

THE UK
SEPSIS
TRUST

BEREAVEMENT FOLLOWING SEPSIS

GUIDANCE FOR NAVIGATING GRIEF

INTRODUCTION

i If you're reading this, it's likely that you've experienced someone close to you dying from sepsis. We'd first like to offer our heartfelt condolences to you and those affected. This booklet has been produced to give you guidance and help during this difficult time. The UK Sepsis Trust (UKST) is here to support you.

It's estimated that as many as 245,000 people develop sepsis each year in the UK, with an estimated 48,000 tragically losing their lives. It can sometimes be confusing, as some people may talk about septicemia, toxic shock syndrome or blood poisoning, but these terms all equate to sepsis.

Sepsis is a life-threatening condition that arises when the body's response to an infection injures its own tissues and organs. It can lead to shock, multiple organ failure and death especially if not recognised early and treated promptly. However, even with early diagnosis and sophisticated treatment, some people will still not survive.

We describe what sepsis is in more detail towards the end of this booklet, but what's key to remember is that it's indiscriminate, in that it can affect people with underlying health problems as well as people who are otherwise healthy.

It can be traumatising to witness a loved one become suddenly unwell, a situation which is likely to leave you with more questions than answers. These feelings might have been made worse if there were visiting restrictions or impaired communication due to COVID-19. As a result, you may well not have grasped quite how unwell your loved one was, and so might not have anticipated the outcome. People describe having to deal with the trauma before beginning to grieve.

As well as a whole host of questions, people can have concerns about their loved one's care or treatment. It's vital that this is acknowledged, and steps are taken to understand what happened.

A good starting point is to have a chat with one of the Support Nurses at UKST, who have a wealth of experience with sepsis and bereavement care. Sharing thoughts and feelings is often helpful, and can also point you in the right direction.

Should it be necessary to escalate concerns, we would suggest you contact the Patient Advice and Liaison Service (PALS) at the hospital where your loved one died. They can act as an intermediary to help raise and resolve any issues you may have.

"Losing someone to sepsis is very traumatic often because of the suddenness of it. There's no time to prepare for it." Jonathon

WHAT IS GRIEF?

i **The trauma of an unexpected death can give rise to deep feelings such as disbelief, shock and numbness. Sometimes it may take a while before a person can begin to grieve.**

Grief is a normal human reaction – it is not a pathological condition, personality disorder or illness, but it can be a long and tumultuous journey which can make us feel unwell.

There is a common and confusing misunderstanding in society that the process of grieving is completed in a particular order. In reality, there are no neat stages – nor are there any reactions so universal that all or even most people experience.

Grief can often be incorrectly labelled as PTSD, ADHD, depression or anxiety. It's possible that grief may share some similar characteristics – it certainly has a profound effect on mind, body and soul. However, like each and every one of us, grief is unique, and looks and feels different for everyone.

“When I look back, I carried grief so heavily that it weighed me down...I was walking around with my head down the whole time.” Terence

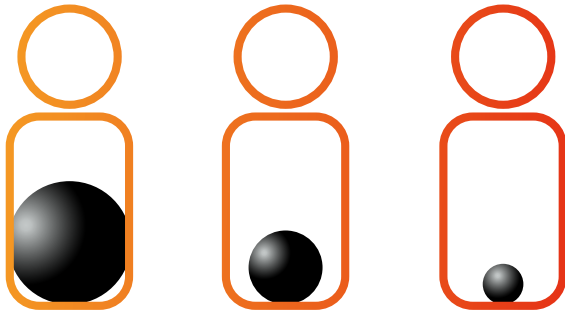
Life will never be the same again after a bereavement. Be prepared to find that some people may behave oddly towards you, and find it hard to know what to say. Over time you'll need to develop ways to cope with this, which may include preparing and rehearsing some answers to people's questions, it's like having a 'script' in your head.

There's no timeline for feeling better, but for most, the intensity will slowly lessen over time, and people will begin to feel more balanced and that they're coping better. They'll start to build a new life around their grief, including finding ways of keeping the connection with their loved one, who has died. It's healthy, natural and important to maintain a continuing bond.

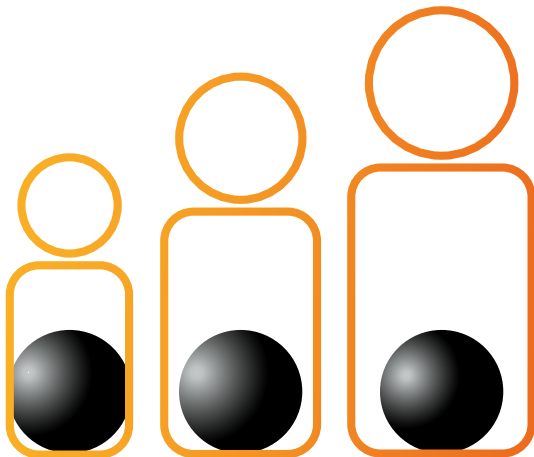
“I encourage those around me not to be afraid to talk about him, which then enables everyone to be more at ease and comfortable.” Teresa

Growing around grief

This diagram shows what many people think happens with grief over time, compared to the reality.



People tend to believe that grief shrinks over time



What really happens is that we grow around our grief

Common thoughts, feelings and actions

- Shock and numbness
- Overwhelming pain and sadness
- Searching for the person who has died. Where could they be?
- Repeatedly thinking about, and replaying what has happened
- Wondering what you could have, should have or would have done differently
- Guilt about the nature or circumstances of the loss, or the relationship you shared with the person who has died
- Loneliness, isolation and hopelessness
- Anger towards yourself, others, the person who has died, or the universe in general
- Agitation and insomnia, or extreme fatigue and over-sleeping

“I experienced trauma and grief. They are two different things... trauma comes first.” Jonathon

Common unhelpful sayings and myths about grief

- “Time heals” – time does not heal, but actions taken over time can lend themselves to healing
- “Be strong” – usually the griever will be asked to be, or feel like they have to be strong for others, thereby impeding their grief
- “Don’t feel sad” – sometimes followed by sentiments like “they are not suffering now” or “you were lucky to have had them in your life”. Comments like these are invalidating the very real feelings of grief people may be struggling with, and can also invoke feelings of guilt
- “Grieve alone” – sometimes by leaving people to ‘have their own space’ can inadvertently imply that grief should be hidden or done alone
- “Keep busy” – very often people mistakenly think keeping busy will help distract them from the death of a loved one, however this can avoid facing grief, processing and completing the feelings of loss

“I don’t want or need to be fixed, I just want to be heard; I want people to know my reality. It may, however, be a different reality later – that’s the essence of grief.” Lyn

SELF CARE

Treat yourself kindly and gently – try to take one day at a time. Listen to your body and allow yourself to acknowledge your feelings. Grieving uses a considerable amount of energy, so try to ensure you get enough sleep, make time to rest, and remember to eat and drink properly to fuel your body.



Keeping a routine

Doing things at set times can help you get started with the day and propel you forward. Things like waking up and going to bed at the same times, having a routine around meals, and setting aside specific times for activities, even if they’re simple like taking a shower or brushing your teeth. Structure around the day can help.



Exercise and activity

The benefits of exercise on the mind and body are well documented – you could start to build this into your daily routine by setting time for a short walk every day. Walking can be a good way to ground yourself and bring yourself into the moment.

“We planted a rose and peony bush that had the same name as him, Ben. It somehow makes me feel closer to him.” Teresa

Talking about what happened

Finding someone you feel safe and comfortable with to talk about how you're feeling can be really helpful. This could be a friend or family member. It can also be valuable to speak with someone who doesn't know you. Counselling can also be beneficial, as can writing down your thoughts and feelings in the form of journaling.

Consciously allow yourself to keep the person who has died present in your life by doing things like talking about them openly, displaying photos and other memories and taking part in commemoration activities and other healthy rituals. For many people, keeping the memory of their loved one alive is an important part of their 'new normal.' There are many ways of doing this – you might enjoy working on some of the ideas on the following page with family or friends, but other projects will be just for yourself.

“I’ve found journaling to be extremely helpful. It’s amazing how many thoughts and feelings come tumbling out when I give them free reign – sometimes these are really ugly, and sometimes they’re just heart-breaking. I’ve found the process extremely cathartic and looking back on previous entries gives me evidence of the progress I’ve made.” Lyn

Things to try could include:

- Creating something – art, craft, poetry, music
- Collecting photographs or video clips, perhaps making something out of them
- Gathering keepsakes for a memory box
- Planting a shrub, or creating an area in the garden
- Creating an online memorial
- Fundraising in their memory by taking on a challenge such as a long-distance walk or cycle ride
- Volunteering for a cause that meant a lot to them, or doing other helpful activities



These activities not only honour the memory of the person who has died, but can also give you a positive focus for your energies and thoughts.



Anniversaries and special times

Birthdays and anniversaries can give rise to particular feelings of sadness. Good and bad memories can come to the surface with renewed vigour. In time you'll learn what you need to do on special days and you'll be able to prepare for them. Some people like solitude and reflection, while others want to celebrate – find what feels right for you.



Healing

The Support Nurses at UKST understand only too well how quickly sepsis can kill and how devastating such a tragic loss can be. We're here to help you understand what happened to your loved one and to try and answer your questions. You can talk to us by calling our Helpline or contacting us by email. A series of one-to-one chats can make all the difference when trying to process the death of a loved one. We can guide you and signpost you in the right direction.

We also facilitate bereavement peer support groups. These groups are relaxed and informal meetings – working on a model of peer support. This involves people drawing on shared personal experience to provide knowledge, social interaction, emotional assistance and practical help to each other, often in a way that is mutually beneficial. They are a powerful support to many of our service users, and can become an important routine in the journey of self-help.

“Accessing the helpline for one-to-one chats when I’m ‘having a moment’ has been a life-line for me. It’s a privilege to have someone to vent to, ask questions of and generally unburden to.” Lyn

“Social media can lead to playing out your grief with the wrong audience, rather than seeking help from more suitable support.” Teresa



Social Media

People find that taking a break from social media can be helpful following the death of a loved one. It's important to recognise that you might be more vulnerable, and we encourage you to care for yourself by choosing which audiences to share your feelings with carefully, as it might feel uncomfortable to be public about your grief at this time.

Memories of, and previous communications with your loved one, may flash up on social media, reminding you of happier times when your loved one was alive, which can bring mixed feelings. Whilst it may be lovely to see and reflect on these memories and ‘hear’ their voice through previous posts, comments and photos, suddenly seeing them without warning can often be difficult. You may accidentally expose yourself to potentially triggering content – even well-meaning comments can be upsetting.

Given time, social media platforms can potentially be a useful outlet where we can pay tribute. We can also use it to highlight charities or subjects that we're interested in, but only if we feel comfortable with this. Like with all aspects of grief, it is the person's own choice as to how they choose to handle it.

GRIEF DOs & DON'Ts

DO

- Talk about the person who has died
- Look after and be kind to yourself
- Give yourself permission to grieve
- Seek help and support if you need it
- Try to stay in the moment by focusing on one hour at a time, eventually moving up to a day at a time when you feel ready
- Go at your own pace, trust your instincts, and do what feels right for you
- Accept that there is no timeframe for grieving. It is individual and there is no 'right way'
- Accept your feelings, even if they're unpleasant – they're a way to express and process grief and won't last forever

“It's so important to look after and be kind to ourselves when we're grieving.” Jonathon

GRIEF DOs & DON'Ts

DON'T

- Isolate yourself
- Bottle up emotions
- Feel weak if you need some help
- Feel guilty if you're struggling
- Overuse any unhealthy short-term coping methods to numb pain, such as overeating, drugs or excessive alcohol

“In the early days, maybe ask someone to do the shopping and help with any other chores, as you'll be in shock and may not be able to think of the basics.” Teresa

BACKGROUND INFORMATION ON SEPSIS

As humans we come into contact with many pathogens, or 'bugs', during our lifetime, some of which cause infections. Our body's natural defence systems and immunity fight these infections, frequently without any need to visit the GP or hospital.

Sepsis can occur when the body's immune system – which normally helps us fight infection – overreacts, causing damage to tissues and organs. The reasons why some people develop sepsis as a consequence of an infection and others do not, aren't entirely understood – medical research institutions are working to understand this better. It's important to note that it's not possible to catch sepsis or pass it on to others.

Not every infection will cause someone to develop sepsis, however almost any infection can develop into sepsis. Sepsis most commonly develops from a bacterial infection, but it can also develop from both fungal and viral infections, including as a consequence of COVID-19.

Common infections precipitating sepsis include:

- Chest infections (pneumonia)
- Urinary tract infections
- Abdominal infections (appendicitis, gall bladder infection)
- Skin, soft tissue infections (cellulitis, wound infections, bites)

i Sepsis is indiscriminate: whilst it primarily affects very young children and older adults and is more common in people with underlying health conditions, it can be triggered in people who are otherwise fit and healthy.

Several factors are likely to play a part in determining whether or not sepsis develops in response to a specific infection:

- Type of 'bug' causing the infection
- Number of 'bugs' present and where in the body they are
- The person's individual factors, such as underlying health conditions and their genetics

We know some groups of people are at a higher risk of developing sepsis. These include:

- Children under 1 year of age
- Adults over 75 years of age or people who are very frail
- People who have impaired immune systems because of illness or medication
- Women who are pregnant

Sepsis can be difficult to diagnose. It can be challenging to spot for the individual, for the loved one and for health professionals, particularly in the earlier stages. There is no single sign and no single diagnostic test. Symptoms can also present differently in adults and children.

SUPPORT

The UK Sepsis Trust

We seek to save lives and improve outcomes for survivors of sepsis by educating healthcare professionals, raising public awareness, providing support for those affected and instigating political change.

To speak with a Support Nurse or learn more about our services, see our contact details below.

0808 800 0029

support@sepsistrust.org
sepsistrust.org

The Good Grief Trust

Run by the bereaved, for the bereaved, the Good Grief Trust exists to help all those affected by grief in the UK. They aim to acknowledge grief and provide reassurance and ongoing support.

thegoodgrieftrust.org

Cruse Bereavement Care

Experienced volunteers provide free and confidential advice, information and support for anyone who has been bereaved, by telephone, email or face-to-face. They also offer support to young people on their website.

hopeagain.org.uk

cruse.org.uk

0808 808 1677

Child Death Helpline

This helpline offers support to anyone affected by the death of a child of any age, under any circumstances, however recent or long ago.

0808 80 06019

childdeathhelpline.org.uk

“The UK Sepsis Trust has been a lifeline to me.... because the online groups are small, and we’re all getting to know each other. We all understand the pain that each one of us is going through. Teresa

At A Loss

Help to ensure that every bereaved person in the UK can find appropriate bereavement support when they need it.

ataloss.org/

The Compassionate Friends

The Compassionate Friends (TCF) is a charitable organisation of bereaved parents, siblings and grandparents dedicated to the support and care of other similarly bereaved family members, who have suffered the death of a child or children of any age and from any cause.

0345 123 2304

tcf.org.uk/

PALS

The Patient Advice and Liaison Service (PALS) offers confidential advice, support and information on health-related matters.

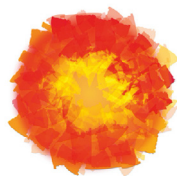
nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service/

Coroners Court Support

Emotional support and practical help to bereaved families, witnesses and others attending an Inquest at a Coroner’s Court.

0300 111 2141

coronerscourtssupportservice.org.uk/



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We'd like to express our heartfelt thanks to **Terence, Jonathon, Teresa and Lyn** for their contributions to this booklet, and to all the people bereaved through sepsis that we support and have learnt so much from.

Terence's brother Mark died in June 2012

Jonathon's wife Cheryl died in February 2016

Teresa's son Ben died in February 2018

Lyn's son Ben died in September 2019

We honour their memories, and that of all those who have lost their lives to sepsis, in the work we do.

"People never die if they stay on the lips of the living."

Gloria Hunniford

One of our main aims is to educate the public about sepsis and the signs to look for, so we're encouraging everyone to become Sepsis Savvy.

Visit **sepsistrust.org/savvy** to find out more.

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