Post-transplant Care Pathway (All Ages)

Commentary

Draft for consultation: September 2018
Background
In April 2018, Anthony Nolan launched a new initiative aimed at improving the commissioning of post-transplant care in England. We know that the fragmented arrangement for funding care after 100 days, when responsibility transfers from national to local commissioners, has led to gaps and variation in the services that transplant centres are able to provide.

Our initial focus has been on the development of an optimum post-transplant care pathway, setting out the key services that adult and paediatric patients need after an allogeneic stem cell transplant. This work has been completed in collaboration with an Expert Steering Group consisting of healthcare professionals, managers and patients. The group is chaired by Dr Fiona Dignan, Consultant Haematologist and Clinical Lead for Haematology at Manchester University NHS Foundation Trust.

It is our intention that the pathway will form part of a larger report for commissioners, to be published in Spring 2019, aimed at ensuring that the needs of patients are fully understood and that transplant centres receive the appropriate support to meet them. Therefore, please note that the pathway is a tool to inform discussions with commissioners and not an immediate set of expectations to be placed on transplant centres.

How to use the pathway and commentary
The pathway and commentary (this document) are intended to be read together. The commentary explains each part of the pathway in more detail, with the numbers used in the pathway corresponding to the numbered paragraphs used in the commentary. For example:

Consultation
Anthony Nolan and the Expert Steering Group are consulting on the pathway for five weeks between Monday 1 October 2018 and Friday 2 November 2019. Specifically, we are interested to know to what extent NHS representatives think our initial ideas represent ‘gold-standard’ post-transplant care for adult and paediatric patients. You can share your views by responding to our online survey, which is available at: www.smartsurvey.co.uk/s/PTCpathway

For more information or if you have any questions, please contact Anthony Nolan on PTCpathway@anthonyanl.org or 020 7424 1391.
1. Throughout the pathway

1.1 All patients should have a named key worker, e.g. Clinical Nurse Specialist (CNS), who they (and their families) can contact at any time post-transplant, even if it is many years later. The key worker should be responsive and support the patient to achieve their personal goals, such as returning to work if this is something that is important to the patient.

1.2 The transplant centre environment should support recovery. This includes good rehabilitation facilities, reliable wi-fi (especially important during isolation, to allow patients to stay connected to the outside world and undertake practical tasks such as internet banking), and the availability of space to help isolate immunocompromised patients.

1.3 All patients (and their families) should have access to information and support at an appropriate time and in an appropriate format, such as peer support, financial advice and help getting back into day-to-day life, which may include managing work/education. More often than not this is provided by the third sector, e.g. Anthony Nolan, Macmillan Cancer Support and Maggie’s Centres. Transplant centres, local hospitals and GPs are all responsible for signposting and helping patients play an active role in their recovery.

1.4 A patient’s care is likely to include a large number of healthcare professionals across a variety of settings. They should all understand the nature of stem cell transplantation (SCT) and the patient as an individual (although this does not mean they need to be a specialist; knowledge of the procedure and its potential impacts is sufficient). It is also essential that everyone communicates effectively, even if they are based in different places, to ensure that the patient’s care is well co-ordinated and they feel safe and supported, even when they are not in hospital.

2. Preparation for stem cell transplantation

2.1 How well (or not) a patient is prepared for SCT can have a significant impact on their recovery. All patients should have a pre-transplant review at their transplant centre and/or local hospital (depending on local arrangements, although patients should at least be able to visit their transplant centre to view the facilities and meet their healthcare team). The review should consist of an assessment of their physical health, e.g. bone marrow, kidney, heart, lung and blood tests, and an assessment of their overall wellbeing and mental health, e.g. quality of life and psychological state. This should all be done in good time before the patient’s transplant to allow any issues that are identified to be acted upon.

2.2 In addition, all patients (and their families) should be given advice on symptom management, self-management and any preparatory rehabilitation available. It is imperative that patients feel well-informed about the challenges they could face after SCT, and know where and how to access the care and support they may need. While much of this information will need to come directly from the transplant centre, they should also be signposted to the third sector.

2.3 To help ensure effective co-ordination of care, the transplant centre (most likely the key worker) should contact the patient’s GP at the earliest available opportunity to update them on the patient’s treatment. At the same time, if the GP has pertinent information that they wish to share with the transplant centre they should be given the chance to do so; two-way discussion is encouraged. The GP is also advised to note the patient’s SCT in the records of their immediate family, in order to help ‘connect the dots’ should a family member present with issues potentially related to the patient’s SCT.
3. Early post-transplant care

3.1 Infection is a significant cause of morbidity and mortality after SCT. This includes viral, bacterial and fungal infections. Patients therefore require antiviral, antibacterial and antifungal prophylaxis.1, 2

3.2 Before being sent home, all patients should be given information on how to protect themselves from infection, and factors that may affect adherence, such as cognition, distress or a lack of social support, should be considered. Patients should also be given 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: this individual is responsible for advising on next steps, e.g. whether or not the patient needs to go to their transplant centre or local hospital (depending on local arrangements).

3.3 In the immediate period after SCT, patients’ physical health, overall wellbeing and mental health should be closely monitored. Physical health includes signs of graft versus host disease (GvHD), relapse, fatigue and weight loss, as well as regularly checking blood counts, and kidney and liver function. Overall wellbeing and mental health includes signs of distress and increased anxiety.

4. Ongoing prevention and monitoring

4.1 Prevention of infection and late effects

4.1.1 Although infectious risk is highest in the first one to two years after SCT, an increased risk of infection can be long-term for some patients, such as those with chronic GvHD who are on extended immunosuppressive therapy.1 In these situations, patients may require continued antiviral, antibacterial and antifungal prophylaxis. Some patients will require antibiotics for life.

4.1.2 To help reduce the risk of various late effects, including respiratory disease, cardiovascular disease, problems with the musculoskeletal system and second cancers, all patients should receive healthy lifestyle advice from their transplant centre on an annual basis (at least). This should include using high SPF sun creams, not smoking, having a healthy balanced diet, reducing alcohol consumption and taking regular exercise.

4.1.3 The FACT-JACIE International Standards make it clear that all patients should receive a schedule of post-transplant vaccinations (B7.9, see appendix 1). These vaccinations should be delivered by the patient’s GP, upon referral by the transplant centre. There may also be situations where vaccination of family members, household contacts and healthcare professionals is recommended to minimise the patient’s exposure to vaccine-preventable diseases. More information on what vaccines should be administered, and when, can be found in existing international and national guidelines2, 3, 4, 5 (although an area that may warrant future consideration is the development of a harmonised UK guideline and/or policy that synthesises best practice recommendations and national licensing considerations, thereby providing transplant centres and GPs with a single reference source6).

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4.2 Monitoring (physical health)

4.2.1 All patients should return to their transplant centre for a comprehensive clinical evaluation at 6 months post-transplant, 1 year post-transplant and annually thereafter (at least). They should be monitored for GvHD, relapse, transfusion-associated iron overload, and problems with the eyes, mouth, lungs, heart, liver, kidneys, musculoskeletal system, nervous system, endocrine system and skin, including signs of second cancers. Assessment of cognitive development, gonadal function and growth are particularly important for paediatric patients.

4.2.2 All patients should book an appointment to see their dentist and their optician on an annual basis (at least). They should receive a thorough examination, and their dentist should provide advice on preventive oral health and good oral hygiene. For paediatric patients, special attention should be paid to teeth development. More detail on both 4.2.1 and 4.2.2 can be found in internationally agreed guidelines on screening and preventive practices for long-term survivors of SCT.

4.2.3 SCT survivors are at a significantly increased risk of developing second cancers compared to the general population, something that has been observed as late as 15 years post-transplant. Screening for second cancers is therefore an essential part of ongoing monitoring. It takes place in a variety of settings; for example, a patient’s clinical evaluation (see 4.2.1) and dental assessment (see 4.2.2) should both include checking for signs of second cancers, such as thyroid cancer and mouth cancer respectively. In contrast, screening for bowel, breast and cervical cancer are delivered via NHS screening programmes, which may be at the patient’s local hospital or GP surgery. An area that warrants further consideration is appropriate access to breast and cervical cancer screening: internationally agreed guidelines for long-term survivors of SCT state that screening should begin earlier and take place more frequently than is dictated by national guidelines for the general population, and as such transplant centres have reported difficulties in accessing these programmes for their patients.

4.2.4 Note that the FACT-JACIE International Standards now state that, at a minimum, long-term monitoring of late effects should include ‘endocrine and reproductive function and osteoporosis, cardiovascular risk factors, respiratory function, chronic renal impairment, secondary malignancies, and growth and development of paediatric patients’ (B7.12.1, see appendix 1). However, it should be stressed that this is very much a minimum and not ‘gold-standard’.

4.3 Monitoring (overall wellbeing and mental health)

4.3.1 SCT can have a significant impact on patients’ overall wellbeing and mental health, and this must be deemed just as important as patients’ physical health. For example, in line with clinical evaluation (see 4.2.1), all patients should return to their transplant centre for an SCT- and age-specific Holistic Needs Assessment (HNA) at 6 months post-transplant, 1 year post-transplant and annually thereafter (at least). This may include, but is not limited to, assessment of quality of life, psychological state, sexual function, symptoms of early menopause, fertility, fatigue, diet and concerns about money

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and work.\textsuperscript{1} The findings of the HNA should be translated into a care plan, which should be shared with other members of the patient’s healthcare team as appropriate.

4.3.2 Specifically for paediatric patients, educational progress should be assessed, e.g. attendance, attainment and peer relationships.\textsuperscript{15} The patient’s school, college or university should receive information about recovery, and collaboration between the patient’s healthcare team and educators should be encouraged at regular intervals (ideally, this would include a visit by the patient’s key worker).

4.3.3 SCT 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. This is recommended by international guidelines\textsuperscript{1} and patients have fed back that, if their family is doing well, this can have a positive impact on their own recovery.

5. Additional treatment and support, including palliative and end-of-life care

5.1 If ongoing monitoring identifies a need for additional treatment and support, the transplant centre should refer/signpost the patient (and/or their family) as soon as possible. Additional treatment and support may be provided by their local hospital, their GP and/or the third sector. Patients need to understand and be able to make decisions about their care and, when they want to be treated as an equal partner alongside their healthcare team, they should be.

5.2 Patients should be able to access a multi-disciplinary team consisting of medical specialists, e.g. endocrinologist, cardiologist, gastroenterologist, gynaecologist and clinical psychologist, Allied Health Professionals (AHPs), e.g. physiotherapist, dietician and occupational therapist, and if appropriate palliative and end-of-life care professionals. Often, these healthcare professionals will be based outside of the transplant centre and the GP may be involved in referring the patient to their local hospital.\textsuperscript{16, 17}

5.3 In the event that a patient’s recovery is uncertain or their condition becomes palliative, Advanced Care Planning (ACP) should begin and this should be shared with the wider multi-disciplinary team.\textsuperscript{18} The patient should also be given the opportunity to discuss their Preferred Priorities of Care (PPC).\textsuperscript{19} If the patient dies, information on bereavement, including emotional and practical concerns, should be given to the family.

5.4 A patient may be referred to their GP for early treatment of cardiovascular risk factors, such as diabetes, high blood pressure and/or high cholesterol. Furthermore, and as described by 5.2, the GP may be involved in referring the patient to their local hospital, if this has been requested by their transplant centre. The GP may also signpost to the third sector.

5.5 As described by 1.3, the third sector can provide a wealth of information and support to patients (and their families) before, during and after SCT, such as peer support, financial advice and help getting back into day-to-day life, which may include managing work/education. Note that this is not limited to support

\textsuperscript{14} Ehrlich, K.B. et al. Pre-transplant emotional support is associated with longer survival after allogeneic hematopoietic stem cell transplantation. Bone Marrow Transplant. 2016;51(12): 1594-1598
\textsuperscript{19} National PCC Review Team. Preferred Priorities for Care, 2007.
returning to work/education, rather it extends to any ongoing issues that the patient may encounter and advice on changing careers, given that some jobs are no longer viable post-transplant.

Appendix 1. The 7th edition of the FACT-JACIE International Standards
The standards most relevant to post-transplant care are highlighted below. Comparing the 7th edition to the 6th edition, standards B7.8 and B7.12 are new.

B3.11 SUPPORT SERVICES STAFF

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 pediatric patients.

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

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