

Navigating Grief:

Coping with loss in multiple births





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Written and illustrated by Emma Fogden

Drawn from her own experience of twins, stillbirth, miscarriages and her professional experience as a counsellor specialising in baby loss. The observations and advice in this booklet have been gathered from grief specialists, medical professionals and fellow counsellors and psychotherapists. Emma has also drawn from what has been useful to her clients who have been courageous enough to open up to her about their baby and twin losses and whose experiences and wisdom have informed this booklet.

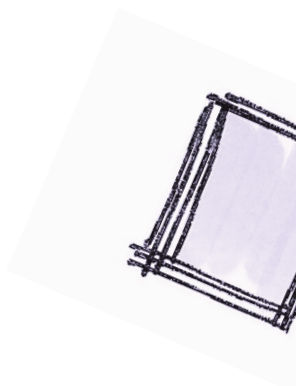
Please note, for ease of reading we use the term 'twin' and reference is made to a single baby dying as part of a multiple pregnancy, but the information is intended to apply to triplets and higher-order multiples as well.

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INTRO

Twins Trust supports all parents and carers of twins, triplets or more who have died whether it was during or after pregnancy. There are several ways to contact us, whether your loss was very recent or some time ago. There are many great resources online and links to groups or services that will be able to support you in a way that suits you.

For more information, please visit
www.twinstrust.org/bereavement.

Although bereavement can be a lonely process, you are not alone. Twins Trust has connections with professionals, volunteers and people who have gone through similar experiences to yours.

Whether you are a mother, a father, a heterosexual or gay couple, a solo parent, a birthing partner or a supportive friend or relative, this booklet offers ideas for navigating bereavement and what might lie ahead.

I have drawn on my own experience of twins, stillbirth, miscarriages and my professional experience as a counsellor specialising in baby loss. The observations and advice in this booklet have been gathered from grief specialists, medical professionals and fellow counsellors and psychotherapists. I've also drawn from what has been useful to my clients. I'd like to thank the hundreds of people who have been courageous enough to open up to me about their baby and twin losses and whose experiences and wisdom have informed this booklet.



TYPES OF LOSS

We hope this booklet is relevant to all bereaved parents of twins or more. However you have lost your baby – whether that was during pregnancy or after birth, you're likely to experience grief.



"Having that support network with Twins Trust has been absolutely amazing for me."



Sadly, twin or multiple pregnancies carry extra risks and so the chance of one or more of the babies dying is higher than with singleton pregnancies. You may lose your baby in ways experienced in singleton pregnancies, such as miscarriage, stillbirth, loss in infancy or termination for medical reasons. But you might experience or hear of complications that are more common to, or restricted to multiple pregnancies, such as disappearing twin syndrome, Twin-to-Twin Transfusion Syndrome (TTTS), foetal growth reduction or selective foetal growth restriction. All these types of loss are explored in more depth on our website. For more information, please visit www.twinstrust.org/bereavement.



GRIEF AND HOW YOU MIGHT FEEL

It can feel exciting to be pregnant with more than one baby and losing one baby, both babies or more, will lead to very difficult and complicated emotions. The feelings may be unfamiliar and unwelcome.

You might feel angry, sad, disbelieving, shocked, exhausted, lacking purpose, unable to find joy in anything, weighed down, devastated or alone. You might feel some of these, all of these or you may feel numb. People experience grief differently.

Grief is messy

Lots of people have heard of the five stages of grief – denial, anger, bargaining, depression and acceptance. They are sometimes talked about as if they happen one after the other. You're more likely to feel a mixture of emotions with no neat order. In fact, Kübler-Rossⁱ who named the five stages, makes it clear that the stages aren't linear. You may feel some of these five emotions, but it's unlikely to feel like a straightforward journey.

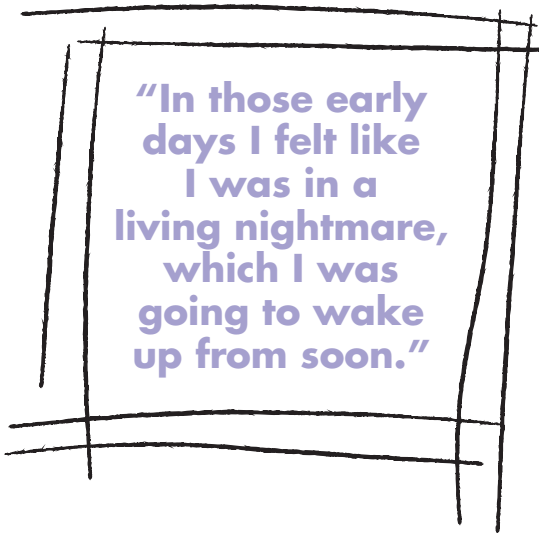
Grief is a deceptively simple word, but you won't just feel sad. You'll probably feel furious, terrified, outraged and frustrated and perhaps you might even feel grateful for your relationship with your baby, however short. You will probably feel everything at once and not be able to distinguish one emotion from another. Losing a baby can mean you lose your sense of stability and trust in the world and this can lead to anxious feelings. You may even have physical symptoms such as heart palpitations, shallow breathing, difficulty sleeping, tiredness, loss of appetite and even pains in your limbs, chest or stomach. These sort of symptoms, linked to anxiety, are very common, but if they continue or you are concerned, speak to your GP.

Nothing you feel is wrong

Society has plenty of unhelpful beliefs and rules about grief and baby loss; the people around us may have too. As losing a twin is more unusual than losing a singleton, there are even more misconceptions to navigate. Remember that every grief journey is unique. There is no normal. Allow yourself to feel as you do.

Your grief is valid

Losing a baby after they are born is devastating, but losing a baby or twins in pregnancy is also hard to bear. There is a misconception that if your baby dies before he or she is born, they don't count as much. Society can make us feel like our grief is disproportionate to our loss and that we're not entitled to grieve or that there is only a certain amount of grief that is acceptable. But babies don't begin at birth, it's long before that – at the point of conception or when we find out we're pregnant. However or whenever you lost your baby you're entitled to grieve.



"In those early days I felt like I was in a living nightmare, which I was going to wake up from soon."

The intensity of love that parents feel for their children isn't in doubt, so the intensity of grief shouldn't be underestimated either. Our grief is proportionate to how much a baby was longed for or how cherished they were in our minds, not what stage of pregnancy you were at when they died. There are few things – if anything – more traumatic than the death of a child. We don't expect to outlive our own children, so it turns the expected order of life upside down.



Tear up the timelines

Most parents agree the sharp pain of grief grows less urgent and painful over time. But many will talk about how it can still feel as though the death happened yesterday, even many years later. Ignore everybody else's timelines on grief. Don't be rushed. Mourning is done in different ways and at different speeds. What's important is that it isn't hidden away, unexamined, to reappear years later.

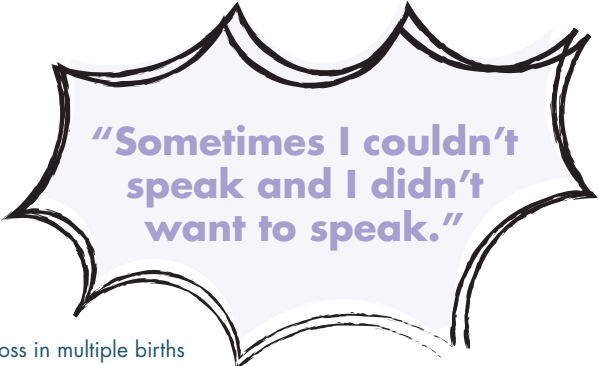
It might be tempting to bottle up your feelings, but that will make things harder in the long run. Parents who don't allow their grief will probably fare reasonably well initially, but in years to come, parents who haven't faced their grief will suffer more socially, emotionally, and even physically than other bereaved parents.ⁱⁱ It's important to allow your grief and if this feels overwhelming, to get help and support – either from friends, family, charities such as ours, or from professionals like your GP or a counsellor or psychotherapist.

Pain and happiness

After loss, grief might feel like the most direct connection to your baby or babies. Painful grief can feel like proof that our babies lived and were loved. If you lost your babies early, you might be one of a handful of people who knew your babies, so it may seem even more important to you that you honour these painful feelings. Happiness might even make you feel guilty for abandoning your baby. But you don't have to prove your suffering to anyone.

It's OK to have moments of happiness. You can spend time with the pain of grief but also put it aside long enough to get things done and feel alright.

The loss of a baby nearly always feels sudden. People dying after a long life can feel easier to accept. Babies or infants dying can feel very unexpected. Sudden death magnifies our sense of powerlessness. Give yourself time; baby loss, at any stage, is shocking.



"Sometimes I couldn't speak and I didn't want to speak."

Loss and belonging

After loss, you might feel like you lose your role, or the role you had looked forward to. You might no longer be an expectant parent or might not be able to look forward to looking after multiples. You may feel like you have lost your purpose. You might struggle to adjust to not having the special experience of multiples or you might struggle to find where you belong now.

The idea of finding closure – that eventually we're going to reach a complete recovery when a baby or babies die – isn't helpful. It shouldn't even be the goal. Relationships continue after death. The love you feel doesn't disappear. Death does end a life, but it doesn't end our relationship with that person. Parents often struggle to work out if their feelings for their babies who have died are appropriate. It might help to remember that we have the capacity to hold past loves within ourselves at the same time as our relationships with those who are living. We can still tend to our relationships with children who are no longer alive and those relationships can be very real and precious.

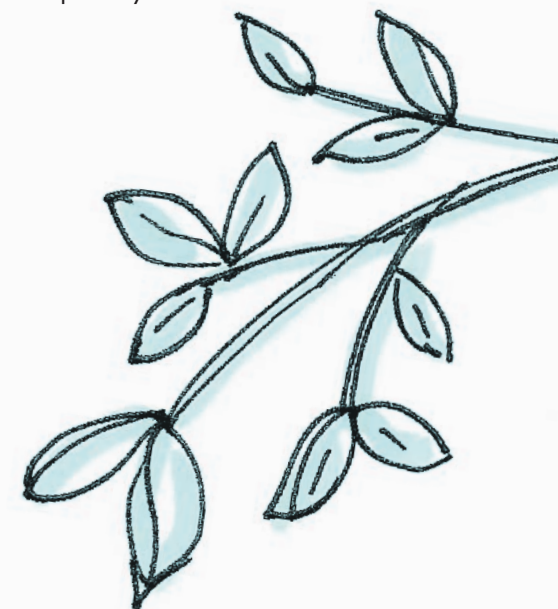


Hope and navigating the journey

There are reasons for hope. Grief doesn't disappear; your loss or losses will be a part of you from now on. But life does, eventually, grow up around it and new meaning can be found.

Healing and grief are hard work, but there are people out there to guide you and skills that you can learn to help you move through your emotions.

Grief can feel like setting off to sea in a leaky boat without a map or compass. We hope that this booklet will provide some help navigating the journey.



COMMON FEELINGS AROUND LOSS

Twins Trust's website has more detailed information about the different types of loss you might face and advice on what to do. For more information, please visit: www.twintrust.org/bereavement.

The emotions that parents feel losing twins or multiples are complex and varied, but there are some feelings that are often expressed. Below there are a selection of emotions, by no means comprehensive, that bereaved parents of twins experience. If you are troubled with any of these feelings, remember that you are not alone and can find people to talk to who will understand your experience.

It's not unusual to feel uncomfortable or ashamed if you didn't realise one of your babies had died; the majority of parents don't realise what's happened until a doctor can't find the heartbeat.

Not knowing why your baby has died can be extremely painful; it's harder to come to terms with what happened without an explanation. You may be consumed by feelings of 'what if' or want to research and find answers that aren't possible to know.

Many mothers blame themselves when they find out an unborn baby has died. It's hugely unlikely that anything you did, didn't do, didn't notice, ate, or drank, affected the baby. It's impossible that anything you felt while pregnant will have damaged your baby. Don't blame yourself, nearly every foetal death is completely beyond the mother's control.

When one or more baby dies but you are still pregnant, many parents feel very torn knowing that the mother is carrying both a living baby and one that has died. Feeling both hope and pain at the same time can be very disconcerting. It may feel impossible to grieve the baby that has died, while still being grateful and excited about the sibling that is still living. Most parents feel they're not doing well at one or either thing.

You may feel worried about seeing your dead baby. This anxiety ranges from what you might see, or have seen, if you have a miscarriage, to delivering a stillborn baby and how the baby will look. These concerns can make parents feel guilty, but they are very common feelings – speak to your nurses or visit www.twintrust.org/bereavement for support and advice.

You might need to grieve that you won't have a carefree pregnancy again. You're likely to lose the feeling of trust that everything will be fine that you might have enjoyed when you were pregnant before loss.

Death after birth is likely to hit all the family hard and will take time to grieve. You may have spent many agonising months visiting your baby in an intensive care unit for ill or premature babies tracking their progress, falling in love with them and hoping they get stronger only to have your dream of taking them home shattered. Give yourself plenty of time and find support.

If you've had to terminate a pregnancy for medical reasons, please search out support and take up any offers of professional help. Parents often blame themselves for their decision and this can be very hard to untangle and deal with alone. For more information about terminations for medical reasons, please read the Twins Trust TFMR booklet found on our resources page: www.twintrust.org/bereavement/support.html

Parents may feel the loss of the special experience of being a parent of twins or triplets. They might also feel grief on behalf of their surviving baby and the loss of their future relationships with their twin or triplet.



WHAT MIGHT BE DIFFICULT

Milestones and the unexpected

Every day might feel difficult. But some days and events are worse than others. Difficult events can be thought of as being divided into two – calendar dates, such as anniversaries, that you know are coming up and might be dreading – and the sideswipes that you weren't expecting and knock your feet from under you.

Milestones

You're likely to be dreading certain dates. Milestones such as due dates, birthdays and anniversaries are going to be difficult, particularly in the first year. Your babies' birthdays or due dates might be particularly hard. You may find your own birthday tricky if you had expected to be able to celebrate with your new babies. Holidays and religious celebrations might leave you feeling bereft as you don't have the family you had hoped for around you. Attending family events, especially those centring around children or attended by children, might be challenging. You may dread Mother's Day – many companies whose mailing lists you are on now have options to turn off online reminders, but it is still hard to avoid. Other events that my clients have struggled with are returning to work or going back to a hospital, even if it's to a different hospital or different part of the hospital.

"Initially I'd set myself goals to strive towards, even if it was just going out for a walk or having coffee with a relative or friend. In the beginning I felt terribly guilty about that but know in my heart my boys would want me to continue living life in the best way I can."

Help with milestones

When a milestone approaches, be gentle with yourself. Try to plan ahead and arrange a more restful day than usual and plan in a treat for yourself. Think in advance about if, and how, you'd like to mark the day. You might want to do something private and simple like lighting a candle or you may want to avoid being alone.

The three Cs

When you're hit by an anniversary, it may be useful to consider the three Cs: Choose, Connect and Communicateⁱⁱⁱ.

Choose – you might not feel like doing things that you used to find easy. Try to recognise your limits. Allow yourself to say 'no' to things that you're dreading or when you have no energy, particularly in the early weeks and months. Attending to your grief will mean putting yourself first sometimes.

Connect – humans are wired for connection. Loneliness and isolation will increase grief, so don't cut yourself off. Search out and reach out to people who make you feel comfortable.

Communicate – let people know what you need and what isn't right for you. This might feel awkward at first if you're not used to doing it.

The unexpected

These are the things that you can't plan for in advance. It might be seeing a pregnant neighbour or a post on social media about an acquaintance's new baby or an invite to a baby shower. It's normal to feel very shocked and emotional. Your reaction might be so intense that you feel physical pain, or your breathing might be affected and this is actually very common.

Help with the unexpected

If you feel really impacted or unregulated by something you see or hear, there are things you can do to calm your body.



Calm your body

When we are shocked, the chemicals adrenaline and cortisol are released into our bloodstream and surge through our bodies. Before long, they will run their course and your body will restore its normal chemical balance, particularly if you try to calm and reassure your body.

A calming exercise

Breathe

Try taking slow deep breaths in, with longer out-breaths. Focus on breathing out as slowly as possible until your lungs feel completely empty. Then allow your lungs to refill gently. Notice the sensation of the air in your lungs and your rib cage filling up. Some people find that counting 7 in and 11 out is about right, but you don't have to count, just concentrate on nice long out-breaths. Look around and remind yourself of your surroundings, the floor beneath your feet or the view out of the window. See if you can let your thoughts come and go without judging or exploring them, like watching leaves floating down a river.

Social media and the internet

The internet is brilliant at providing information immediately and stories and reassurance from people who have suffered similar losses to you. However, you can stumble across things that are painful to read, even from well-meaning people. Lots of social media is unregulated and moderated groups can feel safer. If you would like to join one of our private online peer support communities, please visit www.twinstrust.org/bereavement

"I turned to my other huge source of support; the Twins Trust online communities for bereaved parents. I'd joined the group after my first loss, and found great comfort from the gentle understanding of those who just get it; those who have felt the very things I feel."


Grief top trumps

Don't allow anyone, particularly strangers on the internet, to inadvertently or deliberately belittle your grief by sharing how their losses are worse. If someone tries to play 'Grief Top Trumps' with you, please disengage; it's not useful and you don't need to compare or justify how you feel. After all, a doctor doesn't come into a waiting room and send everyone home except the person with the worst injuries or illness. We're all entitled to compassion and when we're experiencing intense grief, it's not usually helpful to be told that other people have it worse.

Forbidden feelings

Other people's babies and pregnancies are likely to make you feel jealous. Their good fortune can make you feel your own loss even more acutely. Jealousy in less difficult times can be useful, as it shows us what we want. It's harder when we already know we desperately want our baby. Many of us have been taught that jealousy and envy are not acceptable emotions. They are, however, very common and powerful feelings.

When we are dealing with grief, we might struggle to feel pleased about friends' good news, and in turn, feel bad about not being able to be 'a good friend'. Bereaved mothers and fathers often struggle with what they feel are ugly emotions. Be kind to yourself and avoid situations that are confronting for a time. You are not your ugly feelings and you will make things worse if you beat yourself up about having them. Allow the feelings and over time, as your loss becomes more integrated into your life, you're likely to feel more able to appreciate other people's joys and successes.



“I noticed pregnant women and twins everywhere, and at times it felt like the world was mocking us. There were points at which I didn’t know how I was ever going to get past those feelings and found it hard to imagine being happy again.”

Why me?

As their brains struggle to make sense of their loss, it’s very common for parents to ask themselves, ‘what did I do to deserve this?’ or ‘why did this happen to me?’

Distressed brains don’t like uncertainty, they want answers, even when there aren’t any.

It can be hard to accept that something so unfair and awful is random. The only answer is unfortunately life doesn’t hand out bad and good experiences fairly and that, yes, it IS really unfair – you don’t deserve this and it definitely wasn’t anything that you did.

You might try to bargain in your mind, wishing that you could swap your babies’ deaths with someone else’s or even your own. Please know that this is common, although not often talked about. If your feelings are suicidal, please reach out to your GP, or a suicide charity right away. There are lots of professionals and trained volunteers who will not be shocked by your thoughts and are trained to support you.



Flashbacks

It’s normal to run through the most awful moments of your loss again and again. When you remember terrible moments and the details are very vivid and the feelings are almost the same as when they happened, this is called a flashback. Events such as returning from hospital without a baby or going home from a scan knowing your baby is dead, or the moment you were told that the nurse couldn’t find a heartbeat, can be deeply traumatic. These moments might play like a film in your mind. You might feel like you are living through the most difficult events, over and over again.

Flashbacks are especially common with traumatic loss – and losing a baby or babies is traumatic. It’s normal to have flashbacks regularly and for some time following the event. If your flashbacks continue to be just as vivid and just as upsetting after a number of months, you might have post-traumatic stress disorder. Seek help from a GP or professional who will offer advice and perhaps suggest counselling.

Complicated grief or prolonged grief disorder

These terms were categorised relatively recently^{iv} but they are becoming better known. Around 7–10% of those suffering grief fit into this group^v. They describe people who feel very intense grief, undiminished in strength, after 12 months. It’s different from depression, as those who died are more or less constantly in the person’s thoughts and actions. If you feel like this, please go to your GP, or seek professional help long before a year is up. After a year, most people still experience grief, but the waves of grief don’t come so close together and many people get better at predicting when the sea is going to get choppy.

It takes time

Grieving can be a long, sometimes even lifelong process. It doesn’t mean that you’ve somehow got grieving ‘wrong’ if a milestone or the unexpected hits you hard sometime later. You’re just reworking your loss. If you see children heading off to school for example, you may need to grieve that your child didn’t get to do that. If you’re devastated by your baby’s anniversary or years later find yourself breaking down at a friend’s pregnancy, don’t worry, you aren’t back to the beginning when you first experienced your loss. You do still have the resources you’ve built up over time, you’re just readjusting and revisiting what you’ve lost.

PRACTICAL IDEAS FOR DEALING WITH GRIEF

As a therapist, I'm going to promote talking about your feelings and experiences. But self-care is up there too. There are some great suggestions below, but please bear in mind self-care is as individual as grief. It's a really good idea to remind yourself to look after your body and make healthy choices. You might not feel like looking after yourself when you are grief-stricken and that's just when you will need all your strength. It makes perfect sense to take care of ourselves, but we often neglect to do so.

You need to experiment with what helps you. If you set yourself the type of self-care that works for your best friend rather than you, you'll end up frustrated. Social media can make us feel that only doing yoga balanced at the top of mountain will do. Listen to what feels right for you and that might mean yoga, but it might occasionally mean pizza in front of your favourite comedy.

Ideas for self-care

Do your best to eat a balanced diet.

Write a list of five of your good qualities and refer to it if you feel self-criticism creeping in.

If you are religious, draw on your faith and religious community to bring you comfort.

Move! Physical activity can displace anxiety.

Get outside and look up, not at your feet.

Try some breath work: get comfortable, close your eyes and breathe in deeply. Make your out-breath very deliberate and longer than your in-breath. Repeat seven times.

Listen to a playlist of uplifting music.

Get plenty of sleep.

Notice the good moments and write them down.

Drink more water and fewer caffeinated drinks.

Creative ideas

Write a journal, record events, but also let your feelings flow.

Try free writing: write down your thoughts raw and unfiltered.

Write the story of your baby: begin with when you found out you were pregnant. Include conversations you had and plans you made.

Create a collage or piece of artwork to remember your baby.

Catch your feelings in a poem.

Write a letter to your future self or your baby. Don't worry about the finished article, or if you're not artistic – getting your thoughts down on paper can be very cathartic.

The right kind of talking

Search out people who are empathetic and have time to listen. This might be family and friends, but you may find that you get more of the right kind of listening further afield – by connecting to people who have had similar experiences. Consider joining one of Twins Trust's online peer support communities: www.twinstrust.org/bereavement

The tradition of not telling people you are pregnant until after the 12-week scan doesn't always help the bereaved. It could mean that you lose a baby or babies before people know you are pregnant. If you are pregnant again after a loss, consider if there might be people you want to tell earlier, so they can support you. But equally, think about if you find updating people upsetting, or if friends checking in with you feels unsettling. As ever, it comes down to what's right for you.

Dealing with change

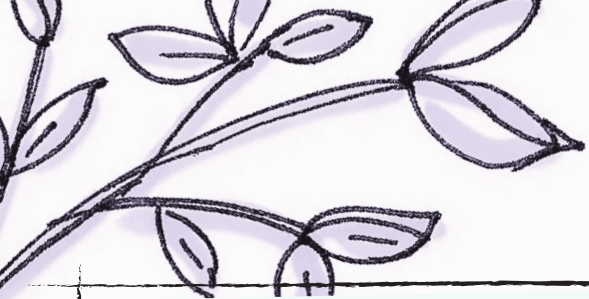
Losing a baby or babies is going to change you. Some families and friends find it hard to accept change or might find it hard to accommodate how you have changed. In groups where change is hard to accept, then open conversations can be hard to have. Try to create an atmosphere where you are honest and ask and answer questions. If this doesn't seem to work, you might find this support and frank conversation in other circles where you feel a better sense of acceptance or belonging.

Flow of energy

Pay attention to your rhythms. Are there times of day when things feel easier? Connect with your grief rather than ignoring your feelings, but then allow yourself to focus on other things when you can.

Dealing with anger

You may feel very angry. Anger can feel more energising than sadness, but it's exhausting to carry anger around in your body day after day. Try discharging it with exercise, laughter or a calming technique.



A calming exercise

Grounding

If you feel overwhelmed with anger, try this simple exercise to stop your feelings overtaking you by connecting with the world around you.

Plant your feet on the floor, then push them firmly down, noticing the ground supporting you. Notice the muscles in your legs tensing and the feelings in your whole body, right from your head. Now picture them flowing down into the ground. Then look around and note what you can see and hear. Slowly pick out five things in the room or your immediate surroundings. Check in with your body and see if your anger has lessened.

Dealing with sadness

Many people fear that their sadness will overwhelm them, or think that if they start crying or talking, they will never stop. It can feel dangerous to open up. This isn't my experience or what I see with nearly all my clients. Most people benefit from expressing their sadness.

When you find time, a private space and an empathetic person to talk to, it's nearly always better to allow your sadness to pass through you, rather than resisting. Pushing down your feelings takes a lot of energy and feelings have a habit of escaping anyway. It might feel dangerous to start feeling and talking honestly, but doing so lets you know that you can be overwhelmed, cry and then gather yourself afterwards to face the rest of the day.

A calming exercise

The five senses

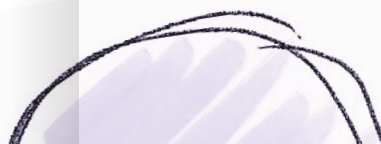
If you feel overwhelmed with sadness, have a go at this short exercise to centre yourself and engage with the world around you.

Pause and notice your breathing. Slow it down and feel your body calming. Engage your five senses one by one. Look around you and pick out one thing you can see. Observe it carefully. Then turn to your sense of touch and feel what your fingers are touching – the material of your chair or the texture of your sleeves. Then engage with your sense of smell. What does the environment you're in smell like? Concentrate on your mouth – can you taste anything? Finally listen and notice everything that you can hear. Return to your breathing. Take deep in-breaths and long out-breaths. Check in with your body again and see if your sadness has reduced.

Dealing with guilt

Parents often feel guilty that they didn't somehow sense there was a problem with their baby earlier, or that they didn't ask more questions or insist on another scan; or any number of other things which are unlikely to have made any difference to the outcome.

It doesn't usually work to tell yourself you aren't guilty and it may feel dismissive if friends simply tell us we didn't do anything wrong. It's like saying, 'don't worry!' to someone who is very worried. It might be helpful to find a friend who is a good listener or a therapist to talk to and ask for time to share your feelings of guilt. Being allowed to express your guilt, however misplaced it is, is often more useful than simply being reassured you didn't do anything wrong – although that has its place too.



Marking your loss

Your baby or babies mattered and lived. Remembering your baby in a concrete way is often a helpful way to mark how important they are. These are ideas that parents have found helpful either to mark anniversaries or just to create a lasting object to treasure.

Create a memory box. Fill it with what you have: photos if you have them, scans, outfits, the death certificate, or a cuddly toy.

Mark your babies' anniversaries with cards and a cake.

Release a balloon.

Light a candle and take time to think about them.

Choose a necklace or bracelet to remember them by.

Raise money for a charity. If you would like to learn more about fundraising for Twins Trust, find out more at www.twintrust.org/bereavement/get-involved/fundraising.html

Write a letter to your baby.

Plant a tree, perhaps with a plaque.

"We light a candle in front of a frame with her date of birth, her weight and date of gestation on it."

Helpful ideas for difficult days

These ideas are drawn from things bereaved parents have told me are comforting ideas or helpful mantras in dark times.

Go with the plan not the mood.

Give in to bad days.

You never get over it, you get on with it.

You don't move on, you move forward.

The weight of loss won't go, but you'll get better at carrying it.

Don't expect yourself to manage things that used to be easy.

Prioritise yourself and say no.

WHAT'S HELPFUL AND WHAT'S NOT

It can be very painful when people say the wrong thing. Remember your family and friends care but they won't always get it right and that can be upsetting or might make you angry. People feel uncomfortable. It's not your job to smooth it over for them, but it might help to remember that if they haven't been through baby loss they won't know what it's like and they will make mistakes.

Unhelpful things you might hear

The things that hurt are different for us all, but these are phrases that you may well hear and are rarely reassuring.

At least... you can get pregnant.

At least... you still have one twin.

When my hamster died, I felt the same. You need to let it go and move on.

Stay positive!

It wasn't meant to be.

It could be worse!

Look on the bright side!

At least... you already have a child.

Early loss is easier.

How can family and friends help?

Offers of practical help can be very welcome, particularly in the early days. Prayers, texts and cards to show bereaved parents that they are in your thoughts can be comforting. But the grief-stricken also need to be listened to – to be given time to talk about their babies and how they're feeling. Do remember that fathers need this too, as they are sometimes overlooked.

Try not to rush your grieving friends or families, either when you listen to them or by making them feel that you had expected them to feel better by now. Grieving parents tell me they really appreciate people who let them remember and dwell on their loss for as long as they need.

Helpful things to say

If you're trying to support someone who has lost twins or other multiples, try these phrases to start a conversation or help them feel heard.

I'm here for you when you want to talk.

I don't know what it's like for you, but I'm here to listen.

I'm sorry that this has happened.

That sounds tough. How can I support you through this?

Healing takes time and it's OK to go at your own pace. I'm here for you however long it takes.

How are you doing today?

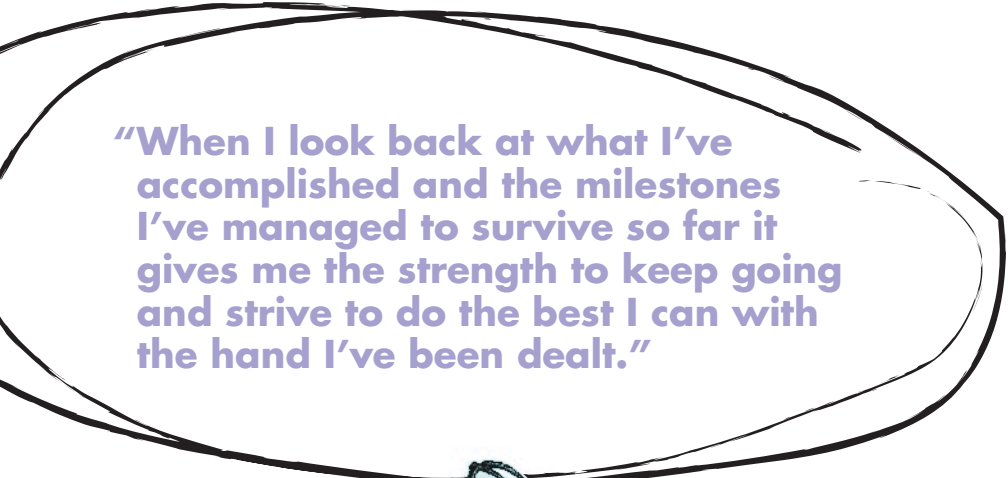
It's completely fine to feel like that.

You and your baby are in my prayers (if you're religious).



Helpful things to do

People who are grieving often find it hard to think clearly or be resourceful, especially in the early weeks and months. It's common for friends or family to say, 'just let me know what I can do.' However well-intentioned the offer, the bereaved parent might be at a loss for what to ask for, so may well not ask for anything. Try taking the initiative and making suggestions. Perhaps also give the person a get-out if they're not feeling up to it. Try this: – 'I'm free for a coffee tomorrow at 11am. Let me know if that suits you and don't worry about cancelling on the day if you're not feeling OK.' Or 'I'm going to bring some food round tomorrow at 5pm. I'll just hand it over if it's not a good time.' Or you could send a text or a card and make it clear you don't need a reply.



"When I look back at what I've accomplished and the milestones I've managed to survive so far it gives me the strength to keep going and strive to do the best I can with the hand I've been dealt."

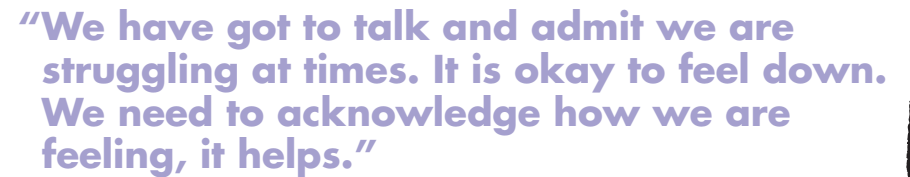


GRIEF'S IMPACT ON OUR RELATIONSHIPS

Grief puts a strain on our relationships. You're experiencing something very difficult and this will impact those around you.

Partners

If you have a partner, be wary of judging their reactions if they aren't the same as yours. Everyone grieves at different speeds and there might be a mismatch in your emotional states. Your partner might appear less devastated than you. Try to let this be a good thing. Perhaps they will be better able to handle the everyday chores that still need doing. Partners can become closer when they endure a loss together, but only if they're both able to communicate how they feel. Consider having counselling together as a couple. Counsellors will be able to facilitate you both being honest about how you feel in a safe space.



"We have got to talk and admit we are struggling at times. It is okay to feel down. We need to acknowledge how we are feeling, it helps."

Grandparents, siblings and relatives

Our relatives may also be sad to have lost a grandchild or niece or nephew, but they won't be as close to the pain as you. Try to recognise where the strengths of the people around you lie and draw on them. Some might be better in a crisis, some practical and some thoughtful. Allow them to play different roles. No one person can provide you with everything you need in grief.

You're bound to feel very tender and sensitive and the people around you will certainly get it wrong from time to time – forgive them wherever possible. You may feel that your family moves on and gets on with their daily lives way before you are ready and this can be lonely and upsetting. Talking to people who have been through twin loss can be comforting at this point.



“Although I miss my grandsons every day, I carry them in my heart and I will never forget them.”



Other children

Having an older child can help with a loss, as parents are forced to carry on for their living children. It can provide purpose. But this is simplistic – sometimes bereaved parents feel that the pain for the death of their child may overwhelm the love they feel for their existing children.

Supporting bereaved children

In the past, children were often shielded from death; well-meaning families kept the truth from them. But this leaves children confused and without the answers they need. Within the psychotherapeutic community, it's now generally accepted that children need information about the death of a sibling, just as adults do. However, this should be conveyed in age-appropriate and clear language. Try to follow the child's lead and don't overload them with information. After telling them something, check what they have understood so far. Without enough facts they might fill in the gaps themselves and what they imagine might be worse than what has actually happened.

There are no rules around whether children should go to funerals. You know your child best, so trust your instincts. If you're having a funeral for your baby, bring up the subject with your child and explain what the purpose of the funeral is and what is likely to happen. Answer their questions and revisit the conversation. Reassure them that they can change their minds about attending or not.

Children sometimes say things that might seem callous or self-absorbed to an adult. They might not be old enough to have absorbed all the social rules around death and what's acceptable to say. Reassure children that there is nothing wrong with their responses, whatever they are. On the other hand, they might seem unaffected, and this is OK too, but continue to have conversations about your baby with them, so they know it's going to be OK to talk about it, if and when they want to.



Men and emotions

It's often said that men avoid expressing their emotions or want to fix things rather than talk or that they 'move on' more quickly than women. This might be outdated and it's certainly a generalisation. But it is statistically true that men are less likely to seek professional support.

This may be because support is not offered to them as frequently, or that they feel they have to be strong for their partner. It might be because they think feelings of sadness are less socially acceptable for men and there is an expectation that they remain steadfast and look like they're coping. Fathers feel as much pain as mothers at the loss of their babies, but they might manage their feelings differently or at least present them differently to the outside world. Looking like they are coping can mean that men get less care and attention from those around them. Men may feel restricted or frustrated by the contrast in what they show to the outside world and the emotional turmoil inside. Some men feel their grief is discounted or passed over and that there are few safe spaces to express the depth of their feelings.



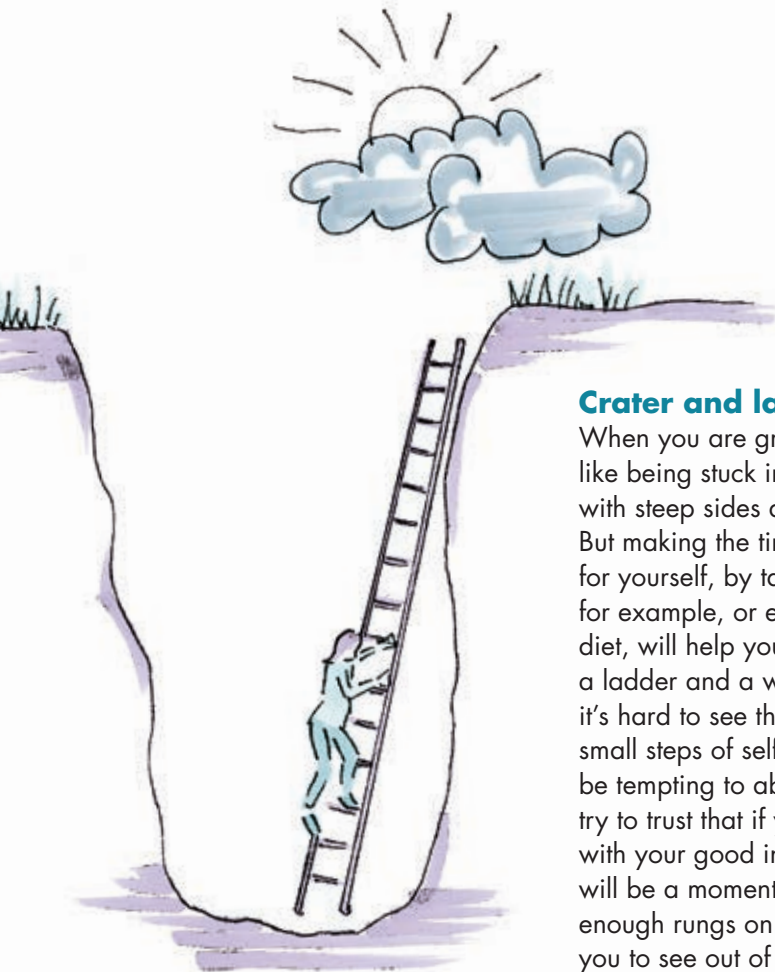
“All my wife wanted to do was cry and talk, but I wasn't ready to talk, all I wanted to do was get back to work and keep busy.”

I'd urge friends and family to ensure they offer support to fathers, not just mothers, particularly as men may need more prompts, invitations and opportunities than women before they feel safe to talk freely.

If you would like to join our online peer support community for dads and partners, please visit www.twintrust.org/bereavement for more information.

USEFUL WAYS TO THINK ABOUT GRIEF

Lots of different models, or ways to picture grief, have been developed over the last couple of decades. In this section I describe a number of them and add in some of my own. I hope one or more of these ideas helps you visualise what's happening to you and gives you comfort.

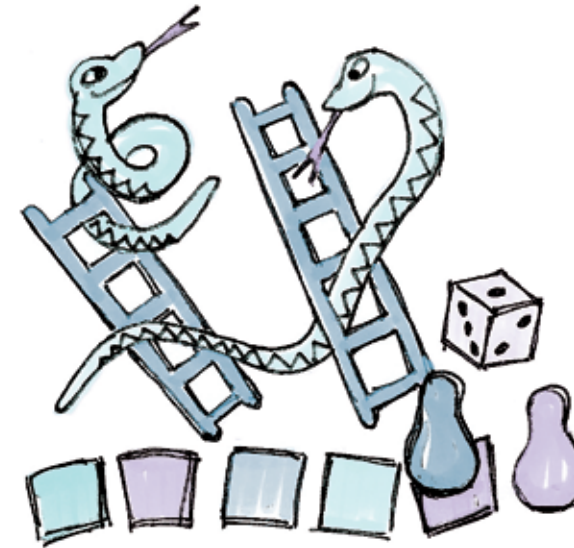


Crater and ladder

When you are grieving it can feel like being stuck in a dark crater with steep sides and no way out. But making the time to take care for yourself, by taking daily walks, for example, or eating a balanced diet, will help you start to build a ladder and a way out. At first, it's hard to see the impact of your small steps of self-care, so it can be tempting to abandon them. But try to trust that if you're consistent with your good intentions, there will be a moment when there are enough rungs on the ladder for you to see out of the dark crater and to the brighter future beyond.

Snakes and ladders

Grief is heavy and intimidating. When we are in the thick of it, it can feel like the solution is something dramatic. We long to throw a double six or to find a ladder to get to the end of the board more quickly. But the opposite approach is better in the long run. What is needed are baby steps – one square at a time, no big leaps. It's better to throw ones and twos and take small steady steps of repair.^{vi}



"I've also come to see some of the traits I now have as a gift from them, as they're things I probably didn't possess before, or at least not to the same degree. I'm a much more understanding person, more sensitive and more empathetic."

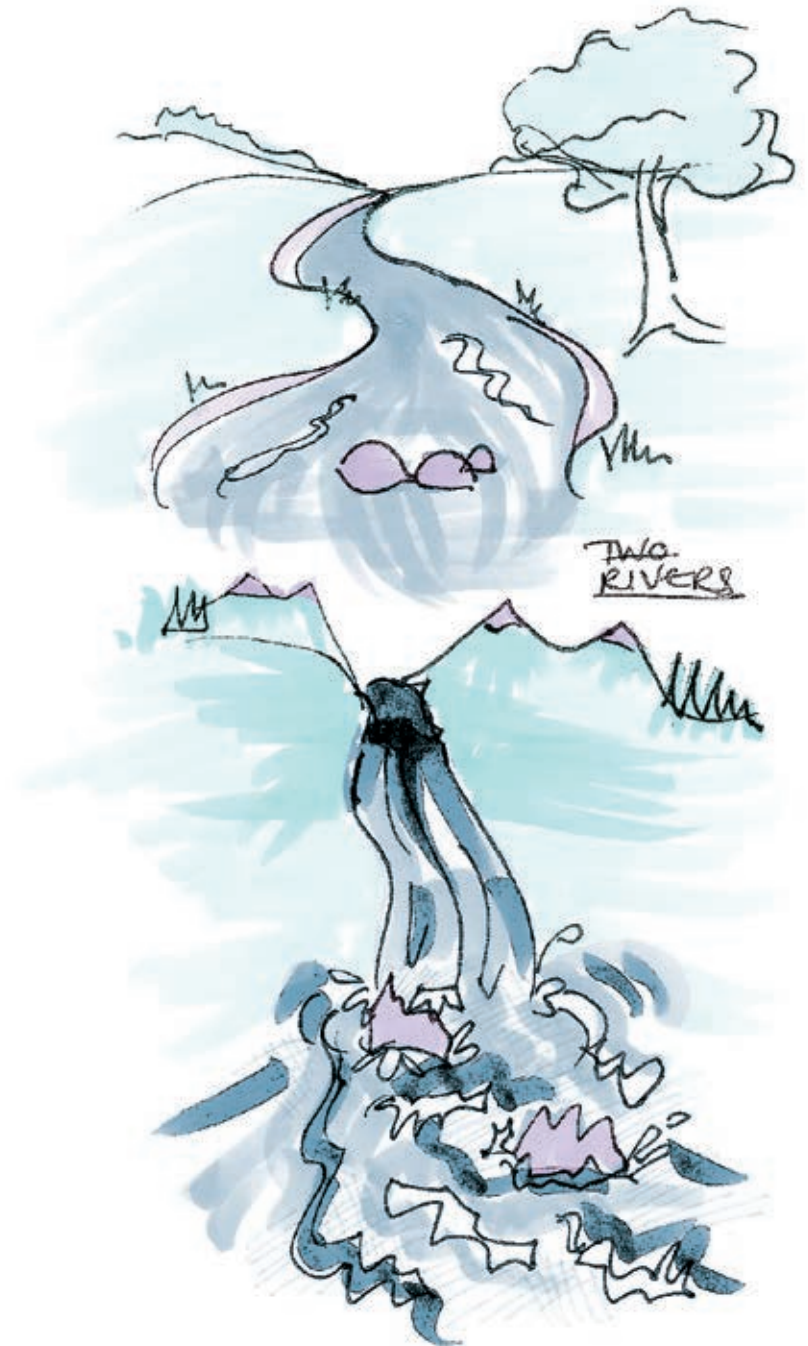
Two rivers

This is formally called the Dual Process Model of Grief^{vii}. The idea of this model is that it's healthy to move or oscillate, between confronting our grief and putting it aside. Although it's healthy to explore and allow our grief, it's exhausting to face grief head-on all the time. This idea is that it's OK to experience grief in doses. There are times when we should confront our grief and others when it's a good idea to avoid, deny or suppress our grief.

This dual process can be pictured as two rivers: one, the grief river, is fast-flowing and can threaten to drown us. The other is slower and more peaceful. The easy river represents switching off from grief using distraction or self-care; it might be something health-enhancing like an exercise class, or it might be meeting up with friends – whatever takes your mind off your grief and allows you to relax and repair for a while. The calm river can help restore your energy. It might also remind you of the possibility of less turbulent times ahead and of moving through grief.

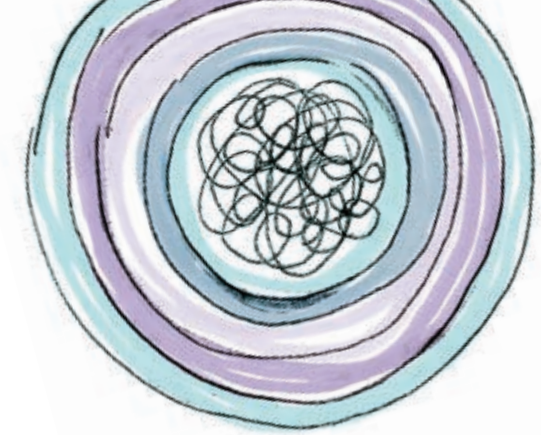
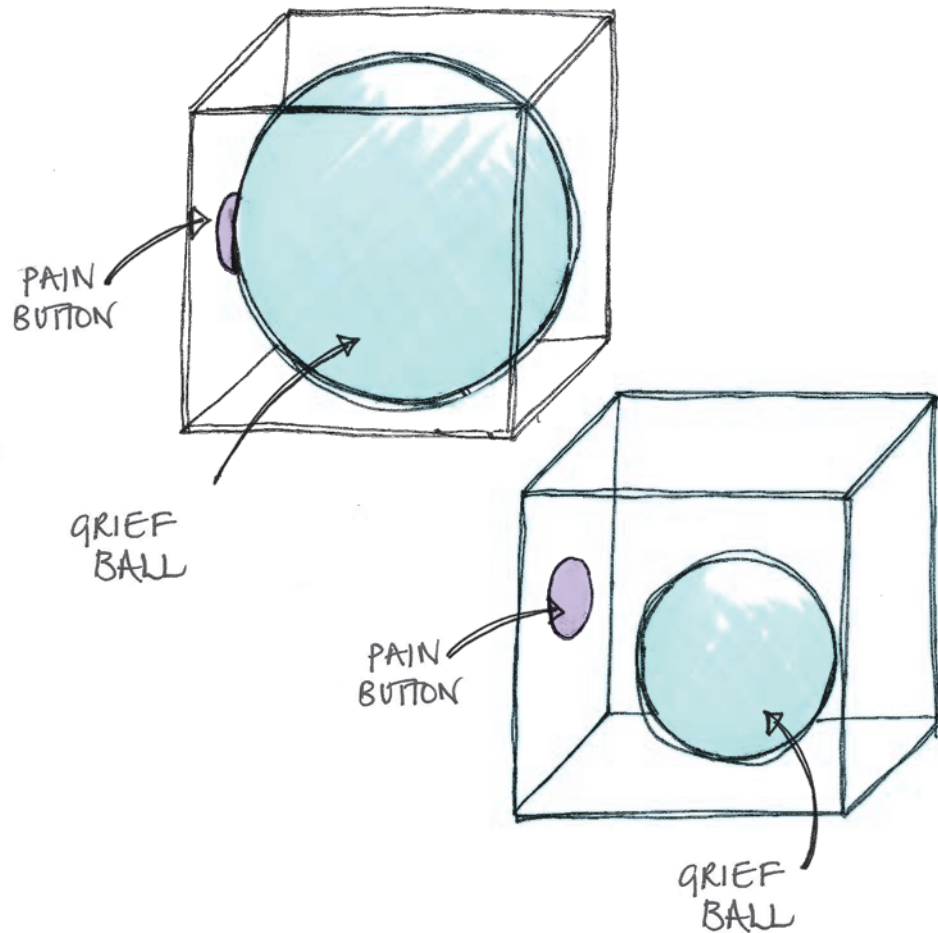
What people sometimes object to with this model is that it can make it sound easy to move freely backwards and forwards between the two rivers. Some people think that it would be great to be floating down stream but find it impossible to get out of the fast-flowing river of grief and despair. Conversely, others may find they want to avoid the grief river at all costs.

Time doesn't simply heal grief, but in my experience, most people, with time, get better at scrambling up the riverbanks and moving to a river that will serve them better. Grief often brings a loss of emotional control, but over time we can develop or discover we have more choice over our emotions. We may find we're pushed into the river of grief less frequently, or if we find ourselves there, we're better equipped to get back to the safety of the banks.



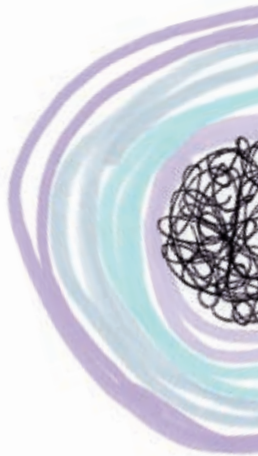
Ball in a box

Dr. Lois Tonkin pictured grief as a ball in a box^{viii}. Immediately after loss, the ball of grief is huge and takes up all the space in the box. Because the ball is so big, it's constantly pressing the pain button. The big ball of grief takes up all of your emotional space and attention. During this period, you might feel like the pain will never go away. But as time passes, the ball of grief gradually gets smaller, which means that it doesn't press the pain button so often. It's still bouncing about, but you start to find breaks in the anguish. Over time the ball may become so small it rarely hits the pain button. It still hurts when the pain button is pressed but it happens less often.



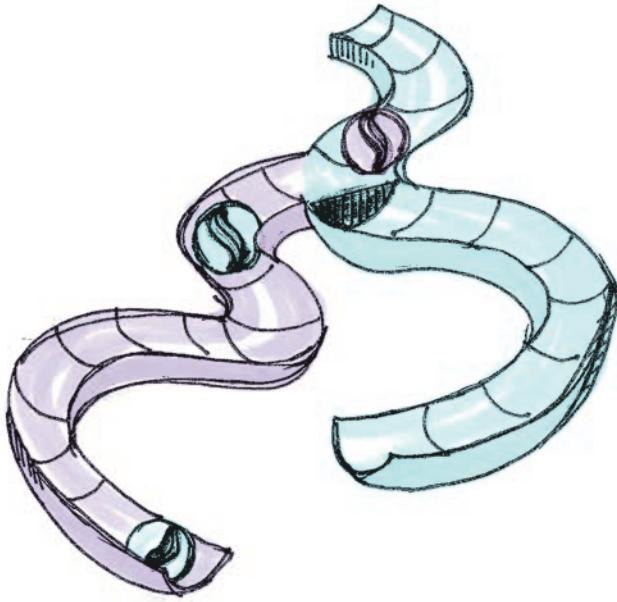
Ball of wool

In my model, adapted from Therese Rando's^{ix} work, grief is pictured as a messy, knotted ball of wool, instead of a bouncy ball. The wool represents the tangled mess of emotions you may feel. In this analogy, the grief, or ball of wool, doesn't shrink with time. Instead, the grief remains the same size and life grows around the grief. Each new experience forms a layer around your grief, or ball of wool. Each experience is like a sheet of wrapping paper. Over time, the layers build up like the layers of wrapping paper around the present at the beginning of the children's party game, 'Pass the Parcel'. You will still carry all you experienced with the loss of your baby or babies and the accompanying grief, and sometimes you'll still experience the intense pain of grief, but the layers that have built up since will enhance your life and grief won't be the only thing.



Marble run

Grief thoughts often run down the same grooves in our brain. The repetitive thoughts can be pictured as marbles taking the same route down the tracks and tunnels in the game 'Marble Run'. If you find yourself turning over the same difficult thoughts again and again, it can be a useful tool to imagine cutting off the thought and redirecting it down a different channel. Imagine adding a gate to a marble's route and redirecting it onto a more positive track.



Creating your story

Models of grief in the past emphasised working through death to reach a place where we could detach. In 1996, Tony Walters^x created an alternative model of 'continuing bonds' where the aim wasn't to detach but to integrate the death into our lives. In his version, grieving serves the purpose of integrating the loss of our babies into our ongoing lives by constructing a new narrative that includes the death. Consider physically writing down the story of your baby. Creating your own story may help you feel some sense of control at a time when it's natural to feel like we have no agency over events. Try joining all the separate memories, good and bad, into a continuous story. Our brains find events that we've thought about, or created a narrative around, easier to 'file' and this can be comforting to a restless mind.



Ideas for growth and hope amidst grief

Just as falling in love or loving someone isn't ever entirely positive, grief although painful, isn't just negative. Grief can contain positives and warm memories. Grief is necessary because if you block the pain of grief, you risk blocking all your feelings, even the good ones, such as your capacity to feel joy.

Grief reminds us of how important our relationship with our baby was. Grief might even help us foster a better sense of what's important in life – that's not to minimise the severity of baby loss or to suggest that it's in any way a good thing.

Sometime later, we may feel more robust and resourceful, knowing we faced something so awful and survived and can enjoy life again.

I hope that everyone reading this can find something in these pages that helps them navigate the choppy waters of baby loss. I'm sorry you are having to go through this and wish you resilience, hope and strong support in your journey.



SOURCES

Badenhorst, W., Rishes, S., Turton, P., and Hughes, P. (2006) 'The Psychological Effects of Stillbirth and Neonatal Death on Fathers: Systematic Review', *Journal of Psychosomatic Obstetrics and Gynecology*, 27, 245-56

Ben-Shahar, Tal (2008) *Happier: Can You Learn To Be Happier?* (Maidenhead: McGraw-Hill)

Bowlby, J. (1979) 'On Knowing What You Are Not Supposed to Know and Feeling What You Are Supposed to Feel', *Canadian Journal of Psychiatry*, 24, 403-8

Devine, M. (2017) *It's OK That You're Not OK: Meeting Grief and Loss in a Culture That Doesn't Understand* (Louisville: Sounds True Adult)

Field, N. P. (2006) 'Continuing Bonds in Adaption to Bereavement: Introduction' *Death Studies*, 30 (8), 709-14

Gendlin, E. T. (2003; 1st edition) *Focusing: How To Get Direct Access to Your Body's Knowledge* (London: Ebury)

Gunn, B., and Buckingham, L. (2022) *The Worst Girl Gang Ever: A Survival Guide for Navigating Miscarriage and Pregnancy Loss* (London: Harper Collins)

Kersting, A., and Wagner, B. (2012) 'Complicated Grief After Perinatal Loss', *Dialogues in Clinical Neuroscience*, 14, 187-93

Lloyd, C. (2023) *You Are Not Alone: A New Way to Grieve* (London: Bloomsbury)

Ngozi Adichie, C. (2021) *Notes on Grief* (London: Fourth Estate)

Piaget, J. (1977) 'Developmental Stage Theory' in Howard Gruber (ed.), *The Essential Piaget* (New York: Basic Books)

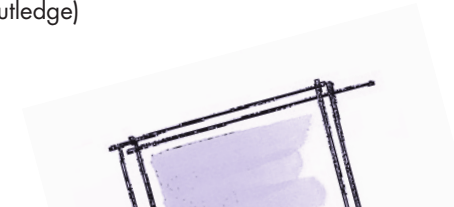
Samuel, J. (2017) *Grief Works: Stories of Life, Death and Surviving* (London: Penguin)

Shapiro, E. R. (1994) *Grief as a Family Process: A Developmental Approach to Clinical Practice* (New York: Guilford Press)

Schore, A. N. (2003) *Affect Regulation and The Repair of the Self* (London: Norton)

Strobe, M. S., and Schut, H. A. W. (1999) 'The Dual Process Model of Coping With Bereavement: Rationale and Description', *Death Studies*, 23 (3), 197-224

Worden, W. J. (2010; 4th edition) *Grief Counselling and Grief Therapy* (London: Routledge)



ENDNOTES

- i Kübler-Ross, E. (2014, reissue edition) *On Death and Dying: What the Dying Have to Teach Doctors, Nurses, Clergy and Their Own Families* (London: Scribner)

Kübler-Ross, E. and Kessler, D. (2014, reissue edition) *On Grief and Grieving: Finding the Meaning of Grief Through the Five Stages of Loss* (London: Simon & Schuster)

Strobe, M. S., Schut, H. A. W., and Boerner, K. (2017) *Cautioning Health Care Professionals: Bereaved Persons Are Misguided Through the Stages of Grief*, *Omega*, 74 (4)

- ii Bergstraesser, E., Inglin, S., Hornung R., and Landolt, M. A. (2015) *Dyadic Coping of Parents After the Death of a Child*, *Death Studies*, 39 (3) 128-138

Dyer, K. A. (2005) 'Identifying, Understanding, and Working with Grieving Parents in NICU: Identifying and Understanding Loss and the Grief Response', *Neonatal Network*, 24, 35-46

Forest, G. C. (1983) 'Mourning the Loss of a Newborn Baby', *Bereavement Care*, 2, 4-11

Keesee, N. J., Currier, J. M, and Neimeyer, R. A. (2008) Predictors of Grief Following the Death of One's Child: The Contribution of Finding Meaning', *Journal of Clinical Psychology*, 64 (10) 1,147-60

- iii Manuel, J. (2021) *Grief and the Holidays Use the 3 Cs to Heal*. Available at: www.ketteringhealth.org/grief-and-the-holidays-use-the-3-cs-to-help-you-heal (Accessed 31 March 2024)

- iv Cruse Bereavement Support (no date) *Understanding Complicated Grief*. Available at: www.cruse.org.uk/understanding-grief/effects-of-grief/complicated-grief (Accessed 31 March 2024)

American Psychiatric Association (2022) www.psychiatry.org/patients-families/prolonged-grief-disorder (Accessed 31 March 2024)

- v Szuhany, K. L., Malgaroli, M., Miron, C. D., & Simon, N. M. (2021). 'Prolonged Grief Disorder: Course, Diagnosis, Assessment, and Treatment'. *Focus* (American Psychiatric Publishing), 19(2), 161-172

- vi Day, E. and Reed Turrell, E. (2024) 'Best Friend Therapy', *Childfree, Not By Choice*, Season 7, Episode 1 [Podcast]. Available at: www.podcasts.apple.com/gb/podcast/best-friend-therapy (Accessed 31 March 2024)

- vii Strobe, M. S., and Schut, H. A. W. (1999) 'The Dual Process Model of coping with Bereavement: Rationale and Description', *Death Studies*, 23 (3), 197-224

- viii Tonkin, L. (1996) 'Growing Around Grief: Another Way of Looking at Grief and Recovery' *Bereavement Care*, 15 (1), 10

- ix Rando, T. (1993) *Treatment of Complicated Mourning* (Champaign, IL: Research Press)

- x Walter, W. (1996) 'A New Model of Grief: Bereavement and Biography', *Mortality*, 1 (1), 7-25

HOW TO GET HELP

For a list of other organisations offering support, please visit www.twintrust.org/bereavement/support/services.html



A SPACE FOR THOUGHTS AND REFLECTIONS

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EMMA FOGDEN

I am a counsellor with a busy private practice in West London and online. My first career was in publishing. During this time, I experienced multiple fertility treatments and many miscarriages. After a devastating stillbirth, I was offered life-changing therapy sessions which in turn led me to retrain to be a counsellor. I gained a first-class degree in Humanistic Counselling from the Metanoia Institute.

I see a wide range of clients, but I specialise in supporting those who have suffered baby loss in all its forms. I work with my clients in a safe space, exploring the things that are troubling them and working with them to notice their patterns and make positive changes.

I have drawn on my own experience of twins, stillbirth, miscarriages and my professional experience as a counsellor specialising in baby loss. The observations and advice in this booklet have been gathered from grief specialists, medical professionals and fellow counsellors and psychotherapists. I've also drawn from what has been useful to my clients. I'd like to thank the hundreds of people who have been courageous enough to open up to me about their baby and twin losses and whose experiences and wisdom have informed this booklet.

BACP Member 382390

Twins trust. Bereavement Service

We support bereaved families with twins, triplets or more...

Who we are

Twins Trust Bereavement Service offers compassionate support to families experiencing the loss of one or more multiples. Established in 1982, the Bereavement Service is a part of Twins Trust; a charity that supports families with twins, triplets and more. We offer a range of support options including peer-to-peer connections, online communities and informational resources. Our devoted service offers a lifeline to parents and their families coping with the unique challenges of loss from a multiple birth.

Contact number: 01252 332344

Email: bereavementsupport@twinstrust.org

www.twinstrust.org/bereavement

