

BEREAVEMENT AND STEM CELL TRANSPLANT



**ANTHONY
NOLAN**

saving the lives
of people with
blood cancer



Produced with support from the Jack Petchey Foundation, in memory of John Petchey.

At Anthony Nolan we take great care to provide up to date and accurate facts about stem cell transplant. We hope the information here will help you to look after yourself.

Each transplant centre will do things differently, so this booklet is just a general guide and isn't intended to replace advice from your doctor and transplant team.

Please speak to your transplant team for more details about your own situation, as they will be able to give you personalised, specific advice.

Ordering more copies

If you'd like to order more copies of this guide please get in touch with us on patientinfo@anthonymolan.org

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The information contained in this booklet is correct at the time of going to print (December 2018). We plan to review this publication within three years. For updates or the latest information, visit anthonymolan.org

Anthony Nolan is a registered charity
No 803716/SC038827

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ANTHONY NOLAN
PATIENT SERVICES

INTRODUCTION

Losing someone close to you after a stem cell transplant can be devastating. Although it is a challenging treatment, there is often a lot of hope that it will give a long-term remission. You are reading this because sadly it has not been successful.

Bereavement is a very personal experience and there is no right or wrong way to grieve. What will follow is a mixture of emotions that can fluctuate over time.

There are lots of very good bereavement guides available (we've listed some at this back of this booklet) but this one focuses on loss after a stem cell transplant.

The post-transplant experience leading up to the bereavement can sometimes be difficult and can leave you with questions and emotions that you might need help with. Although we cannot know what you are experiencing, this is aimed at helping you identify those emotions and answering some questions that you might have.

We've developed this guide by working with people who lost a partner or family member after a stem cell transplant. They wanted to share their experiences to help others, and their input has been invaluable.

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BEREAVEMENT AND STEM CELL TRANSPLANT

The decision to have a stem cell transplant is a tough one. For some it is a choice, while for others it is the only option.

Recovery can be long and challenging and you might now have questions about what happened. Your partner or family member's transplant team will be able to answer questions about their specific treatment, but this booklet will address some of the general concerns you may have.



WAS HAVING THE TRANSPLANT THE RIGHT DECISION?

Stem cell transplant is never considered by the medical team unless it is the best option for a long-term remission.

Many factors are used to decide if a transplant is necessary for your family member or friend, such as their diagnosis and their response to treatment.

In some cases, the transplant needs to happen quite quickly while in others there could be a choice about timing.

Knowledge is growing all the time about what factors improve outcomes for patients. All of this would have been discussed with a multi-disciplinary medical team before the decision to go ahead was made. So you can be sure stem cell transplant was chosen as the best hope of a cure for your family member or friend.

WHY DIDN'T THE TRANSPLANT WORK?

Sadly, even with experience and knowledge, what we hope will be a long-term remission of blood cancer or a blood disorder does not always work. It can be a sign that the disease was aggressive and harder to treat.

Stem cell transplant is a strong treatment, so if it doesn't work then there will be few other successful treatment options. The sooner relapse occurs after transplant, the poorer the prognosis (likely outcome) will be.

After relapse and before other treatment options are decided, consideration would have been given to:

- the time of relapse
- the patient's experience of graft versus host disease (GvHD)
- and the transplant's impact on the patient physically and mentally.

Graft failure (when the body doesn't form a new immune system from the new stem cells as planned) means more stem cells or a new donor will be needed to provide the new immune system. The risk of infection will be high and, in rare cases, the bone marrow does not recover.

THE TRANSPLANT WORKED, SO WHY DID THEY STILL DIE?

In their worst cases, transplant-related side effects (such as infection and GvHD) can be fatal.

Sepsis (overwhelming infection) or chronic infections that prevent the immune system from recovering will leave the patient vulnerable and unable to fight infection. Along with their treatment, GvHD that is uncontrolled or involves several organs can also leave patients weak and vulnerable to infections.

In this very difficult situation, patients can get stuck in a cycle of being unwell and being admitted to hospital, making quality of life poor. To die from post-transplant complications is often complex and not due to just one side effect but a combination of side effects.

I KNEW IT WOULD BE TOUGH BUT I DIDN'T THINK THEY WOULD DIE

We expect recovery from transplant to be challenging. Nevertheless, when it is tough and patients are struggling with side effects, our hope remains that this will achieve a long-term remission.

Patients with complex needs can deteriorate slowly and the constant cycle of admissions and infections can become almost routine.

However, the impact of this will be felt physically and mentally by the patient, and the demands can prove too much. Despite this, it can feel like a shock when patients do not recover.

IT ALL HAPPENED SO QUICKLY, IT WAS SO UNEXPECTED

Sepsis (overwhelming infection) is a risk for any patient recovering from a transplant. It is always a concern for those patients who are struggling, but even those who are doing well are at risk.

In any situation, sepsis will be an emergency and will probably involve treatment in an intensive care unit (ITU). It can be overwhelming and scary, often taking patients away from their usual environment into ITU with healthcare professionals they do not know. Deterioration can happen in days or even hours, and it can feel totally unexpected when the patient dies.

It can feel unfair that, despite everything, your relative or family member has died. It is normal to have many questions in a situation like this.

Talking about how you feel with those who were included in the decision-making will help clarify the choices that were made about treatment. This might be with healthcare professionals or family members who were involved.

You can arrange an appointment to speak with the consultant or clinical nurse specialist (CNS) if you would like to. It is the medical team's responsibility to explain the decisions that were made, so don't feel like you shouldn't ask them.

GRIEF



Grief is a very personal experience and everyone will react differently. There is no right or wrong way to grieve, and how you feel will change and fluctuate over time. Grief might feel overwhelming and intense at times, while there will be other periods that feel calmer.

Below are common feelings expressed by relatives who have lost someone after a transplant. You might also experience some of these, and you might experience them at varying times. But it is completely personal. Don't place expectations on yourself about how you should be feeling, or how long you should grieve for.

I FEEL SO SAD

Having a stem cell transplant can bring hope, and it can be devastating when that hope is lost. The experience from diagnosis, to transplant, to now can leave you feeling drained and exhausted.

Sadness can feel overwhelming and it might seem hard to get through each day. Although these feelings can come and go, over time the intensity should decrease and you will have periods that feel more manageable.

'Grief is different from depression – it can be difficult for people to understand that. I am not depressed, I am grieving. And I want to talk about it.'

Donna, whose 18-year-old daughter Emily died after a stem cell transplant

I FEEL ANGRY

In the same way that lost hope can bring sadness, it can also bring anger. Recovery after transplant might have been difficult or it could feel like their death was unexpected, and you could now be asking yourself: 'Why?'

The effect on the family, and your sense of loss, can leave feelings of anger, frustration and blame. Although unpleasant, these feelings are completely normal and the immediate period after the death can be stressful. It's important to not allow these feelings to grow but instead to talk about how you feel.

'I realise that my rage, which wells up unexpectedly and engulfs me, is a reaction to the unfairness of what has happened. I try not to express it. Sometimes, it slips out and then I forgive myself, because I think people understand.'

Ann, whose daughter Zoe died after a stem cell transplant

I FEEL LOST

Feeling lost and unsure what to do next after a bereavement is very normal. This is especially common after the funeral, when your family and friends must get back to their normal lives and you can be left with large parts of your day that feel empty.

Building relationships with healthcare professionals who were involved in your relative or family member's care, or with other patients or relatives, is a common way of coping at the time. They can provide insight and support about life after transplant, and it might now feel strange to not see them or have that support.

Perhaps you were the carer, attending all the regular visits to hospital and adapting your home life. You may have given up your job and social life and now you may feel there is a hole.

I FEEL RELIEVED, I DIDN'T WANT TO SEE THEM SUFFER ANYMORE

Watching someone you love in distress is tough. The duration of time that this can go on for after a transplant can be prolonged, so to feel relief that it is now over for them is completely normal. It is nothing to feel bad or guilty about.

Due to the challenging nature of recovery, it is common to feel that you already lost part of the person you loved.

You might feel that they changed, or your relationship with them changed. The pressure on patients, families and relationships is hard, and quality of life for everyone involved can be severely affected. It is ok to have a sense of relief that it is now over.

'I initially felt an overwhelming sense of relief that he no longer had to suffer the transplant complications, and that myself and family and friends didn't have to go through the upset and anguish watching him suffering.'

Helen, whose husband died after a stem cell transplant

PHYSICAL EFFECTS OF GRIEF

Grief can affect you physically as well as emotionally. You can feel exhausted, unmotivated, unable to eat, unable to sleep and might even feel ill. You might become more susceptible to infection because you are run down.

As hard as it might seem, you now need to focus on keeping yourself well. Just managing a normal routine of getting up every day, eating well and a bit of physical activity will help you in the long run.

'Don't be hard on yourself. Getting out of bed every day is an achievement.'

Donna, whose 18-year-old daughter Emily died after a stem cell transplant

'Life had been dominated by his treatment and months of being his carer 24 hours a day, and now there was a void in my life. The days and nights seemed incredibly long.'

Helen, whose husband died after a stem cell transplant

ADVICE FROM BEREAVED RELATIVES

'Be kind to yourself.'

'Talk to peers.'

'Crying is good, it can be a relief.'

'Give yourself time – grief comes in waves.'

AFTERCARE AND SUPPORT

With any of these feelings, it's important that you talk to someone. Talking to family and friends can help, especially those who have been involved and have an idea of the experience you had after the transplant.

Peer support

It can be hard for anyone to really understand the impact and emotions that you might be feeling. Consider talking to people who have been in the same or similar situations, and ask at the hospital or your local hospice if they have any support groups for relatives.

Counselling

Professional help with a bereavement counsellor could help. Saying out loud what you feel can be therapeutic, as well as having someone to listen. You can be referred for counselling by the hospital, GP or local hospice. Even if your relative or family member was not being cared for at the hospice, they might have some support services that you can access.



Support groups

If your relative or family member's diagnosis was not a type of blood cancer, or they died of post-transplant complications rather than relapse, it can be difficult to access cancer support groups. But there are other types of support groups you can access. We've listed some on **p35**, as well as suggestions for online groups and forums if you feel this format would be better for you.

Consultant

If you have questions about any part of the transplant, you can arrange to speak to the consultant involved in the care. Give yourself some time to gather your thoughts and consider your questions, and perhaps take someone with you for support.

Practical help

Ask family and friends for help with the practical things such as funeral arrangements, informing banks and cancelling bills etc. They could help with the basics like tidying, cleaning, and cooking meals, too. Family and friends often want to help during a time like this but don't know how to, so this could be a good way for them to give you some support.

Financial help

You can get government help with funeral expenses and might be entitled to benefits such as a Bereavement Support Payment or Bereavement Allowance. More information can be found on **p38**.

'A friend suggested we do a charity walk. It felt like the last thing I wanted to do but training helped me focus and get out of bed every day. It saved me from depression and I felt a sense of achievement when I crossed the line.'

Poonam, whose husband Rakesh died following post-transplant complications



ADVICE FROM BEREAVED RELATIVES

'Don't make any big decisions in the first year.'

'Day-to-day grief is hard and old routines can be painful. If you attempt to make new routines, forgive yourself if you do not initially succeed.'

'Try to have a focus, something like exercise. Setting yourself a goal, like doing a walk or a run, will give you motivation.'

'Your needs will change over time.'

SUPPORTING CHILDREN

Just like adults, children grieve in different ways and there is no right or wrong way to go through this process. Grief will be affected by the child's age, their understanding of what has happened and why.

Losing someone close will be devastating. Their reactions can vary greatly and can change over time, and that's OK.



It can be difficult to support children when you're also dealing with your own grief.

This is a hard balance but it's important that they see that you are grieving too. Don't be afraid to show your children that you are upset but do explain why you are upset, so they know your distress wasn't caused by them. Understanding that it's ok to show emotion will encourage them to do the same.

During recovery after transplant, children might have spent long periods away from the person they loved and home life might have changed. Grandparents might have been more involved, for example, or they could have spent more time with close friends while you were at the hospital.

This can mean that relationships within the family or with friends can change, and children may need time to adapt. They also might have seen physical changes, such as weight loss or skin GvHD, which may have been hard for a child to process and understand. Talking about these things can make sure difficult feelings aren't bottled up.

Like adults, a child's reaction to death can include sadness, anger and feeling lost, but they might not know the words to express how they feel. It may be helpful for you and your children to read books together which explore grief, such as *Sad Book* by Michael Rosen or *The Heart and the Bottle* by Oliver Jeffers. You can find lists of recommended reads on the Child Bereavement UK or Cruse Bereavement Care websites (see 'Other useful contacts' on **p35**).

WHAT SUPPORT IS AVAILABLE FOR CHILDREN?

Many children manage their grief well with support from their family and friends.

However, if you are worried about how your children are grieving, there are some good helplines and websites which can help you decide whether they will need extra support and who to contact. Your hospital, GP and local hospice are also good places to ask for help.

Schools can offer extra support at this time. It is helpful for them to know what has happened so they can help children who need it and take account of the death if academic tests are coming up. Schools often have staff who can give your child time to express their grief using talking, drawing or play. See 'Other useful contacts' on **p35**.

ADVICE FROM BEREAVED RELATIVES

'My three children all grieved in different ways.'

'It was important that the grandchildren know about Mum, so we make sure we talk about her and have her things around the house.'

'Young children will continue to need support as they grow up – it can be intermittent.'

LIVING WITH BEREAVEMENT

The journey through transplant and treatment can be challenging, and you might feel as if life has been on hold. You might now want some time out or just some sense of normality again.

These feelings are completely normal. Over time your bereavement will change. Allow yourself some short, sad moments and in time you will regain hope.



Anniversaries

These can be especially challenging. Although it may be the occasion or date that you dread, often the build up to the day can be worse. You, your family and friends might choose to prepare yourselves for anniversaries differently. This is very personal, and you should all cope with it as you wish.

'The thought of going to a family birthday or friend's party is exhausting. But we're always pleased to be invited and make ourselves go. A tragic thing happened to us, but we are not tragic people.'

Ann, whose daughter Zoe died after a stem cell transplant

Support from others

This can feel overwhelming in the beginning and then, as people return to their normal lives, support can dwindle. This can be hard but try to find a focus to help you cope, like returning to work or setting yourself little goals. Volunteering or taking part in peer support with other people who have had similar experiences can also help.

'18 months after Mum died, I started to have counselling. I didn't think I needed it but actually it really helped.'

Darren, whose mum died after a stem cell transplant

Tribute Funds

You might feel like you want to commemorate your relative or family member but it can be hard to know where to start. If you are looking for an idea, an Anthony Nolan Tribute Fund offers a wonderful online space to share stories, treasured memories and photos with others.

It will also help to raise vital funds for other people with blood cancer or blood disorders, creating a lifesaving legacy in honour of your relative or family member.

For further information see
anthonymolan.org/fundraise-memory

ADVICE FROM BEREAVED RELATIVES

'Meeting other people who had been bereaved but were now doing well can give hope.'

'Bereavement can change you and members of your family. Give yourself time to get to know each other again.'

'The need for counselling can be intermittent. Don't dismiss it as something that you can only have early on.'

'Even though I have now met someone else, I still grieve for my husband.'

WHAT ABOUT THE DONOR?

Bereavement can be especially difficult if the donor for the transplant was you or a family member.

Being a donor brings optimism, but it can also feel like a responsibility. When someone dies, the donor can feel somehow responsible for the transplant not working. This is, of course, not true as without the donor the chance of survival might not have been available.

If the donor was a family member, it's important to consider their feelings. Make sure they are not carrying around feelings of guilt or anger, and encourage them to talk about how they feel and to access support if needed.



CONTACTING THE DONOR

For families of patients who had an unrelated stem cell donor, you might have been thinking about contacting their donor. This is completely up to you. Donors do not expect to be contacted, so don't worry if you don't feel like you want to.

If you do want to contact the donor, you can do this by letter or even arrange to meet. Anthony Nolan's Donor Follow Up team can help you with making this decision. Here are a few things to consider:

- Like with everything, we would advise you to give yourself time before deciding to make contact. Emotions are high and feelings can change, so it's good to be sure that this is definitely what you would like to do.
- Your contact might be the first time the donor learns of the death so it could be a shock to them. They too might feel a sadness and a loss.
- Some donors choose to not know what happens after they have made the donation, and this is their choice. There is no guarantee that they will accept your contact or respond.

- Once contact has been made, the donor might wish to stay in touch so you need to think about what your expectations are, and how you would like to manage this long term.
- For some international donors, there might be some restrictions on contact. Our Donor Follow Up team will be able to advise on this.

For further information on contacting the donor, email **donor@anthohnolan.org**

ANTHONY NOLAN CONTACT DETAILS

WHERE CAN I GET MORE INFORMATION AND SUPPORT?

If you or a loved one is affected by a stem cell or bone marrow transplant, there are many ways we can support you:

NEED TO TALK?

The Patient Services team at Anthony Nolan is here for you.

Call our enquiry line on **0303 303 0303** or email:
patientinfo@anthohnolan.org

GET CONNECTED

Find support from other families and patients by joining our Patients & Families forum at:
anthohnolan.org/forum

FIND INFORMATION

Our website has lots of helpful information about what it's like to go through a transplant.

Download or order our booklets for free, and find links to other places where you can get support at:
anthohnolan.org/patientinfo

OTHER USEFUL CONTACTS

BEREAVEMENT SUPPORT

Cruse Bereavement Care

cruse.org.uk

Helpline: 0808 808 1677 / info@cruse.org.uk

Support and advice following the death of someone close, online, by telephone, email or face-to-face.

The Good Grief Trust

thegoodgrieftrust.org

Useful info, advice and encouraging stories from others who are experiencing bereavement, plus a UK map of support services.

Care for the Family

careforthefamily.org.uk/family-life/bereavement-support

Advice, personal stories and support info for anyone who has lost a family member or is helping a bereaved person.

WAY: Widowed & Young

widowedandyoung.org.uk

Emotional and practical support for anyone who was aged 50 or under when their partner died.

AtaLoss.org

A signposting website to help you find local and appropriate bereavement support, plus messaging service Griefchat for emotional support.

IF A CHILD OR PARENT IS BEREAVED

Winston's Wish

winstonswish.org

Helpline: 08088 020 021

ask@winstonswish.org

Support for children and young people after the death of a parent or sibling.

Child Bereavement UK

childbereavementuk.org

Helpline: 0800 02 888 400

Support for families and professionals when a child or parent is dealing with bereavement.

Childhood Bereavement Network

childhoodbereavementnetwork.org.uk

Advice for young people who have been bereaved, and parents, carers and professionals who support them.

The Compassionate Friends

tcf.org.uk

Wide range of info and advice for bereaved families, after the death of a child of any age. Includes UK map of support services.

Child Death Helpline

childdeathhelpline.org.uk

Helpline: 0800 282 986 (from landline) or

0808 800 6019 (from mobile)

Freephone helpline for anyone affected by the death of a child.

IF SOMEONE DIES WITH CANCER

Macmillan

macmillan.org.uk/information-and-support/coping/at-the-end-of-life

Helpline: 0808 808 00 00

Practical and emotional support at the end of life and through bereavement.

EMOTIONAL SUPPORT

Samaritans

samaritans.org

Helpline: 116 123 / email: jo@samaritans.org

Confidential, non-judgemental emotional support 24 hours a day, by telephone, email, letter or face-to-face.

COUNSELLING

NHS Choices:

Counselling nhs.uk/conditions/counselling

Explains what counselling can help with, the different types of counselling and how to find a qualified counsellor.

PRACTICAL ADVICE

Bereavement Advice Centre

bereavementadvice.org

Helpline: 0800 634 9494

Information and support around how to deal with practical issues following someone's death.

Citizens Advice

citizensadvice.org.uk/family/death-and-wills

Practical information on what to do after someone has died, including how to arrange the funeral and what to do about your loved one's financial affairs and their will.

FINANCIAL HELP

Turn2us

turn2us.org.uk

National charity providing financial support for anyone struggling with money, including advice on benefits and grants.

Widowed Parent's Allowance

gov.uk/widowed-parents-allowance

Official guidelines on who is eligible for Widowed Parent's Allowance, and how to claim it.

Children's Funeral Fund

gov.uk/government/news/childrens-funeral-fund-for-england

Official guidelines on who is eligible for the Children's Funeral Fund for England, for parents who have lost a child, and how to claim it.

NOTES

'GRIEF IS DIFFERENT FROM
DEPRESSION - IT CAN BE
DIFFICULT FOR PEOPLE
TO UNDERSTAND THAT.
I AM NOT DEPRESSED,
I AM GRIEVING. AND I
WANT TO TALK ABOUT IT.'

Donna, whose 18-year-old daughter Emily
died after a stem cell transplant

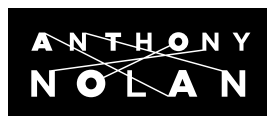
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Reg Charity no 803716/SC038827
1424PA/1218 DOC4341 Version 001 (1218)



Produced with support
from the Jack Petchey
Foundation, in memory
of John Petchey.



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