Information regarding kidney disease and organ donation

My family suffers from autosomal dominant polycystic kidney disease (ADPDK), a progressive disease caused by a genetic mutation that eventually leads to kidney failure. My mother and both my older sisters died of chronic kidney disease quite young; a cousin and a nephew have already succumbed; another cousin and two of my nephews have also been diagnosed and are making plans for kidney transplants.

The main job of kidneys is to cleanse blood of toxins and transform the waste into urine. Kidney function is measured by eGFR (estimated glomerular filtration rate) — the rate at which one's kidneys filter toxins from the body. There are five stages. A GFR of 60[1] or higher is in the normal range. The next three stages (GFR 59–45; 44–30; 29–15) represent declining to severe reduction in kidney function. A GFR of 15 or lower is classified as end stage kidney disease (ESKD), i.e., kidney failure. For the past four years my eGFR has been in the "severe reduction" stage (GFR of between 22 and 15). In November 2022 my GFR dropped to 13, and my nephrologist counselled me in preparation for beginning dialysis, a necessary medical intervention for survival in the absence of kidney function.

With hemodialysis, the treatment for approx. 90% of patients with kidney failure, a machine continuously removes blood from the body for between 3 to 5 hours, filters it through a dialyzer (artificial kidney) and returns the cleansed blood to the body. The process takes place in a hospital three times a week. Generally, one is physically drained after the procedure and returns home to rest. A related treatment, peritoneal dialysis, involves surgical insertion of a catheter in the peritoneal cavity (the abdomen) which is filled with a dialysate into which extra fluid and waste products are drawn. Neither process delivers even 20% of the benefits of real kidney function.

The major disruption to leading a normal life is only the most apparent consequence of dialysis. In addition, life expectancy on dialysis is seriously impacted. After one year of treatment, those on dialysis have a 15–20% mortality rate; survival rate for 5 years is less than 50%. Side effects, among others, include hypotension (nausea and dizziness), sepsis (blood poisoning) and, in the case of peritoneal dialysis, peritonitis (bacterial infections).

Since the 1950s and particularly in the past 40 years, kidney transplants offer an alternative to the life-altering and negative consequences of dialysis. Since one healthy kidney provides all the functionality a person needs, a successful transplant largely restores a patient to a normal and otherwise healthy renal state.[2] A recent study of data on ESKD patients in the US, UK and Canada concluded that the life expectancy of transplant recipients is more than twice that of dialysis patients.

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[1] Specifically, 60 l/min/1.73 m^2.

[2] See description on Israel Ministry of Health website, השתלת כליה: כמו אדם בריא, https://www.gov.il/he/departments/guides/organ-transplant?chapterIndex=3.
As aptly put by one transplant recipient, "I know that dialysis keeps you alive, but a kidney lets you live."

In 95% of cases of live kidney donation, removal of the donated organ is accomplished by minimally invasive laparoscopic or keyhole surgery.[3] The surgery is performed under general anesthetic and is generally followed by a 2-day hospital recovery stay. After a short period of recuperation, the donor leads a completely normal (pre-surgical) life. A 20-year Mayo Clinic study of more than 3,000 living kidney donors concluded that "the risk of major complications for people who donate a kidney via laparoscopic surgery is minimal. … Only 2.5% of patients in the study experienced major complications [infection or hernia related to the incision], and all recovered completely."[4] The advantages of receiving a kidney from a living donor over a deceased donor are significant, in particular a much lower rate of rejection (live donor kidneys work right away in about 95% of cases) and a considerably longer life expectancy of the recipient (anywhere from 15–20 years to, in some instances, decades).

The need to do direct outreach for altruistic (voluntary) donors is dictated by the fact that the number of patients far exceeds current availability of organs from living or deceased donors. There are approximately 850 or more people in need of kidney transplants in Israel, and the waiting time is typically 2 years or longer.

All costs associated with kidney donation by Israeli citizens are covered by Israel's national health insurance. Donors also are entitled to a basket of post-surgical compensation and reimbursements, including among others: compensation for lost workdays (minimum 8,381 NIS; maximum 61,628 NIS); travel expenses (flat payment of NIS 2,724); reimbursement for purchase of various forms of supplemental insurance; 3-year exemption for paying national health tax; etc.[5]

My father z"l (whom I take after in most respects other than the offending organ) lived to the ripe age of 92. As I am otherwise in good health and my nephrologist believes me to be a strong candidate for this procedure, a transplant would endow me with a good number of additional years. I am hopeful that my appeal will generate interest and potential donors.

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[3] A very detailed description at: https://www.mayoclinic.org/tests-procedures/donor-nephrectomy/about/pac-20384867.

[4] https://newsnetwork.mayoclinic.org/discussion/mayo-clinic-study-confirms-living-kidney-donor-surgery-is-low-risk-for-most-patients/?fbclid=IwAR35fHlsP2327WBqYKKf2kaWfXREcLHuuWwVqC_tzlnENijcJi8o6F0UEo4.

[5] Amounts are as of December 2019; statutory list of benefits (without current amounts) listed here: https://www.gov.il/BlobFolder/legalinfo/hashtala02/he/files_legislation_hashtala_Hashtala_02.pdf