



What to Expect when you are Referred for a Transplant Assessment?

- Transplant assessment is a process which takes a number of months and for some of you it can be up to a year. This is because every person with congenital heart disease is different and the tests we need to do are sometimes complicated. Remember we are meeting you for the first time, and though your centre will have sent us lots of information, we often need to do more tests and also involve multiple different specialists in giving the best advice we can about your case.
- People are referred to us from all over the country and numbers of referrals are increasing. At the moment we are able to assess about two of you a week. Sometimes you may have a bit of a wait to get your initial assessment appointment. Please let your specialist nurse know if your wait is getting too long and she can contact us for further details.
- Transplant is one of the treatments we can consider when you are running into difficulties with your heart. We also consider whether mechanical support therapy (a device that can be implanted to help your heart pump), surgery or catheter treatment is an option or whether simply the best treatment is to continue with medication. Each of these treatments has its own advantages and disadvantages and we think about all of them when you come to be assessed. Your views and thoughts are very important. Sometimes these treatments are done to help you get a transplant and sometimes we think they are a better option for you.
- We think transplant is a good option in just under half of you who are referred for assessment. If you are listed, you will still be in for a long wait as we have to wait for suitable donor hearts to become available, if

we think you need an urgent transplant you would have to wait in hospital for this. If we think transplant is not a good option you may be offered one of the other treatment mentioned above.

- We recognise that this process is very difficult for individuals and their families, particularly because waiting for answers when you are not well is hard and also because heart transplant means someone else must die for the treatment to happen. Psychology assessment and support is a normal part of the assessment process for all adults with congenital hearts that we see and for some it may be important to start this before coming for assessment. Please talk to your specialist nurse about this.