What do I need to know about the Transplant Manitoba Deceased Donor Kidney Transplant Wait List?

What is the Transplant Manitoba Deceased Donor Kidney Transplant Wait List?

- The Transplant Manitoba Deceased Donor Kidney Transplant Wait List has the names of people in Manitoba who are waiting for a kidney transplant.
- People on this list do not have a live donor who can give them a kidney so they must wait for a
 deceased donor kidney.
- When a deceased donor kidney comes up for transplant it is given to someone on the list.

Who is on the Transplant Manitoba Deceased Donor Kidney Transplant Wait List?

Adults and children who:

- o Do not have a live donor
- Have had a completed transplant workup
- o Are safe to get a transplant
- Have agreed to get a deceased donor kidney



What does being "READY" on the Transplant Manitoba Deceased Donor Kidney Transplant Wait List mean?

- Being "Ready "on the wait list means you:
 - o Are safe to get a kidney transplant
 - o Have completed your workup
 - o Do not have a live donor to give you a transplant
 - Have agreed to a deceased donor kidney transplant

How are decisions made about who gets a deceased donor kidney from the list?

- The Kidney Doctors decide who gets a deceased donor kidney based on:
 - o The blood compatibility between the donor and the person getting the transplant
 - o The HLA or tissue match
 - The priority of the person getting the kidney. Some people on the list have more priority. Some examples are of people with a higher priority are:
 - Children up to the age of 19
 - Anyone who is running out of dialysis options, is medically unstable and will die without a transplant
 - Anyone who is hard to match because they are highly sensitized with antibodies

Who will call me for a kidney transplant?

When a kidney comes that is a blood compatible and HLA match, the Kidney Doctor will call you.

The doctor will ask you many questions including:

- If you have, or have had a recent infection
- If you are on any antibiotics
- If you are on dialysis and if there are any problems with your dialysis at present
- If you would like to take the kidney being offered
- Any questions you may have

What will the Kidney Doctor tell me about the donor and kidney?

- The doctor <u>can</u> review the blood type and HLA matching between you and the donor.
- The doctor <u>cannot</u> tell you who the kidney came from and why the person died. This information is confidential.
- Sometimes there is something unusual about the kidney or the donor. The doctor will explain what is unusual about the kidney or the donor. The doctor will explain if there are any risks to you in taking the kidney.

What will happen if I decide I don't want to take the kidney?

- You will stay "Ready" on the deceased donor list.
- You will wait for the next deceased donor kidney that is the best one for you.
- You do not lose your priority on the list if you decide not to take a kidney.



What should I do if I decide to take the kidney?

- DO NOT drink or eat anything until the doctor tells you it is OK.
- Go to the Children's Hospital as soon as possible.
 - o The transplant must happen with 24 hours.
 - o There are many tests and procedures to do for the surgery which take time so it is important to get to the hospital as fast as possible.
- Go directly to the ward CK5 –DO NOT STOP in emergency or admitting.
- Bring ALL of your medications with you to the hospital.
- If you are on peritoneal dialysis –bring your dialysis machine with you.
- Bring your Manitoba (or other provincial) health card with you.

What does it mean when my name is on "hold" on the list?

- Being on "hold" on the list means it is not safe for you to get a kidney.
- The Pediatric transplant team will talk to you about the reason you are on hold
- Some of the reasons to be on hold include:
 - Serious illness
 - o Infection
 - o Non-adherence -which means you are not able to stick to your health care plan
- Being on hold is usually temporary. Once it is safe for you to get a transplant your name will be put "ready" on the list

When will I get a call for a kidney transplant?

- You can get a call at any time.
- There is no way to predict when you will be called for a transplant.
- It is important to keep your contact information up to date with the transplant coordinator so if a call for a transplant comes, we can reach you.
- If we cannot reach you within a reasonable time frame, the kidney will be offered to someone else.

Remember you can get a call anytime of the day or night so keep your contact information up to date with your Transplant Coordinator.

What happens if I want to go on vacation?

- Everyone deserves a vacation but some vacation spots may be too far for you to get back to the hospital in time for a transplant.
- Talk about your plans with your transplant coordinator.
- If your vacation is too far away, we can temporarily put your name on hold until you came back.
- You will be put ready again as soon as you are back.
- You do not lose your priority on the list.

We are here to help!

If you have any questions about this information call the Pediatric Kidney Transplant Coordinator at 204-787-4842 OR Toll free at 1-877-499-8774—extension 74947

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Visit the Transplant Manitoba website to read more about kidney allocation in Manitoba: www.transplantmanitoba.ca

