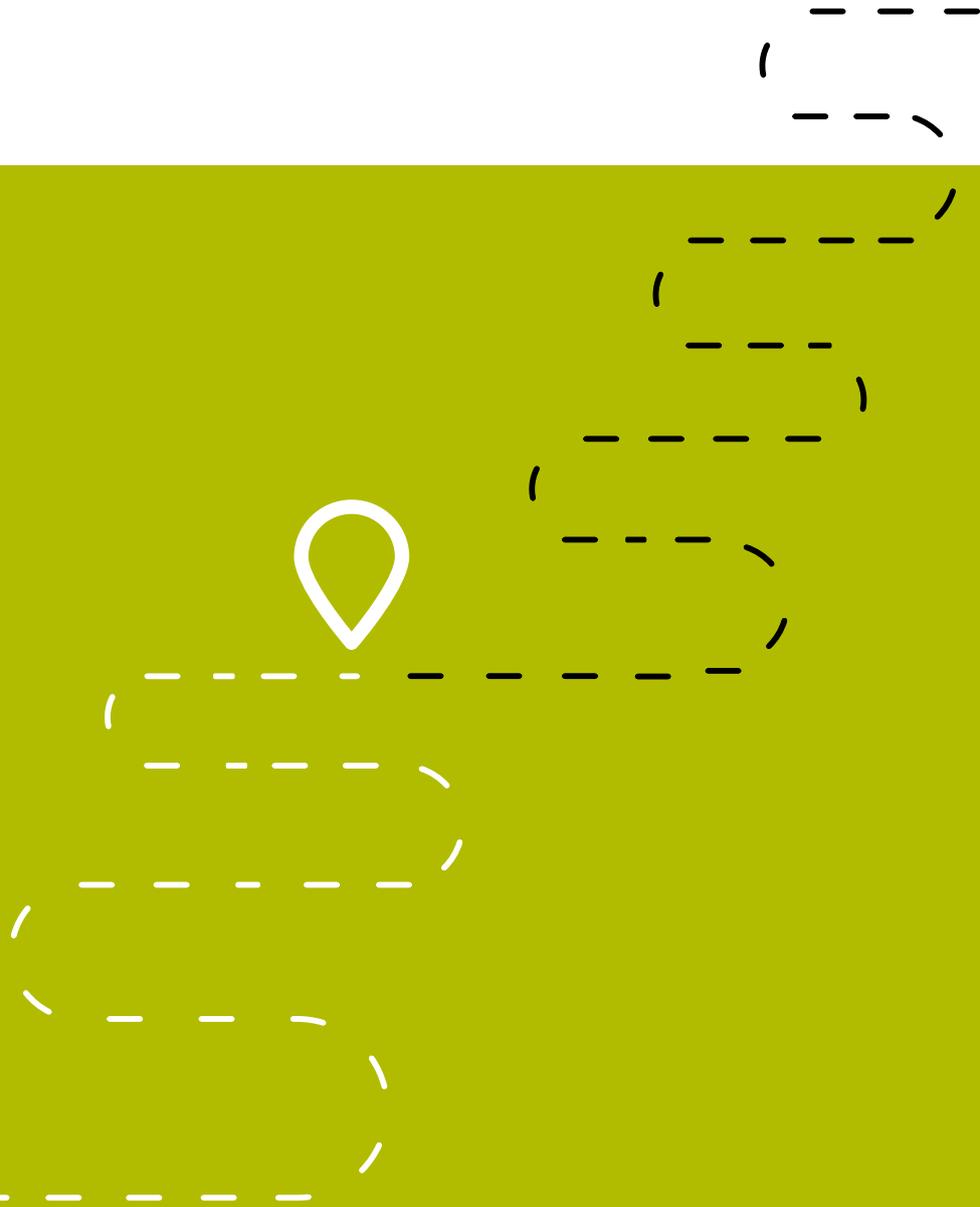


# A PATHWAY FOR POST-TRANSPLANT CARE



**ANTHONY  
NOLAN**

saving the lives  
of people with  
blood cancer

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# FOREWORDS

*'We want to ensure that patients not only survive, rather, they should be enabled to return to active work, home and social lives.'*

**Dr Fiona Dignan,**

Consultant Haematologist and Clinical Director for Haematology, Manchester University NHS Foundation Trust (Expert Steering Group Chair)



In my role as Consultant Haematologist at Manchester Royal Infirmary, I meet people every day whose lives have been saved by a stem cell transplant. However, this does not come without a cost; physical and psychological late-effects (or 'long-term complications') are common, and in some cases ongoing, severe and life-threatening.

The importance of long-term follow-up is widely recognised but, despite the very best efforts of NHS staff, evidence shows that there is substantial variation in the provision of post-transplant care across the UK. As a result, patients do not have equal access to the treatment, care and support they need during their recovery.

This is unacceptable in itself, but even more so considering the potential impact on patient outcomes and experience. Poorly managed late-effects can also put pressure on healthcare providers, for example by increasing readmission rates, inpatient days and associated costs. For commissioners, it makes no sense to invest in stem cell transplantation without ensuring that it has the best chance of success.

A key driver of variation is the fact that there is no agreed minimum standard for post-transplant care, making it difficult to develop and appropriately fund services that reflect patients' needs. I have therefore spent the past year chairing an Expert Steering Group, consisting of leading healthcare professionals, local NHS representatives and patients, looking at just this issue.

Together with Anthony Nolan, we have created a new post-transplant care pathway describing the services and support packages that are central to patients' recovery. We want to ensure that patients not only survive, rather, they should be enabled to return to active work, home and social lives.

It is my hope that commissioners, healthcare professionals and charities will now come together to put the pathway into practice. The report's recommendations reflect the fact that this is a joint effort. As survival rates continue to increase and more people than ever before live with late-effects, high-quality post-transplant care will only become more important.



I was diagnosed with acute myeloid leukaemia (AML) in 2016. For me, the hard part wasn't the six rounds of chemotherapy or the stem cell transplant itself. It was, and still is, right here right now.

At first, things went to plan and about eight weeks after my transplant I was well enough to go home. I was so excited – I was texting friends and family, and telling them all the good news.

But the very next day, things took a turn for the worst and I started struggling to breathe. I was soon told it was the early stages of acute graft versus host disease (GvHD). I ended up having my left lung removed because of fluid build-up around my heart.

More than two and a half years later, I'm still suffering with chronic GvHD. Among other things, this means my eyes are drying out and the nerves in my hands and feet are damaged. As a result, I can't do fine motor skills too well and my feet are in constant pain. I also struggle with eating and drinking.

Despite all of this, I'd say I'm doing incredibly well – I've gotten married and gone back to work as a teacher. Part time, but back at work.

I'm also using my experience to improve post-transplant care for others. When I first left hospital I felt so alone, more or less dropped from a great height and left to deal with it. This isn't how it should be. I feel passionately that the whole person needs to be cared for and not just their illness.

I, and my fellow Expert Steering Group Patient Representatives, have worked hard to ensure that the post-transplant care pathway truly reflects patients' needs. However, it will achieve nothing sitting on a shelf. Now is the time for action and I urge everyone to play their part in implementing the report's recommendations.

*'When I first left hospital I felt so alone, more or less dropped from a great height and left to deal with it. This isn't how it should be. I feel passionately that the whole person needs to be cared for and not just their illness.'*

**Ruth Beaman,**  
Patient Representative (Expert  
Steering Group Vice-Chair)

*'We must now talk openly and honestly about the things that need to change to make the pathway a reality.'*

**Henny Braund,**  
Chief Executive,  
Anthony Nolan



At Anthony Nolan, our ambition is that everyone receives the care and support they need after a stem cell transplant, for as long as necessary and no matter where they live. It is an ambition we know others share.

We already have a dedicated Patient Services team who provide support to patients and their families throughout their transplant journey. I am particularly proud that, since 2014, we have funded a network of Clinical Nurse Specialists (CNSs) across the UK; in 2017/18, seven CNSs supported over 800 patients and their families in London, Glasgow, Nottingham and Bristol.

Unfortunately, our experience on the ground and previous research shows that patients do not have equal access to services that reflect their needs. To help address this problem, we have spent the past year working under the leadership of the Expert Steering Group to develop a new post-transplant care pathway. This has involved reviewing the evidence, and consulting more

than 150 patients, family members and healthcare professionals.

We must now talk openly and honestly about the things that need to change to make the pathway a reality. This includes looking at what more we at Anthony Nolan can do. For example, we have recently started funding three clinical psychologists in Glasgow, London and Southampton to address the unique - and too often, overlooked - psychological impact of a transplant. Over the next three years, we will work with them to evaluate and evidence the impact of their roles, as we do with all our CNSs. We hope this will aid the hosting Hospital Trusts to maintain the funding on a permanent basis.

To build on this report, we will also publish an action plan by the end of 2019/20 setting out the additional steps we will take, in collaboration with partners, to support the implementation of the pathway across the UK. We will not stop until our ambition is realised.



CLINICAL  
NURSE  
SPECIALIST

Barts Health NHS TRUST



**Debbie Anderson**, Clinical Nurse Specialist  
based in Bart's Hospital

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# EXECUTIVE SUMMARY

Everyone should receive the care and support they need after a stem cell transplant, for as long as necessary and no matter where they live. But evidence shows that this is not always the case, which has a negative impact on patients, healthcare providers and commissioners alike. The post-transplant care pathway aims to help address this problem by describing the services and support packages that are central to patients' recovery.



SEE  
PAGES 18-19  
FOR AN  
OVERVIEW  
OF THE  
PATHWAY

## WHY?

- A stem cell transplant is a potentially lifesaving treatment for people with blood cancer and blood disorders. However, during recovery they can experience a **range of physical and psychological late-effects** (or 'long-term complications'), which may be ongoing, severe and life-threatening.
- Despite international consensus around the importance of long-term follow-up, evidence shows that there is **substantial variation** in the provision of post-transplant care across the UK. As a result, patients do not have equal access to treatment, care and support.
- This is unacceptable in itself, but even more so considering the potential impact on patient outcomes and experience, and the pressure that poorly managed late-effects can put on healthcare providers (for example, by increasing readmission rates, inpatient days and associated costs).
- For commissioners, it makes no sense to invest in stem cell transplantation without ensuring that it has the best chance of success. The vast majority of

late-effects are preventable, manageable or treatable, and with the right support people can return to active work, home and social lives.

- A key driver of variation is the fact that there is no agreed minimum standard for post-transplant care. This makes it difficult to develop and appropriately fund services that reflect patients' needs – the pathway aims to fill this gap.

## HOW?

- The pathway was developed by Anthony Nolan under the leadership of an Expert Steering Group, consisting of leading healthcare professionals, local NHS representatives and patients.
- The **Expert Steering Group** was chaired by Dr Fiona Dignan, Consultant Haematologist and Clinical Director for Haematology at Manchester Royal Infirmary, and vice-chaired by Ruth Beaman, who received a stem cell transplant in 2016 after being diagnosed with AML.
- The pathway was also informed by a **rapid review of the existing**

## literature on post-transplant care, and extensive

**consultation** with more than 150 patients, family members and healthcare professionals. This involved two online surveys, three focus groups and four telephone interviews.

## WHAT?

- The pathway consists of **five main building blocks**: (1) throughout recovery, (2) preparation for transplant, (3) early post-transplant care, (4) ongoing prevention and monitoring, and (5) additional treatment and support.
- For each building block we describe the **services and support packages** that are central to patients' recovery. We also indicate who the provider might be, whilst acknowledging that this will vary depending on a range of factors including local arrangements.
- The **pathway applies to all adult and paediatric patients** who are about to receive, or have already received, an allogeneic stem cell transplant. It also highlights instances where support should be extended to patients' family members.

*Now is the time for commissioners, healthcare professionals and charities to work together and make the pathway a reality. The Expert Steering Group and Anthony Nolan recommend that:*

**1** NHS England, working with the Blood and Marrow Transplantation Clinical Reference Group (BMT CRG), should publicly set out the steps it will take to ensure that patients have equal access to services and support packages that reflect their needs. This includes a named key worker, dedicated late-effects clinic, specialist-led psychological support, and appropriate rehabilitation. Similarly, leaders in the Devolved Nations should use the pathway to support the development of their services.

**2** At a local level, all those involved in planning, paying for and providing post-transplant care (including Clinical Commissioning Groups and Hospital Trusts) should commit to reviewing how the pathway could be used to improve and ensure the sustainability of services in their area. Greater sharing of best practice to help grow the evidence base is also strongly encouraged.

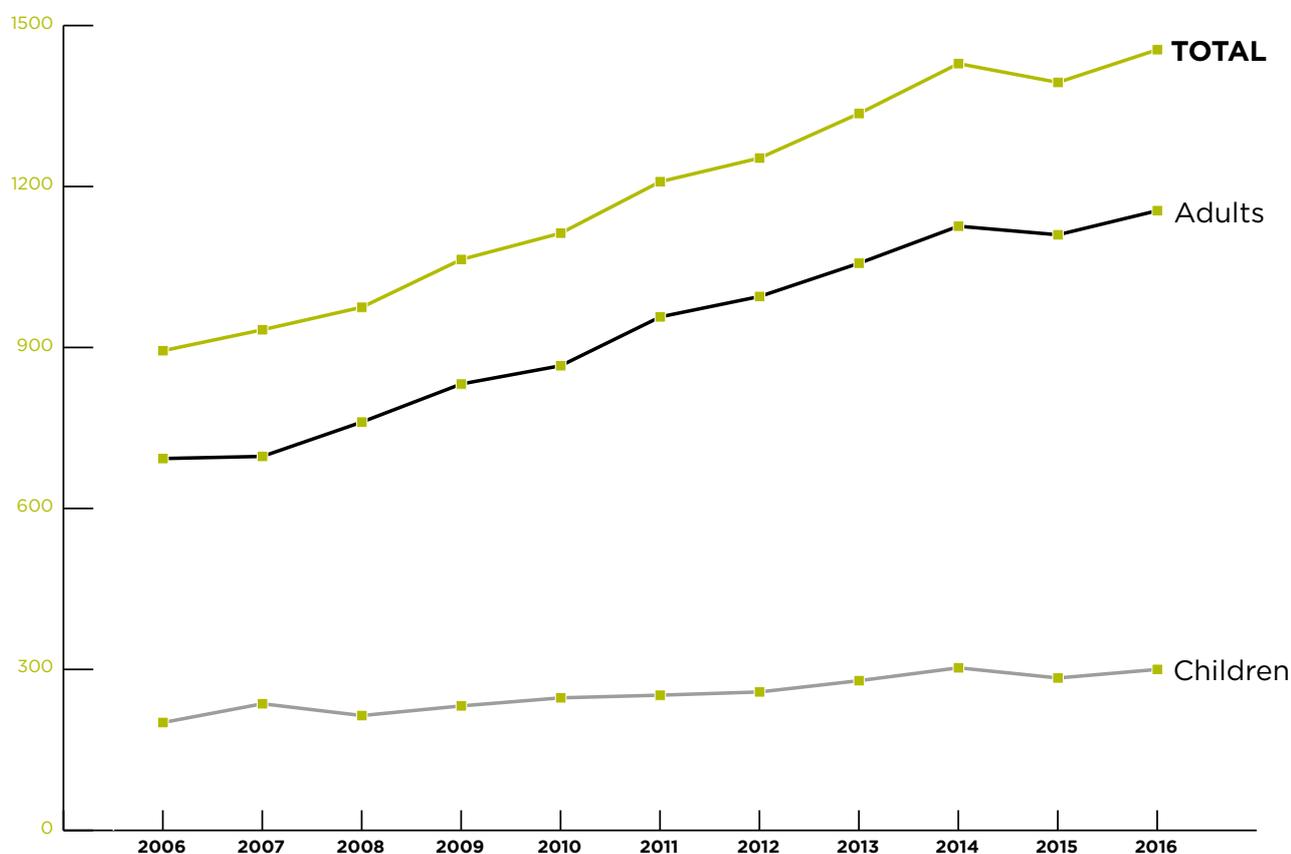
**3** Anthony Nolan should publish an action plan by the end of 2019/20 setting out the steps it will take, in collaboration with partners, to support the implementation of the pathway across the UK. This includes ensuring that patients and their families have access to the support they need, continuously improving the services provided to transplant centres, addressing key knowledge gaps and exploring ways to better monitor the care that patients receive.



# INTRODUCTION

Everyone should receive the care and support they need after a stem cell transplant, for as long as necessary and no matter where they live. But there is substantial variation in the provision of post-transplant care across the UK and, in turn, patients do not have equal access to services that reflect their needs. A key driver of variation is the fact that there is no agreed minimum standard for post-transplant care. The post-transplant care pathway aims to fill this gap by describing the services and support packages that are central to patients' recovery.

## NUMBER OF FIRST ALLOGENEIC TRANSPLANTS PERFORMED IN THE UK



**Figure 1** Number of (first) allogeneic stem cell transplants across the UK between 2006 and 2016. The total number of allogeneic stem cell transplants is increasing at an average rate of 5% every year<sup>[1]</sup>.

### ABOUT STEM CELL TRANSPLANTATION

Every year across the UK, approximately 1,100 adult patients and 300 paediatric patients receive an allogeneic (or 'donor') stem cell transplant (see figure 1).<sup>[1]</sup> This is a potentially lifesaving treatment for people with blood cancer and blood disorders,<sup>[2][3]</sup> most commonly leukaemias, which together accounted for more than half of all allogeneic stem cell transplants in 2016.<sup>[4]</sup>

Advances in stem cell transplantation have resulted in statistically significant increases in the proportion of patients surviving long-term: across the UK, five-year survival rates for adults have risen from 46% to 49% and, for children, the increase is 66% to 75% (2004-2009 vs. 2010-2015).<sup>[1]</sup>

This trend is enormously positive and it is estimated that there will be over 16,000 people living post-transplant by 2020.<sup>[5]</sup>

However, these same people can experience a range of physical and psychological late-effects during their recovery. Estimates vary but, in the first five years after stem cell transplantation, it has been reported that 79% of patients experience at least one late-effect, with 26% experiencing three or more late-effects.<sup>[6][7][8][9][10]</sup>

### PHYSICAL AND PSYCHOLOGICAL LATE-EFFECTS

Physical late-effects include GvHD (when a patient's new immune system sees the patient as 'different' and attacks the patient), problems with the eyes, bones, teeth, joints, muscles, skin and major organs, infertility, premature menopause and sexual dysfunction. Patients are also

at greater risk of infections and second cancers, and evidence suggests they have a higher mortality rate than that of the general population.<sup>[11][12][13]</sup> Psychological late-effects include significant adjustment difficulties and mental health conditions, such as depression and post-traumatic stress disorder.<sup>[14][15][16][17][18]</sup>

There is no 'typical' recovery journey and every person's experience is different. Some will only have mild late-effects, whereas for others they are severe and life-threatening. Late-effects also vary in terms of duration and fluctuate over time, with people having 'good days' and 'bad days'. The impact on their work, home and social lives can be substantial. While stem cell transplant patients have many of the same needs as those living with and beyond cancer, they also experience unique challenges – such as GvHD – and therefore require tailored long-term follow-up.

### VARIATION IN POST-TRANSPLANT CARE

The importance of long-term follow-up to prevent, manage and treat late-effects is widely recognised.<sup>[19][20][21]</sup> The seventh edition of the FACT-JACIE Standards, which transplant centres are required to comply with, now specify that there should be 'an infrastructure and policies or Standard Operating Procedures in place for the provision of appropriate long-term follow-up, treatment and plans of care' (see p.31).<sup>[22]</sup>

Despite this international consensus, evidence shows that there is substantial variation in the provision of post-transplant care across the UK. When adult

allogeneic transplant centres were surveyed in 2014, it revealed that only around 50% of patients were still being followed-up five years after their stem cell transplant. Transplant centres also reported limited access to late-effects multidisciplinary teams (MDTs), breast and cervical cancer screening programmes, and psychological services. It was concluded that there was 'variability in almost every aspect of the service'.<sup>[23]</sup> An earlier evaluation of psychosocial supportive care at three adult allogeneic transplant centres found that, up to 18 months post-transplant, there were limited services for psychology, sexual dysfunction and fertility.<sup>[24]</sup>

As a result of this variation, patients do not have equal access to the treatment, care and support they need during their recovery. Anthony Nolan's 2016 survey of more than 300 UK patients revealed that only around half (54%) of those who felt they needed emotional and psychological support, and only half (50%) of those who felt they needed practical support (such as help getting back to work), actually received it.<sup>[25]</sup>

This is unacceptable in itself, but even more so considering the potential impact on patient outcomes and experience, and the pressure that poorly managed late-effects can put on providers. For example, it has been shown that patients with GvHD have a higher rate and cost of readmission compared to patients without GvHD.<sup>[26]</sup> Urgent steps need to be taken to tackle this variation, a key driver of which is the fact that there is no agreed minimum standard for post-transplant care.

### POST-TRANSPLANT CARE POLICY

While a number of guidelines have been published relating to post-transplant care, including the commonly used 2012 recommendations on screening and preventive practices by Majhail et al,<sup>[19]</sup> these do not always reflect the full range of patient concerns<sup>[27]</sup> and none are specific to the UK.

In England, NHS England commissions (or 'plans and pays for') services 30 days prior to and up to 100 days after stem cell transplantation. These are called 'specialised services'. They are advised by a group of experts known as the BMT CRG. Beyond this point, responsibility transfers to approximately 200 local Clinical Commissioning Groups (CCGs).<sup>[28]</sup> Similar arrangements exist in Scotland<sup>[29]</sup> and Wales,<sup>[30]</sup> although the number of bodies involved is far fewer.

NHS England has published service specifications for both adult and paediatric stem cell transplantation,<sup>[31][32]</sup> but neither has been updated since 2013 and they only state that 'transplant services shall aim to provide a late-effects service' (meaning it is not mandatory). With no oversight of and no minimum standard for post-transplant care, it is difficult to develop and appropriately fund services that reflect patients' needs.

Furthermore, it has been suggested that the 100 day cut-off leads to confusion within the healthcare system about who is responsible for commissioning post-transplant services and, as a result, gaps in the care and support that transplant centres are able to provide.<sup>[25]</sup>

For commissioners, it makes no sense to invest in a treatment without ensuring that it has the best chance of success. The vast majority of late-effects are preventable, manageable or treatable, and with the right support patients can return to active work, home and social lives. We believe that the pathway can bring benefit to patients, healthcare providers and commissioners across the UK.

### SCOPE OF THIS REPORT

The work of the Expert Steering Group focused on England. This is because the sheer number of bodies involved (NHS England, plus approximately 200 CCGs) makes the commissioning of post-transplant care particularly complex and impacts on the treatment, care and support that patients receive during their recovery.

However, we believe that the pathway will serve as a useful tool for all those involved in developing post-transplant care services, whether that is in England, Scotland, Wales or Northern Ireland. Moving forwards, Anthony Nolan has committed to explore how the pathway can be implemented right across the UK.

Note that the pathway applies to adult patients and paediatric patients – that is children, teenagers and young adults – who are about to receive, or who have already received, an allogeneic stem cell transplant. It also highlights instances where support should be extended to patients' family members.

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# APPROACH

**The post-transplant care pathway was informed by a combination of existing literature, the views of the Expert Steering Group, and extensive consultation with patients, families and healthcare professionals.**

## EXISTING LITERATURE

In early 2018, we commissioned a rapid review of the existing literature on post-transplant care. This looked at a number of sources including peer-reviewed journal articles, conference proceedings, government publications and charitable reports.

The review revealed international consensus around the importance of long-term follow-up and highlighted a number of guidelines that have helped inform the pathway. However, the review also revealed that these guidelines do not always reflect the full range of patient concerns and that there is a lack of research on the needs of patients more than two years post-transplant. Furthermore, the experiences and quality of life of stem cell transplant patients in the UK are not systematically monitored.

Where it was not possible to use existing literature to inform the pathway, we relied upon the clinical experience and authoritative views of the Expert Steering Group, and the results of our consultation with patients, families and healthcare professionals.

## EXPERT STEERING GROUP

The Expert Steering Group was established in May 2018 and brought together leading healthcare professionals, local NHS representatives and patients to oversee the development of the pathway. It was chaired by Dr Fiona Dignan, Consultant Haematologist and Clinical Director for Haematology at Manchester University NHS Foundation Trust, and vice-chaired by Ruth Beaman, who received a stem cell transplant in 2016.

MORE  
INFORMATION  
ABOUT THE  
MEMBERS OF  
THE GROUP  
CAN BE FOUND  
ON PAGE 30



**Dr Dignan** leading a meeting of the Expert Steering Group in February 2019

### CONSULTATION WITH PATIENTS, FAMILIES AND HEALTHCARE PROFESSIONALS

Anthony Nolan consulted on the draft pathway between September and November 2018. This consisted of two online surveys, three focus groups and four telephone interviews, quotes from which are used throughout the report.

- **Online survey for patients and families** – the survey was distributed via the networks of Anthony Nolan and other charities. It received 120 completed responses, 78% from patients and 22% from family members. More than half of patients (including relatives) had a stem cell transplant between one and five years ago (58%), and most were aged 26 or older at the time (80%). The vast majority were receiving post-transplant care in England (87%).
- **Online survey for healthcare professionals** – the survey was distributed via the networks of Anthony Nolan, other charities and professional groups. It received 36 completed responses, most commonly from nurses or transplant coordinators (50%), Allied Health Professionals (AHPs, 19%), consultant haematologists (11%), and clinical psychologists or counsellors (11%). The vast majority of respondents were based at organisations in England (89%). In total, 14 UK transplant centres were represented (approximately 40% of all UK transplant centres).

- **Focus groups** – focus group participants were recruited via Anthony Nolan's Patients and Families Panel. We held two focus groups in London and one in Manchester, each lasting approximately four hours. 13 patients and three parents took part, with time since transplant ranging from two years and two months to 10 years and five months.
- **Telephone interviews** – telephone interview participants were recruited via Anthony Nolan's Patients and Families Panel. The interviews were semi-structured and lasted 30 to 60 minutes each. Three patients and one parent took part, with time since transplant ranging from four years and seven months to 19 years and six months. All three patients received their stem cell transplant whilst aged between five and 24 years, allowing us to explore experiences of transitioning to adult care.

The online survey responses, and the transcripts of the focus groups and telephone interviews, were analysed by Anthony Nolan in collaboration with an independent expert (Leela Barham, of Leela Barham Economic Consulting Ltd).

### STRENGTHS AND LIMITATIONS

Consultation participants were self-selecting and are therefore not representative of all patients, families and healthcare professionals. Furthermore, whilst key themes have been identified, it is not possible to exactly quantify the relative importance of each theme. These limitations aside, as far as we are aware this is the first time within the UK that a concerted effort has been made to describe the services and support packages that are central to stem cell transplant patients' recovery.

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# PATIENT STATEMENTS

The following statements were developed by the Expert Steering Group and Anthony Nolan to describe what is most important to patients. The statements underpin the pathway and highlight the need for services to be designed with patients at the centre.

**1** 'I feel well-informed about the challenges I could face after a stem cell transplant, and I know where and how to access the care and support I may need.'

**2** 'I have a healthcare team who communicate effectively with each other, even if they are based in different places. As such, my care is well coordinated and I feel safe and supported, even when I am not in hospital.'

**3** 'I have access to the best possible care and support for my full range of needs, no matter where I live and no matter how long after my stem cell transplant it is.'

**4** 'I have a good relationship with my key worker, e.g. CNS, who is responsive and supports me to achieve my personal goals.'

**5** 'I understand and can make decisions about my care. When I want to be treated as an equal partner alongside my healthcare team, I am.'

**6** 'I can see how my overall wellbeing and mental health is deemed just as important as my physical health.'

**7** 'I have a healthcare team who understand the nature of stem cell transplantation and me as an individual.'

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# POST-TRANSPLANT CARE PATHWAY

The post-transplant care pathway consists of **five main building blocks**:

- (1) throughout recovery,
- (2) preparation for transplant,
- (3) early post-transplant care,
- (4) ongoing prevention and monitoring, and
- (5) additional treatment and support.



SEE  
PAGES 18-19  
FOR AN  
OVERVIEW  
OF THE  
PATHWAY

In this section of the report and for each building block, we describe the services and support packages that are central to patients' recovery. We also indicate who the provider might be, whilst acknowledging that this will vary depending on the original diagnosis, severity of any post-transplant complications, local arrangements (such as shared care between transplant centres and local hospitals), and individual patient choice.

The absence of a clear timeline is intentional because every person's experience is different. For example, at the current 100 day cut-off one person may still be in hospital owing to GvHD, whereas another person may have returned home. Late-effects also fluctuate over time, meaning that even years later people can require periods of hospitalisation or intensive support. The Expert Steering Group feel strongly that the services and support packages offered to people should be based wholly on need, not time since transplant.

The pathway is backed not only by the Expert Steering Group, but also by the patients, families and healthcare professionals who responded to our consultation. When asked for their views on each building block, between 94% and 100% of patients and family members, and between 83% and 100% of healthcare professionals, strongly agreed or agreed that we had covered everything important.

# 1 THROUGHOUT RECOVERY

There are some services and support packages that people should always have access to, be that weeks, months or years after their stem cell transplant. Consultation respondents consistently identified high-quality information, access to a named key worker, psychological support and practical support as being among the most important elements of the entire pathway.

## 1.1 HIGH-QUALITY INFORMATION

Patients should be offered high-quality, age-appropriate information in a format that suits them. This may come from the transplant centre or a charity, but patients should always have multiple opportunities to discuss the information with their healthcare team to ensure understanding.

*'Ours was a very verbal meeting and I don't remember a thing from that meeting. It was just information overload. I personally would have benefitted from maybe a booklet or an app or something.'*

**Family member**

*'[It would help to have] both written and verbal information, and more than one appointment to consolidate all the information – given the complexity and volume.'*

**Nurse**

*'From a teenager point of view, I feel some of the chats around transplant need to be done over a few meetings as they do not take all the info in at once.'*

**Healthcare professional**

## 1.2 NAMED KEY WORKER

Patients should have access to a named key worker (often a CNS) at their transplant centre. This key worker must be knowledgeable about stem cell transplantation, easy to contact, and responsive to any questions and/or concerns that the patient may have. Emergency support needs to be available 24/7, including weekends and bank holidays.

*'[One of the most important things during recovery is] easy access to someone at the end of the phone, who has time to listen and discuss concerns.'*

**Patient**

*'My son's CNS has literally been a lifesaver, we don't know how we would have got through this without her.'*

**Family member**

*'Patients need to know there is someone to communicate concerns with. In turn, the CNS can bridge the gap for other professionals and make necessary referrals.'*

**Allied Health Professional**



# POST-TRANSPLANT CARE PATHWAY



PARITY BETWEEN PHYSICAL HEALTH, AND OVERALL WELLBEING AND MENTAL HEALTH

EFFECTIVE COMMUNICATION AND COORDINATION OF CARE

## TERTIARY CARE (TRANSPLANT CENTRE)

### 1. THROUGHOUT RECOVERY, ALL PATIENTS SHOULD:

- Be offered high-quality, age-appropriate information in a format that suits them, and have multiple opportunities to discuss the information with their healthcare team.
- Have access to a named key worker (often a CNS) who is knowledgeable about stem cell transplantation, easy to contact and responsive to the patient's questions and/or concerns.
- Have access to psychological support overseen by a specialist embedded within the MDT, for example a Clinical Psychologist.
- Be proactively offered practical support, including financial advice and support getting back into day-to-day life.

The transplant centre is ultimately responsible, but everyone involved in the patient's care has an important role to play.

|  |  |  |   |   |  |
|--|--|--|---|---|--|
| <p>Pre-transplant assessment of physical health; pre-transplant assessment of overall wellbeing and mental health; pre-transplant support.</p> | <p>Reducing infection risk; general monitoring of physical health, and overall wellbeing and mental health; support when returning home.</p> | <p>Healthy lifestyle advice and rehabilitation; referral to GP for post-transplant vaccinations.</p> | <p>Clinical evaluation at 6 months, 1 year and at least annually thereafter; screening for second cancers; support transitioning to adult care (for paediatric patients).</p> | <p>HNA at 6 months, 1 year and at least annually thereafter; educational support (for paediatric patients); support for patients' families.</p> | <p>Every person's needs are different, so additional treatment and support should be tailored accordingly.</p> <p>There are four core principles that everyone involved in caring for patients – and their families – should abide by:</p> <ul style="list-style-type: none"> <li>• Rapid referral or signposting</li> <li>• Support of an MDT</li> <li>• Access to palliative and end-of-life care</li> <li>• Bereavement support, if a patient dies</li> </ul> |
| <p>May support preparation for transplant, depending on local arrangements.</p>  | <p>Coordination with the patient's transplant centre as necessary, e.g. in the event that the patient presents with an infection.</p>        | <p>Coordination with the patient's transplant centre and/or GP as necessary.</p>                     | <p>Screening for second cancers via NHS screening programmes.</p>   | <p>Coordination with the patient's transplant centre and/or GP as necessary.</p>  |  |
| <p>Coordination with the patient's transplant centre and/or local hospital as necessary.</p>   | <p>Coordination with the patient's transplant centre as necessary, e.g. in the event that the patient presents with an infection.</p>        | <p>Post-transplant vaccinations upon referral by transplant centre.</p>                              | <p>Dental and optical assessments at least once a year; screening for second cancers via NHS screening programmes.</p>  | <p>Coordination with the patient's transplant centre and/or local hospital as necessary.</p>  |  |

## CHARITIES (E.G. ANTHONY NOLAN, MACMILLAN CANCER SUPPORT, MAGGIE'S CENTRES)

Charities can provide a wide range of support, including information, psychological support (in the form of peer support) and practical support. Patients should also be signposted to local charities and support groups, where applicable.

## POST-TRANSPLANT CARE PATHWAY

### 1. THROUGHOUT RECOVERY

#### 1.3

##### PSYCHOLOGICAL SUPPORT

The psychological needs of patients (and their families) should be proactively addressed by the transplant centre. Provision of psychological support needs to be overseen by a specialist embedded within the MDT, for example a Clinical Psychologist. This must encompass a broad range of elements: universal care, such as access to a peer support group (including those run by charities); enhanced care, such as 'first-line' psychological support by a CNS; and specialist care, such as access to a counsellor, psychologist or psychiatrist. More information can be found in existing guidelines on supporting people affected by cancer. <sup>[33] [34]</sup>

*'[You need] somebody to express your feelings and emotions to, to just... to unburden a bit about how you're feeling. My medical care post-transplant [was] second to none, but the wider issues I've had to deal with pretty much on my own.'*

**Patient**

*'Access to other people who have been through a stem cell transplant is important. Forums etc. where you can ask questions to people who know how it actually feels.'*

**Patient**

*'There is evidence out there that good mental health and emotional support can improve medical outcomes, it just makes sense to make sure we are doing all we can to give patients the best chance of a successful transplant.'*

**Allied Health Professional**

#### 1.4

##### PRACTICAL SUPPORT

Patients (and their families) should be proactively offered practical support. This includes financial advice, such as help with travel expenses and benefits applications, and support getting back into day-to-day life, such as help managing work and education. More often than not this is provided by charities, but transplant centres, local hospitals and GPs are all responsible for signposting.

*'To go up to London to get to an appointment before 11am, if I go with my parents, costs £100 a time...as I get older and I'm travelling up by myself, I don't have that money to pay to go.'*

**Patient**

*'A lot of support [was] needed sorting out benefits. The fatigue is so tough, I didn't have the energy to do it myself.'*

**Patient**

*'I sought out help on how to tackle job interviews and getting back to work...This helped me get my self-respect back and played a big step in my full recovery, I couldn't have done it without the advice I got.'*

**Patient**



## 2 PREPARATION FOR TRANSPLANT

How well people are prepared for their stem cell transplant can have a significant impact on their recovery. Pre-transplant assessments of physical health, and overall wellbeing and mental health, are therefore vital. These assessments must be done in good time before the person's transplant to allow any issues that are identified to be acted upon. Collectively, this process is often referred to as 'prehabilitation'.<sup>[35]</sup>

### 2.1 PRE-TRANSPLANT ASSESSMENT OF PHYSICAL HEALTH

It is already common practice for patients to have a pre-transplant assessment of their physical health, for example bone marrow, kidney, heart, lung and blood tests. If it has not already been discussed, patients should also have the opportunity to explore fertility preservation.

### 2.2 PRE-TRANSPLANT ASSESSMENT OF OVERALL WELLBEING AND MENTAL HEALTH

Equally important is a pre-transplant assessment of patients' overall wellbeing and mental health. This will typically include a Holistic Needs Assessment (HNA), and consider social support, family issues and pre-existing mental health conditions.

*'I think the psychological preparedness is vital for a successful adjustment and specialist assessment would be imperative.'*

**Allied Health Professional**

*'It would be beneficial if there could be increased allocation of funding to enable transplant centres to do a formal psychological assessment of patients pre-transplant, as the holistic assessment often neglects this or is very cursory at best.'*

**Nurse**

### 2.3 PRE-TRANSPLANT SUPPORT

Patients should be offered physical activity, dietary and psychological support tailored to their needs<sup>[35]</sup> to enhance recovery and as directed by the results of their pre-transplant assessments. There is some evidence to suggest that 'good' emotional support pre-transplant is associated with longer overall survival.<sup>[36]</sup>

Pre-transplant assessments and support can take place at the transplant centre or local hospital (depending on local arrangements), but at the very least patients should be able to visit their transplant centre to view the facilities and meet their healthcare team. This is especially important considering that all patients are required to spend at least a few days – often a few weeks – in isolation.



## 3 EARLY POST-TRANSPLANT CARE

Infection is a significant cause of morbidity and mortality,<sup>[11] [12] [13]</sup> and a significant driver of cost,<sup>[37]</sup> after stem cell transplantation. Reducing infection risk is therefore a key part of early post-transplant care, as is general monitoring. It also became evident through our consultation that more needs to be done to ensure that people feel supported when returning home.

### 3.1 REDUCING INFECTION RISK

Patients should receive antiviral, antibacterial and antifungal prophylaxis for as long as necessary, which may be years.<sup>[19]</sup> They should also be given advice on how to protect themselves from infection, and the name and contact details of an individual at their transplant centre (most likely their key worker) who they can get in touch with if they have any concerns. Finally, factors that may affect adherence, such as cognition, distress or a lack of social support should be considered.

*'A simple spelling out of what to do if you feel ill is vital.'*

**Patient**

*'Clear information so that the patient is well informed about managing their risk of infection and who/when to contact if symptomatic, without the patient feeling terrified that they can't go out or socialise at all.'*

**Allied Health Professional**

### 3.2 GENERAL MONITORING

It is vital that patients' general physical health, and overall wellbeing and mental health, are closely monitored by their transplant centre in the immediate period after stem cell transplantation. Physical health includes signs of relapse, GvHD, fatigue and weight loss, as well as physical functioning. Overall wellbeing and mental health includes distress (as reported by the patient) and behavioural signs, such as withdrawal, irritability and non-adherence.

### 3.3 SUPPORT WHEN RETURNING HOME

Patients should feel prepared to return home and make the transition from being an inpatient to an outpatient. As people vary in their readiness to look ahead, transplant centres will need to decide how best to address this on an individual basis. However, a strong theme from our consultation is that many patients and their families want more information on what to expect after stem cell transplantation, both in terms of the challenges they may face and how to access support.

*'It was a surprise to me and my family just how weak I would feel after being sent home from hospital after my transplant, I think we could have been more prepared if we had known.'*

**Patient**

*'Patients sometimes feel abandoned or anxious about being out of hospital, they need to know the team are still looking after them closely.'*

**Allied Health Professional**

## 4 ONGOING PREVENTION AND MONITORING

The importance of long-term follow-up is widely recognised.<sup>[19]</sup>  
<sup>[20]</sup> <sup>[21]</sup> <sup>[22]</sup> In the post-transplant care pathway, we identify three main elements of ongoing prevention and monitoring: prevention of infection and late-effects; monitoring of physical health; and monitoring of overall wellbeing and mental health.

### 4.1

#### PREVENTION OF INFECTION AND LATE-EFFECTS

##### 4.1.1

#### POST-TRANSPLANT VACCINATIONS

Patients should receive a schedule of post-transplant vaccinations, delivered by their GP upon referral by the transplant centre. More information on what vaccines should be administered, and when, can be found in existing international and national guidelines.<sup>[38]</sup> <sup>[39]</sup> <sup>[40]</sup> <sup>[41]</sup> However, an area that warrants further consideration is the development of a harmonised UK guideline and/or policy.<sup>[42]</sup> Responses to our consultation also suggested that patients can sometimes have difficulty in obtaining their vaccinations.

*'I had to tell my GP surgery nurse which vaccinations to give me when, as she had not seen the letter from the consultant. Luckily I had a copy and we worked it out together.'*

**Patient**

*'[My GP] did it but they questioned, well, why...Who told you?'*

**Patient**

### 4.1.2

#### HEALTHY LIFESTYLE ADVICE AND REHABILITATION

Patients should receive healthy lifestyle advice from their transplant centre at least once a year to help reduce the risk of various late-effects, such as second cancers, cardiovascular disease and problems with the musculoskeletal system. This includes using high SPF sun cream, not smoking, having a healthy balanced diet, reducing alcohol consumption and taking regular exercise. Some patients may benefit from additional support from relevant AHPs.

*'Healthy lifestyle is a must. Our daughter had a bone marrow transplant and it feels like following transplant any support around this area, or anything similar, was really missing.'*

**Family member**

*'It would be good if there was more follow up services such as physiotherapy – once you are out of hospital it seems like you don't know how or where to start doing some exercise again!'*

**Patient**

*'There is huge variation in rehabilitation provision throughout the transplant journey for many patients. This is often confounded with not having access to rehabilitation professionals/ services with knowledge and understanding of the specialist needs of transplant patients.'*

**Allied Health Professional**

#### 4.2 MONITORING OF PHYSICAL HEALTH

##### 4.2.1 CLINICAL EVALUATION

Patients should be invited to return to their transplant centre for a comprehensive clinical evaluation at six months post-transplant, one year post-transplant and at least annually thereafter. They should be monitored for GvHD, relapse, transfusion-associated iron overload, premature menopause, and problems with the eyes, mouth, lungs, heart, liver, kidneys, musculoskeletal system, nervous system, endocrine system and skin. Assessment of cognitive development, gonadal function and growth are particularly important for paediatric patients.

##### 4.2.2 DENTAL AND OPTICAL ASSESSMENTS

Patients should be advised to see their dentist and optician for a thorough examination at least once a year. Special attention should be paid to teeth development for paediatric patients. More information on clinical evaluation, and dental and optical assessments, can be found in internationally agreed guidelines on screening and preventive practices for long-term survivors of stem cell transplantation.<sup>[19]</sup>

##### 4.2.3 SCREENING FOR SECOND CANCERS

Stem cell transplant patients are at an increased risk of developing second cancers compared to the general population, so ongoing screening is essential.<sup>[43] [44] [45]</sup>

This takes place in a variety of settings; for example, a patient's clinical evaluation and dental assessment should include checking for signs of second cancers, such as thyroid and mouth cancer respectively.<sup>[19] [45]</sup> Meanwhile, screening for bowel, breast and cervical cancer are delivered via NHS screening programmes. An area that warrants further consideration is access to breast and cervical cancer screening, as transplant centres have reported difficulties in accessing these programmes.<sup>[23]</sup>

##### 4.2.4 SUPPORT TRANSITIONING TO ADULT CARE

In the years after stem cell transplantation, an additional challenge faced by paediatric patients is transitioning to adult care. This can be an extremely difficult time, so it is essential that paediatric and adult transplant centres work together to ensure that patients are properly prepared, and receive seamless care that meets both their physical and psychological needs. Poor transition is associated with an increased risk of non-adherence and loss to follow-up.

*'They sort of just say, well, you know, this is your last day with us, you'll get an appointment through for your next hospital or your next person and then that's when you turn up and that's when you see how different it [adult care] really is...it's so terrifying because you just go from this, yeah, supported feeling to feeling like you're being looked after by people that don't care about you.'*

**Patient**

#### 4.3

#### MONITORING OF OVERALL WELLBEING AND MENTAL HEALTH

People's overall wellbeing and mental health is just as important as their physical health, and this should be reflected in the ongoing monitoring that they receive. Furthermore, although the post-transplant care pathway focuses on the needs of patients, it should be recognised that stem cell transplantation can take a significant emotional toll on their families, who may have needs of their own.

##### 4.3.1

#### HOLISTIC NEEDS ASSESSMENT

In line with clinical evaluation, patients should be invited to complete a stem cell transplant- and age-specific HNA at six months post-transplant, one year post-transplant and at least annually thereafter. In collaboration with their key worker, they should then have the opportunity to create a personalised recovery plan. Issues covered may relate to overall quality of life, psychological wellbeing, sex and relationships, and/or challenges regarding work or education. The plan should be owned by the patient, but they must be properly supported to put it into action.

*'Regular 'check-ups' on mental health – to allow reflection, discussion and normalisation of coping, plus more specialist support as and when required. MH [mental health] check-ups and reviews should be as standard and routine as physical.'*

**Clinical Psychologist**

*'You're kind of warned, right, you're going to not be able to have children – but you're busy thinking, well, I just want to get rid of this cancer to start off with... then you think, well, if I come through this, my relationship...I can't give this person children, so how does that affect my relationship?'*

**Patient**

##### 4.3.2

#### EDUCATIONAL SUPPORT

Paediatric patients' educational progress should be assessed, for example, attendance, attainment and peer relationships.<sup>[20]</sup> Their school, college or university should receive information about recovery from their transplant centre, and collaboration between the patient's healthcare team and educators should be encouraged at regular intervals (ideally, this would include a visit by their key worker).

*'I missed, obviously, a lot of school when I was going through the actual treatment and post-transplant stuff, but school were pretty good. I mean, they sent my mum like binders of schoolwork that I should be doing and I had to fill that in and then they'd send it back.'*

**Patient**

##### 4.3.3

#### SUPPORT FOR PATIENTS' FAMILIES

Stem cell transplantation can take a significant emotional toll on patients' families. It is important that their needs are recognised and that, if necessary, they are referred or signposted to additional support; for example, peer support groups, specialist psychological support or other options if more appropriate, such as primary care counselling.

*'SCT [stem cell transplantation] can also affect the overall wellbeing and mental health of patients' children and other immediate family members. It is important that their needs are recognised and that they are referred/signposted to additional/treatment and support if necessary.'*

**Nurse**

## 5 ADDITIONAL TREATMENT AND SUPPORT

Every person's needs are different, so additional treatment and support should be tailored accordingly. It would not be appropriate for the pathway to be prescriptive, nor is it possible to cover all eventualities; we instead set out four core principles that those involved in caring for patients – and their families – should abide by.

### 5.1 RAPID REFERRAL/SIGNPOSTING

If ongoing monitoring identifies a need for additional treatment and support, the transplant centre should refer or signpost the patient (or their family) as soon as possible. It is vital that patients are not left to find additional treatment and support themselves.

### 5.2 SUPPORT OF A MULTI-DISCIPLINARY TEAM

Patients should have the ongoing support of a MDT consisting of medical specialists (for example cardiologist, gastroenterologist, endocrinologist and clinical psychologist), AHPs (for example physiotherapist, dietician and occupational therapist), and palliative and end-of-life care professionals.

*'The AHP workforce could be increased with the transplant MDT and used to distribute the work required to prevent, monitor and treat some of the common issues arising post-transplant – fatigue management, weight loss, loss of physical functioning – rather than all of this being placed on the CNS workforce.'*

Allied Health Professional

### 5.3 ACCESS TO PALLIATIVE AND END-OF-LIFE CARE

In the event that a patient's recovery becomes uncertain, Advanced Care Planning should begin and this should be shared with the wider MDT. As part of this, the patient should be given the opportunity to discuss their Preferred Priorities of Care.<sup>[46][47]</sup>

*'We shouldn't avoid these discussions even when a situation might be reversed - better to have the conversation than not.'*

Nurse

*'Involving the palliative care team earlier is beneficial for everyone, not least the patient.'*

Nurse

### 5.4 BEREAVEMENT SUPPORT

If a patient dies, a member of their healthcare team should contact the family to offer them an opportunity to discuss any issues or concerns. They should also provide information on emotional and practical support, such as counselling and benefits. If the bereavement is particularly traumatic or complex, for example the family member has a pre-existing mental health condition, this should be highlighted to their GP for follow-up.

*'Sadly, my husband died after his stem cell transplant. He did not receive any palliative care until the day before he died at home, apparently owing to a mistake with our address. I was not aware of what was available so did not chase it up...I have had no contact whatever from any support facility since he died.'*

Family member

## SERVICE DELIVERY

The post-transplant care pathway does not explain how services should be delivered; indeed, there is no clear evidence to support one model of care over any other.<sup>[48]</sup> However, a key theme emerging from our consultation is that post-transplant care is not always as well coordinated as it could be, which can have a significant impact on patient experience.

*'I have had to request immunisation schedules, help with my mental health, monitoring of long term complications...there is no coordination now I am seen as an outpatient. I find it very tiring having to be so proactive with my treatment.'*

**Patient**

*'I have spoken to people who are just coming through SCT [stem cell transplantation] and they are told so many different things at different hospitals. They can't go out for so long, they can't eat certain things, don't touch your pets etc. There doesn't seem to be a consistent approach.'*

**Patient**

We also heard how the transplant centre environment can affect patients' recovery; this includes hospital food, technology and general comfort.

*'Having proper nutritional meals whilst in hospital [is important]. A patient really looks forward to meal times and can be very upset when their meal is not as ordered, in my experience.'*

**Family member**

*'I mean, most hospitals have patient wi-fi now, but it hardly ever seems to work. There used to be televisions, but you have those televisions where you have to put money in and they break down and nobody's got a clue how to work things. I mean, these are really small things but...'*

**Patient**

*'Some of the isolation units didn't even have windows in it and made you feel really claustrophobic. I got really anxious about that and they couldn't understand why that was an issue for me.'*

**Patient**

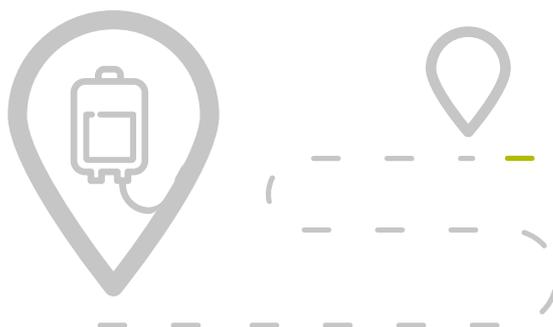
While making recommendations related to service delivery is outside the scope of this report, it is important to note this as an area for further consideration. All those involved in providing post-transplant care are encouraged to pay particular attention to ensuring that care is well coordinated and that, as far as is practical, the transplant centre environment supports recovery. This includes good rehabilitation facilities, reliable wi-fi and adequate space to allow for the protection of immunocompromised patients.

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# CONCLUSION AND RECOMMENDATIONS

The post-transplant care pathway describes the services and support packages that are central to patients' recovery. Now it is time for commissioners, healthcare professionals and charities to work together and make the pathway a reality.

This requires action at both national and local levels. For example, in England – where the commissioning framework is particularly complex – there is no oversight of post-transplant care beyond 100 days. We believe it would bring significant benefit to patients if NHS England, working with the BMT CRG, were to take on this role. At a local level, the pathway can serve as a tool for all those involved in developing post-transplant care services, whether that is in England, Scotland, Wales or Northern Ireland. We also know there is more we could do at Anthony Nolan to ensure that patients, families and transplant centres receive the right support.



*In summary, to help ensure that everyone receives the care and support they need after a stem cell transplant, for as long as necessary and no matter where they live, the Expert Steering Group and Anthony Nolan recommend that:*

- 1** NHS England, working with the BMT CRG, should publicly set out the steps it will take to ensure that patients have equal access to services and support packages that reflect their needs. This includes a named key worker, dedicated late-effects clinic, specialist-led psychological support, and appropriate rehabilitation. Similarly, leaders in the Devolved Nations should use the pathway to support the development of their services.
- 2** At a local level, all those involved in planning, paying for and providing post-transplant care (including CCGs and Hospital Trusts) should commit to reviewing how the pathway could be used to improve and ensure the sustainability of services in their area. Greater sharing of best practice to help grow the evidence base is also strongly encouraged.
- 3** Anthony Nolan should publish an action plan by the end of 2019/20 setting out the steps it will take, in collaboration with partners, to support the implementation of the pathway across the UK. This includes ensuring that patients and their families have access to the support they need, continuously improving the services provided to transplant centres, addressing key knowledge gaps and exploring ways to better monitor the care that patients receive.

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# MEET THE EXPERT STEERING GROUP

## DR FIONA DIGNAN

Consultant Haematologist and Clinical Director for Haematology, Manchester University NHS Foundation Trust (Chair)

Dr Dignan has authored a number of national clinical practice guidelines aimed at improving post-transplant care. She is a member of the BMT CRG and Secretary of the British Society of Blood and Marrow Transplantation (BSBMT) Executive Committee.

## RUTH BEAMAN

Patient Representative (Vice-Chair)

Ruth, a teacher from Yorkshire, received a stem cell transplant in 2016 after being diagnosed with AML. She is passionate about improving post-transplant care and was one of the faces of Anthony Nolan's 'Who Cares?' campaign in 2017.

## GILLIAN ADAMS

Lay Board Member, NHS West Leicestershire CCG

Gillian is the strategic board lead for patient and public engagement. She is also a member of the BMT CRG and Vice-Chair of the European Society of Blood and Marrow Transplantation (EBMT) Patient, Family and Donor Committee. Her husband, Steve, received a stem cell transplant in 2010 after being diagnosed with AML.

## JOANNA CALDER

Patient Representative

Joanna received a stem cell transplant in 2016 to treat AML and has been an advocate for patients ever since, taking part in Anthony Nolan's 'Who Cares?' campaign in 2017. She is a trained nurse with experience of working with both adults and children.

## TOM CONNOLLY

former General Manager for Haematology, University College London Hospitals (UCLH) NHS Foundation Trust

Tom has worked as an operational manager in several specialities, managing haematology, young adult cancer and late effects services at UCLH between 2014 and 2018. He also helped oversee the merger of the UCLH and Royal Free malignant haematology services, resulting in the creation of one of the largest services in the UK.

## DR ROBERT DANBY

Consultant Haematologist, Oxford University Hospitals NHS Foundation Trust and Anthony Nolan

Dr Danby is the lead for novel cellular therapies at Oxford University Hospitals and a senior member of the Anthony Nolan Research Institute, investigating ways to improve transplant outcomes. He is also a member of the EBMT and has co-authored national guidelines on cord blood transplantation.

## DR ADAM GASSAS

Consultant and BMT Director, University Hospitals Bristol NHS Foundation Trust

Dr Gassas works at the Bristol Royal Hospital for Children, specialising in paediatric stem cell transplantation. He also helps maintain global quality standards for stem cell transplantation in his role as a JACIE Inspector.

## MICHELLE KENYON

Consultant Nurse (BMT), King's College Hospital NHS Foundation Trust

In 2013 Michelle co-authored *The Seven Steps: The Next Steps*, a patient information booklet about life after transplant. More recently, she co-edited the *EBMT Textbook for Nurses*, the first book of its kind specifically for nurses in this specialist field. She is President Elect of the EBMT Nurses Group and a member of the BSBMT Executive Committee.

## DR ALEX KING

Consultant Clinical Psychologist, Imperial College Healthcare NHS Trust

Dr King is an expert on the psychological impact of stem cell transplantation, and has a particular interest in treatment decision-making, coping on acute inpatient wards, and long-term effects.

## GEORGE NORTON

Patient Representative

George had a stem cell transplant in 2014 to treat acute lymphoblastic leukaemia (ALL). He is now a patient advocate, ambassador, speaker and writer for a number of charities.

## MARK RITSON

Patient Representative and Trustee, Anthony Nolan

Mark received two stem cell transplants in 2013 to treat his severe aplastic anaemia (a rare blood disorder), later running a marathon with his donor in 2018. He is a member of the BMT CRG and became a Trustee for Anthony Nolan in 2019.

## DR ANN ROBINSON

GP, The Mountfield Surgery and Trustee, Anthony Nolan

Dr Robinson has been a GP for over 20 years, and has also worked as a freelance journalist and broadcaster. Her oldest child, Zoe, died of leukaemia at the age of 15 having received a stem cell transplant. Dr Robinson became a Trustee for Anthony Nolan in 2014.

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# THE FACT-JACIE INTERNATIONAL STANDARDS (SEVENTH EDITION)

All UK transplant centres must be JACIE accredited, meaning that they comply with the FACT-JACIE Standards. The seventh edition, effective from 1 June 2018, includes a number of standards relevant to post-transplant care. Standards B7.8 and B7.12 are new (compared with the sixth edition).

B3.11.1 The Clinical Program shall have one (1) or more designated staff with appropriate training and education to assist in the provision of pre-transplant recipient evaluation, treatment, and post-transplant follow-up and care. Designated staff shall include:

B3.11.1.1 Dietary staff.

B3.11.1.2 Social Services staff.

B3.11.1.3 Psychology Services staff.

B3.11.1.4 Physical Therapy staff.

B3.11.1.5 Data Management staff sufficient to comply with B9.

B7.8 There shall be policies or Standard Operating Procedures in place for planned discharges and provision of post-transplant care.

B7.8.1 When a recipient is discharged prior to engraftment, the Clinical Program shall verify that the following elements are available:

B7.8.1.1 A consult between the attending physician and the receiving health care professionals regarding the applicable elements in Standard B7.7.

B7.8.1.2 Facilities that provide appropriate location, adequate space, and protection from airborne microbial contamination.

B7.8.1.3 Appropriate medications, blood products, and additional care required by the recipient.

B7.8.2 The Clinical Program shall provide appropriate instructions to recipients prior to discharge.

B7.9 There should be policies or Standard Operating Procedures in place for post-transplant vaccination schedules and indications.

B7.12 There shall be an infrastructure and policies or Standard Operating Procedures in place for provision of appropriate long-term follow-up, treatment, and plans of care.

B7.12.1 There shall be policies or Standard Operating Procedures for monitoring by appropriate specialists of recipients for post-cellular therapy late effects, including at a minimum:

B7.12.1.1 Endocrine and reproductive function and osteoporosis.

B7.12.1.2 Cardiovascular risk factors.

B7.12.1.3 Respiratory function.

B7.12.1.4 Chronic renal impairment.

B7.12.1.5 Secondary malignancies.

B7.12.1.6 Growth and development of paediatric patients.

B7.12.2 There shall be policies or Standard Operating Procedures describing the transition of long-term paediatric recipients to adult care as appropriate.

B7.12.2.1 There shall be policies or Standard Operating Procedures describing the acceptance of paediatric recipients into a long-term follow-up clinic for adults.

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# ABBREVIATIONS AND GLOSSARY

## **AHP**

Allied Health Professional. A healthcare professional who is focused on supporting people to live full and active lives. Includes physiotherapists, dieticians and occupational therapists.

## **ALL**

Acute lymphoblastic leukaemia. A form of cancer affecting a type of white blood cell called 'lymphoblasts'. It is more common in children than in adults.

## **AML**

Acute myeloid leukaemia. A form of cancer affecting 'myeloid cells', which include red blood cells, platelets and certain types of white blood cells. It occurs mainly in adults over the age of 60, but it can also affect children.

## **BMT CRG**

Blood and Marrow Transplantation Clinical Reference Group. An expert group of clinicians, commissioners, public health experts, patients and carers responsible for advising NHS England on the delivery of 'specialised' stem cell transplantation services.

## **BSBMT**

British Society for Blood and Marrow Transplantation. A UK organisation for those with a professional interest in stem cell transplantation, including healthcare professionals, data managers and quality managers.

## **CCG**

Clinical Commissioning Group. There are nearly 200 CCGs across England, each responsible for planning and paying for a variety of healthcare services in their local area. This includes most hospital and community care.

## **CNS**

Clinical Nurse Specialist. A nurse who is an expert in a specific area of nursing practice (in the context of this report, this means a nurse who is an expert in caring for stem cell transplant patients).

## **EBMT**

European Society for Blood and Marrow Transplantation. A European organisation for those with a professional interest in stem cell transplantation, including healthcare professionals and scientists.

## **GVHD**

Graft versus host disease. When a patient's new immune system sees the patient as 'different' and therefore attacks the patient. Some GvHD can be a good thing, but too much GvHD can cause unwanted complications and side-effects; it can even be life-threatening.

## **MDT**

Multidisciplinary team. A team of healthcare professionals, for example consultants, nurses and AHPs, who work together to plan a patient's treatment.

# REFERENCES

- [1] British Society for Blood and Marrow Transplantation. *Correspondence*. 2019.
- [2] British Society for Blood and Marrow Transplantation. *BSBMT Indications for Adult BMT*. Available from: [www.bsbmt.org/indications-table/](http://www.bsbmt.org/indications-table/)
- [3] British Society for Blood and Marrow Transplantation. *Indications for HSCT in Children – UK Paediatric BMT Group 2015*. Available from: [www.bsbmt.org/indications-table/](http://www.bsbmt.org/indications-table/)
- [4] British Society for Blood and Marrow Transplantation. *Annual Activity – 2016*. Available from: [www.bsbmt.org/activity/2016](http://www.bsbmt.org/activity/2016)
- [5] British Society for Blood and Marrow Transplantation. *Correspondence*. 2015.
- [6] Bresters, D., van Glis, I., and Kollen, W., et al. High burden of late effects after haematopoietic stem cell transplantation in childhood: a single-centre study. *Bone Marrow Transplantation*. 2010;45(1): 79-85.
- [7] Armenian, S., Sun, C., and Kawashima, T., et al. Long-term health-related outcomes in survivors of childhood cancer treated with HSCT versus conventional therapy: a report from the Bone Marrow Transplant Survivor Study (BMTSS) and Childhood Cancer Survivor Study (CCSS). *Blood*. 2011;118(5): 1413-1420.
- [8] Sun, C., Francisco, L., and Baker, K., et al. Adverse psychological outcomes in long-term survivors of hematopoietic cell transplantation: a report from the Bone Marrow Transplant Survivor Study (BMTSS). *Blood*. 2011;118(17): 4723-4731.
- [9] Khara, N., Storer, B., and Flowers, M., et al. Nonmalignant late effects and compromised functional status in survivors of hematopoietic cell transplantation. *Journal of Clinical Oncology*. 2012;30(1): 71-77.
- [10] Sun, C., Kersey, J., and Francisco, L., et al. Burden of morbidity in 10+ year survivors of hematopoietic cell transplantation: report from the bone marrow transplantation survivor study. *Biology of Blood and Marrow Transplantation*. 2013;19(7): 1073-1080.
- [11] Bhatia, S., Francisco, L., and Carter, A., et al. Late mortality after allogeneic hematopoietic cell transplantation and functional status of long-term survivors: report from the Bone Marrow Transplant Survivor Study. *Blood*. 2007;110(10): 3784-3792.
- [12] Martin, P., Counts, G., and Appelbaum, F., et al. Life expectancy in patients surviving more than 5 years after hematopoietic cell transplantation. *Journal of Clinical Oncology*. 2010;28(6): 1011-1016.
- [13] Wingard, J., Majhail, N., and Brazauskas, R., et al. Long-term survival and late deaths after allogeneic hematopoietic cell transplantation. *Journal of Clinical Oncology*. 2011;29(16): 2230-2239.
- [14] Bhatia, S. Long-term health impacts of hematopoietic stem cell transplantation inform recommendations for follow-up. *Expert Review of Haematology*. 2011;4(4): 437-452.
- [15] Thygesen, K., Schjødt, I., and Jarden, M. The impact of hematopoietic stem cell transplantation on sexuality: a systematic review of the literature. *Bone Marrow Transplantation*. 2012;47(5): 716-724.
- [16] Rueda-Lara, M., and Lopez-Patton, M. Psychiatric and psychosocial challenges in patients undergoing haematopoietic stem cell transplants. *International Review of Psychiatry*. 2014;26(1): 74-86.
- [17] Hilgendorf, I., Greinix, H., and Halter, J., et al. Long-term follow-up after allogeneic stem cell transplantation. *Deutsches Arzteblatt International*. 2015;112(4): 51-58.
- [18] Inamoto, Y., and Lee, S. Late effects of blood and marrow transplantation. *Haematologica*. 2017;102(4): 614-625.
- [19] Majhail, N., Rizzo, J., and Lee, S., et al. Recommended screening and preventive practices for long-term survivors after hematopoietic cell transplantation. *Bone Marrow Transplantation*. 2012;47(3): 337-341.
- [20] Chow, E., Anderson, L., and Baker, K., et al. Late effects surveillance recommendations among survivors of childhood hematopoietic cell transplantation: a Children's Oncology Group report. *Biology of Blood and Marrow Transplantation*. 2016;22(5): 782-795.
- [21] Battiwalla, M., Hashmi, S., and Majhail, N., et al. National Institutes of Health hematopoietic cell transplantation late effects initiative: developing recommendations to improve survivorship and long-term outcomes. *Biology of Blood and Marrow Transplantation*. 2017;23(1): 6-9.
- [22] FACT-JACIE. FACT-JACIE International Standards for Hematopoietic Cellular Therapy Product Collection, Processing and Administration (Seventh Edition 7.0). 2018. Available from: [www.ebmt.org/jacie-standards/7th-edition-effective-june-1st-2018](http://www.ebmt.org/jacie-standards/7th-edition-effective-june-1st-2018)
- [23] Hamblin, A., Greenfield, D., and Gilleece, M., et al. Provision of long-term monitoring and late effects services following adult allogeneic haematopoietic stem cell transplant: a survey of UK NHS-based programmes. *Bone Marrow Transplantation*. 2017;52(6): 889-894.
- [24] Horne, B., Gilleece, M., and Jackson, G., et al. Psychosocial supportive care services for haematopoietic stem cell transplant patients; a service evaluation of three UK transplant centres. *European Journal of Cancer Care*. 2014;23(3): 349-362.
- [25] Anthony Nolan. *Recovery After Transplant: Who Cares?*. 2017. Available from: [www.anthonynolan.org](http://www.anthonynolan.org)
- [26] Dignan, F., Potter, M., and Ethell, M., et al. High readmission rates are associated with a significant economic burden and poor outcome in patients with grade III/IV acute GVHD. *Clinical Transplantation*. 2013;27(1): e56-63.
- [27] Bevans, M., El-Jawahri, A., and Tierney, D. et al. National Institutes of Health Hematopoietic Cell Transplantation Late Effects Initiative: The Patient-Centered Outcomes Working Group Report. *Biology of Blood and Marrow Transplantation*. 2017;23(4): 538-551.
- [28] NHS England. *Manual for Prescribed Specialised Services 2018/19*. 2018. Available from: [www.england.nhs.uk/publication/manual-for-prescribed-specialised-services/](http://www.england.nhs.uk/publication/manual-for-prescribed-specialised-services/)
- [29] NHS National Services Scotland. *Adult stem cell transplantation (Adult bone marrow transplantation)*. Available from: [www.nsd.scot.nhs.uk/services/specserv/bonemarrow.html](http://www.nsd.scot.nhs.uk/services/specserv/bonemarrow.html)
- [30] Welsh Health Specialised Services Committee. *Specialised Services Service Specification: Blood and Marrow Transplantation*. 2014. Available from: [www.whssc.wales.nhs.uk/document/282301](http://www.whssc.wales.nhs.uk/document/282301)
- [31] NHS England. *2013/14 NHS Standard Contract for Haematopoietic Stem Cell Transplantation (Adult)*. 2013. Available from: [www.england.nhs.uk/commissioning/spec-services/npc-crg/blood-and-infection-group-f/f01/](http://www.england.nhs.uk/commissioning/spec-services/npc-crg/blood-and-infection-group-f/f01/)
- [32] NHS England. *2013/14 NHS Standard Contract for Haematopoietic Stem Cell Transplantation (Children)*. 2013. Available from: [www.england.nhs.uk/commissioning/spec-services/npc-crg/blood-and-infection-group-f/f01/](http://www.england.nhs.uk/commissioning/spec-services/npc-crg/blood-and-infection-group-f/f01/)
- [33] National Institute for Health and Care Excellence. *Improving supportive and palliative care for adults with cancer*. 2004. Available from: [www.nice.org.uk/guidance/csg4](http://www.nice.org.uk/guidance/csg4)
- [34] Transforming Cancer Services Team for London. *The psychological impact of cancer: commissioning recommendations, pathway and service specifications on psychosocial support for adults affected by cancer*. 2018. Available from: [www.healthylondon.org/wp-content/uploads/2018/05/Psychological-support-for-people-affected-by-cancer-May-2018.pdf](http://www.healthylondon.org/wp-content/uploads/2018/05/Psychological-support-for-people-affected-by-cancer-May-2018.pdf)
- [35] Macmillan Cancer Support. *Prehabilitation: Evidence and Insight Review*. 2017. Available from: [www.macmillan.org.uk/\\_images/prehabilitation-evidence-and-insight-review\\_tcm9-335025.pdf](http://www.macmillan.org.uk/_images/prehabilitation-evidence-and-insight-review_tcm9-335025.pdf)
- [36] Ehrlich, K., Miller, G., and Scheide, T., et al. Pre-transplant emotional support is associated with longer survival after allogeneic hematopoietic stem cell transplantation. *Bone Marrow Transplantation*. 2015;51(12): 1594-1598.
- [37] Ceesay, M., Sadique, Z., and Harris, R. et al. Prospective evaluation of the cost of diagnosis and treatment of invasive fungal disease in a cohort of adult haematology patients in the UK. *Journal of Antimicrobial Chemotherapy*. 2015;70(4): 1175-1181.
- [38] Tomblyn, M., Chiller, T., and Einsele, H., et al. Guidelines for preventing infectious complications among hematopoietic cell transplantation recipients: a global perspective. *Biology of Blood and Marrow Transplantation*. 2009;15(10): 1143-1238.
- [39] Ljungman, P., Cordonnier, C., and Einsele, H. Vaccination of hematopoietic cell transplant recipients. *Bone Marrow Transplantation*. 2009;44(8): 521-526.
- [40] Rubin, L., Levin, M., and Ljunman, P., et al. 2013 IDSA clinical practice guideline for vaccination of the immunocompromised host. *Clinical Infectious Diseases*. 2014;58(3): 309-318.
- [41] Patel, S., Skinner, R., and Heath, P. *Vaccinations for paediatric patients treated with standard-dose chemotherapy and haematopoietic stem cell transplantation (HSCT) recipients*. 2016. Available from: [www.cclg.org.uk/write/MediaUploads/Member%20area/Treatment%20guidelines/Vaccination\\_recommendations\\_2016.pdf](http://www.cclg.org.uk/write/MediaUploads/Member%20area/Treatment%20guidelines/Vaccination_recommendations_2016.pdf)
- [42] Miller, P., de Silva, T., and Skinner, R., et al. Routine vaccination practice after adult and paediatric allogeneic haematopoietic stem cell transplant: a survey of UK NHS programmes. *Bone Marrow Transplantation*. 2017;52(5): 775-777.
- [43] Rizzo, J., Curtis, R., and Socié, G., et al. Solid cancers after allogeneic hematopoietic cell transplantation. *Blood*. 2009;113(5): 1175-1183.
- [44] Majhail, N., Brazauskas, R., and Rizzo, J., et al. Secondary solid cancers after allogeneic hematopoietic cell transplantation using busulfan-cyclophosphamide conditioning. *Blood*. 2011;117(1): 316-322.
- [45] Inamoto, Y., Shah, N., and Savani, B., et al. Secondary solid cancer screening following hematopoietic cell transplantation. *Bone Marrow Transplantation*. 2015;50(8): 1013-1023.
- [46] NHS Improving Quality. *Planning for your future care: a guide*. 2014. Available from: [www.npcp.org.uk/sites/default/files/planning\\_for\\_your\\_future\\_updated\\_sept\\_2014%20%281%29.pdf](http://www.npcp.org.uk/sites/default/files/planning_for_your_future_updated_sept_2014%20%281%29.pdf)
- [47] Tierney, K., Passaglia, J., and Jenkins, P. Palliative care of hematopoietic cell transplant recipients and Families. *Seminars in Oncology Nursing*. 2014;30(4): 253-261.
- [48] Hashmi, S., Bredeson, C., and Duarte, R., et al. National Institutes of Health Blood and Marrow Transplant Late Effects Initiative: The Healthcare Delivery Working Group Report. *Biology of Blood and Marrow Transplantation*. 2017;23(5): 717-725.

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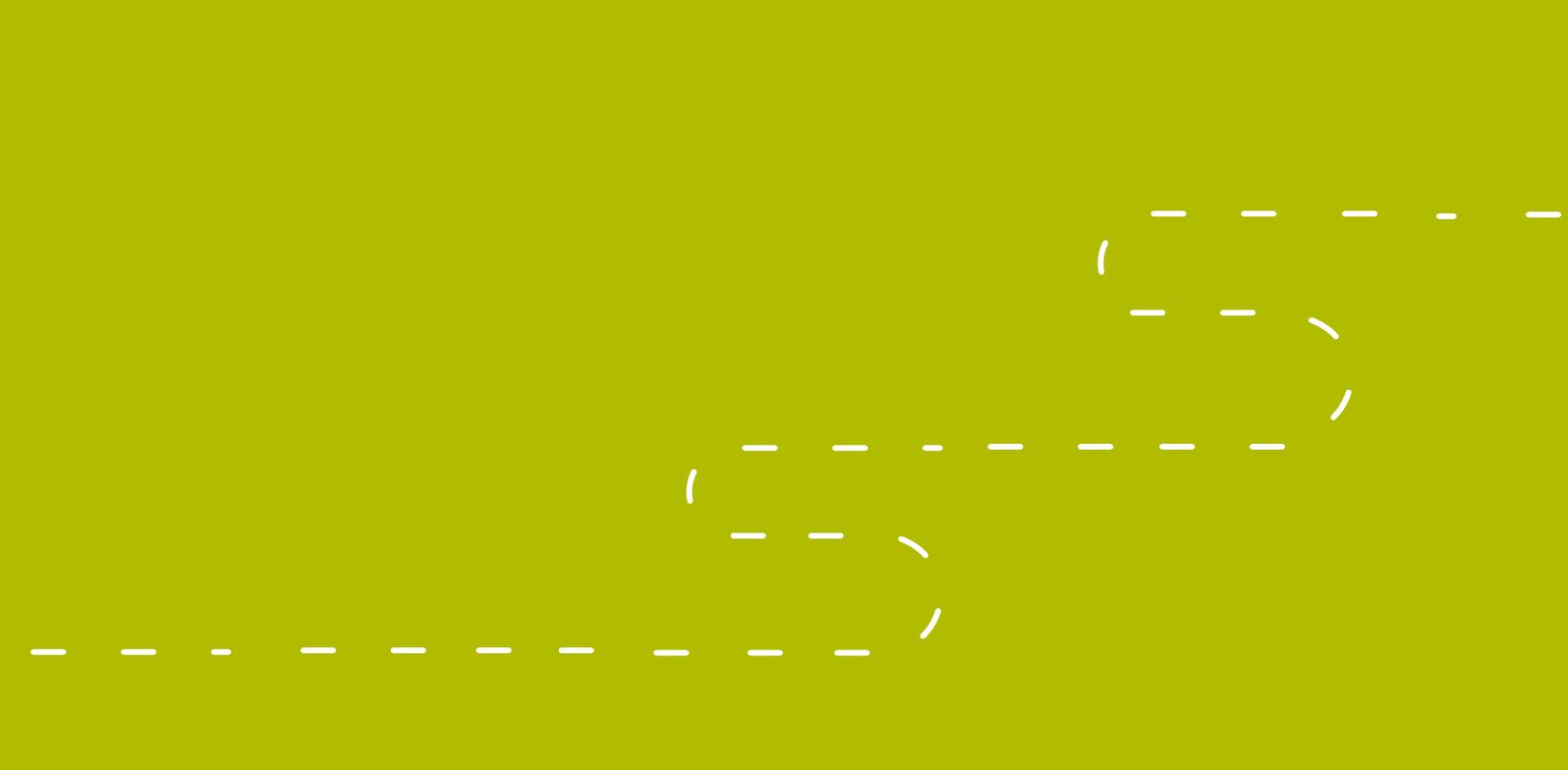
# ABOUT ANTHONY NOLAN AND HOW WE HELP

**Anthony Nolan is the charity that saves and improves the lives of people with blood cancer and blood disorders. We do this by finding matching donors for patients in desperate need of a lifesaving stem cell transplant, supporting patients and their families throughout their transplant journey, and conducting world-class research into stem cell matching and transplants. To continue being there for the patients who need us, we rely on the support and generosity of others, who we are incredibly grateful to.**

Our support for patients and families is overseen by a dedicated Patient Services team and includes a wide range of booklets and web resources, the free patient app 'My Transplant Tracker', financial grants, education days, an online forum and a peer support service.

We also fund a network of CNSs based in transplant centres across the UK - in 2017/18, seven Anthony Nolan CNSs supported over 800 patients and their families in London, Glasgow, Nottingham and Bristol - and have recently funded our first three clinical psychology posts to address the unique psychological impact of having a stem cell transplant.

If you are a patient, family member or healthcare professional who would like to find out more about the support we offer, visit: [anthonymolan.org/patients-and-families](https://anthonymolan.org/patients-and-families).



**Anthony Nolan and the Expert Steering Group  
would like to thank everyone who has contributed  
to this report, including:**

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Dr Troy Chase from Imperial College Healthcare NHS Trust, Anne Crook from The Christie NHS Foundation Trust, and Dr Henrietta Saunders from Barts Health NHS Trust, all of whom helped to review the final report.

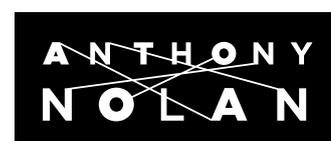
Everyone should receive the care and support they need after a stem cell transplant, for as long as necessary and no matter where they live.



For more information about this report, email [PTCpathway@anthonymolan.org](mailto:PTCpathway@anthonymolan.org)

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