

The grief we carry into adulthood

Alison Penny, Director, CBN

[@NHS_Education](#) [#NESBereavement2023](#) Annual Conference
'The Grief we Carry' 28 November 2023

What I will cover

- Evidence about the long-term impact of bereavement in childhood
- Examples of young people who have gone on to strive and thrive
- Evidence-based ideas about how can we reduce risks and promote resilience



Me and my dad

The grief we carry – our 'invisible suitcase'



<https://www.childbereavementuk.org/the-invisible-suitcase>

How many children are carrying grief?

- 62% of children in Scotland bereaved of a parent, sibling, grandparent or other close family by the age of 10
- Not evenly distributed – children in lowest income households at greater risk than those in highest income (Paul and Vaswani, 2020)
- Almost 5,000 children and young people under 18 bereaved of a parent each year (Childhood Bereavement Network, 2022)
- Many others bereaved of someone else important in their lives
- Still more seeing coverage of death and bereavement

Impact in childhood

- Risks to

- Physical health
- Mental health

Health warning

- ...
- ...
- ...
- ...
- ... about ability to effect change
- Pro-social behaviour

Ways of understanding risk over time

- Adverse Childhood Experiences (ACEs)
 - Should we consider bereavement an ACE? (Vaswani, 2017 <https://www.cycj.org.uk/an-ace-up-your-sleeve/>)
- Three models (Clarke et al., 1996)
 - 'Blunt trauma' model looking back from adults with difficulties
 - Shock/aftershock acknowledging the impact of a child's future development and further changes in the family
 - 'Cascade of events'
- Large population-based and cohort studies over time – particularly from Scandinavia

But what outcomes do we focus on?

- Young people themselves talk about bereavement as a turning point in their lives
- Other outcomes (Brewer & Sparkes, 2011)
 - Positive outlook
 - Gratitude
 - Appreciation of life
 - Living life to the full
 - Altruism
- Many examples of exceptional campaigners and public figures

Ellie Craig, MSYP

- Vice-Chair of the Scottish Youth Parliament, MSYP for Glasgow Cathcart
- 'Grieving and Growing' campaign launched Nov 22
- Training session for youth workers with YouthLink Scotland's No Knives, Better Lives + Cruse Bereavement Scotland and work with 'It's Time'
- June 2023 speech on bereavement support for young people at the annual joint Cabinet meeting between the Scottish Government and Children and Young People
- Instagram takeover with Young Women's Movement
- <https://syp.org.uk/cabinettakeover-2023-bereavement-support/>



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Campaign Aims

- To raise awareness of the adverse effects grief and loss can have on young people
- To highlight the need for young people to have specific individualised support as we have different needs to that of children and adults
- To showcase resources and different support networks already out there for young people who are grieving
- To give other young people a platform to share their stories
- To call for action to be taken to ensure there is a rights-based approach to bereavement support

Ben Kane

- Founder of Clydeview Bereavement Support
- Shared views and ideas with councillors & MSPs
- Rotary Young Citizen Award 2023
- Joined Inverclyde Bereavement Network
- Briefed Stuart McMillan MSP for members' debate in Children's Grief Awareness Week
- <https://www.greenocktelegraph.co.uk/news/23938207.student-ben-kane-raises-awareness-childhood-grief/>

Ben Kane



Rotary Young Citizen 2023 - Ben Kane

BEN KANE
YOUNG CITIZEN AWARD

NOTED BY
GOUROCK ROTARY

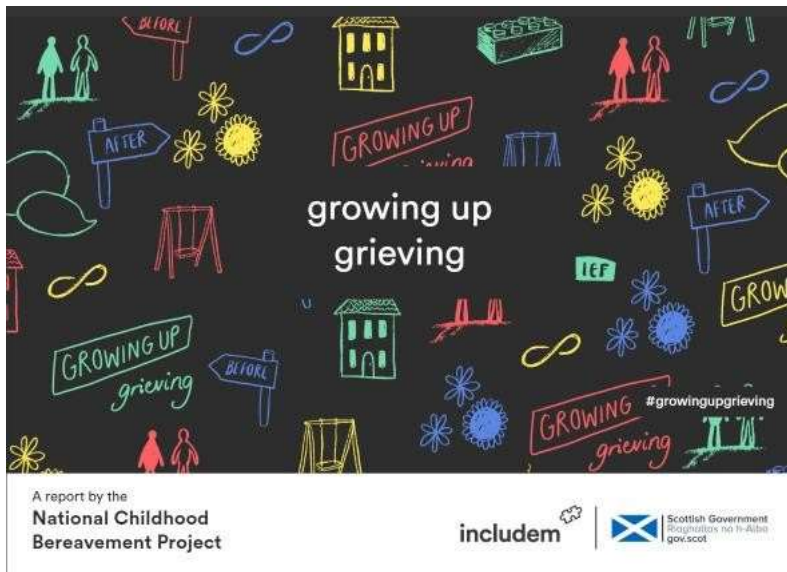
Rotary **YOUNG** CITIZEN AWARDS
Watch on  YouTube

Rotary
Great Britain & Ireland

Share

<https://www.youtube.com/watch?v=WLux94PAOWY>

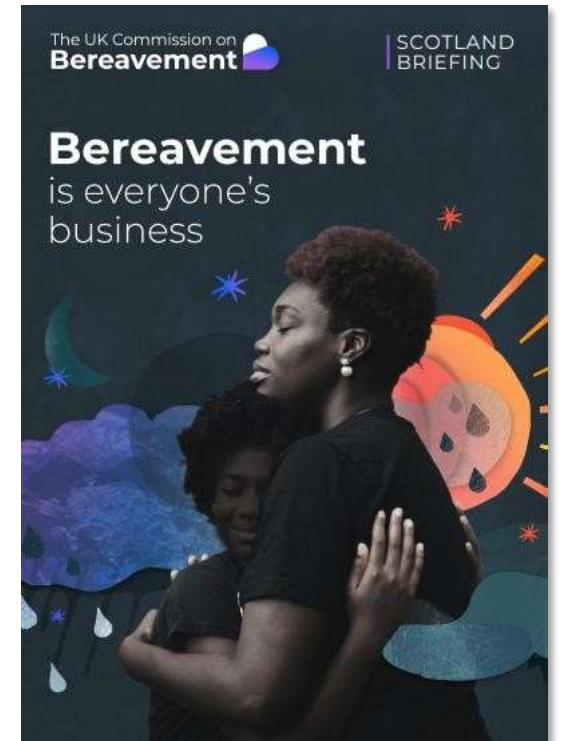
Reports and campaigns



https://issuu.com/include_m2000/docs/ncbp_includem_22_v4

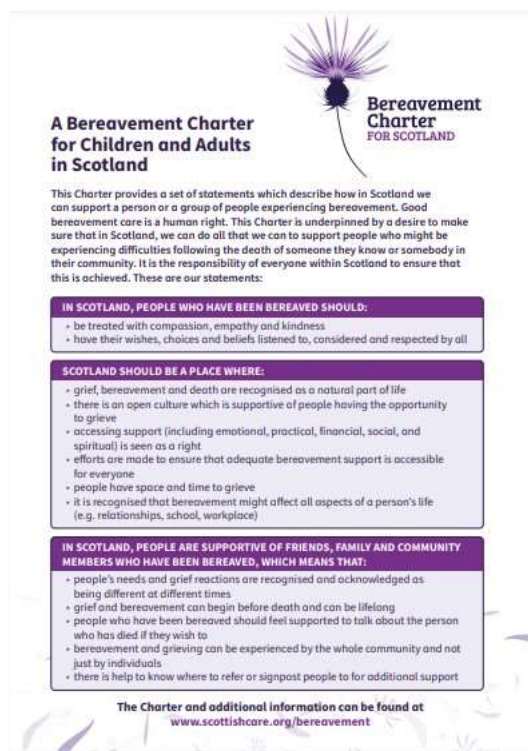


<https://syp.org.uk/cabinettakeover-2023-bereavement-support/>



<https://bereavementcommission.org.uk/ukcb-findings/>

Reports and campaigns



https://www.goodlifedeathgrief.org.uk/content/bereavement_charter/

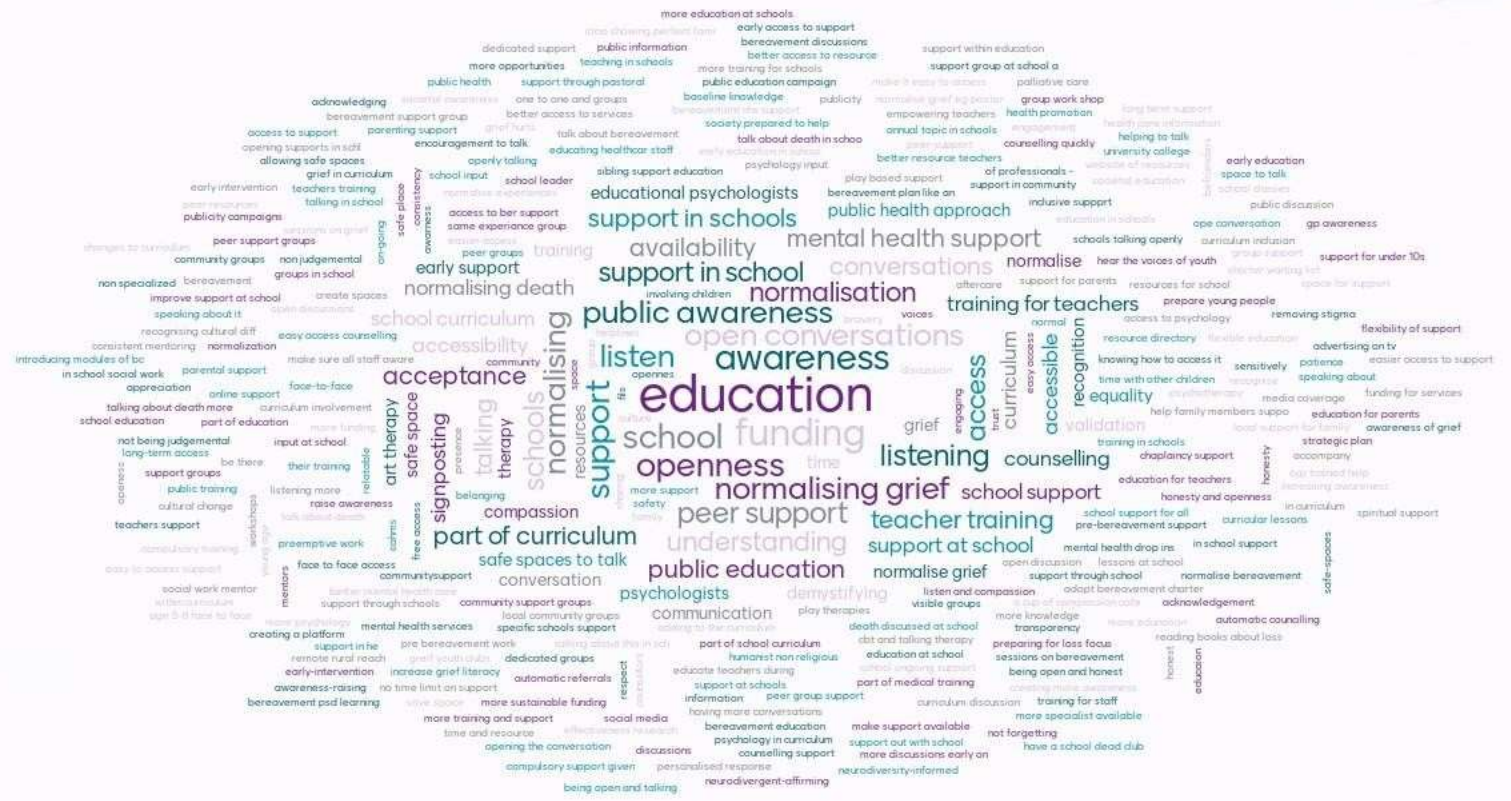
[FINAL Bereavement summit summary June 2023 \(palliativecarescotland.org.uk\)](https://www.palliativecarescotland.org.uk)

What we can and can't change for bereaved children and young people

Risk and protective factors we can't influence (non-modifiable) e.g.	Risk and protective factors we can influence (modifiable) e.g.
<p>Age and developmental stage</p> <p>Cause of death</p> <p>The role played by the person who died</p> <p>Previous experiences of loss and trauma</p>	<p>Preparation for (the) death</p> <p>Family environment</p> <p>Support from social networks</p> <p>Children and young people's views about themselves and the world</p> <p>Coping strategies</p> <p>Other stressful events</p>

What changes could we make nationally that would make the biggest difference to improving support for bereaved children and young people?

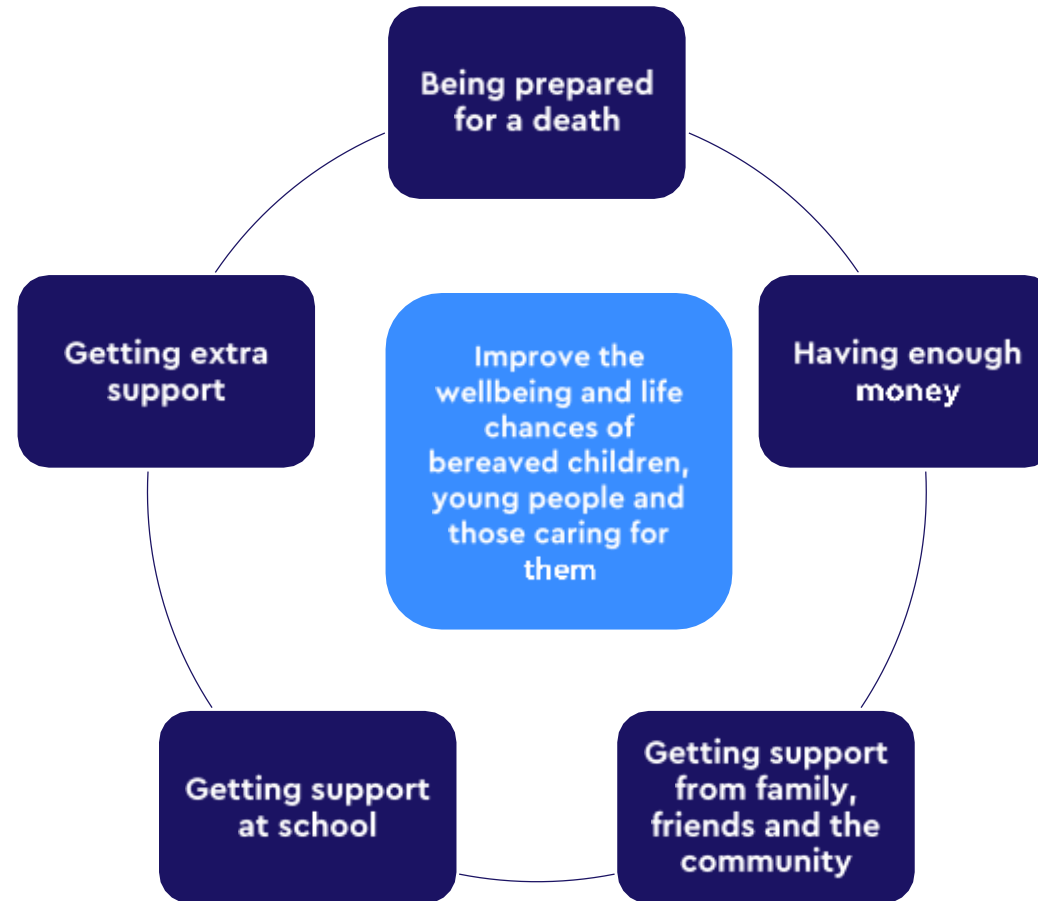
563 responses



Ideas from participants



Our priorities for children and young people



Being prepared for a death – why it matters

- Children and young people often excluded from conversations
- Up to a couple of hours before their parent died from cancer, 43% of young people (n = 622) had not realized that death was imminent (Bylund-Grenklo et al., 2015)
- Not receiving information from healthcare professionals / associated with distrust in care for parent / increased risk of depression 6-9 years later (Bylund-Grenklo et al, 2013)
- Unplanned care arrangements

Being prepared for a death – what can help



Plan if

- All families
 - Putting plans in place
- When there is a diagnosis of life-limiting or life-threatening illness
 - Healthcare professionals having the conversation about children and siblings
 - Supporting families to communicate
 - Protecting children's rights to visit family members at the end of life



<https://www.ulster.ac.uk/research/topic/nursing-and-health/caring-for-people-with-complex-needs/research-themes/cancer/family-centred-cancer-care>

Having enough money – why it matters

- Real concern for children and young people
- Fall in income and additional stresses in the family are risk factors (Christ, 2000)
- Higher income is a protective factor, esp for educational outcomes (Berg et al., 2014; Prix & Erola, 2017; Worden, 1996)

"I wish we had somewhere nicer to live and no money problems as this just makes things even harder for us." (5-12 year old)

"Loss of income, less we can do an more stress on mum" (16/17 year old)

Searching for participants

Did your parent die when you were between the ages of 18-25?

Who can take part?

- Your parent died when you were between the ages of 18 and 25
- Your parent died over 3 years ago
- You have lived in the UK since your parent died
- You are currently 34 years old or younger

We are studying the financial impact of losing a parent between the ages of 18 and 25. The results will help us understand the financial risks of losing a parent at this time of life and could help shape future bereavement support.



Online Interview



All interviews will be done online and anything you say will be anonymous, and used for only this project.

For more information

Terumi Okaku  to336@bath.ac.uk

Website URL: <https://www.parentaldeath.net/>



Please share on social media



Your participation will be completely confidential and you are free to pull out at any time.

Having enough money – why it matters

Having enough money – what can help

- ✓ Extending bereavement support to cohabiting couples
- ✓ New Special Rules for benefits for people nearing the end of life
- ✓ Extension of support for carers from 8 to 12 weeks after the person being cared for dies

? Extending bereavement support to other groups

x Restoring longer term support for families with children

x Uprating bereavement support in line with inflation

x Extending bereavement support to other groups

Having enough money – what can help

Thousands of cohabiting parents who could be eligible for a back payment of bereavement benefits have not yet claimed.

The window closes 8 Feb 2024.

Could you be eligible?

Can you help us #Findthe21k?



Find out more at
www.childhoodbereavementnetwork.org.uk/cohabiting

Getting support from family, friends and the community – why it matters

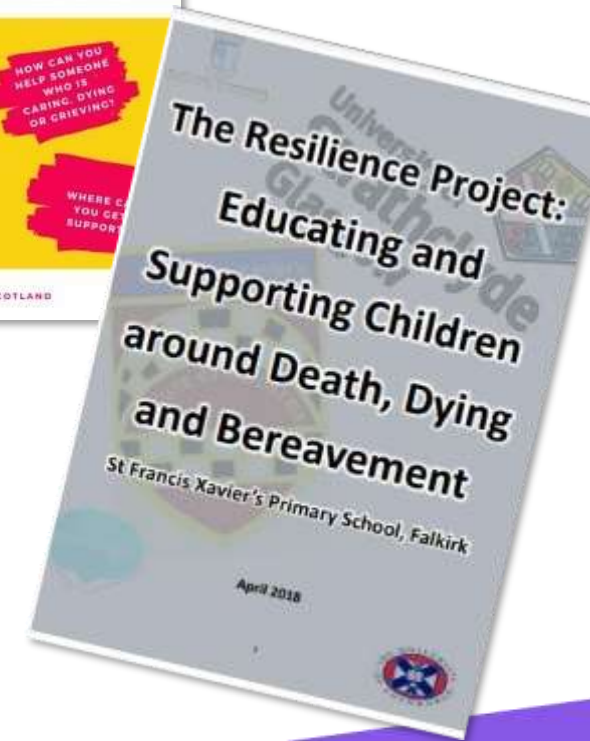
- The people around us – our day-to-day networks
- Relationship with surviving parents and their capacity to provide warm, consistent caring environment are among the most influential factors (Christ, 2000; Haine et al., 2008; Worden, 1996)
- Children and young people often report loneliness (Ribbens McCarthy, 2006) and some report outright bullying (Cross, 2002; Worden, 1996)

Getting support from family, friends and the community – what can help

- Open communication, talking together, empathy, warmth, effective discipline, accuracy of perception
- Supporting the mental health of other family members
- Protecting family from further stressful events (Christ 2000; Worden, 1996)
- Helping adults and peers to understand grief
 - Public education
 - The next generation – grief education in school

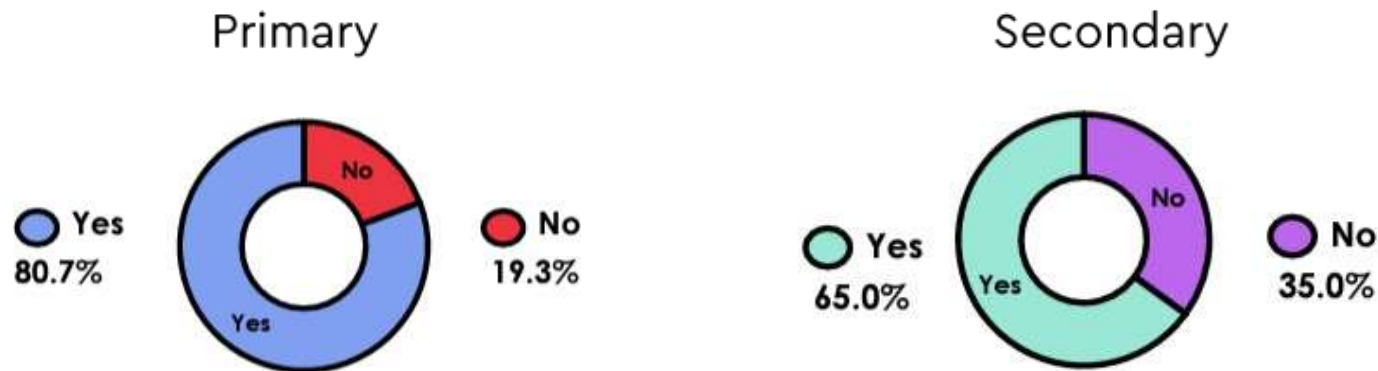


Walk a mile in mine



Getting support from family, friends and the community – what can help

Would you know how to support a friend if someone important to them died?



Votes for Schools results 17-24 November 2023
38,000 pupils across the UK

"Yes ... I know what makes my friends happy and what I could do to make them feel better. You can empathise with them if you know what it feels like."

"No, because I feel like I will say something wrong and upset them."

Getting support at school – why it matters

- Can disrupt education (attendance, concentration, attainment)
- Opposite effects
- Support is inconsistent

“Teachers to understand we get angry and upset, can't concentrate and can't always get organised as a lot happens and our adults have a lot to sort out, people to speak to and sometimes are crying. Getting to school at all can be a huge task.” Girl, 12 years old

“I knew my teachers all knew, but no-one spoke to me about the fact they knew, so it felt like an unspoken secret.” (13-15 year old)

Getting support at school – what can help

- Using existing legislation e.g. Additional Support for Learning Act, GIRFEC framework and SHANARRI principles
- Proactive, not reactive
 - Supportive culture
 - Named person
 - Good communication
 - Plan for adjustments – over time
 - Peer support opportunities
 - Bereavement policy + staff training

"The new school have been fantastic offering help, respecting certain dates are hard and having plans in place before them dates come across." (Parent of 5-12 year old)

"There is also someone I can talk to who makes me a cup of tea and we can chat, and she goes when I need or want some alone time" (16/17 year old)

Getting extra support if needed – why it matters

- 1:1 and peer support
- Children and young people and parents clear about benefits
- Systematic reviews and meta-analyses find small to moderate effects (Currier et al. 2007; Rosner et al., 2010)
- Valued and valuable when it's available – but gaps and barriers

"I liked [the service] with the other super siblings" (child aged 5-12)

"My counsellor really understood what I was going through" (young person aged 16-17)

Getting extra support if needed – the barriers

- Lack of recognition of needs
- Lack of knowledge about what is available – proactive signposting
- Lack of availability of services
- Support not available at the right time or for the right duration
- Services not fitted to needs

"Adults are 'gatekeepers' to their children; bereavement services only ever see those children where an adult in their life has recognised their needs; family 'culture' may mean that adults do not see the need for/value of bereavement support for a child/young person. Also, education establishments which are less bereavement-aware may result in a pupil/staff member not getting the support they need."

(Children's bereavement support organisation)

"Too often services feel inaccessible to them because they are built around and adult lens of what adults think children's issues are" (Children's bereavement support organisation)

Getting extra support if needed the focus

- Addressing different grief reactions / dimensions

- Separation distress

'How can I continue to feel connected to them, so that they remain an important part of my life?'

- Existential/identity distress

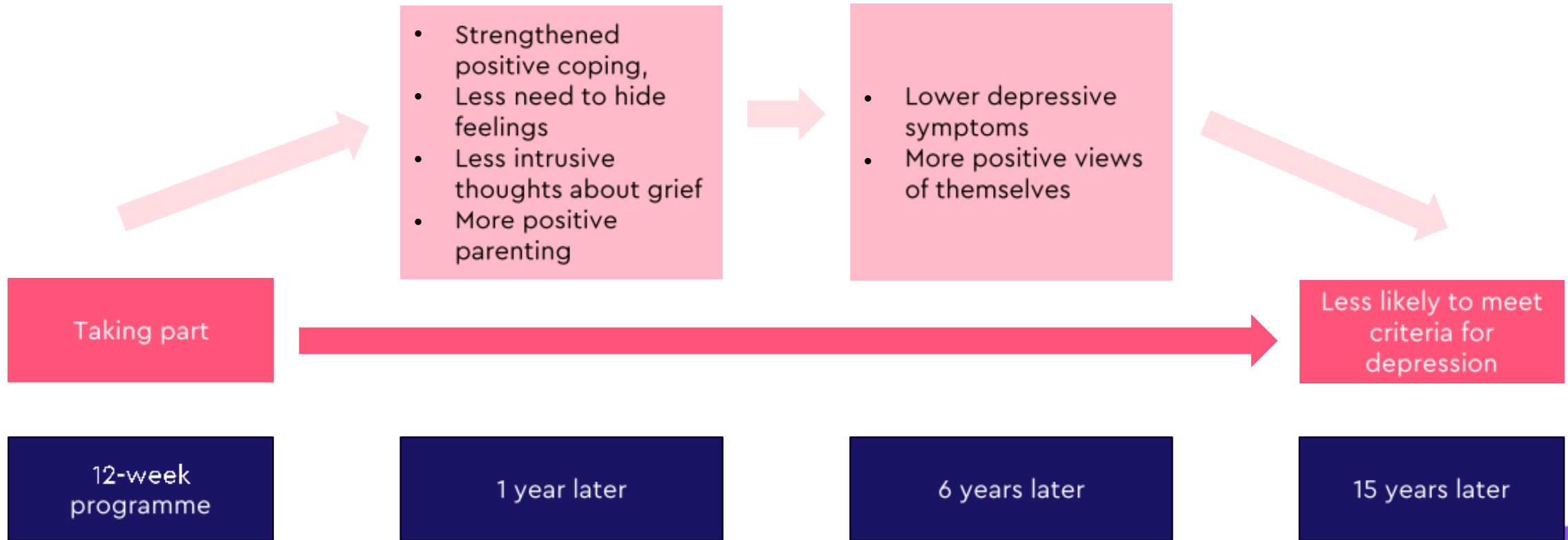
'Who am I as a person, and what is the purpose of my life, now that they are physically absent?'

- Circumstance-related distress

How do I manage my upsetting thoughts, beliefs, wishes, fantasies, emotions and impulses evoked by how they died?'

(adapted from Layne et al., 2017 – Multi-dimensional Grief Theory)

Getting extra support if needed – how it can make a difference



In summary

What can we do to support children who are carrying grief into adulthood?

- Think about promoting resilience as well as reducing risk
- Focus on what we can change
- Use a public health approach
- Hold on to hope
- Work together – network



In summary

What can we do to support children who are carrying grief into adulthood?

- Think about promoting resilience as well as reducing risk
- Focus on what we can change
- Use a public health approach
- Hold on to hope
- Cherish our networks



Making grieving children and young people a priority for change.

Take our children and young people surveys.

<https://childhoodbereavementnetwork.org.uk/about-cbn/childrens-grief-awareness-week/making-grieving-children-and-young-people-priority-change>

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