

2021 ACTION PLAN

A PATHWAY FOR POST-TRANSPLANT CARE



Anthony Nolan is the charity that makes lifesaving connections between people with blood cancer and incredible strangers ready to donate their stem cells. We're saving lives right now. Three lives a day, in fact. But we can't do it without you.
Without you, there is no cure.



saving the lives
of people with
blood cancer

INTRODUCTION

In 2019, Anthony Nolan published the report **A pathway for post-transplant care**. In this report, we set out that 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 does not always happen.

The post-transplant care pathway addresses gaps in service provision and outlines the support packages that are vital to patient recovery. The pathway was developed in consultation with healthcare professionals, local NHS representatives, patients and their families.

The pathway consists of **five building blocks**:



Over the following pages, this action plan sets out the activities Anthony Nolan has undertaken to help implement the pathway and our ongoing actions. This includes continuously **supporting transplant centres** to improve the services they provide, **addressing key knowledge gaps**, exploring ways to better monitor the care that patients receive, and **empowering patients and their families** to ensure they have access to the support they need.

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SUPPORTING TRANSPLANT CENTRES

WHAT ARE WE DOING?

Producing late effects practice guidelines (LEPG) on administration of post-transplant vaccinations.

WHAT ARE WE AIMING TO ACHIEVE?

We want to talk to patients and healthcare professionals to develop a clear understanding of the barriers to accessing post-transplant vaccinations in care pathways. We will use these insights to produce practice guidelines for healthcare professionals and a vaccination passport. This document will contain information about vaccinations post-transplant, with the ultimate aim of creating consistency of care across the UK and improved patient education.

4. ONGOING PREVENTION AND MONITORING

KEY MILESTONES

We will have the guidelines completed and passport ready for use by June 2022. Results from the research will be disseminated within the transplant community and presented at national and international events.

WHAT ARE WE DOING?

Conducting research into financial and resource-related barriers to delivering post-transplant care.

WHAT ARE WE AIMING TO ACHIEVE?

We commissioned independent analysis of hospital activity and costs following allogeneic stem cell transplantation in England. The analysis, published in January 2021 by EY, showed that there is a case to review the payment model for transplant services to ensure that the significant longer-term costs associated with allogeneic stem cell transplants are better recognised. We will use these findings, together with insights from interviews we have conducted with transplant centre representatives, to propose new solutions for the commissioning of stem cell transplants in discussions with decision-makers.

1. THROUGHOUT RECOVERY

5. ADDITIONAL TREATMENT AND SUPPORT

KEY MILESTONES

The EY report was published in January 2021 and its recommendations will be shared with NHS commissioners, transplant centres and other stakeholders throughout 2021.

WHAT ARE WE DOING?

Holding education days for nurses and Allied Health Professionals (AHPs).

WHAT ARE WE AIMING TO ACHIEVE?

We want to grow the attendance of nurses and AHPs at our education days to share best practice, receive updates on new treatments and research, and provide a space to learn from each other's experiences. These insights can then be applied to their own work settings, contributing to service improvements.

1. THROUGHOUT RECOVERY

5. ADDITIONAL TREATMENT AND SUPPORT

KEY MILESTONES

Two virtual events were held in November 2020, with 80 attendees. This is an increase of 40% from the previous year (2020 was the first time we had a paediatric day). Both events were accredited by the Royal College of Nursing (RCN). We plan to run the education days again in Summer 2021.

SUPPORTING TRANSPLANT CENTRES



HENRIETTA SAUNDERS

Anthony Nolan Clinical Psychologist at Bart's Hospital

Our funded posts support the transplant centres where they work, as well as share their experiences more widely which helps the development of other centres too.

'A key aspect of developing my role as an Anthony Nolan Clinical Psychologist has been listening to and learning from others, particularly the experiences and perspectives of people who have had stem cell transplants and multi-disciplinary team colleagues.'

'Working closely with an Anthony Nolan Post-Transplant Clinical Nurse Specialist (CNS) and having the opportunity to share with others in the field, such as through presenting at Anthony Nolan CNS Education Days, has been important.'

'I have also helped bring together psychological professionals working across the UK in adult and paediatric stem cell transplant services. This provides an opportunity to meet and network, to share learning and best practice which will support the development of our services and improve psychological care for transplant patients.'

ADDRESSING KNOWLEDGE GAPS

WHAT ARE WE DOING?

Conducting research into psychological support.

WHAT ARE WE AIMING TO ACHIEVE?

We have already conducted a survey of transplant centres to learn more about the psychological support they currently provide and the barriers they may face. The survey covered their workforce capacity, the design of their services and their views on stem cell transplant patients' needs. The next stage is to conduct in-depth interviews with patients to develop a rich picture of the emotional and psychological support that they would like after a stem cell transplant.

1. THROUGHOUT RECOVERY

KEY MILESTONES

Research has been delayed due to the pandemic, once all elements of the research are completed we will be publishing key findings in a relevant transplant journal as well as submitting the work to scientific conferences such as the one held annually by the European Society for Blood and Marrow Transplantation.

WHAT ARE WE DOING?

Conducting research to understand patients' quality of life before, during and after a stem cell transplant.

WHAT ARE WE AIMING TO ACHIEVE?

Crucially, this research will help us to better understand the factors that contribute to quality of life and how we can improve patient wellbeing. As a result, we hope to provide more effective, more personalised and more consistent services to our patients in the future.

1. THROUGHOUT RECOVERY

KEY MILESTONES

Research will begin in 2021 and the first results will be published in early 2022.

WHAT ARE WE DOING?

Collecting evidence to understand what patients need from remote and digital ways of delivering post-transplant care.

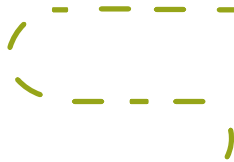
WHAT ARE WE AIMING TO ACHIEVE?

During COVID-19, many different ways of providing remote care have been introduced. We want to understand how patients feel about these new ways of receiving care to inform how digital and remote consultations can work to best meet patient needs.

1. THROUGHOUT RECOVERY

KEY MILESTONES

Research is underway and we will publish our findings and recommendations in 2021.



SUPPORTING TRANSPLANT CENTRES



ROSALINA NAIDOO

Medical Officer at Anthony Nolan

Rosalina has been undertaking a research project at Anthony Nolan to grow the evidence base around the psychological support that is currently available to stem cell transplant patients.

'I identified a gap in the research and wanted to look at whether UK transplant centres are providing patients with the psychological support they need.'

'To understand this, I have been exploring how psychological care is delivered and made available to patients in transplant centres across the UK.'

'I will be conducting a study involving patients to explore their experience of undergoing a stem cell transplant, particularly with regards to how easy they thought it was to access psychological support. I hope that this research will enable patients to access appropriate levels of psychological care before, during and after their transplant.'

EMPOWERING PATIENTS AND THEIR FAMILIES

WHAT ARE WE DOING?

We have produced three activity books (before, during and after transplant) for patients aged 5-11. We are also producing a supplementary guide for parents. All these resources will be available for free to patients, families and healthcare professionals.

WHAT ARE WE AIMING TO ACHIEVE?

We developed these guides alongside children who have had stem cell transplants, their parents and healthcare professionals. Throughout, the aim has been to complement the information given by each child's transplant team with an engaging series of activity books which demystify the transplant process for children. We want to make the process 'less scary' for the children and to support their parents with information and advice throughout their child's transplant journey.

4. ONGOING PREVENTION AND MONITORING

KEY MILESTONES

These resources have been published as a complete set of four booklets in October 2020. We are aiming to have 200 sets of activity books ordered by families or the patient's healthcare team every six months for the next three years.

WHAT ARE WE DOING?

Holding another family camp, in partnership with Over the Wall, for families with a child who has had a stem cell transplant

WHAT ARE WE AIMING TO ACHIEVE?

The first family camp was held in 2019 and was attended by 13 families, benefitting more than 50 people altogether. It provided an opportunity for families to have fun, discover new skills and meet other families who had gone through similar experiences. It was incredibly successful, so we want to host another, even better, family camp in 2022.

5. ADDITIONAL TREATMENT AND SUPPORT

KEY MILESTONES

Due to pandemic restrictions, we have been unable to hold the next family camp as soon as we would have liked. For our next family camp in 2022, we hope to recruit around 40 families and we will aim to capture all feedback for post-event analysis, making sure we can keep improving our offer year on year.

WHAT ARE WE DOING?

Funding Anthony Nolan Clinical Nurse Specialists (CNSs) and Clinical Psychologists.

WHAT ARE WE AIMING TO ACHIEVE?

Our CNSs and Clinical Psychologists provide invaluable care and support to patients throughout their transplant journey. They do this by ensuring that patients know what to expect from their treatment and are better prepared to deal with potential side effects. In 2019, our CNSs supported 684 new post-transplant patients. We will build on this in 2021 by funding new posts. We will evaluate and highlight the impact of all our roles to show decision-makers the difference they make so that they will create permanent posts.

1. THROUGHOUT RECOVERY

KEY MILESTONES

Overall, we have funded 12 CNSs in UK Transplant Centres and three Clinical Psychologists, nine of these posts have finished their funding from Anthony Nolan with eight having the funding continued by their Trust. We agreed funding for two more Clinical Psychologists and one CNS in 2020/21.



EMPOWERING PATIENTS AND THEIR FAMILIES



GEORGE NORTON

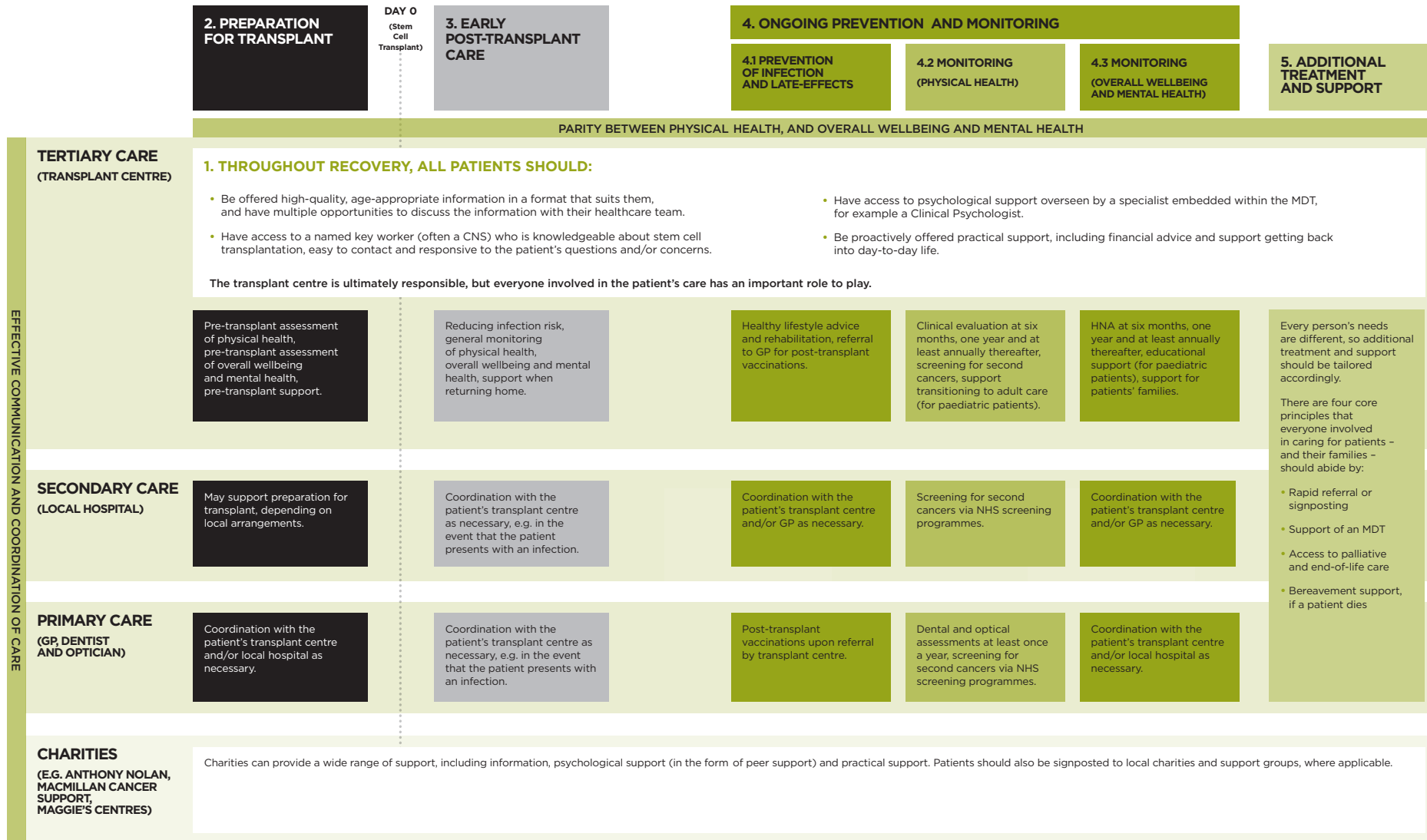
Patient representative

George is one of the patient representatives on the Expert Steering Group who co-created the pathway for post-transplant care.

‘Being part of the Expert Steering Group meant our experiences and the experiences of others who have had stem cell transplants have played a vital role in driving discussions and decisions. We’ve been equal partners with those working on the pathway at Anthony Nolan since the beginning, as it should be since we know better than anyone what transplant patients need.’

‘It’s been rewarding to call on our expertise to identify these needs and to use our critical voice to ensure the pathway is truly patient-centric. Now it’s time to make sure ideas turn into action. I’m very much looking forward to this stage and the opportunity to transform the lives of people going through stem cell transplants through the implementation of the pathway.’

POST-TRANSPLANT CARE PATHWAY



See the full report published in 2019
A pathway for post-transplant care

NEXT STEPS

The work Anthony Nolan is undertaking will help meet the services and support packages that are central to patients' recovery as set out in the report **A pathway for post-transplant care.**

But we still have a long way to go. That's why we will continue to work with healthcare professionals and local NHS representatives to ensure that patients have equal access to services and support packages that reflect their needs.

For someone with blood cancer, a stem cell transplant could be their last chance of survival. Donations from our generous supporters could fund the search for a matching donor who could give that person, their family and their friends a second chance of life.

If you'd like to support our work, please visit **anthohnolan.org/give**

For more information about this report, email **public.affairs@anthohnolan.org**



saving the lives
of people with
blood cancer