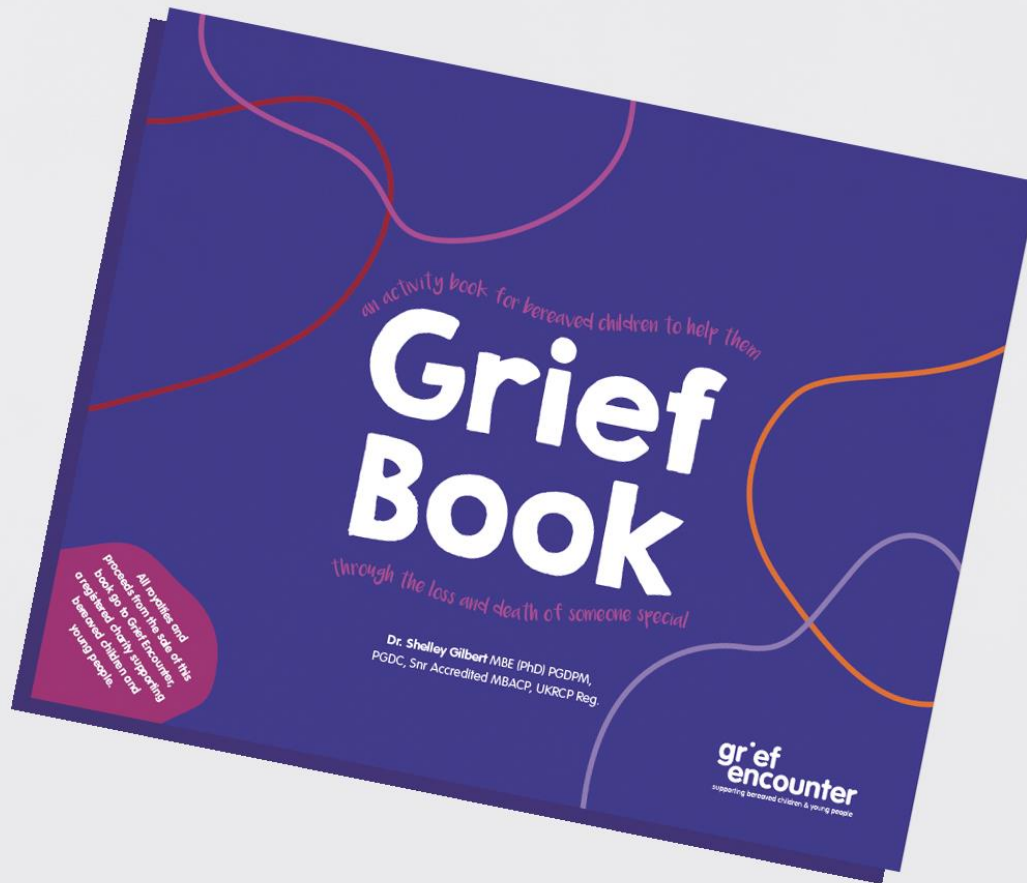
# Implications for psychotherapeutic practice

managing the trauma  
use of support tools  
changing paradigms

# Implications for further research

- **10 Reasons Why :** 10 further research papers, with a collaboration with Anna Freud Centre which continue to address issues associated with grief and trauma.
- Currently, we are researching the impact of counsellors working therapeutically online with grief
- **Further research opportunities**
  - to substantiate the findings from this study could be conducted on a larger scale, as with Brent et al.'s research (2012) with more focus on diversity such as race, sex, socioeconomic condition and environment.
  - A focus on the cultural and religious aspects of bereavement would address one of the limitations of this study.
  - The use of social media, which was barely mentioned in these studies is an essential area.
  - Following the success of the use of creative tools (i.e. the feelings figure in this study) to access the young person's emotional and psychological world or the film used in Chown's (2008) study, using expressive arts therapy for research purposes may elicit deeper understandings whilst engaging participants therapeutically (Thompson and Berger, 2011).

# Griefbook



# Feelings figures

Everyone has different feelings;  
we often feel them in our body. Colour on the  
feelings figure where your feelings may be.

## Some Feelings

Happy  
Sad  
Angry  
Afraid  
Confused  
Worried  
Frustrated  
Ashamed

## Some Colours

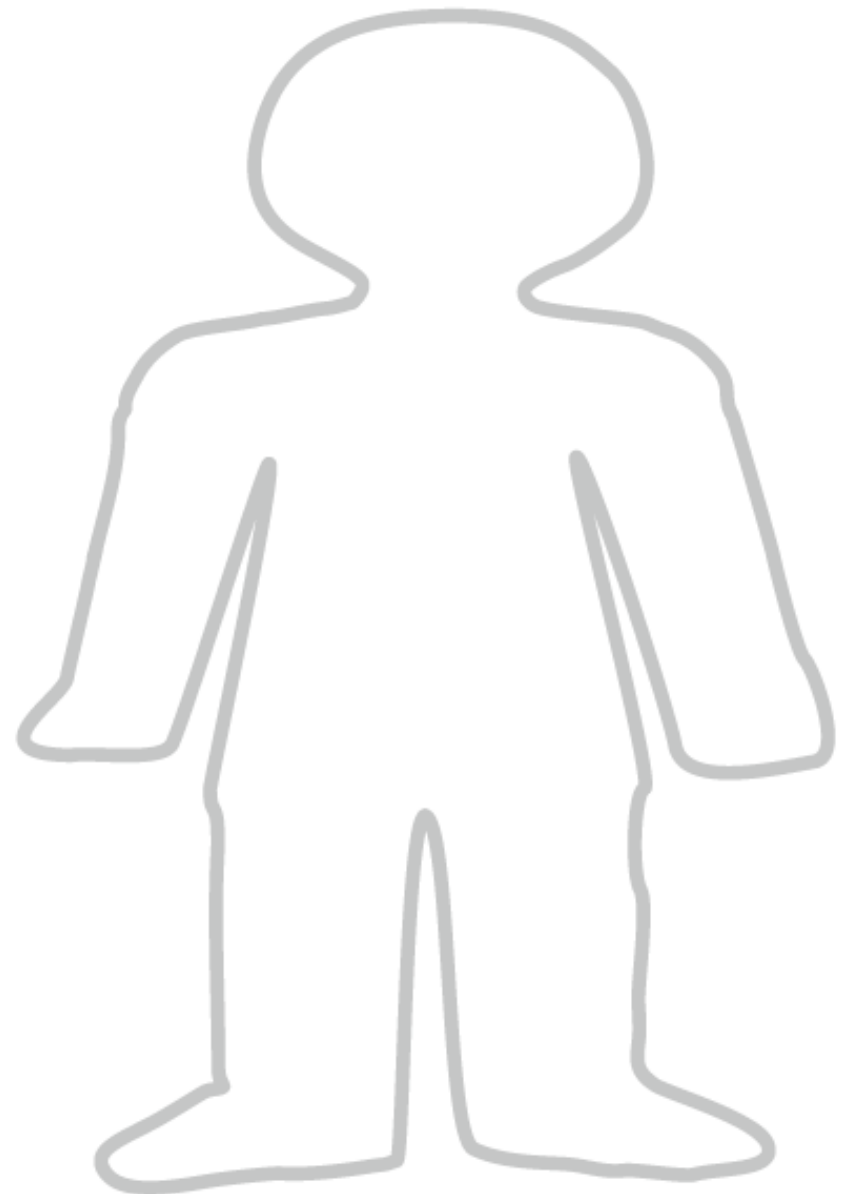
Yellow  
Blue  
Red  
Black  
Green  
Pink  
Purple  
Orange

## ...More Feelings

.....  
.....  
.....  
.....  
.....

## ...More Colours

.....  
.....  
.....  
.....  
.....



## about you

My name and how I got my name

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Age

---

Haircolour

---

Eye colour

---

Height

---

Weight

---

Any illnesses

---

Best TV programme

---

Best film

---

Favourite sports

---

Favourite colour

---

Best day out ever

---

Best school subject

---

Favourite foods

---

Best music

---

Favourite country

---

Favourite animal

---

Best present ever

---

## about your special person who has died

Date of birth

Date of death

---

Their name and your relationship

---

Age

---

Haircolour

---

Eye colour

---

Height

---

Weight

---

Any illnesses

---

Best TV programme

---

Best film

---

Favourite sports

---

Favourite colour

---

Best day out ever

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Best school subject

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Best music

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Favourite animal

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Best present ever

---

# **grief postcards**

It's often hard to answer when people ask how you are.  
And, often people stop asking. Tick the boxes that apply  
to you and give these out to parent/carer, teacher, friends.

## **Things I can't tell you but want you to know**

- ☐ Please talk to me about the person that has died. I need to talk about them over and over (in the right place at the right time).
- ☐ I dip in and out of my grief – every day can be different.
- ☐ It's not all doom and gloom – a good laugh can really help.
- ☐ You won't upset me more if you make me cry; I'm already upset inside.
- ☐ My whole world has been blown apart and I don't feel safe anymore.
- ☐ I am not just going to 'get better' – this isn't a cold or flu.
- ☐ My world is painful and if you don't approach me I will feel even more lonely.
- ☐ I need help from a professional to make sense of the senseless.
- ☐ I need to hear the facts as they are.
- ☐ Please help me find a group of other people that have also lost someone.
- ☐ I am not necessarily brave or strong. I've just found a place to hide my thoughts and feelings... Or the feelings come out in a different way.
- ☐ I am a different person now – love me for who I am and please don't tell me the right and wrong things to do, just encourage me (but still tell me if I'm wrong!!)
- ☐ If I look OK outside, look through my eyes; it doesn't mean I'm alright inside.
- ☐ I won't be over this in a day, or a week or a month.
- ☐ I'm getting used to all the changes; stay on the journey with me.
- ☐ If you are worried about what to say or do, just say that you're worried too. Listening without judging is a great help.
- ☐ I just don't know what I need just now... Probably just to know that people genuinely care and remember.
- ☐ Understand how painful it is to hear the word MUM / DAD / SISTER / BROTHER – please don't stop using it though.
- ☐ Look out for me and make me feel special.
- ☐ I will find a way forward, I just need patience and help.

Thank you for taking the time to read this and trying to help me.

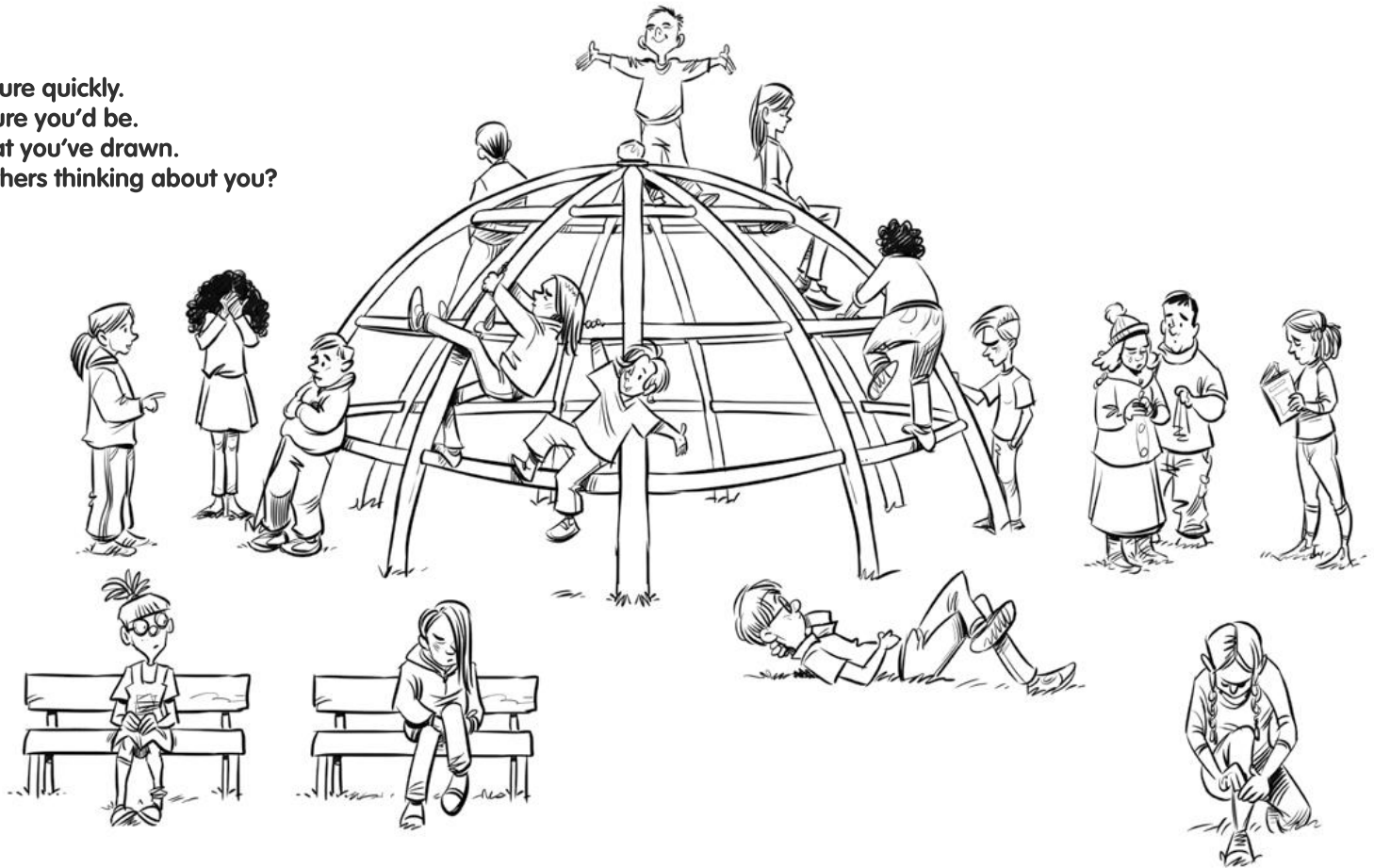
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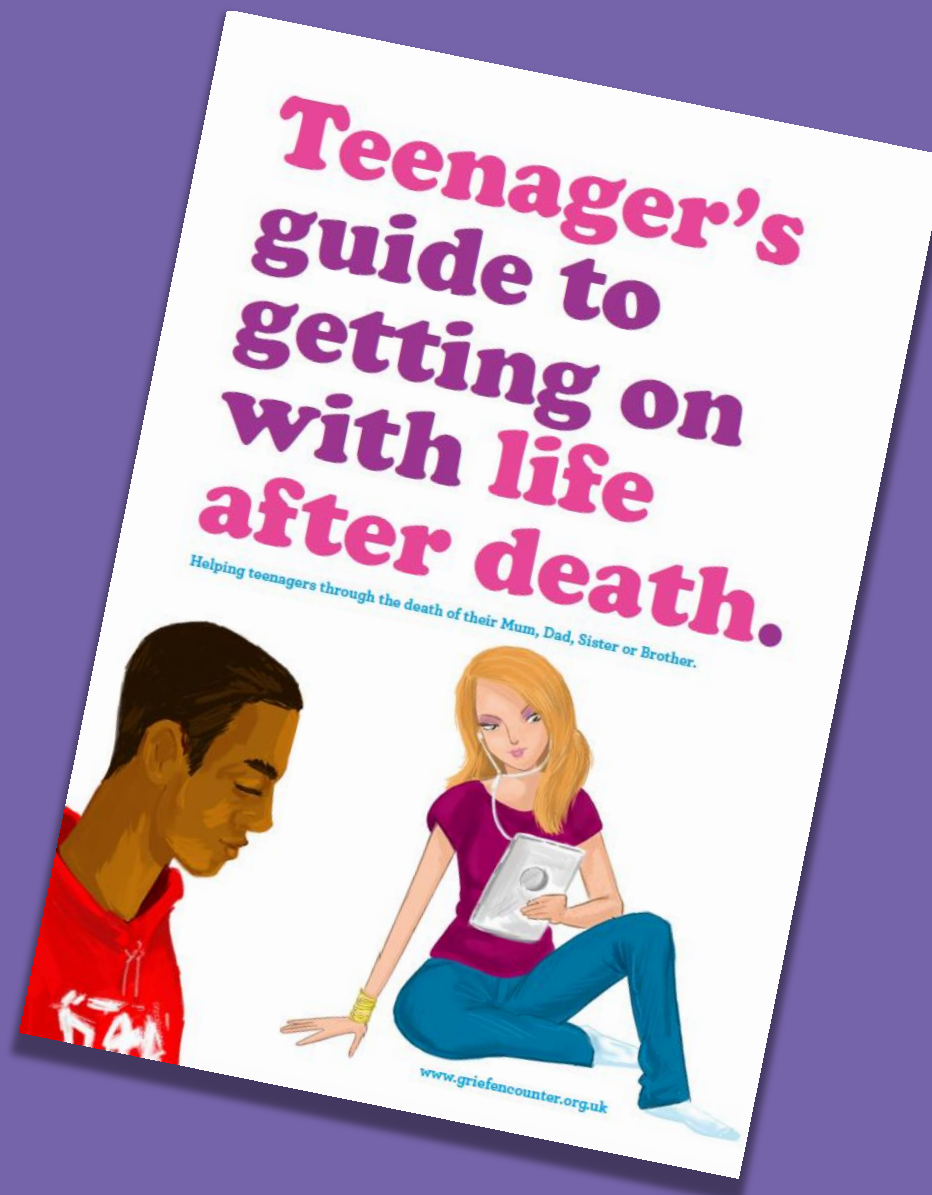
Thank you for taking the time to read this and trying to help me.

# where are you?

Look at this picture quickly.  
Mark which figure you'd be.  
Chat about what you've drawn.  
What are the others thinking about you?



# Teen Guide





# confused. com

"I don't know. I was confused. I didn't really know what to do like. I was just like, I wasn't too sure about anything back then."

Andrew

gone forever and not coming back is pretty hard to cope with. Lots of young people tell us they have regrets that they argued or didn't love their parent enough. "I wanted to do things over, but it was too late." Andrew, age 11, when his Dad died. Hey ho, its not late...

Vicky  
"I was confused like everything in my head felt confused... I didn't know where I was because I was so tired."

"Just like the whys and ifs and all the questions you can ask. It's so confusing."

Pippa, 11 when Dad died.

# Inside hurts



"Just like the whys and ifs and all the questions you can ask. It's so confusing."

Pippa, 11 when Dad died.

"I felt sad in my heart because I... I'd lost my dad but I didn't show it in my face."

Melinda, 11 when her Dad died.

It can be hard to trust others when the world feels unsafe. It may feel easier to pretend, hide the hurts and keep it all inside. Adults often don't know how to help with the pain and often you don't know either. You may be playing the "mutual pretence" game of 'I'm alright', so not to upset those around you.

**Meeting bereaved others may help.**

"I don't want everyone's sympathy, pity, bring an end down or the sorry but I do want to be understood."

Penny, 12 when Dad died.



# Forever

*Memories*

"I don't want to let anyone else take his place."  
Pippa, 11 when Dad died.



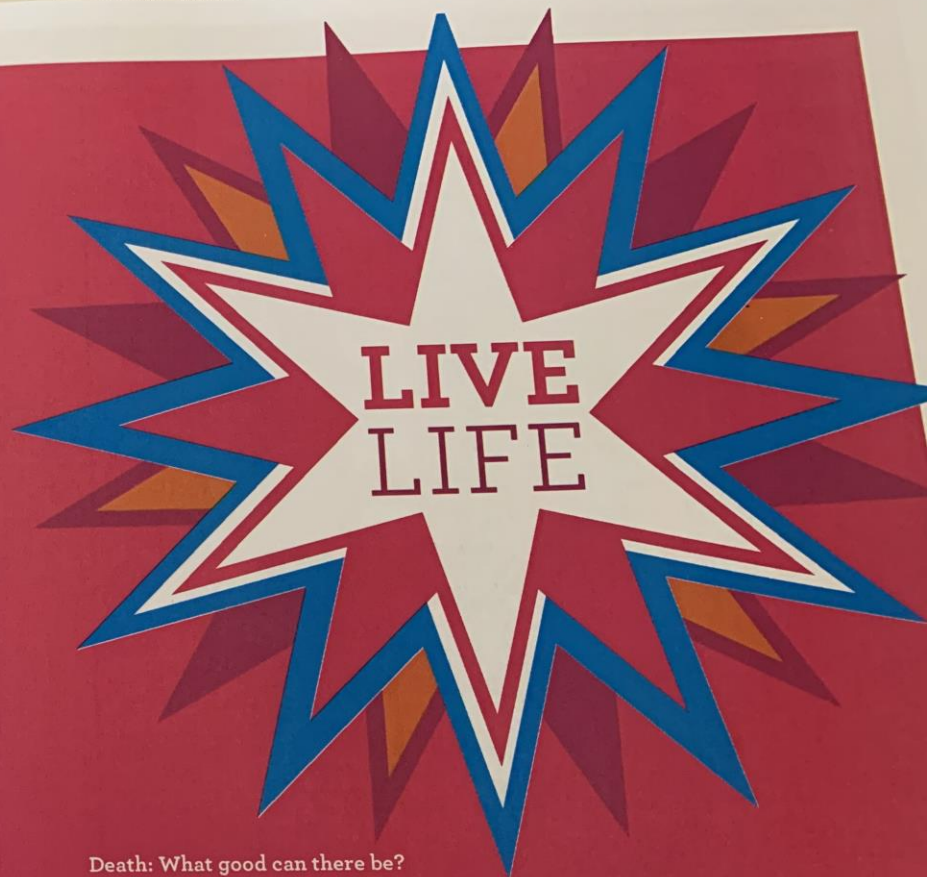
Tell us about your ideas on the website.

[griefencounter.org.uk](http://griefencounter.org.uk)

The gone forever and not coming back is pretty hard to cope with. Lots of young people tell us they have regrets that they argued or didn't love their parent enough. "I wanted to do things over, but it was too late." Andrew, 11 when Dad died.

There are big empty spaces to fill. Somehow or other, you need a new space for the dead person. And, to keep remembering them as they were and what they mean to you now. Finding somewhere to "put" the memories so you can be comfortable thinking about them. For example, making a Mum/Dad/Sister/Brother journal, Facebook Timeline, a Tribute Site or Remembrance Days. Forever.

At Grief Encounter, we help people to keep remembering not to forget. For instance, making journals, memory boxes, Facebook timelines, remembrance times and days... and our new "Name a Star" in memory: [nameastar.org.uk](http://nameastar.org.uk)



## Death: What good can there be?

As bereaved people, the worst has happened so we know we can survive anything. This experience will have made us more understanding of other's pain and maybe more able to help others. Maybe, we know now we only have one life-its not a rehearsal - so we have to go out and LIVE life-make it meaningful and enjoy!

"Death makes you realise what's important in life."

Belinda

"You can't change the past but you can change the future."

Melinda, Dad died when she was 11.

"If you suffer something like this, you'll become stronger."

Vicky, 10 when Dad died.

# Relationships



Trusting the right people is difficult now. You may look to the wrong person for the love you have lost.

Many teens now find close relationships more difficult to manage. You may look to the wrong person for the love that you have lost or cling to the wrong person as you are scared to trust any one new. If your parent has died and if Dad was the one who told you that you looked pretty or Mum the one who helped you choose your clothes, then who can you look to for trusted advice? Or, was Dad was the one giving 'parental guidance' on the way to play football? You may have laughed at him at the time but miss it now.

"I don't want no-one else to be there, I just want him."

Penny, 12 when her parent died.

# Lots of other losses too...



It's not only about the death of your parent/sibling, but also about losing loads of other things. Like losing family, money, friends who haven't been helpful, a happy home life...

Taking risks is harder as your experience of change is not great.

"It's lost me a lot of connection with my Dad's side of the family."

Melinda whose Dad died when she was 11.

# Good Grief Training

## Good Grief Training

Middlesex University Accredited Training  
starting in September 2021



**Middlesex  
University**

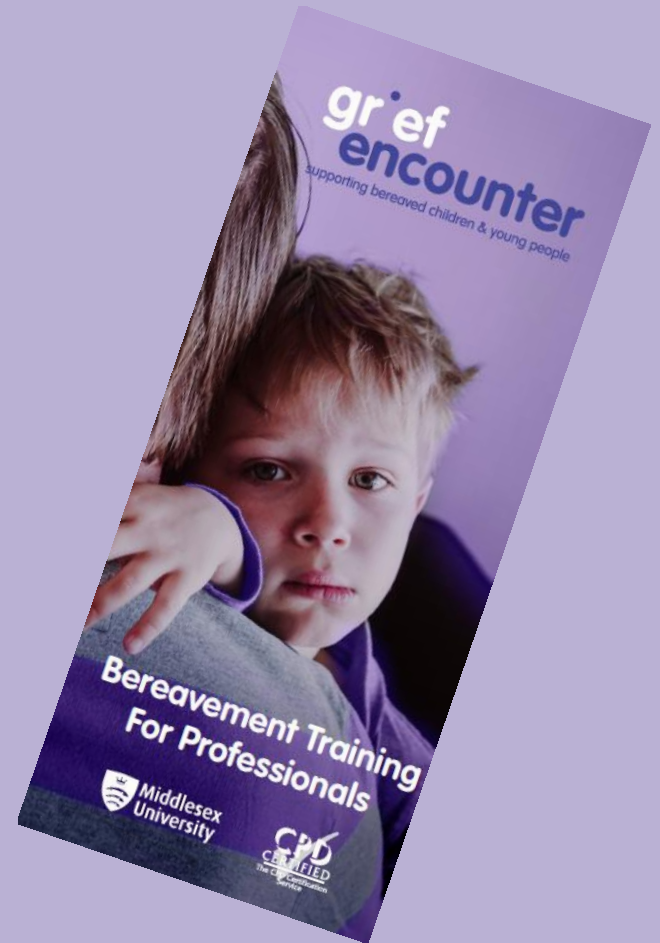
**Others:**

**Education/schools Services**

**Webinar Online Training Courses**

**Bespoke Training**

**Consultancy Training**





# To the palace



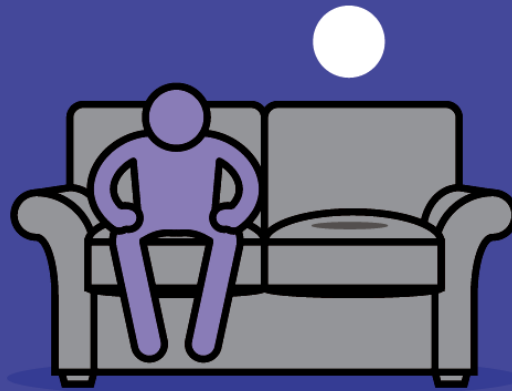
# Products: support tools



# gr'ef encounter

supporting bereaved children & young people

**we are  
here to listen**



**gr'eftalk helpline  
0808 802 0111**

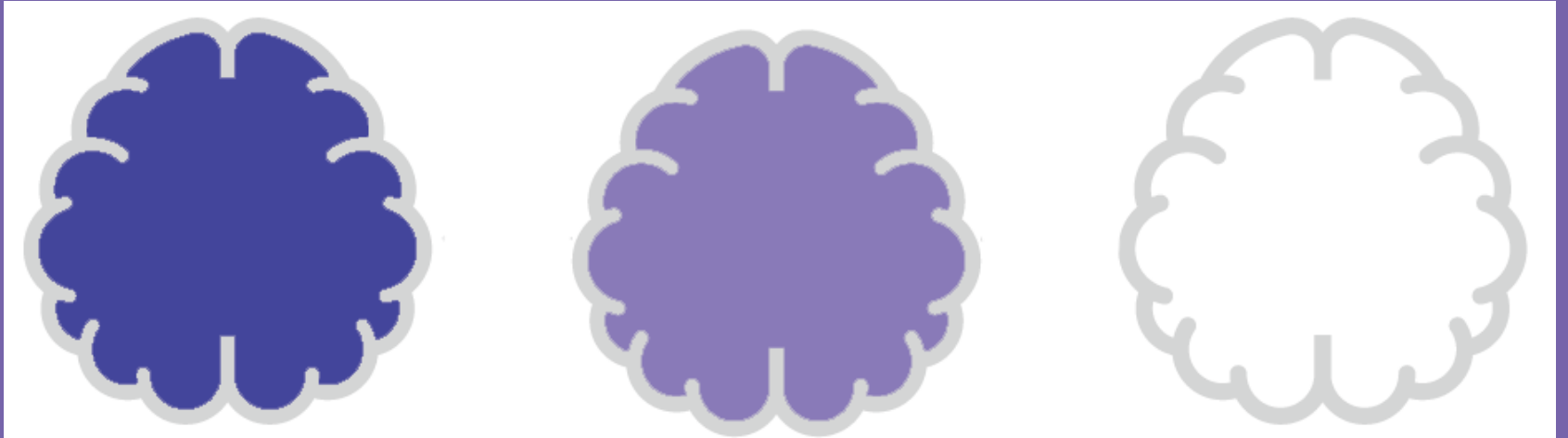
Grieve Forever

Love Forever

Love Life

Live Life





We need to put our circuitry right again: we are in charge of the trauma not the other way around.