

Bereavement Support Resources

Supporting Bereaved Families

Working with families can be emotionally challenging; which can feel daunting, especially when a baby or child has died. Supporting bereaved families includes good communication and being emotionally self-aware. It is important to be able to reflect on your own experiences and needs and your own attitudes to death and dying. This can help you to be aware of your own reactions and therefore how you support others.

Poor communication can intensify and prolong a families distress; good communication can help families in their grief with long-lasting positive effects.

Good communication involves:

- Listening to the words, tone of voice and feelings of others.
- Observing body language & facial expressions & noticing what is not being said as well as what is.
- Showing your interest through good eye contact, your tone of voice & body language.
- Checking with the person that they have both heard and understood what is being said.

What can help

- Acknowledge their bereavement.
- Be led and guided by the family.
- Offer any support that you can.
- Offer to find additional support and sign post if appropriate.
- Be patient.
- Seek support yourself

Child Bereavement UK Webinar - Primary School Age

CBUK

Support children, young people (up to 25 years), parents and families. They also support professionals to support bereaved families.

Tel: 0800 02 888 40

Email: support@childbereavementuk.org Website: www.childbereavementuk.org

Child Bereavement UK are offering free bereavement awareness webinars for schools (but it would be useful for anyone working with children). Professionals can book via the following link

<https://www.childbereavementuk.org/bereavement-awareness-training-for-education-providers>

Each training session focuses on:

- An overview of grief and bereavement
- Children's understanding of death
- Models of grief and an understanding of children's responses
- Factors affecting grief
- Practical ideas for managing pupil's responses to their grief
- Creating a bereavement aware culture; policies and procedures
- Local and national pathways for support

Death, Grief and Bereavement

It is common to worry about saying the wrong thing, but saying nothing can be perceived as not caring. The worst has already happened; no words can make the situation worse so just say it.

Grief reactions

- Emotions: sadness, anger, fear, guilt, relief, numbness, confusion loneliness, shock/anxiety.
- Sleep problems.
- Eating problems.
- Imagined illness: knot in throat/stomach, headache. May be due to emotion rather than physical.
- Regression in behaviour, sleep, development
- Separation anxiety
- Lack of confidence.
- Loss of focus/concentration

Children are good at masking or pretending all is ok.

School is seen as a place of normality, stability and security. It offers routine, refuge and support by trusted adults. COVID-19 has made this more difficult; more children may be bereaved and lots of going to school, they have lost routine and trusted adults.

Few children require specialist support.

Some children cope with 121, family or peer/group support.

Most children cope and don't need any specialist support; they can use current trusting relationships.

When someone is not expected to live information sheet -

<https://www.childbereavementuk.org/Handlers/Download.ashx?IDMF=bb9053ac-6e5d-4351-8400-863896a9cc26>

Sudden death including accidents, suicide and homicide –

<https://www.childbereavementuk.org/sudden-death-including-accidents-suicide-and-homicide>
<https://www.childbereavementuk.org/managing-a-sudden-death>

| Helpful Language | Unhelpful Language |
|---|--|
| It is not your fault – offers reassurance | She is a star watching you – increases anxiety, may feel they're being watched; take it literally |
| Most will get better | You need to be brave – they need to acknowledge emotions and shouldn't take on any responsibilities. |
| Body isn't working anymore; it doesn't need food/drink, it doesn't feel pain. | Grandad has passed away – they can take it literally, needs explanation. |
| What is your favourite memory | Grandma died in her sleep – may lead to sleep problems. |

Try not to use euphemisms; explain clearly what has happened. Use the proper language; children are exposed to death and dying through media and talking to friends.

Children's Understanding of Death

<https://www.childbereavementuk.org/Handlers/Download.ashx?IDMF=6c118a29-2f1a-4024-ba9e-c44701b1ff3e>

| Age | Conceptual Understanding | Feelings/Behaviour |
|--------------------|---|---|
| Up to 6 months | <ul style="list-style-type: none"> • Withdrawal of familiar person • Emotional withdrawal of main carer | <ul style="list-style-type: none"> • Abandonment; insecurity; crying in protest. • Disrupted sleep and feeding patterns. |
| 6 months – 2 years | <ul style="list-style-type: none"> • Developing 'object constancy awareness' • Can 'miss' someone. | <ul style="list-style-type: none"> • Separation anxiety, searching behaviour. • Withdrawal. |
| 2 – 5 years | <ul style="list-style-type: none"> • Interested in death, but no sense of its permanence or irreversibility. • Concrete thinking. | <ul style="list-style-type: none"> • Expectation of return/clingy. • Constant questions. • Regression |
| 5 – 8 years | <ul style="list-style-type: none"> • Fuller understanding of death. • Magical Thinking • Developing 'conscience' so can feel guilty. | <ul style="list-style-type: none"> • Fear the death of others. • Often extremes of good/bad behaviour. • Egocentric. |
| 8 – 12 years | <ul style="list-style-type: none"> • Understands permanence, universality and consequences of death. • May develop fear of own mortality. | <ul style="list-style-type: none"> • Anxiety about own health/death. • Preoccupied at school. • Possibility of social withdrawal. |
| 12+ years | <ul style="list-style-type: none"> • Puberty – time of great change. • Understands impact of death on their life. • Emotional maturity may not equate to physical development. | <ul style="list-style-type: none"> • Strongly held views; reluctant to ask for help. • Challenge own beliefs and those of others. • Question their own mortality. • May take grief outside of family. |

Theories of Grief

<https://www.childbereavementuk.org/how-we-grieve-and-what-may-help>

Worden's Four Tasks of Mourning

To accept the reality of the loss.

TASK #1



TASK #2

To process the pain of the grief.

To adjust to a world without the deceased.

TASK #3



TASK #4

To find an enduring connection with the deceased while embarking on a new life.

Reference:
Worden, W. (2009). *Grief Counselling and Grief Therapy - A Handbook for the Mental Health Practitioner*. New York, USA: Springer Publishing Company.

Have to work through the stages; it can be hard. Individuals don't have to move through the stages in order and can go back & forth between them and re-visit stages.

GROWING AROUND GRIEF

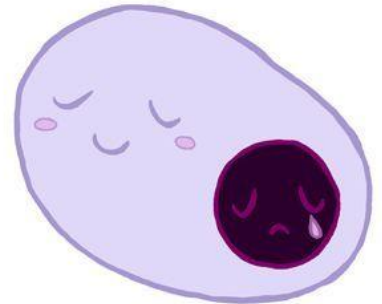
HERE IS A NEW WAY OF THINKING ABOUT GRIEF AND RECOVERY:



THIS CIRCLE REPRESENTS A LIFE THAT IS TOTALLY CONSUMED BY GRIEF.



ONE SHOULD ACCEPT THAT THE GRIEF WILL NEVER ENTIRELY DISAPPEAR, BUT OVER TIME IT WILL BECOME A SMALLER, MORE MANAGEABLE PART OF LIFE.

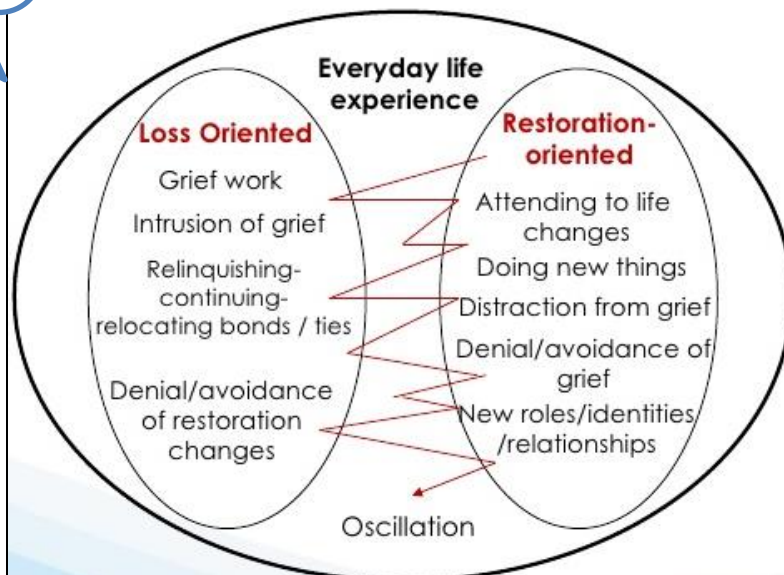


EVEN THOUGH THE GRIEF IS STILL THERE, A NEW LIFE EXPANDS AROUND IT; ONE IS ABLE TO GROW AROUND GRIEF.

People can jump between the different stages quickly and without warning.

The Dual Process Model

Stroebe & Schut, 1999



- Factors that can affect the grieving process:
 - Relationship with the person who died
 - The Circumstances of death
 - The environment
 - The individual; personality & background.
- Grief is personal and different for everyone and therefore people have different needs.
- Try to focus on the grief rather than the circumstances of death; can be particularly difficult after a traumatic death/suicide.
- Don't make assumptions about how the child/family are coping or about culture can impact.
- Given children the opportunity to talk, but don't worry if they don't want to. Offer reassurance. Help children to understand that members of their family may be feeling sad and may respond in different ways in some situations.
- There is no quick fix.

Secondary losses

Although these are adult worries, they will impact on children. They may feel they have more responsibilities or they will see the impact of the worries on their Parents/Family members.

- Home life changes
- Financial
- Security
- Friends
- Role in family

Children's behaviour can change as they go through the grief process. It's important to focus on their bereavement rather than their behaviour. Offer support rather than discipline. Encourage children to talk about it "tell me about it", "how does it make you feel". Acknowledge what they say, they may not say it again and be aware of the bigger picture. Triggers may be at puberty/maturity, anniversaries, changes at home etc. Keep boundaries in place, but be flexible.

What to Children need from School?

- Acknowledgement
- Understanding
- Control/normality.
- Space and time to grieve; allow them to leave the room if they feel stressed/emotional
- Someone to share their journey; have a named person that the child can go to
- Honesty
- Permission to grieve.
- Ask open questions, allow for silence.
- There is no magic cure.
- Grief can ripple through a friends/peer group; it's important to support the other pupils too.
- There is a bereavement policy framework and template letters on CBUK website
<https://www.childbereavementuk.org/developing-a-bereavement-policy>

Why is it important to teach death, grief and bereavement

- To prepare for the future
- Normalises feelings
- Develops emotional literacy and resilience.
- Teaches children about empathy
- Highlights myths and euphemisms.

- Gives children the opportunity to ask questions.

Other Resources

<https://www.childbereavementuk.org/online-learning-for-schools> - supporting a bereaved pupil. Free training tool for school staff to help understanding, skills and confidence to support pupils and their families and how to incorporate the concept of death and grief within the classroom curriculum. Includes SEND understanding of death.

http://sabp.lgfl.org.uk/section_B3_a.html - Managing grief - emotions
http://sabp.lgfl.org.uk/section_B3_b.html - Managing grief - behaviours

<https://www.childbereavementuk.org/get-your-elephants-tea-party-download-pack> - a free to download activity pack for primary age children and secondary school children. Helps to introduce the concept of death in the class if a pupil has been affected.

<https://www.childbereavementuk.org/coronavirus-supporting-children> - supporting children through Covid-19, particularly important if not in school or seeing anyone. With links to useful information including: Delivering sad news, managing grief, remembering & understanding death.

<https://www.childbereavementuk.org/supporting-bereaved-children-and-young-people> - specific information sheets available for supporting bereaved children.

<https://finkcards.com/products/conversations-about-loss-and-change> - fink cards to aid conversation. They are available for KS1/2/3 for a charge.

<https://www.childbereavementuk.org/Pages/Category/working-with-bereaved-families>

<https://www.childbereavementuk.org/resources-for-children-and-young-people> - books for different age groups.

CBUK Care for the Caregiver

- ☀️ Be gentle with yourself!
- ☀️ Remind yourself that you are an enabler not a magician. We cannot change anyone else, we can only change how we relate to them.
- ☀️ Find a hermit spot. Use it daily.
- ☀️ Give support, encouragement and praise to peers and to management.
- ☀️ Learn to accept it in return.
- ☀️ Remember that in the light of all the pain we see, we are bound to feel helpless at times. Admit it without shame. Caring and being there are sometimes more important than doing.
- ☀️ Make space for some flexibility and spontaneity in your life.
- ☀️ Learn to recognise the difference between complaining that relieves and complaining that reinforces negative stress.
- ☀️ On the way home, focus on a good thing that occurred during the day.
- ☀️ Be a resource to yourself! Get creative – try new approaches. Be an artist as well as a technician.
- ☀️ Use supervision or the buddy system regularly as a source of support, assurance and re-direction.
- ☀️ Avoid 'shop talk' during breaks and when socialising with colleagues.
- ☀️ Schedule 'withdraw' periods during the week – limit interruptions.
- ☀️ Say "I choose" rather than "I should", "I ought to" or "I have to", say "I won't" rather than "I can't".
- ☀️ If you never say "no" – what is your "yes" worth?
- ☀️ Aloofness and indifference are far more harmful than admitting an inability to do more.

June 2020

SANDS – Supporting families through pregnancy loss & the death of a baby

Sands is the leading stillbirth and neonatal death charity in the UK. It aims to reduce the number of babies dying and to ensure anyone affected by the death of a baby receives the best possible care and support as long as they need it. Sands provides bereavement support via free helpline, mobile app, online community and through support groups.

Tel: 0808 164 3332

Email: helpline@sands.org.uk Website: <https://sands.org.uk/>

App: Sands bereavement support app available on apple and google play.

Sands are offering free webinars for any professionals working in maternity and neonatal services or supporting a family following a loss of a baby. <https://sandswebinar.eventbrite.co.uk/> The sessions cover principles of excellent bereavement care and are designed to support professionals to support families. Each session covers the following topics:

- The patient experience
- Grief, loss & trauma
- Effective communication
- Memory making
- Enabling informed choice
- National bereavement pathway
- Support for professionals.

#finding the words. The death of a baby is life changing for families and excellent care is crucial to their long term wellbeing. When staff are well supported, families are well supported. Be gentle with yourself – we are all human. <https://youtu.be/jSw8rIRFeE> .

Baby Loss:

- Miscarriage
- Termination of pregnancy due to fetal anomaly
- Stillbirth/intrauterine death
- Neonatal death
- Sudden and unexpected death of an infant (SUDI)

Parents are likely to experience shock, grief, trauma, disbelief and emotional anaesthesia. They are also more likely to develop mental health conditions such as depression, anxiety, post-traumatic stress and phobias. High quality care and communication can moderate this immediate and long term negative outcomes.

Understanding the nature of baby loss:

- The uniqueness of the experience – every pregnancy, birth, death and loss is different.
- Physical nature of birth and postnatal recovery.
- Feeling of isolation
- The lifelong impact
- Impact on self-esteem and self-image
- Sense of pride for a much loved baby.

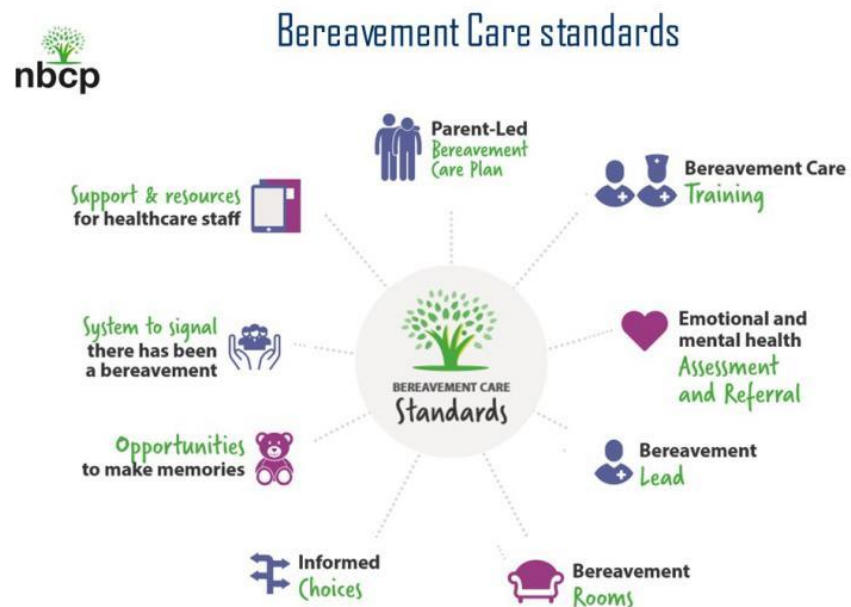
National Bereavement Care Pathway - <https://nbcpathway.org.uk/>

The NBCP seeks to improve the quality and consistency of bereavement care received by Parents in NHS trusts after pregnancy or baby loss.

There are 5 pathways in total:

1. Miscarriage (including molar and ectopic pregnancy) <https://nbcpathway.org.uk/pathways/miscarriage-bereavement-care-pathway>
2. Termination of Pregnancy for fetal abnormality. <https://nbcpathway.org.uk/pathways/termination-pregnancy-fetal-anomaly-topfa-bereavement-care-pathway>
3. Stillbirth <https://nbcpathway.org.uk/pathways/stillbirth-bereavement-care-pathway>
4. Neonatal death <https://nbcpathway.org.uk/pathways/neonatal-death-bereavement-care-pathway>
5. Sudden unexpected death of an infant. <https://nbcpathway.org.uk/pathways/sudden-unexpected-death-infancy-sudi-bereavement-care-pathway>

The 9 bereavement care standards were launched during baby loss awareness week in 2018. They form the basis of the national programme.



Every NHS trust should ensure the following:

1. A Parent-led bereavement care plan is in place for all families, providing continuity between settings and into any subsequent pregnancies.
2. Bereavement care training is offered to staff who come into contact with bereavement parents, and staff are supported to access this training.
3. All bereaved parents are informed about and, if requested, referred for emotional support and for specialist mental health support when needed.
4. There is a bereavement lead in every healthcare setting where a pregnancy or baby loss may occur.
5. Bereavement rooms are available and accessible in hospitals.
6. The preferences of all bereaved families are sought and all bereaved parents are offered informed choices about decisions relating to their care and care of their babies.
7. All bereaved parents are offered opportunities to make memories.

8. A system is in place to clearly signal to all healthcare professionals that a parent has experienced a bereavement to enable continuity of care.
9. Healthcare staff are provided with, and can access, support and resources to deliver high quality bereavement care.

The Importance of Sensitive Communication

- Take time to gather your thoughts
- Be gentle, clear and honest
- Sit down, use eye contact, don't rush
- Consider your language
- Listen carefully, take the parents lead, use the babies name
- Express compassion, say I'm sorry

Empathy vs Sympathy:

<https://youtu.be/LB0PF14VAww>

“Sometimes I feel like my heart is going to break”
Sympathetic response – “Oh no that’s awful, I feel so sorry for you”

Empathetic response – “I am so sorry to hear how devastating and heart breaking its been for you”

Parents don't need people to feel sorry for them, but for them to understand what they may be going through, recognise their emotions and communicate back.

Helpful things to say:

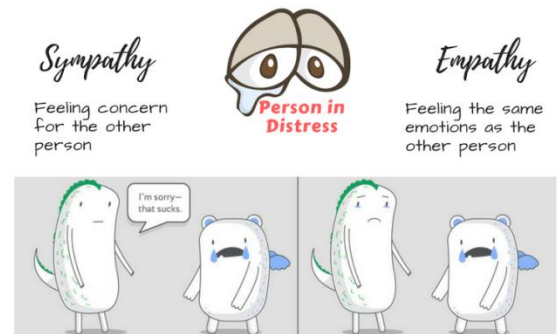
“Do what’s right for you and your family.”

“Take one step/day at a time.”

“This support is available...use what is helpful to you and leave what is not”.

<https://www.sands.org.uk/professionalsprofessional-resources/sensitive-and-effective-communication>

| SYMPATHY | EMPATHY |
|---|---|
| <p>1 Older Word</p> <p>The term Sympathy is the older of the two terms. By the mid-1500s it had already made its way into English language</p> | <p>Recent Word</p> <p>Empathy is the newer of both words and first appeared in English in 1909 when it was translated by Edward Bradford Titchener from the German 'Einführung'</p> |
| <p>2 About Showing Care or Concern</p> <p>A feeling of care and concern for someone, accompanied by a wish to see him better off or happier.</p> | <p>About Sharing Emotions</p> <p>The ability to recognize and share the emotions of another person. It involves seeing someone else's situation from his perspective and sharing his emotions.</p> |
| <p>3 Does Not Require Imagination</p> <p>Sympathy does not require imagination, you only have to feel concern for what the other person is experiencing.</p> | <p>Requires Imagination</p> <p>Empathy requires some imagination to allow an individual project their personality into understanding what the other person is experiencing</p> |



Empathy and Sympathy are similar words but they are not the same. The ability to express sympathy or empathy is important when dealing with people. When things go wrong sometimes it boils down to knowing the difference between the two words

Review & Investigation

Reviewing the death of every baby is not about blame, it's vital to:

- Understand what happened
- Identify improvements in care for future families

Staff Wellbeing and Support

- Acknowledge your own feelings of loss and/or trauma

June 2020

- Talk to colleagues, friends or the Sands helpline
- Access support systems already in place such as formal clinical debriefs
- Self-refer to professional support
- Remember to take care of yourself. You can't pour from an empty cup.

Additional Resources

<https://www.sands.org.uk/sands-bereavement-support-book>

<https://www.sands.org.uk/about-sands/sands-bereavement-support-app>

<https://www.sands.org.uk/sibling-support>

<https://www.sands.org.uk/support-you/how-we-offer-support/memory-box>

<https://nbcpathway.org.uk/professionals/training-healthcare-professionals>

<https://sands.org.uk/professionals/fewer-baby-deaths/reviewing-every-baby-death>

<https://people.nhs.uk/>

Please give families as much time, kindness, compassion, support, informed choice and signposting as you possibly can. You will only get one chance to help them through this devastating experience, and you have the potential to have a hugely positive impact on them.

Additional Useful Links

www.derbyshirebereavementhub.co.uk—provides information and links to organisations and services for bereaved people (of all ages) in Derby City & Derbyshire.

www.winstonswish.org—offers support to bereaved children, their families and professionals who support them.

www.treetopshospice.org.uk—Provides counselling, support and therapy to families.

www.thelauracentrederby.co.uk - offer counselling & support to parents whose child has died and to children who have been bereaved of a parent or significant other.

www.rainbows.co.uk—offer long term bereavement support, a bereavement suite with cold room, can assist with funeral arrangements & offer practical and emotional support.

www.derbysands.org.uk—stillbirth and neonatal death charity. Supporting anyone affected by the death of a baby.