



**Derian House Children's Hospice conducted research with 70 bereaved families from September to November, 2023.**

The charity spoke to 70 families whose loss spanned more than three decades. Participants answered questions both online and in paper formats, which were then mailed to the charity.

The majority of families who took part have accessed services at Derian House, but a small number of bereaved parents who took part were recruited through social media on the charity's Facebook page.

The over-riding finding was that bereaved families desperately want you to talk about their child, and that nothing anyone can say will ever be as bad as simply avoiding the subject.

Many participants expressed relief and thanked the charity for bringing this issue to light.

### When asked:

1. Do you ever feel that nobody, other than your close family (spouse, children) talk about your child anymore?



2. Has this become more apparent as time has gone on?



3. Do you feel that your child has been forgotten by family, friends and acquaintances?



4. Do you feel like your workplace understood?



5. Do you feel that people's feelings have changed over time?

#### Themes

- People forget over time, which gradually gets worse.
- There's an expectation to move on and get over it – but we can't and won't ever be able to.
- Support and understanding reduce over time.

"Yes. People wrongly think you have to come to terms with things. You just learn to live a different way."

"It's over 30 years now. Many people in my life now don't know. "

"Yes. People think you have moved on in life and that it is now better because there aren't the same restrictions to your life."

6. Do you feel there is a stigma around child loss?

#### Themes

- People become awkward or uncomfortable around you.
- People avoid you because they don't know what to say, or are scared of saying the wrong thing.

"Yes, people avoided me and my parents, crossed the road, didn't know what to say."

"Yes. The grief in losing a child is so much different than the grief in losing parents or grandparents."

"Yes, it's awkward. You feel like you're different if people know your situation. "

7. Have you ever felt that people have ignored you because they don't know what to say?

#### Themes

- As well as losing our child, we've lost friends.
- People ignore you because they don't know how to act or what to say.
- Communication reduces.

"Yes. Walking to school with my younger child I would often be asked if I would like a lift. This stopped when she died in (a lot of cases, not all) people were afraid they would upset me I think."

"Husband's boss's wife saw me with my next child and asked where he was then without a word realised and walked away."

"Yes. People are frightened to approach the subject for fear of saying the wrong thing and upsetting you so they avoid you or the subject."

## 8. Do you feel that medical practitioners had a grasp of how to speak to you sensitively?

### Themes

- Mixed responses – some did, others didn't. Lack of consistency.
- More training is needed to speak sensitively.

"Not at all, the visiting midwife for our second born was insensitive to our situation, they need to do their research before visiting."

"They were always kind, funny and helpful. Supporting, not abrupt or dismissive."

"Some were good but many were not. One actually said we might have a better idea what is wrong with Jenny when we do an autopsy."

## 9. If you could give advice to someone who doesn't know how to speak to a parent whose child has died, what is the one thing you would like to tell people NOT to say?

### Themes

- Don't say anything that starts with "at least". This feels like minimising our pain.
- Don't imply we should move on after a certain amount of time – we can't.
- Don't compare our loss to losing a grandparent or even a pet.
- Don't impose a religious belief on us.

"At least you have other children."

"Time is a great healer."

"I know how you must be feeling, I've just lost my dog/cat."

## 10. What is the one thing people SHOULD do?

### Themes

- Mention our child, give us opportunities to talk about them and share any memoirs you have.
- Remember, acknowledge and include them. This might look like continuing to write their name on our Christmas card or texting us a love heart on their anniversary.
- Make an effort. Saying or doing something is always better than avoiding the subject.
- Try to be normal around us.
- You can't fix our pain, but just listening helps.

"Mention your child. They may not be around to see anymore but they are still part of your life and will always remain so. People are afraid to upset you. But you will find comfort in talking about them."

"Bring the child into conversations, stop missing them off, just because they are dead doesn't stop them being part of the family."

"Ask us about our child. If you have memories of our child, share them with us. We may not have heard it before and it makes our heart smile."

## 11. Is there anything you'd like to add?

### Themes

- It is important to raise awareness of this subject. This means so much to us.
- We are lonely.
- There's no time limit to grief.
- We want change to break the taboo.

"Even after 22 years Jenny is still very much in our thoughts and not in a sad way. But has inspired us to become the people we are today."

"Please bring more awareness, it's such a lonely place sometimes."

"There is no time limit on grief."

Research carried out by Caroline Taylor, Derian House Children's Hospice.

Sponsors: Karen Edwards OBE, Chief Executive, Derian House Children's Hospice, Kiki Deville, Patron, Derian House Children's Hospice.

For your bravery, honesty and generosity. Thank you to the parents of:

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