ANTHONY NOLAN

Saving lives through stem cells

How we can improve the mental health and wellbeing of cell therapy patients

AN ANTHONY NOLAN REPORT

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About this report

This report highlights the impact of a stem cell transplant and other cellular therapies on the mental health and wellbeing of patients and their loved ones, and the gaps in support available to them.

While these treatments offer hope, the emotional toll they take on patients and their families can be overwhelming.

Informed by in-depth interviews with patients, family members, stem cell donors and specialist transplant psychologists, as well as published evidence, this report outlines the actions needed to improve the mental health support offered to patients going through stem cell transplantation, CAR-T and other cell therapies.

Anthony Nolan is a stem cell charity founded in 1974. We unite people and science – matching stem cell donors to those in need of transplants and treatments and growing our world-leading stem cell register, so everyone can find the lifesaving match they need. We also support the development of new cell therapies, offer essential support to patients and families, and advocate for better care.

Key findings

Stem cell transplant has a significant impact on mental health

Stem cell transplant patients commonly experience many mental health challenges, including anxiety, depression and post-traumatic stress disorder (PTSD). These symptoms are often exacerbated by long periods of isolation during treatment and recovery, the financial burden of illness and treatment, and the marked uncertainty surrounding outcomes.[1, 2]

Families and caregivers are also negatively affected. The caregiving role often leads to high levels of stress, fatigue, and financial strain[3]. Family and sibling stem cell donors face unique psychological challenges, including guilt, anxiety, and fear of unsuccessful outcomes[4]. Managing patients' mental health and wellbeing can lead to better health outcomes and overall quality of life[1].

Psychological support is highly variable

Although many transplant centres in the UK provide excellent psychological support to stem cell transplant patients, there are gaps and inequalities in what's available nationwide.[5]

The biggest gaps are in:

- The psychological support available to patients with non-cancer diagnoses
- Long-term psychological follow-up
- Care for family members and sibling donors

Policy recommendations

1. Embed specialist clinical psychologists in all transplant centres
2. Empower all patient-facing staff in stem cell transplant to support mental health
3. Expand the availability of peer support
4. Expand the psychosocial support available to families, siblings and sibling donors

This report urges policymakers and commissioners to take action to address the unmet psychological needs of stem cell transplant and CAR-T patients. Psychological support isn't just the right thing to do – it's essential for improving recovery, helping patients feel cared for, and transforming their overall quality of life.

Foreword

At Anthony Nolan, we are proud to have always been at the forefront of providing holistic support to stem cell transplant patients and their families. Our Patient Services team offers a vital lifeline of practical and emotional support. From offering telephone counselling and financial grants, funding clinical psychologist posts in transplant centres and connecting patients with one another and sharing advice and resources, we strive to ease the mental health challenges that so many transplant patients and their families face.

However, as this report shows, much more needs to be done as far too many patients and their families are falling through the cracks.

The next steps, as outlined in this report, are clear. We must work with policymakers, NHS leaders, and clinicians to ensure psychological care is an integral part of every patient's journey. This includes ensuring psychological assessments are available from the outset, and that specialist support continues long after treatment ends. Only then can we truly say we are supporting our patients and their families in every way possible.

We hope this report serves as a catalyst for the change that is so urgently needed. We are deeply grateful to the patients, families, caregivers and healthcare professionals who have shared their stories and experiences with us, and we will continue to call for better, more compassionate, care for all.

Together, we can ensure no one faces their transplant journey alone.

Henny Braund
Chief Executive, Anthony Nolan

About stem cell transplantation and cellular therapy

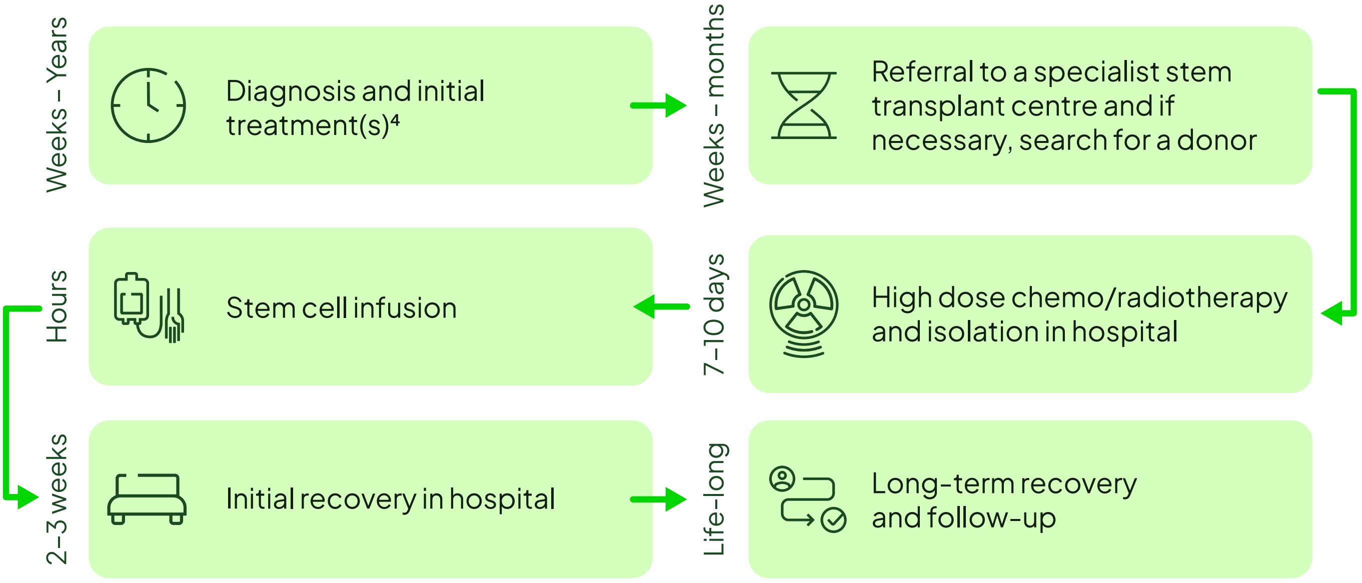
Stem cell transplant, and similar cell therapies such as chimeric antigen receptor T-cell (CAR-T) therapy, are often the only curative option for patients with blood cancers and blood disorders. Patients can receive their own cells (autologous transplant), or cells from a donor such as a sibling or an unrelated volunteer (allogeneic transplant).

There are around 3,650 stem cell transplants and 300 CAR-T procedures performed in the UK every year.[6] Approximately 93% of transplants, and all CAR-T therapies, are for malignant (cancer) indications such as myeloma, leukaemia and lymphoma, although there are increasing numbers of transplant patients with non-malignant conditions such as aplastic anaemia, sickle cell disorder and thalassaemia.[6]

While these therapies are potentially lifesaving, they also have substantial physical, emotional, and psychological effects on patients and their families. The transplant process is intensive and complex. Patients typically spend long periods of time in hospital before, during and after their transplant or CAR-T therapy.

Long-term survival after transplant ranges from 95% for patients receiving an autologous transplant for a non-cancer condition to 53% for adult patients receiving a donor transplant for cancer.[6]

A typical stem cell transplant patient journey



Weeks - Years: Diagnosis and initial treatment(s)[4]

Weeks - months: Referral to a specialist stem transplant centre and if necessary, search for a donor

7–10 days: High dose chemo/radiotherapy and isolation in hospital

Hours: Stem cell infusion

2–3 weeks: Initial recovery in hospital

Life-long: Long-term recovery and follow-up

How stem cell transplantation impacts mental health and wellbeing

> “Mentally, it never leaves you.”

NIGEL **STEM CELL TRANSPLANT RECIPIENT**

Stem cell transplant patients are vulnerable to a wide range of mental health conditions, including anxiety, depression, PTSD, and sleep disturbances. These conditions arise at different stages of the treatment process and are influenced by factors such as prolonged isolation, uncertainty about recovery, and financial stressors.[1]

Causes of psychological distress

- Prolonged isolation
- Physical effects of treatment
- Uncertainty about recovery
- Financial difficulties
- Disruptions to family and social life

Key stats

40% of patients experience anxiety before transplant[7]

35% experience depression during or after transplant[8]

20% experience PTSD [8]

Referral to treatment

The period leading up to transplant or CAR-T therapy is often filled with uncertainty. Research shows that up to 40% of patients experience heightened anxiety before transplantation[7], as they grapple with questions about their survival, and the risks involved. Similarly, nearly half of CAR-T patients report depression or anxiety at the time of their infusion.[8]

For many patients the time waiting for a suitable stem cell donor to be found is particularly difficult. This can be especially tough for patients from minority ethnic backgrounds, for whom it can be more difficult to find a match.

> “There was a lot of uncertainty whether this would work, which was really scary.”

JEMMA **ALEX’S WIFE**

Supanya's story

Experiencing stem cell transplant and loss as a parent

The period before our daughter Lara's stem cell transplant was one of the most stressful times of my life. From the moment we learned she had high-risk AML, the doctors made it clear a transplant was her best chance. Hearing that was devastating, not just because of the treatment itself, but because we knew finding a match would be incredibly difficult due to her ethnicity.

We launched the Match for Lara campaign, and while we knew it wouldn't necessarily directly help Lara, it gave us something positive to focus on. It was amazing to see so many people respond – thousands signed up as donors – but deep down, the uncertainty was always there. Even when potential donors were identified on global registries, they weren't suitable. That rollercoaster of hope and disappointment was exhausting.

And going public came with challenges. When you search her name now, pages of her story pop up. While much of the response was positive, we also dealt with unpleasant comments. No one warned us about the long-term impact of such visibility, and although I am glad we ran the campaign, it would have been useful to have been prepared for the potential impact.

> **"I felt like I had to keep it together, to be strong for her, while inside, I was falling apart."**
>
> **SUPANYA** **LARA'S MUM**

Lara had to continue treatment while we waited for a match and watching her go through it was heartbreaking. Chemotherapy took a huge toll on her, and every hospital admission was filled with fear – what if this round doesn't work? What if she gets an infection? There was one point where she ended up in intensive care before her second transplant, and we didn't know if her body could handle more treatment. I felt like I had to keep it together, to be strong for her, while inside, I was falling apart.

Lara faced her journey with resilience and grace. The team at University College London Hospitals (UCLH) was amazing – they didn't just treat her medically; they supported her personal goals. Lara wanted to travel, see friends, and even get our dog 'married', and her doctors made it possible. She managed to attend weddings, travel to Thailand, and participate in the Transplant Games. Lara never talked about dying, she always talked about living and wanting to live her life with the time she had.

Hospitalisation and treatment

The prolonged periods of hospitalisation and isolation are among the most psychologically taxing aspects of treatment. Patients are required to remain in protective isolation to avoid infection, often leading to intense feelings of loneliness, disempowerment and demoralisation. Studies indicate that 35% of patients develop depressive symptoms during or after their hospital stay.[1]

> **"The isolation was overwhelming – that was probably the worst part."**
>
> **NIGEL**
>
> **STEM CELL TRANSPLANT RECIPIENT**

Ross' story

Isolation and loneliness during CAR-T therapy

Being hospitalised during my CAR-T therapy was a deeply isolating and emotionally draining experience. The treatment itself was daunting, but it was the psychological impact of being separated from my family that really hit hard.

Isolation, on top of COVID-19 restrictions, was brutal. I wasn't allowed any visitors, not even my husband, who would drive an hour and a half each way just to pick up my laundry. The worst part was knowing he was downstairs but couldn't come up to see me. That separation, combined with the stress of being confined to one room for weeks, took a toll on my mental health. I often felt like I was in prison.

For four weeks after I was discharged, I needed to live within 15 minutes of the CAR-T centre. The hospital didn't provide accommodation, so my family had to start a fundraiser to rent a flat nearby for me to stay. Moving into that flat felt like freedom after being in hospital, but it came with its own challenges. Adjusting to life in an unfamiliar place, while trying to manage my recovery, only deepened my feelings of depression and anxiety.

One of the most frustrating aspects was the way my concerns were dismissed by some healthcare staff. For example, the strong perfume worn by nurses made me physically sick due to sensory changes caused by CAR-T, but my complaints weren't taken seriously.

Psychological help was non-existent throughout the whole process. What helped was the patient helplines of charities like Anthony Nolan, and my faith, which gave me strength. However, more structured psychological care – something embedded into the hospital experience – would have made a huge difference.

Recovery

Following their transplant, patients face a lengthy recovery that often includes severe fatigue and physical complications and challenges associated with immunosuppression.[7] The uncertainty surrounding long-term outcomes can prevent patients from moving forward with their lives and planning for the future.

> **"Patients often think 'once I've got through the transplant everything will be brilliant' but the reality is different."**

JENNA **BMT CLINICAL PSYCHOLOGIST**

Between 8–15% of patients receiving an allogeneic stem cell transplant develop chronic graft versus host disease (GvHD).[6] Up to 50% of patients with chronic GvHD experience ongoing mental health challenges such as anxiety, depression, and PTSD.[9]

In addition, the impact on self-esteem and identity can be profound – for both patients and families. Many patients experience changes to their personal relationships, including a low sex drive and a loss of self-confidence. Sexual problems are a frequent complication, affecting 80% of women and 50% of men.[10] Such problems have a serious impact on patients' quality of life and are often underreported.

Another significantly under-explored area is the impact of a loss of fertility after transplant on the identity and mental wellbeing of patients and their loved ones.[10] Many transplant patients experience difficulty having biological children after transplant, this can be particularly difficult for people treated before they have had a chance to start a family. Adding to this trauma is the difficulty of navigating complicated fertility preservation pathways – for example, in England every Integrated Care Board (ICB) has different criteria for who qualifies for sperm or egg storage and for how long they will store eggs.

For children and adolescents, the psychological challenges are compounded by the disruption to key developmental milestones. Young patients must cope with being separated from their peers, missing out on formative educational and social experiences.[11]

Between 8–15% of patients receiving an allogeneic stem cell transplant develop chronic GvHD.[6]

Lucy and Opie's story

Experiencing treatment far from home

When my son Opie was diagnosed with B-ALL at just five months old, our world turned upside down. Life became an endless cycle of hospital stays, separation from family, and managing the unmanageable. Opie had only been with us a few months before we were completely separated from the rest of the family.

One of the hardest parts was the physical and emotional isolation. For weeks at a time, I was with Opie in a shared ward, surrounded by noise, with nothing but a curtain for privacy. Processing everything alone in the quiet hours of the night was the loneliest, hardest part. It was impossible to have meaningful conversations with the hospital counsellor in that environment – it would feel tokenistic.

Being transferred to a specialist hospital three and a half hours from home was another challenge.

I stayed in a room with Opie for a month without seeing anyone, while my husband looked after our other children. The emotional toll on our family was immense.

The psychological support we received varied dramatically between hospitals. It wasn't until treatment at Great Ormond Street Hospital (GOSH) after his relapse, that I truly felt I received psychological support. Their psychologist proactively reached out and gave me therapy sessions, supporting me through so I could be there for Opie.

> **"I stayed on the ward with Opie for a month without seeing anyone."**
>
> **LUCY** **OPIE'S MUM**

Still, the moment we left the hospital, the psychological support disappeared. That's when I needed it the most. It's hard to explain how life after treatment feels – it's like emerging from a bubble into a new normal you never wanted. People assume you should be grateful and move on, but the trauma doesn't just end when the treatment does.

For Opie, the long-term effects of all his treatment are still unclear. He missed out on so much. My other children struggled too, and I've had to privately fund therapy for all of us.

Looking back, there's so much that could have been done differently. A dedicated psychologist following us through the journey would have been invaluable, as would access to emotional and psychological support for the whole family.

Impact on families and caregivers

The psychological impact of stem cell transplant and CAR-T therapy extends beyond patients themselves.

The complexity of these therapies places a significant emotional strain on caregivers. The caregiving role can be emotionally and physically exhausting, particularly during the intensive post-transplant recovery period when patients require round-the-clock care.[12]

For families, particularly those with children undergoing transplant, the emotional strain is intensified by separation from other family members. Families have to balance caregiving with personal and family responsibilities. Caregivers also often struggle with anticipatory grief, fearing the potential loss of their loved one.[13]

Financial stress

The financial burden of undergoing a stem cell transplants is significant. Families face loss of income due to time taken off work, the costs of travel to treatment centres, and additional medical expenses. Patients and families often struggle to navigate the financial support available to them. Social workers can provide invaluable help with navigating applications for government or other support, but not every transplant centre has a social worker available or if they do, they are often only available to patients with a cancer indication for transplant.

The impact of stem cell transplant on family finances: Results from the 2024 Anthony Nolan survey

83% of SCT/CT patients/carers had given up work or reduced their working hours

63% had been unable to afford nutritious food

27% had been unable to pay their rent or mortgage

38% had been unable to pay energy bills

40% said the financial support they have received has not covered the additional costs "at all"

The average loss of family income following diagnosis was approximately **£30,000**

Kathi and Oscar's story

Dealing with stem cell transplant as a young family

Caring for my son Oscar through his transplant was incredibly challenging. As a mother of two young children, I had to juggle being his advocate, navigating the medical system, and ensuring the rest of our family didn't fall apart – all while managing my own mental health.

Oscar's treatment journey was long and gruelling. We spent five months in hospital in London, then four more in Austria. The isolation was intense and the separation from my younger child was tough. For Oscar, his hospital bed became everything: his eating place, his school, his play area, and sleeping space.

One of the hardest parts was feeling like I couldn't just be his mum. I had to take on the roles of carer and coordinator, often mediating between doctors and nurses.

The impact on our family as a whole was immense but the lack of support was stark. While there was a part-time psychologist at the hospital, her time was spread thinly across the entire paediatric ward. My younger daughter was overlooked entirely. Eventually, she developed severe anxiety and stopped attending school, but addressing her needs was left entirely up to us.

> **"The impact on our family as a whole was immense but the lack of support was stark."**
>
> **KATHI** **OSCAR'S MUM**

Looking back, it's clear that the system is not designed for the whole family. I don't think the intense pressure and undertaking on the family is understood. Psychological care needs to be integrated into transplant journeys – not just for the patient but for siblings and parents, too. Hospitals also need dedicated social workers to help families navigate the financial and logistical burdens.

The aftermath of the transplant has been one of the hardest parts. It plays a big impact on my mental health, my self-worth, my relationship. People assume things are 'fixed' because Oscar looks healthy, but our lives are still piecing themselves back together. Families need ongoing support, not just during the hospital stay but long after treatment ends. It's a very lonely experience.

Dr Jenna Love's perspective

Gaps in access to psychological support for non-malignant patients

As a clinical psychologist working with patients undergoing transplant, I've seen how different conditions shape their emotional and psychological needs – and how uneven the support can be. Patients going through transplant with non-malignant conditions like sickle cell often face unique challenges compared to those with blood cancers, and these differences aren't always reflected in the care provided.

In terms of access to psychological care non-malignant transplant patients often find themselves overlooked. Because my position was funded by Anthony Nolan, I could provide support to all transplant patients at our centre, regardless of their condition. But this isn't the norm.

Sources of support like those provided by national cancer charities are often unavailable to non-cancer transplant patients. That creates a sense of inequity.

There are also cultural and socioeconomic barriers that disproportionately affect non-malignant patients. Many sickle cell patients, for instance, face additional challenges like language barriers or financial strain. I've had patients living in damp, overcrowded conditions where infection control is almost impossible. These issues compound their stress, making psychological support even more critical.

Impact on stem cell donors

While the majority of stem cell donors report a positive psychological impact from their decision to donate cells[14], in some cases donors – particularly those who donate to a sibling or family member – experience unique psychological challenges.

The donation process can evoke a wide range of conflicting emotions, including anxiety, fear, pride, and responsibility.[15] These feelings are particularly intense for sibling donors, who often feel an overwhelming responsibility to save their sibling's life.[4] Some sibling donors have even reported feeling pressured to donate and that they did not have a voice in the decision-making process.[15]

In cases where the patient's transplant is unsuccessful, donors can feel guilt and blame for the patient's death.[4]

Mary's story

Donating stem cells to her brother

When I found out I was a stem cell match for my brother, I felt a mix of emotions. My brother's cancer had returned after years in remission, and I felt grateful to have the chance to help him.

The donation itself was physically straightforward but emotionally overwhelming. Being the only match in my family left me with a huge sense of responsibility. When the transplant initially seemed to work, I felt relief, but when my brother's health deteriorated, I spiralled into guilt. I couldn't shake the thought that my donation wasn't good enough and I blamed myself.

The hardest part came after my brother passed away. The grief was made worse by the feeling that it was my fault. It was difficult to talk about my feelings openly, even within my family, because everyone was grieving in their own way.

One source of support I received was from the Anthony Nolan Donor Follow Up team. They were a lifeline, arranging for me to speak with a counsellor. Those sessions were invaluable – they helped me process my feelings of guilt and reframe my thoughts. I was encouraged to see that I wasn't responsible for the outcome, which was a huge weight lifted off my shoulders.

> **"Being the only match in my family left me with a huge sense of responsibility."**

MARY **STEM CELL DONOR**

Looking back, I wish there had been more structured support throughout the process. Before donating, no one screened my mental health or prepared me for what could go wrong. The focus was entirely on the physical procedure, with little consideration for the emotional toll if the transplant wasn't successful.

I think donors would benefit from peer support. Talking to someone who's been through the same experience – especially when things don't go as hoped – would be incredibly helpful. It's one thing to hear reassurances from professionals, but it's different to connect with someone who truly understands.

Despite the challenges, I don't regret donating. It was my chance to try and give my brother a lifeline, and I hold onto that. But the psychological impact shouldn't be underestimated, and future donors need more holistic care to navigate the complexities of this experience.

Existing provision of psychological support services: where are the gaps?

Psychological support services for stem cell transplant and CAR-T therapy patients are recognised as essential to improving patient outcomes and quality of life. The international FACT-JACIE standards that every UK transplant centre must follow require “dedicated psychological staff to assist in pre-transplant recipient evaluation and treatment, and post-transplant care”.[16] NHS England’s service specifications for CAR-T and stem cell transplant both note the importance of providing psychological support to patients.[17]

Despite this, significant disparities exist across transplant centres in the UK in terms of accessibility, continuity, and the comprehensiveness of psychological support.

Less than half

40%

of transplant centres offer routine psychological screening before transplant[5]

Only

17%

of UK transplant centres have a psychologist embedded in the stem cell transplant team[16]

Under a third

29%

of psychological care services are available to those with a non-cancer diagnosis[5]

85% & **39%**

of doctors **of nurses**

report receiving **no training** for assessing and managing the psychological needs of patients.[18]

Under a quarter

24%

of transplant centres offer peer support.[5]

Using the testimony from our patient and family experts and clinicians, we have identified the following key gaps and variations in current practice:

Psychological screening

Why it matters: Screening prior to transplant or CAR-T helps to identify patients and carers at risk of mental health distress and connect them to support early. Risk factors may include a prior history of mental illness, a limited support network, and financial difficulty. Yet only 40% of transplant centres offer routine psychological screening before transplant[5], leaving many patients without early mental health support.

Access to a clinical psychologist with a specialism in cell therapy

Why it matters: Stem cell transplantation is a unique treatment with relatively small patient numbers. Patients and their families have complex treatment journeys and face many risks and decision points. It is important to patients and families that the mental health support they receive comes from professionals who understand their circumstances and concerns.

Just one third of UK stem cell transplant centres have a psychologist based within haematology and only 17% have a psychologist embedded in the transplant team.[16] This means that many teams rely on shared oncology psychologists who are likely to be over-capacity and may have limited expertise in stem cell transplantation. Worryingly, there are even fewer clinical psychologists available to patients and families with a non-malignant indication for transplant. This is a major inequality in stem cell transplant and cell therapy.

Clinical psychologists can also support other members of the multidisciplinary care team to support the mental health needs of patients and families. When they are not a part of the team, this is much more difficult to do.

Just one third of UK stem cell transplant centres have a psychologist based within haematology and only 17% have a psychologist embedded in the transplant team.[16]

Dr Kofi Anie's perspective

The importance of embedding psychology into the multidisciplinary team

Having dedicated over 26 years to working primarily with sickle cell and thalassaemia patients, I've witnessed firsthand the massive impact of integrating a clinical psychologist into the care team. People with sickle cell often face unique challenges – both physical and psychological – and having regular access to a psychologist as part of their care can transform their experience.

The multidisciplinary model we use at our clinic is critical. I see every patient, not just those in crisis. I join every clinic alongside consultants, haematologists, doctors, and clinical nurse specialists. Whether it's a formal psychological intervention or an informal chat, this approach helps normalise psychological care. Many patients don't think their struggles qualify as 'mental health' issues. But by having consistent, everyday conversations with me during clinic visits or ward rounds, they're more likely to open up.

When patients are referred for a stem cell transplant, the transition to a transplant centre can be daunting. I work with patients long before their transplant referral, so I can provide the BMT psychologist with a baseline of their emotional and cognitive health. This continuity helps smooth the process and ensures they feel supported every step of the way.

> **"What's clear is that embedding a psychologist in the care team allows us to be proactive rather than reactive."**

DR KOFI ANIE

CONSULTANT PSYCHOLOGIST

What's clear is that embedding a psychologist in the care team allows us to be proactive rather than reactive. But most positions like my own are not funded full-time and there are lots of areas that do not have these roles. Expanding this model to other hospitals could bridge gaps in care and offer patients and families the comprehensive support they deserve.

Ability of the full care team to support mental health

Why it matters: Every interaction a patient has with their care team can support or impact their mental health and wellbeing.

Patients have noted that psychological care is sometimes overshadowed by medical care. In many cases, patients and family members feel that difficult conversations, for example about the risks of transplant, could have been delivered more sensitively, or that signs that they were struggling with their mental health were not picked up on.

> **"I was treated very much from a medical perspective; it was very matter of fact."**
>
> **ROSS** STEM CELL TRANSPLANT AND CAR-T THERAPY PATIENT

Some patients told us that their medical team, and in particular their clinical nurse specialist (CNS), provided some support for their mental health. They often felt however that they didn't want to "burden" the medical team with too many questions or concerns.

Peer support

> **"Being able to talk to someone who had gone through the same process would have been absolutely invaluable."**
>
> **DAVE** STEM CELL TRANSPLANT PATIENT

Why it matters: Peer support connects patients to others who have been through a similar treatment journey. Peer support can help provide a sense of solidarity and mutual understanding that is especially valuable during the isolation of hospitalisation. Patients have told us that this support alleviates feelings of loneliness, provides emotional comfort and fosters hope.

Some centres have peer support volunteers or arrange for previous transplant patients to connect with current inpatients. However, less than a quarter of transplant centres offer structured peer support, and most lack staff dedicated to coordinating these connections.[5]

It is worth noting that peer support interventions can carry risk, as sometimes incorrect or inappropriate information is exchanged. Clinicians warn that it's no substitute for professional psychological support and stress the importance of training and supervision.

Jemma’s story

Navigating grief and loss

Navigating my husband Alex’s stem cell transplants was a rollercoaster of experiences. The care we received varied dramatically depending on the hospital, and those differences had a huge impact on both Alex and me.

At the hospital where Alex had his last two transplants, the support was incredible. The transplant coordinator, consultant, CNS, and social worker were always checking in with us, providing not just medical updates but also emotional reassurance. I had a bed in his room, so I could be with him throughout his isolation. They even brought in an exercise bike for me to help manage my own stress. The social worker felt like a friend, and the whole team made us feel cared for.

In contrast, at the hospital where Alex had his first transplant, there was no continuity of care – our previous support team was replaced, and the new team was stretched too thin. I don’t remember ever having contact with a CNS; Alex became just a number. The lack of support and connection made this period emotionally exhausting.

One constant throughout Alex’s journey was the vital role of social workers. The social worker was incredible, and honestly a lifeline. She did everything from organising legal paperwork for our wedding to sitting with Alex when I had to work. She even acted as a bridge between us and the medical team, filtering our concerns and ensuring we felt heard.

> **“In the months leading up to Alex’s death, the level of care we received left us feeling isolated and unsupported.”**

JEMMA **ALEX’S WIFE**

In the months leading up to Alex’s death, decisions about Alex’s pain relief and end-of-life care were traumatic, and our relationship with the palliative care team suffered. It was horrific to watch somebody I love in that much pain.

A chaplain prayed with us daily in Alex’s final weeks, offering support that truly respected our wishes. Those are the moments that stick with me now.

Support for families and carers

Why it matters: Caregivers assume most of the responsibility for patient care, leading to high levels of stress, anxiety, and fatigue.

While some transplant centres offer family counselling sessions or educational programmes, very few provide dedicated support for caregivers and other family members. Many families end up relying on charities or, for those who can afford it, private mental health services.

Support for donors

Why it matters: Stem cell donors, particularly family and sibling donors, face complex emotional effects from the donation process. 40% of sibling donors feel they were not provided with adequate emotional support post-donation.[4]

Over half of transplant centres do not conduct post-donation psychosocial assessments [15], leaving many donors without essential support to manage feelings of guilt, responsibility, and emotional detachment. While most donors do report a positive experience, efforts should be made to provide adequate support for those who have a difficult experience.

Follow-up care

The transition from inpatient care recovery at home is fraught with challenges. Patients and families often face psychological stress, financial strain, and sometimes a sense of abandonment as they adjust to the realities of recovery outside of the hospital setting.

> **"The focus was always on the physical treatment and the moment we left the hospital, the psychological support disappeared. That's when I needed it the most."**

LUCY OPIE'S MUM

Many patients report that they felt left on their own after leaving hospital, with minimal psychological care to support them.

Long-term psychological follow up is crucial for patients due to the persistent physical and psychological impacts of transplant and CAR-T. Patients who received consistent follow-up care report a reduction in long-term depressive symptoms compared to those who did not have access to structured psychological support. However, while some transplant centres provide ongoing counselling sessions or refer patients to external mental health providers, availability remains limited.

Bereavement support

> **“The casket of a child is the heaviest because so many memories, dreams, and visions are all gone with it.”**

EBI **NATHANIEL’S DAD**

For families and caregivers who lose a loved one during or after transplantation, bereavement support is an essential yet often overlooked component of psychological care. Currently, bereavement services are inconsistently available, with many transplant centres lacking support for grieving families.

Comprehensive bereavement care is not only compassionate but can also foster long-term resilience and emotional healing for surviving family members.[19,20] Studies indicate that families who receive tailored bereavement support report fewer long-term psychological impacts, such as depression and complicated grief, compared to those without access to such services.

Studies indicate that families who receive tailored bereavement support report fewer long-term psychological impacts.

Ebi and Nathaniel's story

How psychological support helped Nathaniel's family to cope with his loss

My son Nathaniel's leukaemia diagnosis at such a young age was devastating, and hearing that a stem cell transplant wasn't likely to cure him only made it worse. It's a journey no parent should face, but we did our best to navigate it. The support offered to Nathaniel and us as a family made a huge difference.

At GOSH Nathaniel received incredible care, including play therapy and physiotherapy. Seeing him laugh and play during treatment helped lighten the emotional load for me as his dad. It's hard to describe how much it means to see your child find moments of joy in such a difficult time.

GOSH also assigned us a psychologist, who was a huge source of support for me. She called before treatment began, and it was comforting to know I could reach out when I needed. A charity provided us with a great social worker who helped us navigate the maze of information and signposted financial aid like Universal Credit and Disability Living Allowance.

My daughters weren't forgotten either. At our local hospital, they received drama therapy. It gave them a way to process their feelings while I focused on Nathaniel's care. However, the strain on our family was still immense.

The financial and logistical challenges of traveling to GOSH added another layer of stress. While hospital transport was sometimes available, the wait times were long, and juggling childcare with frequent hospital visits was exhausting. I eventually returned to work earlier than I wanted to, to make ends meet.

After Nathaniel passed away, GOSH continued to offer support, including a Bereaved Men's Service and annual remembrance events, which I still attend. Visiting his resting place fortnightly also helps – it's a moment of reflection and connection.

Every bit of support during Nathaniel's treatment felt like a piece of light in a very dark time.

Recommendations for transforming psychological support

Anthony Nolan has worked with patients, families and clinicians to develop recommendations that will help to improve the psychological care and support that stem cell transplant and CAR-T patients receive.

These recommendations align with EBMT and British Society of Blood and Marrow Transplantation and Cellular Therapy (BSBMTCT) guidelines and aim to create a patient-centred approach, offering comprehensive care to address the diverse needs of both patients and their families.

Implementing these recommendations will embed a robust framework for psychological care that acknowledges the unique challenges faced by stem cell transplant and CAR-T therapy patients. Through dedicated psychological support, holistic services, and increased resource, we can ensure that all patients and their families receive compassionate, continuous care.

By fostering collaboration between clinicians, commissioners and patient organisations, we can provide a comprehensive, personalised care model that transforms the stem cell transplant and CAR-T therapy experience for all.

RECOMMENDATION		LEAD RESPONSIBILITY
1	**Embed specialist clinical psychologists in all transplant centres:** Ensure every transplant centre has a dedicated clinical psychologist to provide ongoing, specialist psychological care, including psychological assessments, tailored interventions, and collaboration with the multidisciplinary team (MDT).	NHS commissioners and providers
2	**Empower all patient-facing staff in stem cell transplant to support mental health:** Provide the whole MDT with training and support to identify psychological distress, incorporate psychological care into treatment plans, and ensure coordination with primary care, referring hospitals, and community mental health services.	NHS commissioners and providers
3	**Expand the availability of peer support:** Establish formal peer support programmes that can be accessed nationally.	NHS commissioners and providers, patient organisations
4	**Expand the psychosocial support available to families, including siblings and sibling donors:** Ensure all transplant services have clear pathways to proactively offer and support parents, siblings and carers with psychological support, including around end of life and bereavement.	NHS commissioners and providers

Conclusion: A future where every patient can survive and thrive

Stem cell transplantation and CAR-T therapy are transformative treatments that offer hope to patients facing life-threatening conditions. Yet, as shown throughout this report, the psychological burden of these procedures is profound and pervasive, affecting patients, families, caregivers, and donors. For many, the hope of survival is overshadowed by the reality of isolation, uncertainty, and a lack of support.

Current gaps in psychological support not only compromise mental health but also hinder recovery, affecting both clinical outcomes and quality of life. Inconsistent access to specialised psychological care and inadequate support for families and caregivers, leave many without the necessary support at the most challenging points in their journey.

Patients deserve to be seen as whole people – not just recipients of a treatment, and families need to be supported as they navigate their caregiving roles.

The recommendations outlined in this report offer an opportunity for a compassionate and person-centred approach to psychological care. **Embedding specialist psychologists in transplant centres** will provide the expertise needed to address the unique challenges of this patient group. **Standardised psychological screening** will ensure no patient or family member slips through the cracks. **Expanding peer support and family counselling** will create networks of connection and resilience. And **advancing research on donor experiences** will ensure they, too, receive the care they need.

These changes are not just aspirational – they are achievable. By investing in the psychology workforce, training multidisciplinary BMT teams, and integrating psychological care into long-term follow-up, the UK can lead the way in creating a truly holistic model of care for stem cell transplant patients and their families.

Through collaboration and ambition to supporting patients to thrive beyond survival, the healthcare system can close the gap in psychological care and ensure that every patient and their family receives the support they deserve. By working together, we can make this vision a reality.

Appendix

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The patients and family members who shared their stories with honesty and vulnerability. Your journeys have highlighted the challenges and needs of those navigating the transplant journey and inspired the recommendations in this report.

The clinicians who gave their time and insights, helping us understand the realities of providing psychological care and the opportunities for improvement. Particular thanks to Dr Rosa Naidoo, whose expertise and guidance have been invaluable in shaping this report.

Sanofi, our funder, whose support made this project possible and helped to highlight these important issues in patient care.

We extend our heartfelt thanks to everyone who contributed to this report. Your voices and experiences are at the centre of our mission to ensure that all patients and families receive the psychological support they deserve. Together, we can create a future where no one faces the transplant journey alone.

Glossary of terms

Allo:	allogeneic (donor) transplant using cells donated from another person
Auto:	autologous transplant using your own cells
B-ALL:	B-cell acute lymphoblastic leukaemia
BMT:	bone marrow transplantation
BSBMTCT:	British Society of Blood and Marrow Transplantation and Cellular Therapy
CAR-T:	chimeric antigen receptor T-cell therapy, a pioneering cellular therapy that modifies T-cells to target cancerous cells
CBT:	cognitive behavioural therapy, a type of counselling
CNS:	clinical nurse specialist
DHSC:	Department for Health and Social Care
DLA:	Disability Living Allowance
DWP:	Department for Work and Pensions
EBMT:	European Society for Blood and Marrow Transplantation
GvHD:	graft versus host disease, a common complication of allogeneic stem cell transplant when the donor cells harm the recipient
HEE:	Health Education England
HCT:	haematopoietic cell transplant using stem cells from the bone marrow, umbilical cord blood or peripheral blood
ICB:	Integrated Care Board
MDT:	multi-disciplinary team, a group of health and care staff who are members of different professions
NHSBT:	NHS Blood and Transplant
NHSE:	NHS England
NICE:	National Institute for Health and Care Excellence
PIP:	Personal Independence Payment
PTSD:	post-traumatic stress disorder
UKSCSF:	UK Stem Cell Strategic Forum

Methodology: How we gathered insight for this report

Literature review

We systematically reviewed peer-reviewed journals, clinical guidelines, studies, reports, and other relevant materials to understand what's already known about psychological needs and support in transplant care. This helped us identify gaps in current UK service provision and shaped the recommendations in this report.

Online patient survey

We asked patients and their families to share their experiences and views through an online survey. The survey captured quantitative and qualitative data about their experience of the financial costs of undergoing treatment, the support they received, and what was missing. Their responses provided valuable insights into what matters most to those affected.

Qualitative interviews

We held in-depth, semi-structured interviews with patients, caregivers, donors, and healthcare professionals. These conversations gave us a deeper understanding of their personal experiences, challenges, and ideas for improving psychological care. A purposive sampling strategy ensured a diverse range of participants, including those from underrepresented groups.

Thematic analysis

We carefully analysed and coded all the insights we collected to identify key themes and patterns. This step helped us focus on the most important issues and solutions.

Focus group

We convened our Policy Insights Panel, a group of patients and families with an interest in policy, to discuss our findings and draft recommendations. The panel provided critical feedback, highlighted key priorities, and helped refine our proposals to make them as effective and aligned with patient voice as possible.

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