

Information for the kidney live donor concerning the long-term risk of donor nephrectomy

Introduction: The informed consent is meant to help the donor in understanding all aspects of living kidney donation, including the fact that the donor's decision to proceed to donation must be autonomous, that the donor has the freedom to withdraw consent at any time, and that the process of donor assessment is confidential. The donor must also be fully informed of the expected outcomes for the recipient, of the pros and cons of alternatives (e.g. dialysis, deceased donor transplantation), of the surgical procedure and the perioperative complications of donor nephrectomy, of the recovery period, and of any potential financial consequence. Below we limit our focus on how to summarize in an accessible way the best current knowledge regarding **long-term risks** of living kidney donation. We do not provide handouts or electronic informative material based on the text below, but we encourage each Transplant Center to use any practical tool that might assist the donor to grasp all the required information.

Informed consent on long-term risk.

- *Donor nephrectomy may carry an increased risk of long-term health consequences, the most common being mild increases of arterial blood pressure, and minor laboratory manifestations of decreased renal function. However, in rare instances, donor nephrectomy may minimally increase your long-term (i.e. decades after donation) risk of dialysis, or even death.*
- *It is likely that you will not encounter any of the severe consequences, as they affect only a strict minority of donors. For instance, the probability that donor nephrectomy will eventually cause you ending up with dialysis is usually less than one in 100. This risk may vary (i.e. be higher or lower) depending of your individual characteristics, such as age, blood pressure, renal function, and of other known, unknown or unpredictable factors. As opposed to the risk of dialysis, the long-term risk of death is more difficult to quantify. In this regard, you should be aware that there is one recent study performed in the Norwegian population, which found an increased risk of death 15 to 25 years after donation (up to 3-5%), but most transplant professionals, including ourselves, have questioned the validity of the findings from this study. Overall, your risk for dialysis and death seems to be lower than in the general population, because you are healthier compared to the general population. But compared to a very healthy population your risks may be increased.*
- *Rather, if you will, you may check what is your intrinsic individual risk of dialysis based on your own characteristics, using the calculator available on the Web at www.transplantmodels.com/esrdrisk.*
- *Note that you have to multiply this figure by 3 to 5 times to get a rough estimate of how your risk increases 15 years after donor nephrectomy. Even after this correction, you will realize that your final risk of dialysis may remain as low as a fraction of 1 percent.*
- *However, you should take into account that the longer the time you want to foresee the higher the level of uncertainty of the calculator prediction. For instance, lifetime predictions are more uncertain if you are very young (e.g. below 25 to 35 years) rather than if your age is, say, above 50. This problem might be more relevant if you are a very young donor and also have a family history of renal disease and/or of diabetes, rather than if you are very young but you do not have a close relative (e.g. brother, sister) suffering from renal diseases or diabetes.*

- *Regardless of the extent of your individual risk, both before and after donation you should make sure that your lifestyle habits are optimized. For instance, if you are a smoker, you should quit. Post-donation, you should also engage in regular physical activity, and avoid being overweight. You also need to undergo regular follow-up in an outpatient clinic (e.g. yearly visits at the Hospital of your Transplant Center) because, if you happens to develop in the course of your life, as any other non-donating subject can do, risk factors such as hypertension, loss of protein in the urine, overweight, and mild increase in fasting blood glucose levels, detection and early intervention on these factors can largely prevent the long-term risks outlined above.*
- *If you are a woman in childbearing age, and you want to have children post-donation, you should know that donor-nephrectomy somewhat increases the risk of preeclampsia and gestational hypertension. The risk increases in small amount: donor nephrectomy might cause your individual risk, which is currently lower than the risk of an average woman (due to the fact that you are very healthy!), become more similar to the risk of an average woman. It is however also important to know that preeclampsia and gestational hypertension can be treated, without significantly increasing the risk of any adverse pregnancy outcome, such as such as caesarean section, postpartum hemorrhage, preterm birth, low birth weight, stillbirth, maternal or neonatal death.*