A “WISH LIST”: TIPS FROM BEREAVED PARENTS

HOW TO HELP GRIEVING FAMILIES

The death of a child is possibly the most profound human experience. Bereaved parents describe their devastation, their grief and their isolation. This isolation can be helped by a “wish list” written by bereaved parents, for bereaved parents to give to others.

Bereaved parents want to talk about their child. At a time when their need for understanding and support is paramount, they tell us that their family and friends are clearly uncomfortable talking about the child who has died. They usually understand the reason: people do not know what to say, but that does not mean the hurt parents feel is any the less. They sometimes describe avoidance behaviour where friends will cross the street so as not to engage them in conversation.

In order to gain support, bereaved parents may need to become the teacher themselves and educate their family and friends about what they are experiencing and need. Offering the bereaved parents a “wish list”, for them to give to others, can empower them. The bereaved parents might find it difficult to verbalise their needs so it can be helpful to have a tool that does not require too much explanation. If a parent is uncomfortable with the idea of actually handing the list to someone, perhaps it can be posted or left on the family notice board where it can be seen.

Such a list may give family and friends permission to be near a grief with all its pain. It may educate them that grief can have periods of anger, tears, sadness, depression, withdrawal, questioning, frustration and even laughter - and that this is all normal.

The list can explain that some days, the feelings are too raw and the bereaved parent may not want to talk. A hug communicates a lot.

Perhaps today is an anniversary, perhaps the child would have started school today or his little soccer team won the grand final without him. Birthdays and anniversaries are difficult - sometimes the anticipation is as bad, if not worse, than the day itself - but there can be other less recognisable events that cause distress also. Remembering an anniversary, in whatever way the parents wish, shows that their child is remembered and valued, and that they are not alone.

Friends and family need to understand that there isn’t a time limit on grief. It isn’t going to be “better” in 12 months or 2 years or 5. The void created by the death of their child cannot be filled with something or someone else and will continue to be empty forever. Even when well meant, saying that they should “move on” or “well, it is 2 years” shows a lack of understanding.

Whilst faith is a great comfort to many, well-meaning religious or other platitudes are not right for many bereaved families. Saying “she is in a better place” when a family does not have a religious background can cause distress. Similarly, if a family or the dead child had a strong faith, then a comment reflecting this will be welcomed and a comfort, while not necessarily lessening the parent’s grief. Having that awareness, perhaps not always shared, shows empathy.

Parents want and need to talk about their dead child. They want their family and friends to keep photos of them where they have always been. They want to hear stories of their child when they were in their aunt’s home. Perhaps it is a story they had not heard before and the telling of it will be a gift, a further part of the story of their son or daughter. Not all memories are sad and parents wish to talk about the happy times as well.

Perhaps more than anything else, a friend or extended family member needs to listen. Talking of their pain can be healing to a parent, as can crying. Being able to sit with a grieving mother or father, maybe in silence, can be a powerful thing. Sometimes you do not need to understand everything about another person’s grief to share it and help that person to heal.
Parents to whom I have given these lists report them to be helpful. They have said they reflect what they would have written themselves and it has made it easier in their relationships with their extended families. The lists can teach friends how to sit with despair without needing to change it.

It was Winston Churchill who said “Courage is what it takes to stand up and speak. Courage is also what it takes to sit down and listen.”

I have gathered these lists from various sources - some from Very Special Kids in Melbourne, Australia and some form part of the Bereavement Service, Footprints in the Sand, at Bear Cottage in Sydney, Australia.

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Bear Cottage is an initiative of The Children’s Hospital at Westmead
Sometimes family and friends find it very hard to know what to say to help and support people whose child has died. Often they worry about saying the wrong thing and upsetting the parents. Even more so, they avoid the subject or worse still, avoid you altogether. It is not that they don't want to be there for you. They may not know how to be there for you. This can be very difficult because in your grief, you will need the support of your family and friends.

Here is a wish list from a parent who has lost a child. This list could be given to family or friends or even just stuck on your fridge at home, to help your loved ones have more insight into what you need them to be, or say.

- I wish my child hadn't died; I wish I had them back.
- I wish you would not be afraid to speak my child's name. My child lived and was very important to me. I need to hear that they were important to you also.
- If I cry or get emotional when we talk about my child, I want you to know that it is not because you have hurt me. It is their death that has caused my tears. You have allowed me to cry and I thank you. Crying and emotional outbursts are healing.
- I wish you would not let my loved one die again by removing their pictures, artwork or other remembrances from your home.
- Being a bereaved parent is not contagious, so I wish you wouldn't shy away from me. I need you now more than ever.
- I need diversions, so I do want to hear about you, but I also want you to hear about me.
- I might be sad and I might cry, but I wish you would let me talk about my child, my favourite topic of the day.
- I know that you think of me and pray for me often. I also know that my child's death pains you too.
- I wish you would let me know those things through a phone call, card, note or a big hug.
- I wish you wouldn't expect my grief to be over in a short period of time. I wish you could understand that my grief will never be over.
- I will suffer the death of my child until the day I die. Grief is a life-long process.
- I am working very hard in my recovery, but I wish you could understand that I will never fully recover.
- I will always miss my child and I will always grieve that they have died.
- I wish you wouldn't expect me "not to think about it" or "to be happy" Neither may happen for a very long time, so don't frustrate yourself.
- I don't want to have a "pity party" but I wish you would let me grieve. I must hurt before I can heal.
- I wish you understood how my world has shattered. I know it is miserable for you to be around me when I am feeling miserable. Please be as patient with me as I am with you.

The Compassionate Friends.

Part of ‘Footprints in the Sand’: Bear Cottage’s Bereavement Service
From A Parent who has lost a Child .... My Wish List:

1. I wish you would not be afraid to speak my loved one’s name. They lived and were important and I need to hear their name.

2. If I cry or get emotional when we talk about my loved one, I wish you knew that it is not because you have hurt me, the fact they have died has caused my tears. You have allowed me to cry and I thank you. Crying and emotional outbursts are healing.

3. I wish you would not let my loved one die again by removing from your home their pictures, artwork, or other remembrances.

4. I will have emotional highs and lows, ups and downs; I wish you would not think that if I have a good day, my grief is all over, or if I have a bad day I need psychiatric counselling.

5. I wish you knew that the death of a child is different from other losses and must be viewed separately. It is the ultimate tragedy and I wish you would not compare it to your loss of a parent, a spouse, or a pet.

6. Being a bereaved person is not contagious, so I wish you would not stay away from me.

7. I wish you knew all the crazy grief reactions that I am having are in fact normal. Depression, anger, frustration, hopelessness, and the questioning of values and beliefs are to be expected following a death.

8. I wish you would not expect my grief to be over in six months. The first two years are going to be exceedingly traumatic for us. As with alcoholics, I will never be a “cured” or a “formerly bereaved” person, but forevermore be recovering from my bereavement.

9. I wish you understood the physical reaction to grief. I may gain weight or lose weight, sleep all the time or not at all, develop a host of illnesses and be accident prone, all of which are related to grief.

10. Our loved one’s birthday, the anniversary of their death, and the holidays are terrible times for us. I wish you could tell us that you are thinking about them on these days. And if we get quiet and withdrawn, just know that we are thinking about them and don’t try to coerce us into being cheerful.

11. I wish you would not offer to take me out for a drink, or to a party, this is only a temporary crutch and the only way I can get through this grief is to experience. I have hurt before and I can heal.

12. I wish you knew that grief changes people. I am not the same person I was before my loved one died and I will never be that person again. If you keep waiting for me to “get back to my old self” you will stay frustrated. I am a new creature with new thoughts, dreams, aspirations, values and beliefs. Please try to get to know the new me — maybe you will still like me.
Poems to teach others about your grief

Sometimes family and friends find it difficult to know how to relate to grieving parents and it can be good to give them some assistance.

Writing a letter to let them know how to support you can be easier than telling them face to face.

In addition here are a few poems that you may like to show someone you know:

PLEASE, don't ask me if I'm over it yet.
I'll never be over it.
PLEASE, don't tell me "he's in a better place."
He isn't here with me.
PLEASE, don't say "at least he isn't suffering."
I haven't come to terms with why he had to suffer of all.
PLEASE, don't tell me you know how I feel,
Unless you have lost a child.
PLEASE, don't ask me if I feel better.
Bereavement isn't a condition that clears up.
PLEASE, don't tell me "at least you had him for so many years"
What year would you choose your child to die?
PLEASE, don't tell me "God never gives us more than we can bear."
PLEASE, just say you are sorry.
PLEASE, just say you remember my child, if you do.
PLEASE, just let me talk about my child.
PLEASE, mention my child's name.
PLEASE, just let me cry.
You Can't Win With Me

If you say to me “How are you going?” with such sympathy and meaning in your voice. I reply “I'm fine” and brush you off, because to talk about my loss with you today is too painful.

If you see me and don’t mention the loss that is consuming my thoughts, I think you don’t care enough, or are too scared to mention it for fear that you might upset me.

You can't win with me.

If you say "I'm sorry your baby died," it is hard for me to reply to that.

What do you expect me to say?

I want to say "I'm sorry too!" or "It's awful."

I want to scream "It's not fair."

But I won't because I don't want to upset myself today, not in front of you. So I reply “Thank you.”

That thanks mean so much more than that.

It means thanks for caring, thanks for trying to help, thanks for realising that I'm still in pain.

If you don't know what to say to me, that's okay because I don't know what to say to you either.

If you see me smile or laugh don't assume I must have forgotten my baby for the moment, I haven't, I can't, I never will.

Tell me I look good today. I will know what you mean.

I'm getting good at picking up on unspoken cues from you.

If you see me and think I look upset or sad you are probably right.

Today might be an anniversary day for me, or some other event might have triggered a wave of grief in me.

If you don't say anything I'll think you don't care about me but if you do say something, it might make me feel worse.

You could try asking if I want to talk, and don't be surprised if I say no.

You can't win with me.

Don't give up on me, please don't give up.

I need your attempts however feeble, however trite you might feel they are.

Need your thoughts: need your prayers: need your love: need your persistence.

Need all that but most of all I need to be treated normally, like it used to be before all this happened.

I know it's impossible. That carefree, naïve person is gone forever, and I am mourning that loss too.

So you can’t win with me.

By Jane Warland (1994)