

Presentation Day 2

Planning (long-term and short-term) for Kidney Transplant and Living Your Best Life Possible After Kidney Transplant

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Thanks to previous research, new medications and therapies, people living with cystinosis are living much healthier lives and may not need to deal with kidney failure, dialysis or transplant until their late teenage years and even young adulthood. But sooner or later, for most of these people, treatment of kidney failure is expected. It is empowering to be able to trend the progression of your kidney function to be able to make short and long-term plans about the need for a plan for managing kidney failure. The optimum management is a "preemptive" kidney transplant, where you have enough waiting time to get a deceased donor kidney or you have a living donor worked up and "ready to go" With planning, when your kidney function numbers go below a certain threshold or you are having symptoms you can move on to transplantation quickly. Unfortunately waiting lists are long, and many people may not have a living donor who is healthy enough to donate a kidney, so dialysis options may need to be considered in this planning.

In the United States, the average kidney transplant from a deceased donor functions around 11 or 12 years with the average kidney transplant from a living donor functioning 19 years. This means that most young people who receive a kidney transplant will need more than one in their lifetime. Keeping track of indicators of kidney function will help you keep an eye on this so it is not a surprise, and you can make plans as a young or older adult. There are lifestyle choices and food choices that directly affect how well and how long your transplanted kidney will work. There are choices that affect the kind of dialysis you can receive. We hope that by the time you need a 2nd kidney transplant, research will have advanced to the point where kidneys may be grown in the lab, or in genetically engineered pigs.

There are many myths about what you can or can't do while you live with the kidney transplant and there are other choices you can make to keep yourself as healthy as possible. Some of these will be discussed.

If we have time, I hope we will be able to touch on the planning that is required for a woman living with the kidney transplant to be able to have children safely for both herself and her unborn child.