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# Living Anonymous Renal Donors Do Not Regret: Intermediate and Long-Term Follow-Up with a Focus on Motives and Psychosocial Outcomes

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Study Design A
Data Collection B
Statistical Analysis C
Data Interpretation D
Manuscript Preparation E
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**Background:** Living anonymous donation (LAD) of kidneys was introduced in Sweden in 2004. This study reports on outcomes of Swedish LAD experiences from 2004 to 2016, focusing on donors' motives, the care they received, psychosocial aspects, and medical status at follow-up.

**Material/Methods:** Donor data were collected through a physician interview, medical check-up, review of medical charts, the Hospital Anxiety Depression Scale (HADS), and a routine national questionnaire. Of the 26 LADs during the study period, 1 donor died and 1 declined to participate, leaving a study population of 24.

**Results:** Half of the donors were male, which is a higher proportion than for directed living donors. The major motive detected was altruism. Of the 24 LADs, 96% were very satisfied and would donate again if possible, 46% noted increased self-esteem, and a third were happier after the donation. Sixty-two percent received anonymous information about the recipient and 40% would have liked to meet the recipient. HADS scores were normal. Two donors had antidepressant treatment, 1 of whom had received treatment before donation. Half mentioned that the pre-donation assessment took too long. At follow-up, mean eGFR was 62±12 mL/min/1.73 $m^2$, of which 16 were in CKD II and 8 were in CKD III. Four donors had developed hypertension, 1 of whom also developed type 2 diabetes.

**Conclusions:** Swedish LADs are very satisfied and medical outcomes are acceptable. We propose that the transplant community and the National Board of Health and Welfare take a more active approach to informing the general public about LAD.

**MeSH Keywords:** **Altruism • Kidney Transplantation • Living Donors**

**Abbreviations:** **eGFR** – estimated glomerular filtration rate; **ESRD** – end-stage renal disease; **HADS** – Health Anxiety Depression Scale; **LAD** – living anonymous donor/donation; **LD** – living donor; **OGTT** – oral glucose tolerance test

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## Background

Kidneys from living donors (LDs) have been of great importance for the treatment of end-stage renal disease (ESRD) ever since transplantation of kidneys began in Sweden in 1964. Graft survival and patient survival are better compared with kidney transplants from deceased donors [1,2]. Since 1988, living unrelated kidney donors have been accepted in Sweden, and spouse-to-spouse kidney donation has been a major success [3] and has opened the way for other unrelated donors such as friends or co-workers [4,5]. Living kidney donation is an elective surgical procedure with a low risk for complications, with a mortality rate of 0.03% and surgical complications (mostly minor) rate of <10% [6,7].

Occasionally, people have contacted healthcare facilities to ask if they can donate a kidney even though they have no relative or close friend in need of a kidney transplant. They want to donate to anyone waiting for a kidney. Healthcare in Sweden has, historically, not been set up to receive these offers. Abroad, kidney donations from the first living anonymous donors (LADs) were accepted at the end of the 1990s in Minneapolis, USA. In 2004, they reported on a series of 22 donors who had undergone donor surgery, predominantly middle-aged white men motivated mainly by a sense of duty [8]. LADs are also known as non-directed, anonymous, unspecified, Good Samaritan, or altruistic donors.

In Sweden, non-directed LD began in 2004. An individual had called the National Board of Health and Welfare stating willingness to donate a kidney. At a meeting with representatives from all of Sweden's transplant centers (Uppsala, Malmö, Gothenburg, and Stockholm), a decision was taken to accept LADs and no changes in legal requirements were needed to do this. According to our joint definition, LAD involves a donor who does not know the kidney recipient, where the donation is non-directed, and where donor and recipient are not allowed to meet unless both parties agree to do so (at the earliest, 6 months after surgery). The person who made this phone call became the first LAD in Sweden, and the first experiences of LAD in Sweden were published in 2008 [9].

The investigations and work-up for LAD follow the Swedish guidelines for live kidney donation (available online at: *https://svensktransplantationsforening.se*), with the addition of a compulsory psychological assessment. In Sweden, an independent living donor advocate is not required.

In the case of anonymous donation, the transplant team selects the recipient. The physicians assessing the donor are not involved in the selection of a recipient. All donors are given information regarding long- and short-term risks, give informed consent before the donation, and are told that the recipient shall remain anonymous. The recipient must be approved and on the waiting list for a kidney transplant from a deceased donor when there is no LD available. The recipients in the present study were chosen according to local principles after crossmatch and tissue typing. Recipients with special circumstances and significant additional needs such as access problems, young age or long expected graft survival, and/or a very well-matched kidney were given priority. All of the centers involved agreed that recipients and donors were not to meet before or in connection with the donation. LADs therefore received surgical care in another department or at another hospital.

The present study looks at the LAD experience in Sweden from 2004 to 2016. The focus of the study is to characterize who the donors were and what their motives were. We further report on the donors' own experiences: the care they received, their view of the anonymity requirement, and their psychosocial and medical status at follow-up.

## Material and Methods

### Study population

All LADs received written information about the study and, after giving their consent, were called to an interview at the respective transplantation center or regional hospital where they were originally investigated. One donor had died due to a non-donation-related cause (malignancy), and 1 donor did not want to participate, leaving a study population at follow-up of 24.

The donors were interviewed by a physician and data were collected from their local pre- and post-donation follow-up medical charts. They also completed a questionnaire and the Hospital Anxiety Depression Scale (HADS) [10,11]. The HADS is a self-reported rating scale designed to measure anxiety and depression. It is a widely used instrument, has been tested for validity, and contains a total of 14 questions (7 on anxiety and 7 on depression), with a maximum score of 21. A score of 8–10 indicates possible anxiety or depression, and a score of 11 and above is regarded as indicating probable anxiety or depression. In connection with the introduction of LAD in Sweden in 2004, a national questionnaire was designed by members of the Swedish Transplantation Society and is routinely sent to anonymous donors approximately 6 months after the donation as part of the routine follow-up. This questionnaire has not been psychometrically validated. Donor renal function at follow-up was calculated according to the cystatin-C- and s-creatinine-based Lund-Malmö method as described by Nyman et al. [12].





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**Table 1.** Donor characteristics pre-donation (n=26) and at follow-up (n=24) expressed as absolute numbers, mean with standard deviation, and range.

| | | n | Mean | Range |
|---|---|---|---|---|
| Pre-donation | Gender (Male/Female) | 13/13 | | |
| | Age (years) | 26 | 42±13 | 25–69 |
| | eGFR (mL/min/1.73 m$^2$) | | 101±14 | 86–131 |
| | Blood pressure (mmHg) | | 121±12/74±8 | |
| Follow up | Age (years) | 24 | 48±13 | 31–79 |
| | Creatinine (µmol/L) | | 107±23 | 62–162 |
| | eGFR (mL/min/1.73 m$^2$) | | 62±12 | 35–68 |
| | Blood pressure (mmHg) | | 123±12/77±7 | |

### Statistical methods

Demographics and data are presented in absolute numbers, means (or median when more appropriate) ±SD, range, and/or percentages.

### Ethics committee

The study was approved by the Regional Ethics Committee, registration no. 2016/26-31/4, at the Karolinska Institute, Stockholm, Sweden.

## Results

### Donor characteristics pre-donation

During the study period (2004–2016) there were 26 LAD operations performed in Sweden (12 in Stockholm, 6 in Uppsala, 5 in Gothenburg, and 3 in Malmö). The male-female gender distribution was equal, with 13 men and 13 women. The mean age was 42±13 years (range 25–69), with 4 donors over 60 years old. At follow-up, the mean age was 48±13 years (range 31–79).

All donors had good renal function prior to donation, as measured with Iohexol or Chrom-EDTA clearance corrected for body surface area, with a mean of 101±14 mL/min/1.73 m$^2$ (range 86–131). Mean systolic blood pressure before donation was 121±12 mmHg and mean diastolic pressure was 74±8 mmHg. There was no albuminuria or other pathological findings contraindicating kidney donation (Table 1).

Most LADs had donated blood or other tissues before. Sixteen were current blood donors and 4 former blood donors no longer permitted to give blood due to age, previous malaria, or low body weight. Five donors gave plasma, 6 were registered with the Swedish national registry for donors of bone marrow, 1 was a sperm donor, and 1 was an egg donor. Their occupations and areas of work varied: healthcare (6), social work (2), business (3), education (1), service staff (6), lawyer (2), student (1), technical work (4) and unspecified (1).

All donors underwent an assessment by a psychiatrist or a psychologist prior to donation. The psychiatric assessment was in accordance with local routines supplemented with different psychological tests for personality disorder. Three donors underwent mental health testing with the Global Assessment of Functioning (GAF) instrument. The scores were normal in all cases: 85, 85, and 92 points, respectively. The scale ranges from 0 to 100, with 100–91 considered as "superior functioning" and 90–81 as "absent or minimal symptoms". Five also took the Psychological General Well-Being Index (PGWB) test, all scoring in the normal range (above 100). One of these patients also took the Drug Use Disorders Identification Test (DUDIT) and the Alcohol Use Disorders Identification Test (AUDIT), neither of which showed any signs of drug/alcohol abuse. Donor medical history included traumatic experiences (1), addiction (1), depression (3), and post-traumatic stress (1), but no absolute contraindications to donation were found. However, 3 donors were identified as potentially psychologically/emotionally vulnerable and increased observation was recommended post-donation.

### The motivation to donate

Quotes from the donors' responses to the question about their decision and motivation to donate are shown in Table 2. The predominating motivation for LADs was a strong desire to help and the will to do good. Other motives for donating a kidney generally had to do with something that had inspired them, like a radio or TV broadcast, newspaper article, or personal experience. Donors' reasons included knowing or knowing of a transplant recipient who felt great, examples of successful kidney or heart transplants, recognizing that some people have a poor quality of life and die waiting for organs, or knowing of a father who had





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**Table 2.** Quotations from donor responses to the question on decision and motivation to donate.

| | |
|---|---|
| A | Ethical, love for others, self-realization |
| B | A long process. Took 10 years. In 2002, I read an article about many people who die while waiting for a kidney |
| C | To help someone sick |
| D | Why not donate at 65+? A good friend's son received a heart transplant in 1984 |
| E | To do good. For me – a short period of suffering, for the recipient – a long period of relief and better quality of life |
| F | Father-in-law had a kidney transplant; saw that he felt so good |
| G | I am healthy, to do something good |
| H | To help save lives without getting hurt |
| I | To live a secure life, based in Christianity, to do good, everything will be alright |
| J | Nondescript will, inspired by a radio program |
| K | An accident in 2000, now want to help another with serious illness to live a normal life |
| L | Can live well with one kidney. Someone needs the other one more |
| M | Have been thinking of this since the age of 15. To give without getting anything in return. Happy to donate, would also like to donate a liver lobe |
| N | Met those who are unwell and need a transplant |
| O | An accident, want to give back. A relative of boyfriend at the time had kidney failure, been thinking of it for several years |
| P | To help another person |
| Q | I am healthy, to do something for fellow human to have a better life |
| R | A blood donor, am registered in the Tobias Registry (for bone marrow donation), want to help someone |
| S | Hard to see others suffering without doing something |
| T | Want to help someone have a better life |
| U | To help someone sick who really needs help |
| V | Want to give another person a better life |
| W | To help a relative have a better life |
| X | A sick relative who passed away |

donated a liver lobe. Two of the LADs had been involved in major accidents and received life-saving care and felt that they wanted to "give back" to society and the healthcare system (Figure 1).

With a response rate of 24 (100%, corresponding to 92% of all LADs), the questionnaire shows that almost all of the respondents (96%) were happy to have donated and could imagine doing it again if it were possible (Table 3). It was not as obvious, however, that they would recommend donation to others. As one donor put it, "it has to come from within." Most of the donors (83%) received emotional support from relatives after the donation. About half reported an increase in self-esteem, and one-third stated that they were happier after the donation.

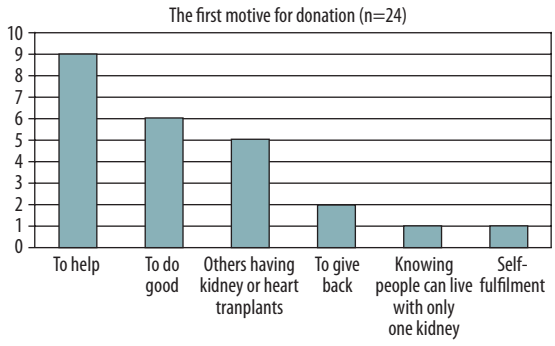


**Figure 1.** Motives for donating as stated in questionnaires completed by LADs (n= 24). If several motives were given, the first was chosen.

**Questions related to the pre-operative assessments, donor surgery, and the recipient**

Whether they would like to meet the recipient was a difficult question for donors. About one-third of the donors stated





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**Table 3.** Summary of the answers in the routine questionnaire sent out approximately 6 months after donation.

| | Yes | No | Don't know |
|---|---|---|---|
| If it were possible, would you donate a kidney anonymously again? | 23 (96%) | 0 | 1 (4%) |
| Would you recommend others to donate a kidney anonymously? | 17 (71%) | 5 (21%) | 2 (8%) |
| Do you feel that you have received support from your relatives after the kidney donation itself, i.e. during the recovery phase? | 20 (83%) | 2 (8%) | 2 (8%) |
| Have you experienced that your decision to anonymously donate a kidney has been challenged? | 3 (13%) | 20 (83%) | 1 (4%) |
| Do you feel that your mental mood as a whole was improved by kidney donation? | 9 (38%) | 14 (58%) | 1 (4%) |
| Do you feel that your self-esteem was improved by kidney donation? | 11 (46%) | 13 (54%) | 0 |
| Would you like information about the person who received your kidney? | 17 (71%) | 6 (25%) | 1 (4%) |
| If it had been possible, would you like to have had contact with the person who received your kidney? | 10 (42%) | 8 (33%) | 6 (25%) |
| If it had been possible, would you have wanted to influence who got your kidney? | 4 (17%) | 20 (83%) | 0 |
| Assuming you had a relative that needed a kidney, would you rather donate your kidney to this person than to an unknown person? (n=23) | 11 (46%) | 5 (21%) | 7 (29%) |
| Was the entire process as you had imagined? | 7 (29%) | 14 (58%) | 3 (13%) |

a clear "No" and expressed that it was "Nice not to know anything about the recipient" (Table 3). Those who did want to meet or know more about the recipient were less specific in their answers. At the time of the interview, some had changed their minds and were no longer interested in meeting the recipient.

Most LADs (83%) did not wish to have an influence on the choice of recipient (Table 3), but, if it had been needed, about half would have preferred to give their kidney to a relative. In response to the question regarding the assessment, surgery, and aftercare, a majority (58%) stated that it had not turned out as they had expected. Eleven of the LADs (46%) felt that the investigation time was too long. The mean time from the first assessment visit until the day of surgery was 15±5.8 months (range 7–26 months) with no trend toward longer or shorter assessment times observed over the study period.

**Surgical procedure and post-operative time**

Three donors underwent open nephrectomy and 23 underwent laparoscopic surgery, 1 of which was converted to open surgery due to intra-operative bleeding. The complications encountered were: bleeding (3), infection (wound infection and pneumonia) (2), more pain than expected (4), and transient muscle weakness (1). Hospital stays ranged from 4 to 14 days, with a median of 7 days, and sick leave (including part-time sick leave) ranged from 0 to 20 weeks, with a median of 8 weeks.

After the operation, but still in connection with the hospital stay, 15 (62%) had received, via medical staff, some anonymous information about the kidney recipient. The information given was sparse and limited mainly to the recipient's gender and age group, and how the transplanted kidney was functioning. Some LADS did receive an anonymous "thank you" from the recipient early after the operation, in the form of a letter, flowers, or a small gift. Some of the others noted that they would have liked to. At follow-up, 17 of the donors felt that they had left the donation behind them and no longer thought about it, but 8 still wished to meet the recipient.

**Post-donation medical check-ups**

In accordance with established routines, regular check-ups of living donors are performed at the renal clinic where the donors are first assessed. These check-ups are free of charge. All of the LADs in the study had been to check-ups, but not always regularly. The mean systolic blood pressure for the donors was 123±12 mmHg and the mean diastolic pressure 77±7 mmHg (n=24). Four donors were treated for high blood pressure. In addition to hypertension, one of the donors also developed type 2 diabetes.





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The donors' renal function showed a mean serum creatinine at the last follow-up of 107±23 μmol/L (range 62–162), and the mean estimated GFR according to the Lund-Malmö equation was 62±12 mL/min/1.73 $m^2$ (range 35–68). A total of 16 LADs were classified as CKD stage II and 8 were CKD stage III.

The response rate for the HADS survey was 21/24. The median score for anxiety was 2 (range 0–6) and the median score for depression was 1 (range 0–6). Thus, none showed signs of current anxiety or depression. One donor, previously healthy, did receive treatment for depression but stated that it was not related to the donation. Concerning the patients with a medical history, the one with post-traumatic stress experienced a relapse, but also stated that this was not related to the donation. The others did not differ in outcomes and did not have any relapse of depression or addiction. Two of the 3 donors identified as vulnerable had a bit more complicated post-operative course. One experienced pain in the wound that lasted 3 months, subsequently developed fibromyalgia, and is under the care of the pain management clinic. He also had psychosocial problems at work and with family, for which he received consultation with social workers for 2.5 years. In addition, he was also unhappy with the cosmetic result of the scar. The second patient developed a wound infection post-operatively, which was drained and treated with antibiotics and painkiller. A CT scan of the abdomen was normal and he subsequently recovered but was also not satisfied with the scar. The third patient developed a hematoma, but recovered fully after 2 months. He had a period of alcohol abuse in his medical history, but had no relapse and continued to attend Alcoholics Anonymous. He has also offered to be an anonymous liver donor, but this request has been declined. None developed drug addiction or alcohol problems. All donors were either working or retired due to age.

## Discussion

This study summarizes the experience of the 26 living anonymous kidney donations (LADs) performed in Sweden from its inception in 2004 until 2016. During that period, a total of 1942 living donor kidney transplantations were performed. LADs thus constitute a very small fraction (1.3%) of all of the country's living kidney donations. In Sweden there are no activities to promote LAD. The fact that 96% of the LADs in our study were "very satisfied" with their kidney donation experience and would donate a kidney again if it were possible could possibly be an incentive for a more active approach.

It was striking that most of the LADs had earlier also donated blood or other tissues. This was also noted in a UK survey [13] of non-directed kidney donors, with most stating altruism was the main motive. As in the UK study, gender distribution among Swedish LADs was equal. However, the present study was too small to draw any definitive conclusions about the gender distribution of LADs in Sweden. Among Swedish living kidney donors in general, approximately 60% are women [14–16]. One study from Minneapolis and another from the Netherlands showed a predominance of men among LAD donors [8,17].

The most common complaint from donors in the present study was that the pre-operative assessment took too long. Many of the donors had been thinking about donating anonymously for several years. Once they made their decision, they expected the donation to take place within a short time, but the median investigation time was 15 months. Some donors expressed that the lengthy assessment time gave them time to consolidate their decision to donate.

During the follow-up, 1 person developed depression and 1 had a relapse of a psychiatric disorder. According to a major US survey, the RELIVE study, 9% of live renal and pulmonary donors report poor psychosocial outcomes [18]. This was associated with: fair or poor overall donor experience, increased financial burden, regret or discomfort with the decision to donate, or psychological difficulties since donation. Recipient graft failure was the only predictor for reporting 1 or more of these poor psychosocial outcomes [18]. In our study, donors have not met or received ongoing information about the recipient. They therefore have sparse knowledge of the recipient's outcome. Although all LADs agreed to anonymity before the nephrectomy, some expressed a wish to meet the recipient. Arguments for maintaining anonymity throughout the process include the allocation being fair, avoiding commercialization, protecting altruism, and protecting the privacy of both parties [16]. In Sweden, all kidney donors are entitled to full compensation for expenses and lost earnings associated with the donation process. With respect to financial compensation, most were satisfied, although some complained that the reimbursement process was complicated and time-consuming.

Six donors had a psychiatric history and 3 were identified as potentially psychologically/emotionally vulnerable. One of the donors with a psychiatric history of post-traumatic stress experienced a relapse, but stated that this was not related to the donation. The rest did well. The potentially vulnerable donors, however, had a more complicated post-operative course. Without any obvious causal relationship, 1 developed wound infection and 1 had a hematoma. The third developed fibromyalgia at a later stage. Two of the 3 were unhappy with the cosmetic result. This indicates that this category of donors might be better advised to direct their altruistic endeavors to other activities that do not include surgical procedures.

The incidence of surgical complications in our study was a bit higher than expected. In larger living-donor studies, surgical complication rates range from 0.4% to 2% [7]. From Oslo, Mjoen et al.





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report a reoperation rate of up to 2.9%, depending on surgical technique [19]. Other surgical complications, including blood transfusion, urinary tract infection, pneumonia, pulmonary embolism, thrombosis, scrotum swelling, and paresthesia due to positioning on the operating table, range from 1% to 20% [20,21]. Some donors who were treated post-operatively in non-transplant departments stated that they did not feel satisfied with the post-operative care and that they had limited contact with doctors specializing in their nephrectomy. Discussion is therefore warranted regarding whether donors should be treated in departments less experienced in kidney donor care.

Length of hospital stays and sick leave seem to be similar to that seen after directed donation in Sweden (unpublished data). Regarding hospital stays, it should be noted that the donors were permitted to stay as long as they wanted. Sweden's welfare/health care system is generous in this respect.

All of the donors in our study had check-ups with a physician or nurse, measurement of blood pressure, and blood and urine tests. In Sweden, where 50–82% of kidney donors attend regular check-ups and have long-term follow-up, hypertension has been observed in about half of donors, and the blood pressure of half of those hypertensive donors is not optimally treated [15,22,23]. Among the LADs, hypertension was discovered during follow-up in 4 out of 24 (17%) patients. All of the donors, including the 4 treated for hypertension, showed normal blood pressure by the final follow-up.

LAD is more common in the Netherlands and the United Kingdom, where using LADs in kidney donation chains has further increased the number of living donor kidney transplants [17,24]. A corresponding program with the Scandiatransplant Kidney Exchange Programme (STEP) is under development in Scandinavia. LADs have not only been inspired by patients with ESRD, friends, or neighbors, but primarily by the media, and call for more information about LAD from healthcare authorities.

## Conclusions

In summary, this study shows that 96% of the LADs were very satisfied, and, if it were possible, they would donate a kidney again. Several pointed out that it is the best thing they have ever done. Many donors stated that the time required for pre-operative investigations and assessment was too long. In addition, their experiences indicate that some aspects of the post-operative kidney donor could be improved upon. LADs are a significant addition to the living kidney donor pool, especially with the development of kidney exchange programs, which is important because live donor rates are falling both in Sweden and in other countries with long-standing living kidney donor programs

We conclude that, overall, the LADs were very satisfied, but that potential donors with a psychiatric history or who are considered emotionally vulnerable could be at increased risk of unfavorable outcomes and should be counseled accordingly. We also suggest that Sweden's transplant community and the National Board of Health and Welfare could take a more active approach to informing the general public about LAD.

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**Conflict of interest**

None.

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