The new National Liver Offering Scheme: Frequently Asked Questions



1	Who decides if I am eligible for a transplant?	As now, your family doctor or referring consultant will decide if a transplant will be of benefit to you. Priority is always given to those patients on the 'super urgent' list (this list is for very sick patients expected to die within days without a liver transplant).
2	What is the criteria for referral?	Most people who undergo liver transplant have a chronic liver disease which is limiting their life expectancy. Without a transplant they may only have a few years to live. Other patients have a very poor quality of life due to the symptoms of liver disease. For them the aim of the transplant is to restore their health and improve their quality of life. In this situation, liver transplant is offered only if all other forms of treatment have failed.*
3	What is the 'Transplant Benefit Score' (TBS)?	Before the new scheme was introduced, patients with a liver disease were assessed on their need for a liver transplant based on their UKELD score (United Kingdom Model for End Stage Liver Disease). Clinicians calculated this score by looking at 4 different patient characteristics from the liver patient.
		The new scheme is designed to be more in-depth and takes into account 7 characteristics from the donor; these donor characteristics are then 'matched' with 21 patient characteristics. The patient with the best match will be shown at the top of the list and will have the highest transplant benefit score.
		The TBS predicts which patient will benefit the most from the transplanted liver – who will live the longest with the transplant, but also who can survive the longest on the list without receiving a transplant and is, therefore, able to safely wait a while longer before being offered a liver transplant.
4	Are some livers 'better' than others?	Yes – those livers from brain stem dead donors have less damage than a liver from a donor following circulatory death and this is due to how the liver is retrieved; and obviously a liver from a young and previously fit donor with an isolated head injury will be a better liver than one retrieved from an elderly donor who smokes and who has diabetes.
5	Once I have been put on the liver transplant list, how long will I have to wait?	It's not possible to predict accurately how long you will need to wait for a transplant. Each case is different and the new scheme is designed to ensure that any liver that becomes available is matched to the best recipient depending on the Transplant Benefit Score. As stated above, priority is always given to those patients on the 'super urgent' list (this list is for very sick patients expected to die within days without a liver transplant).
6	Will the existing time that I have already been waiting on the list be transferred?	Yes, waiting time accrued on the current list will be carried over into the new scheme.

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7	Do I have a better chance of a liver transplant if I live in a particular area or am being seen at a particular hospital?	No, the new scheme is a national offer scheme. All patient data is held centrally and each time a liver becomes available the system generates a 'matching run'. The patient with the best match for the available liver will be offered the organ – regardless of location.
8	I am on the liver transplant list now, how will this new policy change affect me?	The change to the new scheme will be seamless for all patients; your transplant centre has already supplied the information needed to work out your TBS for any liver being offered for transplantation. Your centre will update your information any time there is a change in your circumstances, but must also do so every three months. Therefore, it is very important that you attend your clinics on a regular basis, so that your data is current and accurately reflects your condition.
9	How will the new scheme affect those with a variant syndrome?	The computer will produce a matching run for variant syndrome patients with a frequency based on the statistical incidence of patients registered as variant syndrome patients. This currently stands at 10% of patients on the transplant waiting list. Therefore, on average, around 10 in every 100 matching runs will be for variant syndrome patients. These recipients will be ranked in the offering sequence according to how long they have been registered on the waiting list.
10	How can you ensure a fair distribution of livers to all Centres?	The way the system works is not centre driven. The Transplant Benefit Score uses 7 characteristics from the donor; these donor characteristics are then 'matched' with 21 patient characteristics. The patient with the best match will be shown at the top of the list and will have the highest transplant benefit score, regardless of geographical location.
11	Will I know who my donor is?	Organ donation is confidential, so while you may be given some details about the person donating their organs you will not be given any identifiable information and you will not be told who they are. You may have different feelings about your transplant, from relief to fear. You may well feel sad for the person who has died and for their grieving family. It is important to remember that organ donation is something positive that can come out of what is otherwise a tragic event: this can bring a lot of comfort to the bereaved family.
		Whatever your thoughts are now, you may feel differently after your transplant. After your transplant you may wish to write to the donor's family. There is no rush to do this; in many ways it is better to wait until you are out of hospital and well on the road to recovery before you write. This also allows the family to come to terms with their loss and to grieve.*

^{*}Extract from Queen Elizabeth Hospital Birmingham Charity publication 'Liver Transplantation: What does it mean to me and my family?