RECOVERY AFTER TRANSPLANT

WHO CARES?

saving the lives of people with blood cancer
Chris (front cover) received a transplant in December 2007 to treat mantle cell lymphoma.
INTRODUCTION

Stem cell transplant patients are often described as ‘patients for life’.

While a stem cell transplant can offer a second chance of life for people with blood cancer and other blood disorders, recovering from the treatment can be a long and difficult journey – and no two journeys are the same.

For some patients the side effects of transplant may be relatively mild, whilst for others the consequences could be extremely serious and potentially life-limiting. Whereas some patients might experience challenges early on in their recovery journey, for others they may arise months or even years later.

Of those living with the long-term effects of transplant, approximately half will suffer from graft versus host disease (GvHD), when their immune system attacks their own body. In general, these patients require closer monitoring and more frequent readmissions to hospital. These patients can also experience a number of health effects including infertility, premature menopause, sexual dysfunction, fatigue, and problems with eyes, bones, teeth, joints and muscles, and other major organs. Such patients are also at higher risk of infections, problems with their immune system, and secondary cancers.

As well as experiencing physical effects of transplant, it is also common for patients to experience psychological effects, ranging from depression to post-traumatic stress disorder.

All patients face uncertainty as they leave hospital and begin their recovery journey, and all have questions about what lies ahead.

Who can I speak to about my recovery? Who is coordinating my care? Who can help me come to terms with my experience? Who will help support my family? Who is responsible for the services I need?

Every patient should have a clear answer to these questions, but our research reveals that significant gaps in post-transplant care and support are leaving many patients wondering: ‘Who cares’?
OUR RESEARCH

To understand the experiences of patients on their recovery journey, Anthony Nolan invited the views of people across the UK who had received a stem cell transplant. We surveyed over 300 patients and conducted in-depth interviews and a focus group.

Our aim was to understand the patient perspective of the recovery journey following treatment. The vast majority of participants told us that they were generally happy with the care they received from health service staff, with 9 in 10 patients (89%) saying that the people treating and supporting them worked hard to give them the best possible care.

However, other findings revealed considerable variation in the care and support that patients were able to access during their long-term recovery. The results of our survey are discussed in parts 1-4 of this report. In part 5 we report on information we have received from Clinical Commissioning Groups in England, which revealed a worrying lack of clarity about which parts of the health service are responsible for paying for (or ‘commissioning’) the services after stem cell transplant.

Our findings indicate that the commissioning of post-transplant services is not working for every patient. The failure to plan and pay for appropriate care and support increases the burden on patients and their families, making their recovery journey all the more difficult. As such we are calling on health commissioners to urgently review existing arrangements for post-transplant care and support.

ABOUT OUR RESEARCH

Anthony Nolan conducted a study of the experiences of stem cell transplant patients after their treatment. We used a mixed methods approach, using a survey, in-depth interviews and a focus group. The survey was distributed at twelve transplant centres in England, Scotland and Wales, and promoted online to patient audiences by eight charities.

The statistical information from the survey is based on the responses of 302 participants:

- 51% of which were male and 49% female
- The majority (61%) of respondents were 45 years or older
- Nearly 9 in 10 (86%) were White British
- Over 7 in 10 (72%) had undergone a transplant a year or more previously; less than 1 in 3 (29%) had undergone a transplant four years or more previously
• Less than 1 in 3 (28%) had undergone a transplant in the past year
• 8 in 10 respondents received an allograft transplant:
  − Over half (55%) received a stem cell donation from an unrelated donor
  − Over 1 in 5 (22%) had received their donation from a sibling
  − 3% of respondents received cells from umbilical cord
• The remaining 1 in 5 respondents (20%) received an autograft transplant
• The majority (52%) ranked their health state as 7 out of 10 or worse. 1 in 4 (25%) ranked their health state as 9 or 10 out of 10 (with 10 being the best health they could imagine)
• Half of respondents (50%) stated that they experienced no pain or discomfort
• The majority (61%) of respondents stated they were not feeling anxious or depressed, meaning that nearly 2 in 5 (39%) were feeling moderately or extremely anxious or depressed.

Alongside the survey, seven semi-structured in-depth interviews were conducted (four female, three male) in addition to a focus group with six participants (four female, two male). The research and analysis was carried out between August and December 2016.

The survey, focus group and in-depth interviews were designed and carried out by Jessica Spencer-Keyse. Additional support was provided by Anneliese Levy. The data were processed and analysed by Justice Studio Ltd.

ACKNOWLEDGEMENTS

We are grateful to staff at the following transplant centres for helping to distribute the survey to people who have had a stem cell transplant:

Addenbrooke’s Hospital       Western General Hospital Edinburgh
Birmingham Heartlands Hospital        St James’s University Hospital
The Christie                      Royal Hallamshire Hospital
Manchester Royal Infirmary         St Bartholomew’s Hospital
Queen Elizabeth Hospital Birmingham University College London Hospital
Queen Elizabeth University Hospital Glasgow University Hospital of Wales

We are also grateful to the following organisations for helping to promote the survey through their networks:

The Aplastic Anaemia Trust        Lymphoma Association
Bloodwise                       Macmillan Cancer Support
DKMS UK                         MDS UK Patient Support
Leukaemia CARE

We would like to thank all those who took part in this research by responding to the survey and/or participating in an interview or focus group. We are extremely grateful for your contribution.

The quotes used throughout this report were shared anonymously by patients responding to our online survey, focus group and in-depth interviews.
‘IT TRULY SHOCKED ME HOW POOR THE SUPPORT AFTER TREATMENT CAN BE’
CHRIS’S STORY

Chris received a transplant in December 2007 to treat mantle cell lymphoma.

‘I had my stem cell transplant nearly 10 years ago, and since then, I’ve suffered with various complications. There were times when I felt I might be over the worst, but then something else would happen.

‘In 2011, I started to think about returning to work. But then I got another infection and was seriously ill with graft versus host disease (GvHD), which required further treatment.

‘All this meant I couldn’t go back to my old job. I used to travel extensively and loved working hard and the rewards that came with that. With all these complications, I felt like a prisoner to the disease.

‘Though I was glad to be alive, it’s not the only thing that’s important. It truly shocked me how poor the support after treatment can be, and nothing could’ve prepared me for what I faced.

‘Years later, I’m now doing well and I’ve started a new career raising awareness of cancer in the community. But it’s been incredibly challenging getting back to my life after treatment.’
1. WHO CAN I SPEAK TO ABOUT MY RECOVERY?

Whilst a stem cell transplant may offer hope of a cure for people with blood cancer and blood disorders, the effects of the treatment can also lead to great uncertainty, and leave patients with a long list of questions.

Many people are unfamiliar with the concept of a stem cell transplant when the treatment is first mentioned by their doctor. Both the treatment and the recovery journey present many physical, emotional and practical challenges, and it can be particularly difficult to prepare for the journey that lies ahead after leaving hospital for the first time.

The range of possible late effects:

**PHYSICAL HEALTH**
Problems with the skin, joints, muscles, eyes, mouth, teeth, bones, bowels, kidneys, bladder, liver, lungs, heart, thyroid and other glands

**MENTAL HEALTH**
Memory changes, stress, anxiety and post traumatic stress disorder

**SEXUAL HEALTH**
Infertility, premature menopause and sexual dysfunction

**RISKS**
Infections, secondary cancers

‘A lot [of people] have said that I was actually more well when I had leukaemia than I am now... I wasn't stupid enough to think I'd be the person I was before I had leukaemia, but I thought I'd be better health-wise than I have been. In fact, what I've ended up with has been chronically ill for the last five and a bit years and I wasn't prepared for that at all.’
For both patients and their families, it can make a huge difference to know that there is somebody on hand to support them who has an expert understanding of stem cell transplant and its long-term effects. In general, patients who responded to our survey were happy with the care they received from health service staff:

9 in 10 patients (89%) said that the people treating and supporting them worked hard to give them the best possible care.

However, while patients told us that they valued the health professionals who cared for them, they were also concerned about their experience of an overstretched health service, and there was a feeling that the system was at times chaotic. Patients said that this made it harder to get the support they needed.

‘[The NHS is] very, very busy… you’re probably looking at 50, 60 maybe 70 people to get through in a morning… It’s a lot of people so they’re not going to have time to sit there and give you any emotional support or anything other than to ask you how you are.’

‘My concerns about the health service in terms of its ability to actually exist in its current form is worrying the hell out of me… I saw this registrar and I thought he was going to cry… [The health service] is absolutely falling apart at the seams… It’s heart-breaking because individual people are trying their best… It’s just awful to watch really.’

‘It would have been nice in hospital if the nurses could spend a bit more time with you just so you can have a chat one day, but they can’t…’
We were told by some patients that they needed to be pro-active in order to get answers to their questions about recovery. A common theme that emerged from our research was the need for patients to seek out help and advice independently, as well as through conversations with other patients. Our research highlighted that many patients rely on ‘overhearing’ due to a lack of signposting to key information.

“It is quite scary when you’re discharged from hospital and then you haven’t got the clinical support… The GPs don’t get in touch with you and say ‘is there anything we can do?’ They don’t seem to be in the loop at all… It’s left pretty much to you to chase them if you’re feeling unwell or if you have any concerns.’

‘I think [my husband] found that [patients were entitled to a parking permit] in the last month or something. He was talking to somebody in the room where the relatives sat and he heard somebody talking about a parking permit and he went, ‘what, what, what? What do you mean parking permit?’ So if you’ve got the sense to ask the questions, they’ll tell you but they won’t actually volunteer any information that might be of help and often you don’t know what the right questions are until much later.’

While patients shared concerns about the difficulties of accessing information and advice, there was positive feedback in relation to the support offered by dedicated post-transplant Clinical Nurse Specialists. Those patients who reported having access to a specialist nurse praised them as being responsive and supportive. One commented that the specialist nurses ‘were a sort of champion for us’.

‘I have contacted my nurse probably hundreds of times. I have called her to check appointments, seek advice, talk to her if I was having a really bad day, to be referred to a specialist… to get her to speak to other medical professionals to tell them what I need… My nurse is always there and will ring me back if I can’t get hold of her right away.’
This feedback highlighted the importance of patients having a single point of contact at the transplant centre who they can get in touch with if they have questions, concerns or need emotional support. This point of contact should be someone who understands the individual patient’s recovery needs and is equipped to respond, as opposed to those staff who are focussed on the transplant itself.

However, there are many patients who do not have access to a health professional who is focussed on supporting them throughout their recovery journey. Of those who responded to our survey:

Just over two thirds of patients (68%) reported having a Clinical Nurse Specialist who was easy to contact throughout their long-term care.

To help address this challenge, Anthony Nolan funds a network of dedicated specialist post-transplant nurses based in hospitals across the UK. By April 2018, Anthony Nolan will have funded nine Clinical Nurse Specialist posts in transplant centres. In other transplant centres similar positions may be funded by hospital trusts, depending on the resource available.

While health service staff were praised for being responsive and supportive, patients shared concerns about an over-stretched health service and a lack of clear information and advice. Our research highlights that many patients do not have easy access to a dedicated post-transplant Clinical Nurse Specialist to support them during their long-term recovery, which could make an enormous difference.
Hayley supported Sarah as a Clinical Nurse Specialist at the Royal Marsden hospital.
SARAH’S STORY

Hayley (pictured), Anthony Nolan Clinical Nurse Specialist at The Royal Marsden, and her patient Sarah.

‘Sarah* had developed chronic graft versus host disease (GvHD) following her second transplant. She was on oxygen everyday and her prognosis was poor. I found out that she had been struggling at home; physically, financially and psychologically. Because of her illness, Sarah has no income to fall back on and she had used up all her savings.

‘Talking to her, it became clear that we needed to make plans to properly support her at home. I was able to coordinate with the discharge team so that she had carers visit her home three times a week to help her with washing and dressing. We also arranged for a bed and a commode to be placed downstairs so she could be more comfortable and referred her to a hospice that provided ongoing support.

‘I was also able to help her apply for an Anthony Nolan patient grant to buy a heater for her home. She also received advice about her financial situation and was able to get further information regarding any benefits she was entitled to.

‘Thanks to this support, Sarah’s quality of life dramatically improved and we were able to make her feel comfortable and well supported in her own home during the final few months of her life.’

*This name has been changed to protect anonymity of patient
2. WHO IS COORDINATING MY CARE DURING RECOVERY?

After leaving hospital following a stem cell transplant, patients should feel confident that they will still be able to access the services they need from different parts of the healthcare system – and that these different parts are working together.

Throughout their recovery patients may require access to specialists with an understanding of the specific challenges presented by a stem cell transplant. This is particularly important for those who experience complications and late effects, such as graft versus host disease (GvHD).

Our research suggests that access to specialist care is inconsistent. Over two thirds (68%) of respondents stated that hospital staff offered them care from specialists outside the transplant team, such as dieticians, physiotherapists and gynaecologists. However, 1 in 5 (20%) said that they were not offered any support like this at all.

1 in 5 patients (20%) said that they were not offered any specialist support.

Patients also shared their frustration that some healthcare professionals outside the transplant centre setting didn’t fully understand the impact of a stem cell transplant. While it’s recognised that it isn’t the role of the GP to provide specialist care, they often found themselves reliant on their GP to access services. As one patient said, ‘my GP was fantastic, but basically relied on what I was telling her.’
‘When I came home there was no aftercare from my local GP or district nurses and I ended up having a nervous breakdown and bad anxiety… I think if I had a local health professional coming to see me at home I wouldn’t have had a breakdown.’

In this situation, communication between the hospital and the GP is very important, but often lacking. Many who took part in our research reported feeling let down by a lack of coordination in their care, which added stress and anxiety to their already difficult recovery process. However, where there was good coordination between the two, patients had a positive experience.

‘My GP was fully kept up to date with all my treatment… and they have been great; they have fulfilled their role in terms of providing sick notes for work and they have re-filled my prescriptions.’

‘I was given a sheet for a list of vaccinations… But when I took that to my GP and gave it to them they weren’t proactive. They expected me to phone them and sort that out on the three months, six months, 12 months thing, they wouldn’t look at that list or contact me and say, “Look you’re due for this vaccination now.” Again it was down to me to sort out… there doesn’t seem to be any co-ordination from the GPs.’

‘When more than one hospital is involved, there needs to be very clear communication involving the patient between the two, making it clear who is taking responsibility for what, and not leaving the patient in the dark as to what’s been shared and what hasn’t.’

When it comes to coordination and communication across the health service, a dedicated post-transplant Clinical Nurse Specialist can play a key role. As an advocate for the patient, a specialist nurse can help ensure that the responsibility of managing care does not transfer across to the patient and their family, and become a burden.

Our research reveals that access to specialist care varies across the UK, and that many patients experience poorly coordinated care once they leave hospital. It is particularly important to patients that there is clear, regular communication between the hospital and other parts of the health service.
‘I’VE FOUND IT LONELIER BEING AT HOME THAN IN HOSPITAL’
RUTH’S STORY

Ruth received a transplant in 2016 to treat acute myeloid leukaemia (AML).

‘The biggest downside of my whole transplant experience has been the complete lack of support since leaving hospital. It felt like I was on my own - my GP has offered me nothing. I’m on the waiting list for a counsellor, but it’s very long.

‘I’m quite a strong character, but when I go to hospital and sit in the waiting room, I see people who are genuinely not coping. They are too afraid to go out. I’m surprised you’re not referred to a counsellor as soon as you’re diagnosed.

‘When you’re out of hospital, people seem to forget you’re ill or at risk of infection or relapse. Once you’re home, people think you’re fine. I’ve found it lonelier being at home than in hospital.’
People recovering from a stem cell transplant face not only the long-term physical effects of the treatment, but also the challenge of coming to terms with the experience. The intensity of the treatment, and the uncertainty of what lies ahead, can often take a significant emotional toll on patients.

The challenge is all the greater where there is a lack of dedicated support during their recovery journey, or if care is poorly coordinated. In our research, some patients reported that they felt as if they had been left completely alone once they left hospital.

‘I think the support afterwards... it’s like falling off a cliff really, you’re really left pretty much to yourself.’

It was clear from our research that recovery is not an easy journey to face alone. In addition to support received from transplant centre staff, it is important that patients are able to access emotional support from professionals to understand and be prepared to deal with the impact of an intensive treatment like a stem cell transplant.

Nearly half (47%) of the respondents to our survey said that they felt they needed emotional and psychological services such as counselling and group therapy. Worryingly, however, of those who said they needed it, only half (54%) actually received it.
Of those who did receive emotional and psychological support, 9 in 10 people (89%) found it beneficial.

Our research also showed that patients do not always receive information about services that they might need. More than 1 in 3 patients (36%) said that they wanted information about support or self-help groups for people who have had a stem cell transplant, but did not receive it. As such, respondents told us that they had to pro-actively seek out support for their emotional and psychological effects.

‘My physical medical care was brilliant. But there is sadly no time to make sure people are doing mentally ok. The further from transplant I got, the more mentally stressed I got, but there is no funding for help with this’

‘I wasn’t looking for [psychological support services] particularly, but you still have ups and downs obviously because it’s been a very stressful time and traumatic.’

‘Medically I was treated as best as I can imagine... I feel that once you leave the hospital after the transplant, you are kind of left to get on with it. It would have been nice to have a meeting to discuss any complications, side effects, emotional well-being’

A stem cell transplant can take a significant emotional toll on patients, and it is vital that everyone in this position has access to help they may need such as counselling, group therapy and support groups. Our research suggests an urgent need for improved provision of services where they don’t yet exist, as well as improved signposting to services where they are already provided.
‘I WISH THERE HAD BEEN MORE PSYCHOLOGICAL SUPPORT FOR ME AND MY FAMILY’
JOANNA’S STORY

Joanna received a transplant in 2016 to treat acute myeloid leukaemia (AML).

‘After my transplant, I was desperate to get out of hospital, but once I was home, I couldn’t really get off the sofa or out of bed. You just don’t bounce back – it’s a very slow process and it’s probably the worst I felt the whole time since diagnosis.

‘I think my lowest emotional time was after the transplant. I questioned why I’d gone through this experience and just couldn’t see an end in those first three to four months. I really wasn’t prepared for the psychological impact of a transplant.

‘I was given information about where to look for support when I was in hospital, but I had no energy to engage with it. When I got home and we were all trying to get on with life, that’s when I needed psychological support.

‘My family were really affected too. My daughter was 13 when I was first diagnosed, and the caring role of mother to child had to be reversed, and that’s quite hard to accept.

‘The immediate post-transplant recovery was harder than I expected. Emotionally I’ve had to dig deeper than I ever anticipated. I wish there had been more psychological support for me and my family – even though staff tried their best, when I really needed help, it just wasn’t there.’
The recovery journey following a transplant can be difficult not only for those receiving stem cells, but also their family and friends. All of the challenges, setbacks and worries are experienced by the individual patient, and also by the people they are close to.

Patients often face a range of practical challenges in their recovery. They may require additional help with household tasks, extra support with childcare, or financial advice. There can also be considerable challenges returning to employment, as we highlighted in our report, The Way Back to Work.

Nearly half (46%) of patients responding to our survey stated that they needed practical support services, such as help at home, getting back to work and financial advice. However, only half (50%) of those respondents reported being offered these services. Of those who did receive practical support, over 9 in 10 people (97%) said it was useful.

When patients don’t have access to services which support their recovery and help accelerate a return to an active life, they may rely more on a support network of family and friends. Our research highlighted that, for many, the support offered by family members is vitally important in overcoming the practical challenges that arise during recovery.

‘For someone who didn’t have a partner, someone to provide transport would be essential, especially on journeys of 50 miles each way... in a reduced immunity situation, you can’t be taking public transport all the time.... but because I had family and a partner close it was okay.’

‘I was extremely lucky in that my husband has a flexible job and that he was able to basically take me to all my appointments.’
However our research shows that, despite the important role played by the patient’s own support network, **over 1 in 4 people (28%)** stated that their family and/or friends did not receive enough practical support themselves.

One of the key practical considerations highlighted by respondents was the financial burden of travelling to and from hospital, particularly given the number of regular visits patients are required to make over the course of many months.

**63% of respondents believed that their family and/or friends needed more help with transport, including transportation, fuel and parking costs.**

‘Car parking charges, for cancer sufferers, were disgusting and prohibitive. I was averaging between £8 and £14 per visit and still find it unbelievable that the hospital should charge such extortionate sums of money from sick people who would rather be anywhere than in a hospital. It is criminal.’

‘We could have done with some financial help in claiming mileage. We live in Scottish borders, had the transplant in Glasgow and received care in Edinburgh and Glasgow, but nobody would accept responsibility for our mileage claim which still isn’t resolved and we did struggle.’
Respondents also told us that they worried about the emotional burden placed on their family.

Nearly half (44%) of patients said that their family and/or friends were not given enough emotional and psychological support, such as counselling or support groups.

‘Obviously if we were out for three hours or four hours for an appointment then she would try and make that time up [at work] when she could, so yeah, it had a big impact on my wife... I mean I’m not sure which is worse; having the stem cell transplant or watching somebody you care for have a stem cell transplant. I think they’re equally bad.’

‘I think my mum dealt with it in her own way, as did the rest of the family. I know my mum was on antidepressants for a while... I think she dealt with it through her GP.’

‘I think it’s a really difficult time for family and friends because the patient is in the middle of this whole circus of stuff and everybody is concentrating on the patient... but it’s the friends and family I think sometimes feel very, kind of, at sea with it all.’

The family members who support patients often have practical and emotional needs of their own that are not always recognised or supported. Early signposting and information can alleviate the stress and anxiety that may be experienced by patients and those who are close to them, as well as access to emotional support such as counselling and support groups. Our research reveals a particular need for families to have more support when it comes to transportation and travel costs.
5. WHO IS RESPONSIBLE FOR THE SERVICES I NEED?

No patient’s recovery journey should be made harder by a lack of appropriate care and support, but health professionals can only provide this if they have the resources to do so. It is vital that it is clear which parts of the healthcare system are responsible for commissioning post-transplant care.

However, it is worrying that there is not a straightforward answer to this question. While stem cell transplants are funded by national commissioners as a ‘specialised service’ for the first 100 days following a transplant, responsibility for commissioning services after that point lies with local commissioners. This change in funding arrangements takes place despite the fact that patients may experience the effects of treatment months or years beyond the 100 day point.

As we highlighted in our Destination: Cure report, there is evidence that this 100 day cut-off leads to gaps in the post-transplant services that hospitals are able to provide. Alongside our patient survey we also approached the groups who are responsible for paying for post-transplant services in England, known as ‘Clinical Commissioning Groups’ (CCGs). ‘Commissioning’ is the process of planning and funding services within the NHS.

A Freedom of Information request that we submitted to every CCG in England suggests that only 1 in 10 clinical commissioning groups has specific arrangements in place to provide services that help stem cell transplant patients recover from their treatment.

Worryingly, more than a third (36%) of CCGs responding to our request incorrectly suggested that NHS England was responsible for funding and planning the services available to patients after the 100 day cut-off. Over half (54%) of CCGs acknowledged their responsibility for commissioning services after 100 days, but indicated that they had no specific arrangements in place.

Our research reveals that there is confusion within the healthcare system about who is responsible for ensuring that stem cell transplant patients have access to care and support throughout their recovery journey. There is an urgent need to review the way that post-transplant services are commissioned after the 100 day cut-off.
‘Please confirm whether or not the CCG has arrangements in place for the commissioning of care for blood and marrow transplantation (BMT) patients who are beyond 100 days following a stem cell or bone marrow transplant.’

Of 164 responses received from Clinical Commissioning Groups in England:

- **36% (59 CCGs)** Indicated that it was NHS England’s responsibility to make these arrangements.
- **54% (89 CCGs)** Acknowledged their commissioning responsibility but said that they had no specific arrangements in place.
- **10% (16 CCGs)** Indicated that they had specific arrangements in place.

Responses received between 21 December 2016 and 1 March 2017.
Throughout our research we found that patients were positive about the health service staff that cared for them, and were keen to express their gratitude for the support they provided throughout this very intensive, life-altering treatment.

This feedback is a testament to the fantastic work that goes on within the health service every single day. As some patients highlighted, this continues despite the many competing demands on NHS staff and resources.

Once the initial treatment phase is over, however, experiences are far more mixed. We heard that patients and their families don’t necessarily feel equipped for the potentially long and challenging journey that they faced after leaving hospital. Services are often uncoordinated, and many of those who want advice and information are not able to access it easily, if at all.

Many patients do not feel that they have a dedicated point of contact they can approach with questions and concerns. It can feel, as one patient commented, ‘like falling off a cliff’.

In the absence of clear information and signposting, patients reported having to take a pro-active approach to accessing care and support and managing their own recovery. There are also particularly worrying gaps when it comes to emotional and practical support services for both patients and their families.

Anthony Nolan is able to provide dedicated post-transplant Clinical Nurse Specialists in several UK transplant centres. These nurses help patients through their recovery journey, plugging some of the gaps that would otherwise exist. Ensuring that all patients have this level of support is vital, but it is only part of the solution.

Every stem cell transplant patient should receive an answer to a simple question: ‘Who cares about my recovery after transplant?’ But this question will not be answered while there is confusion within the healthcare system about who is responsible for commissioning the services that patients need after the 100 day cut-off.
Our research shows that the commissioning of post-transplant services is not working for every patient. The failure to plan and pay for appropriate care and support increases the burden on patients and their families, making their recovery journey all the more difficult.

We are calling on health commissioners in the UK to:

1. Review existing arrangements for commissioning post-transplant care and support to identify gaps in services, including the impact of the 100 day cut-off

2. Work with Anthony Nolan and the clinical community to develop a plan to ensure post-transplant commissioning works for every patient
From the moment a patient is told that they may need a stem cell transplant, to recovery and beyond, Anthony Nolan provides support and advice for patients and their families.

Anthony Nolan can help patients and families find answers to their questions, or just provide a listening ear. The Patient Services team (pictured) provides free information materials to patients and transplant centres, hosts an online patient forum and offers small financial grants for those affected by transplant with limited savings.

The Patient Services team also coordinates a network of dedicated specialist post-transplant nurses based in transplant centres. By April 2018, Anthony Nolan will have funded nine Clinical Nurse Specialist posts in transplant centres across the UK.

To find out more about the support we offer, visit: [www.anthonynolan.org/patients-and-families](http://www.anthonynolan.org/patients-and-families)
ANTHONY NOLAN
IS CAMPAIGNING TO ENSURE EVERY PATIENT HAS ACCESS TO THE CARE AND SUPPORT THEY NEED AFTER A STEM CELL TRANSPLANT.

Find out more at anthonynolan.org

For more information about this report email campaigns@anthonynolan.org

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