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Giving hope to grieving children

Voices of adults bereaved as children

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Introduction

This report focuses upon interviews with 11 adults who were bereaved as children, where we talked about their experience of being a bereaved child and the possible long-term impact from this as they grew into adulthood. The sister report to this one is a literature review undertaken on the impact on adults of parental or sibling bereavement as a child.¹ In it we also explored the role that schools do and might play. This report aims to represent a sample of the voices of those bereaved. We undertook interviews with a small group of people.

The interviews

As part of our re-examination of the experience of bereavement as a child we interviewed 11 adults over 18 years of age who had been bereaved in their childhood or adolescence. They were all volunteers and were connected to the research team through Winston's Wish. They were not selected as a random sample or as a representative one, but they were indicative. We undertook individual interviews with each person either via Skype or in person. The interviews ranged from 30 minutes to 90 minutes. The interviewers were three researchers from the Faculty of Education at the University of Cambridge. All participants knew their words would be public and gave consent as well as reviewing the final transcript of the interview. They also chose a pseudonym. We have chosen not to identify anyone in these quotations.

Our purpose in the interviews was to explore the following questions:

- What was the experience or story of being bereaved as a child under 18?
- What were the actual supports at the time of the bereavement and what were the interviewees' perceptions of that support or lack of it?
- What were the helpful and unhelpful responses and factors?
- What are the 'life course' experiences of adults who have experienced the death of a parent or sibling before the age of 18?

We aimed to explore the critical incidents in the post-bereavement experience as well as the turning points. We wanted to know about the elements of loss which continued over a longer term, such as the ongoing reminders and the returning feelings, and to know their strength. We were interested to see if there was any impact on the life course and at different stages.

¹ McLaughlin, C., Lytje, M. and Holliday, C. (2019) *Consequences of childhood bereavement in the context of the British school system*. Cheltenham, UK: Winston's Wish.

The report's main themes

The summary of current research evidence showed that 'loss and bereavement are very much part of being human and as such are normal, painful, predictable life events. Grief is not an illness. Customs around death have changed and are cultural. Beliefs about children and death mean that children are at times still excluded from mourning rituals and not always provided with information about own and other family members' critical illness.' These points are mirrored in the interviews we undertook which covered a wide chronological period. Some people were reporting experiences of 40 years ago, some of 10 or fewer, so these are unfortunately ongoing themes.

The report also showed that the loss of a parent or sibling as a child can lead to increased vulnerability later in life, but this does depend very much on the context. Recent research has emphasised that the contextual factors around bereavement can either diminish or enhance the risk to the child. The emotional environment is important, as are social, financial and other aspects. Meaningful support is important at this time and schools are a key site for providing such support. Many students report a lack of support. There is evidence that schools want to support at times of bereavement but are challenged and the climate is highly pressured. Young people need to be listened to at this time. There is a need for a holistic integrated response from schools. There is a lack of involvement of young people in research and planning

The interviews mirrored the research findings showing the struggle, pain and joy. The intensity of the grief is clearly documented. It is a fine example of the power of hearing the voices of children and adults.

What was heard – the voices

Experiencing the loss

The people who were interviewed were all adults who were bereaved as children. The age of the child at the time of the bereavement varied, and the manner of the death varied. Here we re-present some of the stories of how they experienced the loss. People told emotional stories of pain, shock, disbelief, anger and fear. What is apparent is the range of responses to the death:

I just heard my father, sort of, scream in a really animal sort of way. It was a sound that I'd never heard before and even now I feel the sound physically in my body and that's what it was like for me as a child. I was lying in bed and I just heard my father let out this scream and it was just like being stabbed all over my body. I just felt this, sort of, physical pain and I kind of knew, although I didn't know, I knew from this awful sound that I heard that my mother had died.

The above quote captures the visceral and physical intensity of the experience, as does the quote below in the recollection of the initial complete physical collapse. This person then goes on to recount how the faculties slowly returned.

She turned round and said 'Daddy is dead' and I turned round and said 'What, your daddy?' because I assumed it was my grandpa, just because I think as a child there's a natural succession you assume occurs. I could just see her staring at me and I saw her eyes start to tear up and I just completely collapsed on the floor, broke down in tears. Took me about five minutes to kind of... I don't remember that time, like that five minutes, it's almost like my brain just locked it out because it hurt too much. And then kind of slowly my brain turned on again and I worked out... because it was my first school disco, which is a very shallow thing to think at the time, but it was that weekend and I remember thinking 'Oh that's really annoying', because I managed to get a bottle of vodka sneaked into school and I was really ready for it.

People described their sense of anger and outrage at being excluded and from not being told about the impending death:

I didn't know that he was going to die and... then... So I was cross about that. My mother still tells me that I was cross about it whenever we talk about it. And then there was a great debate about his funeral and whether or not I should be allowed to attend his funeral. The belief was from some parents at that time – 1973 – that it was too much for a child to get involved with. My parents actually said 'No, he should be there to be able to say...' so I was saying goodbye to a coffin, I was not saying goodbye to a person.

I knew he was ill but I don't think I knew how ill he was. And the actual loss, he was at home, I went to bed, he was in bed and by the time I woke up in the morning he had passed away and the body had been collected and was gone. And I was very cross at six years old.

Another describes calmness and shock, followed by a painful dawning of the implications of the loss and a sense of absence:

Everyone was more upset than I was but I mean some people say it's because I was nine, but I think it was more because I was more of a calm individual, I was more thinking okay, this has happened and we're waiting for something else to happen. And then we came back home and it was... I think shock as well played a big factor in it, it's just... it just happened and you don't realise the implications of it till much later, like he's never going to sit at the table with us, he's never going to pick me up from school, just all the little things, I just came back home to the same house and everything had been left exactly as how he'd left it, you know, how he'd left as well, so all his stuff was out and it's just coming back to him not being there.

These implications are far-reaching and the poignancy and pain of the loss touches so many areas of life:

It was the fact that I felt that most of... a huge element of my life was gone, I was never going to have it again and you know just watching... I had to learn to shave by watching boys at my boarding school and how they do it, you know not saying anything, just looking to the side at the mirror to see how they got rid of their facial hair etc. and all the other things that dads do, parents' days or whatever, you are different, you don't have a dad and everyone else does and my dad was pretty great, so he wasn't like a non-existent one, he was there for me all the time and he was just a huge part of my life, he was everything.

Feeling the loss, physically and emotionally

As the stories unfolded people expressed more of the feelings associated with the loss and how they responded to those feelings. They told us about both physical and emotional reactions to the loss. The pain and the utter terror of the child are apparent in these vignettes from the interviews and these chime with the experiences cited in the literature.

Sometimes the pain is experienced as physical:

It really hurts like inside and my stomach really hurts but it's not like it's an emotional pain, it's a physical one.

Or sometimes physical reactions are ascribed to the loss:

I'd keep getting colds and falling ill and at one point I developed these weird, they weren't chicken pox, but these red spots one day and it started spreading all over, and we went to the doctors there were two doctors looking at me because they had to bring another one in and they weren't sure what was causing it. It was a little bit itchy but not very itchy, but they didn't know what was wrong, so they gave me this lotion and after a couple of days it died down, but I just think it was my immune system just completely....

I never really struggled with that before and there was quite a long period at school, probably about two years where I was probably about 80% of that time was in some form of bad place shall we say. I developed quite bad insomnia as well and yeah, I mean my insomnia didn't help because I wasn't sleeping at all and I'd wake up and then I'd get nosebleeds and I'd feel faint and all these other things that come with it, and that was a real struggle, but I just kind of... You just get on with it. I got up just about every day and I just did my best to at least come across to everyone else as being normal.

For some a way of coping with the feelings was to use alcohol:

So, you know, I think it was at that time when I was, between the ages of 16, 17 and 23 I would binge drink. I would work and then I'd be worked out completely and then I would drink. And then I wouldn't drink again for another few weeks, and then...

Another response to the loss was not to remember:

I had an essay on different types of our brain and the way that they have been impacted by a life event... that three parts of my brain that would have been impacted by trauma are all massively related to memory, so then I was all of a sudden, like, oh, well that explains why I can't remember... I'm like I don't remember that, but everyone else does and a lot of my memories from childhood / it's quite strange because a lot of them are kind of other people's memories and I've heard stories and because I've heard them so many times, I've like adopted them as my own memories

Responses to the loss were also psychological, including the need for validation, experiences of anxiety and depression. In the following vignette, we hear the importance of being validated and prized and therefore the importance of the presence of appropriate adults who are able to understand the child's experience, and particularly their emotional experience, and to communicate that understanding to the child.

There was a huge hole. I mean, you know, there was this huge hole in my heart, this emptiness and this hole. In fact, I hadn't just lost my mother, I'd lost my father, so I was, in a way, an orphaned child but not. I looked for love. I wanted love. I wanted to be held. I wanted to be validated and told that I was okay, so I went to men. I started cultivating relationships with men when I was very young, but it was a way of just having someone to hold me and tell me I was okay.

This need for validation is a basic human psychological need, to the extent that it is likened to our physiological need for oxygen (Kohut, 1984). The need for validation in childhood is normally fulfilled by a parent, so when a parent dies the child will need to seek others to validate them.

There was further resonance with the literature in the area of psychological consequences (section 3.1 of the review) as people talked about their fears and anxieties, and their depression.

Anxiety

Anxiety not a response to a direct threat but rather it is anticipation of feeling a painful emotion or of something bad happening. It is often related to a past experience so if we have experienced pain or loss then we are likely to anticipate that happening again in the future. This was the experience of some of the interviewees who talked about their anxious feelings.

I couldn't sleep, I was scared to go to sleep, because I have nightmares, genuinely they terrify me, and it was always my parents dying and... I remember going to sleep and thinking oh please, let it be okay, and then like my subconscious is torturing me during the time and then I'd wake up and I'd be disappointed I woke up because that meant my parents weren't alive. I used to dream they were, but then I'd also be relieved because I didn't just witness their death again, but I already had, so it's a bit weird. But I'd have the same, similar dreams or basically me trying to save my mum, but it never really worked out. And the thing is I'd have the same dream, but I'd always forget that she's dead, which is really weird, like I am very gullible in dreams, I'll believe anything.

I used to worry a lot. Especially when I was early teens, I used to worry about absolutely everything. I'd worry if there was nothing to worry about and it would get in to like this deep cycle of sort of like panic. I have had a panic attack, I don't think it was related to, well I guess it was, it was in an exam. No one else in my family worries at all, so I don't know why I've got that, but yes.

Depression

Section 3.1 of the sister report of the literature review (McLaughlin et al, 2019) reports that depression can be a consequence that is associated with bereavement in childhood – see section 3.1. This is also a theme that emerged in the interviews:

It's like your foundation is just totally removed, everything you believe in in the world is shattered and it's like every comprehension I thought I understood and had just disappeared for me and it was... I don't know, it basically just completely... I don't know why, I couldn't give a reason as to why I was depressed.

There was something about my father's illness and his slow demise and I just remember thinking, 'What the fuck is life about? You know, my mother died at 53 of a horrible disease and now I have to watch my father, who was lucky enough to reach 80, now lose his dignity, lose his ability to think, to remember. A very proud man now has to have someone wipe his backside.' What came out of me was anger but actually I was depressed, really seriously depressed.

Talking about the loss

A recurring theme across the interviews was how little the children talked about their experience of loss at the time. Often children didn't want to upset the surviving parent in the cases of parental bereavement. Or they didn't want to cause embarrassment or social unease. This is a particularly poignant finding because the research literature consistently supports the notion that parent-child communication is especially important for bereaved children, together with parental warmth and the opportunity for the child's emotional experience to be understood by a significant other (Haine et al., 2008). So, at a time when the bereaved child is most in need of emotional support and someone to talk to, many report that this didn't happen. This must be an area in which we can make a difference.

It did definitely make me feel different. I think a lot of the time I can feel really awkward because everyone doesn't know how to react and I'm like oh well I've created a very awkward situation now, where everyone is uncomfortable. I think when I was in the first two years I didn't really ever do anything about it, because I didn't want to attract attention to myself and be upset about it.

I just never really talked about it, because obviously you know everyone who has been through it is trying to sort themselves out, so it's quite hard to. I didn't really ever want to upset Mum and I didn't want to upset my sisters and I didn't have anyone else to really talk to properly about it. Whereas now I can speak about it and not feel guilty almost that I'm making someone else worry that I'm upset when I'm fine.

I heard adults saying the clichéd things like, 'She'll get over it very quickly,' that sort of thing. I heard people saying that around me, 'Children are resilient.' I heard those things, but no one talked to me.

I don't really want their pity. I don't really like how uncomfortable it makes the situation. The way they look at me afterwards and once I've gotten to know the person, and then I tell them, I prefer that, as opposed to telling them in the beginning, because some of my friends (I only told a couple of people), when I did tell them, there was a change in their behaviour and didn't like that.

It's just, when you tell them, it's like it's the classic, it's like you hit them on the head, umm, they look horrified, which makes sense, it is quite something, I mean you wouldn't expect it.

Yes, exactly, and even just people that / not necessarily / because obviously with my mum if I was to talk about, I would worry I'd upset her, whereas if it was like with a friend, I wasn't worried I would upset them, I was worried that they would think that I was upset.

When there have been opportunities to talk about the experience of bereavement, e.g. with friends or professionals, these have been appreciated and have been helpful:

I'm very understanding that lots of people don't really know how to talk about or manage someone else's bereavement, but I've always really appreciated when people don't shy away from it, so lots of my good friends will know that, and so you know if I mention something, what I don't want in an ideal world, is someone then to just like shut down the conversation. If I bring my dad up it's not because I want to have like a big or deep or emotional conversation. I'm just bringing him up as part of the general conversation.

What worked well was, when I went to Cruse, and I had the one-on-one counselling, just speaking to someone who was also like just there, and they were an outsider completely.

What the person did was they also mentioned their mum, because they lost when they were younger as well, which was nice to hear, and they'd always... but they wouldn't make it about themselves, they'd bring it back to me in a sense.

I can talk to my friends about it, in quite a like, oh yes, this happened, it was crap, but we've moved on and like just continue the conversation without it being like oh my God, I didn't know that had happened, I'm so sorry, just making you feel guilty for thinking that you're upset, it's just / I think that it's a much more relaxed conversation.

Good support

People were clear about the nature of what constituted good support. An accepting presence and ability to listen were themes in the interviews:

She just sat with me and she gave me a hug and she was just really nice, so just listened, and then she was very comforting, reassuring.

There were times when I would feel like upset and I couldn't explain why really so, and then she'd just come and sit with me and wouldn't really talk, she just, I just, she was like what's wrong, I'm like, oh I'm just thinking about stuff and then she's like it's okay and then she'd just sit with me and that was enough for me, like sitting next to her and not really doing much. Or she'd be

praying, or doing the ironing or something and that was nice, and sometimes she'd be like do you want to talk about it, and I was like, no, there's not really much to say, or we would, umm...

The biggest support for me has always been my mum though, I mean I called her... I still call her every night and I probably always will and she's my best friend and my greatest supporter really.

For some people the continuing everyday conversations about the deceased were important:

We never actually sat down and talked about his death, it was just always a natural part of the conversation. So we never had a conversation where we sat around and Mum was like how are you all feeling, and it was just always very organic.

For others a sense of ritual and of deliberate remembering are valued:

Every year, on the day that he died, we are always together and on the morning we each have these candles which we got from Winston's Wish and we light them in turn and we all like all say a memory. We all get together and like do that and that's really the only formal thing we've ever done in terms of like as a family, in terms of like dealing with my dad's death.

Practical support, as well as emotional support, was significant:

I mean my gran was the person that sort of took over from my mum and I saw her every day until she died. I mean she was 74 when my mum died so she was taking on me and my dad, cooking our meals, cleaning our house and washing all the bedding and stuff like that.

Loss and the family

Responses from the family were hugely important with some experiences being painful and unhelpful.

What is striking in these more painful accounts is how the needs of the child were overlooked and the needs of the adults were prioritized:

They had been living, smelling, breathing, feeling the pain, everything for those two years from diagnosis that they were totally immersed in it, and they thought that their grief as parents... this is my belief, that their grief as parents was considerably higher up the pecking order and the scale of grief.... And when I had this discussion with my mother at the beginning of January... my parents were so clear about their own grief that they forgot to ask me about mine.

My mum always kept a diary right from when she was like 16 up to the week before she died. I left them with my gran so that they could be safe. And then when I bought my own house I went back to my gran and said 'Where are the diaries?' and she said 'I don't know where they are.' And it wasn't until just before she died she said 'I burnt them, because I didn't want anyone to read what your mother had written' you know, my gran burnt everything, photographs, there was no photographs in my gran's house, everything she just set fire to. So that was the only thing that I really missed, because I haven't got access to that, when I was born and when my mum died.

My father has never got over it, I mean he's got a partner now but no one sort of lived up to my mother. The house became more like a museum. My mum's clothes stayed in the wardrobe for 25 years, nothing moved, nothing changed in the house. It was exactly as she left it, so that was, I was basically living in a museum.

Not all the accounts were of difficulties: some siblings became closer after the death of their father:

So I had two older brothers. The youngest one, we've always had a typical sibling rivalry, fighting, all the time, hits, punches, fighting over the TV, never getting along, our parents would always call us cats and dogs because that's how we fought, we'd fight about stupid things then we wouldn't talk to each other for like days straight, but then we'd always make up. My eldest brother he was the most responsible, so it was always okay with him. Then after my father first passed away, our relationship between me and my younger brother got better, we still fought, just not as much and then when my mum passed away it got better.

Others took on more caring roles in the family and became supporters of other family members:

Out of the family I am probably the 'strongest' and even at that age my temperament would have been I am the one that makes the least fuss, that gets on with stuff, so again, it's hard to know whether that turned me into what I am now, or whether I was like that kind of inherently, but I would have been the support for others, if anything.

My sister learnt to withdraw, particularly when things are chaotic around her, and my sister's really battled with engaging in the world in a pretty fundamental way. She said to me out of the blue, 'You know what? It could all just be a hoax. He could be living around the corner and we would never know.' I was like 'You've got to be kidding.' It was only then did I realise that because of the age difference I was old enough to absorb the reality, whereas she probably hadn't fully absorbed the reality. So, I suppose we manifested in me going into kind of hardcore reality and mechanical fixing and my sister going into 'Well, everybody else is manically sorting stuff out, I'm just going to shut down and go into myself.'

For me what kicked in was 'I need to be good, I need to make it better, I need to care for everybody because that'll help the situation.'

Loss and the school

The participants described both their own and others' reactions. They used the language of survival and 'getting through it'. The perseverance of children in the face of difficulty came through in these accounts.

I think if I just dealt with it, sooner in a way, especially when I was younger... if I'd have spoken about it, umm, and in secondary school, I mean I got through it, but when I think back it was a horrible time, but I did get through it.

I wasn't properly addressing the problem. I just kind of went with the motions of school, GCSEs, and then when that happened I was like, right, I need to sort myself out, because this is going to – I'm like pushing it down.

In school the participants experienced a distancing from peers and felt different too. Faced with this the participants described not expressing themselves or being provocative in order to seek the attention they longed for. They were also struggling with complex emotions and others' reactions.

It was very hard going back to it after losing my mum... my friends would have all these superficial problems and... they'll be crying about oh I didn't get the option I wanted and I'm just there like I never really said anything because even if I said something, if people would just change their perspective of me, and they'd react differently and I'd make them uncomfortable. I don't really like making people uncomfortable and I don't want their pity either.... I distanced myself from my friends a little bit, but not so much.

I didn't want the fuss but I wanted the attention. Attention but not drama or heightened emotion. I guess I didn't kind of ask for help and I didn't know I needed help.

I think I kind of wanted to be quite provocative. I don't think I wanted sympathy. I think I was aggressively provocative. I kind of wanted people to feel bad I think, in a way, so I didn't want oh... I wanted people to think, oh my God, I've just said she's wearing black and it's her mum's funeral, it must be awful. I probably wanted people to feel quite uncomfortable about it. I don't know why, maybe because it felt like for the whole of that time up until the death none of us had paid a lot of attention to it.

They also described the responses of others, both peers and teachers. Friends were described as kind but not knowing what to say.

The children in the class didn't know how to speak to me, they still were normal.

Teachers and other professionals in schools came across as either kind and understanding or rather clumsy and naive, people who did not know what to do. Many of these accounts were of practice up to 50 years ago when understandings were very different about children and feeling, and children and death.

They were always very considerate of things, the teacher would always just stay around for a bit longer because they obviously knew that Mum wouldn't be able to like force herself to get there any sooner, so they were quite supportive in quite a creative way and they were really, really understanding. I know that, I think every month or something, I would always end up just being like I don't want to do the rest of the day in school, so I would just go and sit in the library and I'd be able to bring friends with me and to do things like that.

I know when they notified the other teachers I remember thinking, ahh, the other teachers know now, they must have sent a bulk email, because it was a Friday and I'd just had a history lesson and the teacher was talking and throughout the whole history lesson he would make extra eye

contact with me. I think that also adds to the fact that he acted differently, but he was very nice. I mean it was nice in a way because I knew if I wasn't doing well, or if there was a problem, they are more understanding so probably more likely to do something about it, as opposed to just tell me off.

One teacher can only be described as unfeeling.

My teacher smacked me. After, when I went back to school, because I was crying. And my mother found out and literally went, I mean she was furious and took me out of the school and caused a very, very big amount of noise in the school. So, it wasn't kind, it wasn't sensitive, it wasn't caring. It was mean, isolating. (Participant born in the 50s)

Another showed a lack of understanding of what children need. We know now the importance of such symbolic acts as the child wanting to put a card on the grave.

We only had one problem in school where I wanted to make a Father's Day card, for Father's Day, and put it on his grave and they wouldn't let me... I remember just being really confused, because I was so little.

The lack of consultation with children about their preferred options is clear. It was a rare interview that described children being negotiated with or listened to. This is an area highlighted in our review and we make a strong recommendation for more listening to and consulting with young people around bereavement.

Because it was the year when I was just about to do my 11 plus and they thought that my mother's death might upset my chances of passing my 11 plus. Again, without asking me, it was decided that I would stay down a year and that was really upsetting. It was upsetting because I lost the friendship group that I had. It made me feel like I was stupid, plus I had to do a whole year of work again that I'd already done and I remember that made me really angry.

The final quotation here sums up well the desire of bereaved children to be listened to and noticed in a constructive way.

My matron was there the whole time and was absolutely amazing... when I couldn't really cope with smiling to everyone she wouldn't mind if I would just kind of go into her office and she would just have a cup of tea with me just to give me a kind of space. She just made me feel like there was someone who gave a shit and, you know, when I wasn't well and once when I woke up, passed out, had a nosebleed and kind of woke up covered in my own blood she then opened the door and found me. She just looked after me.

These interviews support the need for teachers and other adults to be helped to understand the needs of children who have been bereaved and to have policy and processes to support them during such difficult times, which require sensitive and complex responses from adults.

Growth and self-perception

The participants were clear about some of the things they learned from the experience of bereavement. Perseverance or resilience was one theme, as was self-care and developing self-sufficiency. This is helpful but also unhelpful as becoming an adult too early has its own issues.

You learn to stick up for yourself. You haven't got anyone else to fight for you, so you have to get on with it. And I think that's the thing, my father used to say 'Yes, but you go for something and destroy everybody else that gets in the way. If you've got a goal to do this then you do that and to hell with everybody else.'

I didn't learn that there was space for me in the world to care for me as well because I was so busy caring for everybody else and sorting everybody else out. So that's the downside of what I learnt; I didn't learn the other muscle, which I've had to learn the hard way. Whereas my sister just doesn't get it and went into her own head and world, whereas I went into caring for everybody.

Even now moving furniture around the house or... I would rather do it all myself, do it on my own, rely on myself.

Many other aspects of life became highly valued and for some a sense of proportion developed out of the loss. Death had shown the precariousness of life and this was a lesson that was not forgotten.

It definitely has made me who I am. It's made me a better person because I'm so much more appreciative and grateful and I feel like I can connect to people on a different level, especially if they've been bereaved, and it does make you appreciate the support you've got around you.

I think that because of obviously dealing with such a big thing, at such a young age, everything else has just been put in to perspective, so when I get a bad grade back or something, I'm like, oh well, could be a lot worse. I'm sort of aware of bad things can happen, from nowhere... any small problems that I would have... I can deal with because of what's happened to me... I've learnt to cope with it and learning to talk about it, things like that.

It's made me want to go and do things more because you don't know what's going to happen tomorrow, you could be in a freak plane accident, you could step out on to a car, if it's your day, it's your day...

Many of the participants talked about the extreme difficulty of coping but also about how the experience had strengthened them and made them more mature in responding to difficulty.

It has made me the person I am and I'm really proud of a lot of that; I can look at it and I can be grateful for having had it happen to me because I've done the most incredible things and had a level of emotional maturity and agility that I don't think I would have had if I hadn't had that happen. So, yeah. Because I almost honed a muscle that I shouldn't have honed at such a young age as a coping mechanism.

But there was also a reminder that this is not the case for all.

... for some people, not for everyone, some people it just breaks their lives forever and they don't seem to get out of it, but for those who can get through it it makes them a stronger person.

One person felt it had affected her choice of career.

... I'm now a doctor. So in that way it's like obviously I never wanted to be a doctor before, so that's had its impact in that way. And I guess also it's hard to know whether that would have been the case if my dad was alive...

The interviewees described eloquently the bittersweet experience of having had a terrible loss but also seeing the value of some of its legacy.

It's like being in some type of secret club, that you don't want to be part of, but you're kind of glad you are, because I guess the other thing is it kind of feels that once you know that, you can either define it as, oh it's so awful, that life is going to be awful, but it almost felt to me maybe once you've had that nothing can get any worse, I don't know that I could ever think anything in my life would be any worse than that, which has made me more robust and resilient because what's worse than your mum dying when you're a kid, it can define you in a positive way in terms of how you/what you learn from it.

I think if you turned around to me and said, 'If you could undo the past and have your dad live', obviously your gut would instantly say yes, but I'm not actually sure that I would because although he was everything to me it's made me so much of a stronger person and I'm so close with my family because we've had to be, because of the pain and because of everything else we've just pulled together rather than ripped apart.

I can spot a bereaved child adult a mile off, I smell it. I can't tell you what it is, but I can, if I spend a little bit of time with someone, I'm like 'Oh', I'd never wade in and say, but I can just feel it. There is a, I think there is an intuitive depth or an utter void, like an utter void of connection, and it's one or the other. And I feel really strongly that it's part of my story, it's part of who I am, I have fought it for years and in some ways, it's made me, it's given me the fuel to do what I do in the world.

Long-term consequences

When the adults interviewed described the long-term consequences some talked of the spiritual impact upon them and how they thought hard about meaning in life.

My mortality, like I did think about that as well, when my parents died, like I am next, type person, but now I have a sense of I just pray that there is a God instead of praying to a God, because the horrifying thought for me is, what if at the end of it, there is nothing, like just like before, we don't exist anymore, that's like something which obviously my peers don't actually experience and I shouldn't really be experiencing this until I'm like 60 or something, but now I just think about how I'm going to die and how it's going to happen, the thought of not existing.

In the review the self-blame that can occur for children was discussed and this was a theme in one of the interviews.

I spent many years thinking it was my fault, as you do when you're a child, and that I could have done something else and I could have done something better and all of the narrative when you're a young child around 'I'm different, I'm not like the other children', I suppose you don't say it in your head but it manifests in 'I'm weird because I don't have the other parent.'

The symbolic moments of life were reminders of a missing parent. Births and marriages and other important moments in life showed up the loss.

When I see people being walked down the aisle with their dad, that's like one of those moments it's like very much in your mind that even I actually wouldn't have my dad walk me down the aisle.

When you get older and you start to become the person that they were, working and being in a relationship, having children, that's when you start to realise what you lost as a child at not having your dad.

My wife knows that I think about it on his birthday. I very often take the day off in advance because I might want to go and see him. If I have major life decisions to make I sometimes talk to him.

The more complex aspects of bereavement were also touched upon, such as the idealisation of a dead parent or partner.

If I talk to my mother about him, he is a saint. He's perfect. And, I'm not questioning the fact that he was or wasn't, but it's not authentic, it's an empty shell and I think when you start to explore this person and you realise there is very few places to go to colour in the shell, it's a bit of a, okay, you've got two choices. You can either spend the rest of your life searching for the colouring in or you can accept that it is what it is...

There was also a stark reminder that grief is a process and it can sometimes take a long time to heal or it is only later in our lives that we can face the task.

I've been dealing with this bereavement for 44 years, I'm only now finding the voice because I've got enough money, my kids are grown up, that I'm actually allowed to finally think about my grief. I think I've been doing a lot of mourning and I really like... that's really helpful to me to say there is grief and there is mourning, but I'm only now allowing myself to really reflect on it.

Advice to bereaved children

At the end of the interviews we asked if the participants to look back and offer advice to the child and to the adult where someone had lost a parent or a sibling. There was unanimity in the responses, no

matter how varied the reactions to and conditions of the loss. All participants emphasised that acceptance of feeling is important.

Whatever they are feeling it's okay, there is no right or wrong. And don't think of it as a time. Like for me especially [I used to think], oh after a month you'll be fine, it unfortunately it will stay with you for the rest of your life but you probably remember the bad times now. You might even be too shocked to remember anything, but just know that whatever you are feeling that's okay, you'll deal with it in your own way.

... it's fine to talk about it, it's fine to cry, it's fine to ask to be left alone. Then the next day you just might feel quite fine and quite relieved and quite free and you might just want to go out and play with your friends or have a good time, have fun and you mustn't feel guilty about that because it's all part of the same thing. The sadness, the grief you feel will come and go and it's okay to experience and feel whatever comes up for you and it's alright to talk about it and to ask about things that you don't understand or things that might frighten you about the moment or about the future.

They all emphasised the importance of talking as helpful, even though many of them had not done this due to the context or the response of the adults. The research evidence strongly supports this view.

Talking does help, even if it's just to talk about the most random things and I would suggest seeking support because it really does help and talking within your family as well... Try not to be so isolated I think because then you're left alone with your thoughts because I did go down a very dark path.

They also talked about getting the balance right between grieving and living and between support and suffocation, and about reassurance that hard times would change and that the child will survive.

That's a tricky one because you also want to provide them with support but you don't want to suffocate them at the same time.

It's not the end of the world. You can keep going. There might be times when you don't want to keep going or you don't feel like you can keep going, but you've got to think what would that parent want for you? That's the thing.

In the case of a predicted death due to illness the importance of preparation was mentioned.

If it was something that was going to be known about I would have tried to prepare them as much as possible. Even if I thought it was over their head, you know, educationally, I would try and say to them this is where you are going to see your brother, he's going to be poorly. This machine helps him breathe, this machine helps his blood, this machine does whatever – so some preparation. I wouldn't hide behind it.

The participants wanted to give children in grief permission to speak, want and act as they needed to.

... kids are clever, kids are smart, they absorb like sponges. I would say it's okay to cry. I'd say it's okay to miss them. It's okay to celebrate his birthday. It's okay to celebrate your parent's birthday if they weren't there. It's okay to draw your parent a picture about something you did at school.

It's okay to write them a letter and have a postbox in the house. If it's your parent it's okay to keep their phone number on your mobile phone, if you want to call them just call them. It's okay to talk to them, it's okay to share and you will find some comfort at some stage as to what you're doing.

Advice to adults supporting bereaved children

In focusing upon what adults could do to support grieving children some mirror suggestions were made. The importance of not denying the reality was a strong theme and talking about death and what had happened was emphasised strongly.

I understand why it can be such a stigmatising thing to talk about... we don't talk about death, we don't talk about death during childhood because so many people deal with it, so why would we not talk about it and why wouldn't we make it a normal thing for a lot of people to understand?

Overall, I would say to be able to encourage more conversations you have to really normalise it and make it just another part of life.

Looking ahead and anticipating later needs in life such as the need to remember and make meaning of the past were also key themes.

... in whatever way possible, to hold on to those memories, and even if it is just things like once a month, watch an old video like of a family meet up or something like that.

Memories. Memories, memories, memories, memories. Find ways to capture memories. From the past, from that period. And just put them away and one day you'll be asked. There will come a time where it will start to come out and when that time comes have something that you can give, tangibly give a child so that they can piece it together, even as adult.

Finding any way to remember which fits with the child's needs was emphasised.

How do you want to remember him? Do you want to have a birthday party for him on his birthday every year, even though he is not there, do you want to have a birthday party? Do you want to make a special book of things that you would like to tell him? Would you like to share things with him that would make him laugh, cry, be proud, be cross?

A warning was given that children are highly astute and pick up on what is happening even if the adults think they are not. There was a plea to be honest and authentic and a reminder that we all need to make meaning. If we don't have a story we will make up our own.

Don't be afraid of telling them the truth, because it's going to hit them at some point. You've got to let them in and let them experience what's going on, because otherwise they try to fill gaps with more wild thoughts than what the reality is. If a person is dead, a person is dead. There isn't a lot you can do about it.

Finally, the advice was to be kind, loving and open.

Be loving, be open. Be as honest as you possibly can, taking into account the age of the child, but just know that your child is going to sensitively pick up on the environment and what's going on, so just always check in with the child and say, 'How are you doing? What's going on? Are you worried?' Openness and communication is really important.

There was also a reminder that children will protect their remaining parent and are quick to pick up if the adult is having difficulty.

Definitely don't be scared to talk to who they have left about it, because even just the small things that I would say / because I think what's stopped me from talking to Mum was I had a dream about Dad, not too long after he died, I think she obviously was very upset by that and I think that probably put me off talking to her about it, which is probably why I spoke more about it to my teachers at school, if I was I can talk to someone, whereas I never wanted to upset my sisters or my mum, and other people didn't understand it, so I just kind of kept it to myself. It's going to be okay. It's going to be okay. No, maybe I wouldn't. I would say 'You're not alone.'

Advice to schools

Schools were asked to recognise openly the loss that children experience and the number of bereaved children in school would strongly support this. The Childhood Bereavement Network (2016) estimated that in 2015, approximately 41,000 children born in the United Kingdom lost a parent before the age of 18.

Treat them like any other child. It's not that I don't mind being a goat in all the sheep, this is normal, but please don't treat me like this isn't normal, because it doesn't make my life any easier.

Don't be delicate around them, because of the circumstance, because actually that's just not helping anyone I don't think. But it's awareness and so if that person... does get upset, then they know to support them and potentially how they can support them, just don't alienate them.

There was a plea for informed and age appropriate support. This included recognition of the enormity of the death of a parent. There was also a recognition that this requires preparation and training of staff.

I think teachers often treat children like children and actually, especially when you are a teenager, you aren't really a child, you're a young adult and talking to you as if you are an adult, sharing your own experiences is really, really helpful and powerful...

I think when I was early teen years, I remember people being, oh, I know how horrible it must be and I remember getting really angry like, you don't know, it's not something you can compare, oh my parents are getting divorced, I'm like, yes, you've still got both of them don't you...

So, I would personally like a lot more in education around the number of children and young people that are at school who have important people die, I mean, that teacher sees person after person after person, so if they were better equipped to deal with it, and be the best they could be, I think that would be really helpful. There's two sides to it, having the confidence to be able to deal with it, and then the confidence to ask, which I guess partly comes from feeling you could deal with it.

This final quotation emphasised the need for recognition and education of the emotions.

What I think we are dealing with, in this country, many generations of ill-equipped adults, emotionally ill-equipped adults, who are, who have been for whatever reason underinvested in from an emotional sensitivity perspective and therefore helping adults to get more emotionally fit will help children to process the world. It's quite simple. And I think there is a massive backlog of generations in this country of adults who have not been developed as emotional beings, and in order to underpin the generations of the future, yes, you've got to do the schooling and all of that stuff but you've got to help adults to help the children to not proliferate the cycle.

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