

Appendix 1

Cardiothoracic Transplant Patient Feedback

1. Introduction

1.1 To ensure that the CTPG is focusing on the key issues that have the greatest impact on the patient group a regular feedback form is completed for each meeting.

1.2 Support group leads are offered the opportunity to complete the form to inform this process

1.3 On this occasion 10 support groups have taken up this opportunity, as follows;

- Freeman Heart & Lung Transplant Café (professionally led, online meeting)
- Heart and Lung Transplant Patients Birmingham QEH (patient led, social media)
- QE Transplant Friends (patient led, social media)
- CAV Patient Interest Group (patient led, remote discussions)

- Wythenshawe Pre Transplant Heart & Lung Support Group (professionally led, online meeting)
- Royal Papworth Social & Support Group (patient led, social media)
- Pulmonary Fibrosis Transplant Patients Support Group (charity led, online meeting)
- Heart Transplant Families UK (patient led, social media)
- Zoom Hearts (patient led, online meeting)
- Harefield Transplant Club (patient led, in person, events and social media)

1.4 Combined the groups have an extensive depth across the patient community including traditionally hard to reach communities and their support with this piece of work is greatly appreciated.

2. Feedback

2.1 The feedback is extremely rich, and, in most cases, the same issues are being replicated across each group. The key purpose of this exercise is to distil the most frequently occurring issues.

2.2 The following boxes summarise the key themes and issues from the feedback received

Covid 19

Covid 19 continues to remain a significant factor in the physical and mental wellbeing of the transplant community. Feedback on the Covid 19 booster programs has been positive. There is a widespread lack of knowledge and concern among the transplant community of how to access treatment when testing positive for Covid 19. Experiences of receiving the appropriate treatment in a timely manner are variable and it is an ICS / nation lottery. The provision of information to the transplant community is very poor.

Transplant Centres

Feedback regarding the care and ongoing support from transplant centres is variable. Much, especially inpatient treatment is positive, however, some services do receive criticism. This is usually centre / organ specific. Across the whole community patients do find difficulty accessing advice from centres at the weekends. Concerns regarding communication from the transplant centres with other clinical teams are also not uncommon.

Post Transplant Life and Complications

Health and wellbeing post-transplant play a significant role in many patients' lives. Whilst patients are alive thanks to the transplant, life post-transplant is often medically challenging. Post transplant complications such as infection, acute rejection, CAV / CLAD, and the side effects of lifelong immunosuppression are commonplace and impact on morbidity and mortality.

Some patients experience long periods of wellbeing and have many significant post-transplant achievements.

Primary Care

There is continued concern about the ability to access General Practice. This includes concerns around the ability to access routine blood tests locally and the communication links between primary care and transplant centres.

Psychology Support

The psychological burden on the whole cardiothoracic transplant community is very high. Psychological issues associated with transplant at all stages of the pathway are widespread.

There is extremely positive feedback regarding the various support groups available, such as transplant cafés, social media groups and online peer to peer meetings. These provide an essential opportunity for patients to seek peer support and advice.

However, patients continue to report significant challenges with accessing specialist psychological support at most centres.

Pre-Transplant Waits and Mortality

Concerns around receiving a suitable organ before the point of terminal health deterioration or reaching an age restriction remain commonplace in the pre transplant community. This is a significant psychological burden on patients and their families.

Financial concerns / Cost of Living

Widespread financial and cost of living issues are being raised by patients. These encompass several areas such as access to benefits, prescription costs and the inability of many to work or work more than part time.

3. Summary and Recommendations

3.1 CTAG Hearts are asked to note the report.

3.2 From a reassuring perspective the October 2023 CTPG Agenda includes a number of these issues such as psychological support, Covid 19, social work provision, and a frequent post-transplant complication.