

5th May 2020**Heart transplantation during the COVID-19 pandemic**

Royal Papworth Hospital has continued to perform Super-Urgent and Urgent heart transplantation during the COVID-19 pandemic. We are planning to re-start non-urgent transplantation for patients stable on the waiting list at home. There has been a significant decrease in organ donation during the pandemic (approximately 80% lower) but donor numbers are now starting to increase. Nevertheless, the number of heart transplants is likely to remain lower than usual for the duration of the pandemic. Transplanting during the pandemic does create some additional risks that we want you to know about. It is hard to be completely accurate about these risks because we are still learning about the virus and how it affects people. It is likely that the increased risk to those receiving heart transplants will remain for many months.

As a patient with severe heart failure you are considered to be clinically vulnerable, meaning you are at higher risk of severe illness from coronavirus infection. You should minimise contact with others outside your household. If you develop symptoms consistent with COVID-19 then you should seek NHS 111 advice and obtain a nose and throat swab to see if you have contracted the virus. Those with a positive swab result would be suspended temporarily from the waiting list. Once you have recovered and are symptom-free for more than 28 days, you can be considered for re-activation on the list. You would need to have two negative nose and throat swabs taken at least 24 hours apart. This would provide reassurance that the infection has been cleared. The length of time suspended from the waiting list will be according to an assessment of each individual's circumstances.

When a potential donor heart becomes available, we will contact you by telephone. We will ask you about COVID-19 symptoms and whether you have had contact with any confirmed or suspected COVID-19 cases. We will ask about social distancing practices within your household. If we think that you might have

COVID-19, then we would not bring you into hospital for a heart transplant. This is because transplantation in a patient with COVID-19 is thought to carry a significant risk of early death.

If you are admitted to hospital for a heart transplant, then you will be asked once more about COVID-19 symptoms and you will be examined for signs of COVID-19. A number of tests will be performed, including a nose and throat swab for coronavirus, but this test result may not be available before we need to start the heart transplant. In line with national guidance, all potential donors are tested for coronavirus and must be negative before they can donate their organs. We believe these steps will minimise the risk that you already have coronavirus before your heart transplant and will also minimise the risk that you contract coronavirus from your donor. However, it is important to tell you that testing for coronavirus is not perfect. A small number of tests are 'false negative' and we can never be 100% certain that an individual is free of coronavirus infection. In addition, a small number of tests are 'false positive' and a patient with a positive test result may later turn out not to have been infected. It is reassuring that the UK has had no definite cases of COVID 19 in which the recipient of a transplant has caught coronavirus infection from their donor to date.

When you are admitted to Royal Papworth Hospital before your heart transplant, you will be given a single room and this will be on a ward without COVID-19 patients whenever possible. After the heart transplant, you will continue to be looked after in a single room, both on the Intensive Care Unit and then on the wards. In the longer term, we will maintain social distancing within the outpatient department. We follow strict infection control guidelines at all times, including use of personal protective equipment and shielding of vulnerable patients. We take the possibility of infection among members of staff very seriously. Any member of staff with symptoms must self-isolate at home and staff testing is increasing during the pandemic period. However, it is also possible that you might be looked after by a member of staff who has contracted the virus and is not showing any symptoms. Despite all our precautions, there is still a risk that you could catch coronavirus whilst in the hospital and it is important that we are honest with you about this.

During the pandemic we have all been advised to socially distance from each other to reduce the risk of transmitting the virus. That is difficult in hospital but is necessary to protect staff, carers and patients. Visitors will not be allowed during the hospital stay for your transplant. We understand this is distressing at a highly stressful time and we will do our best to make this tolerable using video conferencing. If you think this would make you want to delay your transplant then, it is important to discuss this with your family and

the transplant team when considering the balance of the various competing risks. After transplantation, you would be considered extremely vulnerable to COVID-19 disease and would be requested to 'shield'. This means you would be strongly advised to stay at home at all times and avoid any face-to-face contact to protect yourself. However, we still need to follow you very closely after transplant and you will still need to attend hospital regularly for face to face out-patient review, heart biopsies and other tests for at least the first 6 months after the transplant. There remains an increased risk of catching the virus whilst you are attending for your out-patient visit.

After heart transplantation we use medicines to stop the body rejecting the donor heart. This means that the body has a reduced immune system and you are more likely to be seriously ill with infections. We don't have much information about how unwell you might be if you did get COVID-19 after your transplant, particularly in the first few weeks and months. Only a few patients have developed COVID-19 within the first 6 months after heart transplantation, most have been several years after their operation. This limited experience suggests that most patients have survived with mild or moderate disease. However, some individuals may become seriously ill or even die from COVID-19. We may need to decrease the doses of the anti-rejection drugs but this has to be balanced with the risk of you developing rejection of the new heart.

We understand you may be concerned over the increase in risk of undertaking transplantation during the pandemic. However it is important to balance the risk of getting sicker and too high risk to transplant or even dying from your health problems if you decide to wait until the pandemic is over. We think it will be many months before the pandemic will allow us to return to a hospital environment without the risk of COVID-19 and we need to carefully balance those risks with you individually.

I understand the increased risk the COVID-19 pandemic might have and am happy to be active on the heart transplant waiting list during the COVID-19 pandemic.

Yes ☐ No ☐

(Signature)

Date

If you have any questions relating to these issues please discuss them further with the heart transplant team. There may also be other potential contraindications that we haven't considered in this document. Please feel free to raise them at any time.

SAMPLE