

# Living Organ Donation

Guidebook





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## Introduction

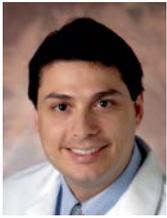
The AdventHealth Transplant Institute was founded in 1973, and our surgeons have performed over 4,000 kidney transplants, with more than 800 of those being living donor transplants. This makes us one of the busiest transplant centers in the nation, while being consistently ranked above the national average in clinical outcomes.

This guidebook is designed to educate you on the many aspects of and considerations for live kidney donation. This information is provided to you as a tool to be used in the decision-making process. You will also find a resource guide, located after the glossary, where more information can be found about donation and transplantation.

A living-donor coordinator will guide you through the process of donation and an independent living-donor advocate will inform you of your donor rights. The living-donor advocate's role in transplantation is to make sure donation is in your best interest. The entire donor team, including the donor advocate, donor coordinator, donor physician, transplant surgeon, social worker, dietitian and pharmacist will be available to answer any further questions you may have.



# Transplant Physicians



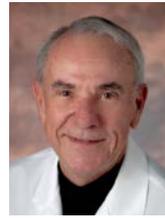
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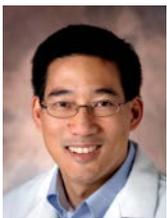
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## The Decision Process

Live kidney donation is a very personal decision. There are many factors to consider before you make your decision. These are some basic questions you should ask yourself:

- How will your family be affected by your donation and recovery?
- How will donation affect your relationship with the recipient?
- How will you feel if the evaluation process rules you out as a potential donor?
- How will you manage your work responsibilities during your time off?
- Who will provide support to you during the evaluation and after the surgery?
- Do you have any conflicting spiritual beliefs about organ donation and transplantation?

The best way to make a decision is to be informed. As you are learning more about donation, you may decide that it is not right for you, and that is all right. Donation is not for everyone. In addition, all donor evaluations are kept separate and confidential from the recipient so any concerns discussed, medical information or personal information will not be shared. If at any time you are unsure of your decision, we can postpone your evaluation until you feel more confident about proceeding.

## Eligibility

Living kidney donors must be willing to donate of their own free will without outside pressure. There is no maximum age limit for donation, but you must be at least 18 years of age. Donors must be healthy and free from chronic conditions such as heart disease, cancer or other serious medical conditions that could place them at higher risk for surgical or long-term complications from donation.

## Medical Evaluation

Once the basic donor criterion is met, the evaluation can begin. The initial compatibility test can be done locally or by mail and is comprised of:

- Blood typing
- HLA typing (genetic testing)
- Cross-matching (compatibility)

This test will determine if you are compatible with your recipient and how closely you match. You do not have to be a perfect match to be a donor. If you are found to be a match, the medical testing will be comprised of the following:

- 24-hour urine testing
- Blood tests
- Chest X-ray
- Electrocardiogram (EKG)

You will then meet privately with a social worker to discuss your decision to donate, and any financial and/or physical stressors you may be experiencing. You will also meet with the living-donor advocate who will give you more information on the donation process. At this time you may be asked to sign a consent form to confirm you have been given this information and understand it.

If the initial medical testing does not show any signs of medical problems, you will be scheduled for the final phase of evaluation, which will include:

- Medical evaluation by a donor physician
- Surgical evaluation by a donor surgeon
- Computed tomography (CT) scan of the abdomen

The CT scan allows the physician to view the kidneys, rule out any abnormalities and determine how many arteries and veins lead to each. This will help establish which kidney can be utilized for donation. If a stress test of the heart is needed (usually for anyone over 50 years of age) a referral to a cardiologist will be provided to you.

Once the evaluation is complete, all donor cases must go through an approval process. The entire donor team will meet to discuss the results of the evaluation. If the donor is approved for kidney donation, the surgery can be scheduled.

# Benefits & Risks

## Benefits to the recipient include:

- Success rates are generally higher with living donor transplantation. This is because living donor kidneys are transplanted immediately after removal, and the kidney may be able to function in the recipient much quicker.
- Potential donors can be tested ahead of time to find a donor whose kidney will be most compatible with the recipient. If the match is close enough, the recipient can often take lower doses of the anti-rejection medication, meaning fewer side effects. This happens most usually with related donors, such as siblings.
- While dialysis is a life-sustaining treatment, over time it can take its toll on the body and shorten one's lifespan. With living donation, the recipient can avoid a long wait for a kidney and the negative effects of long-term dialysis treatments.
- Live donor kidneys, on average, function almost twice as long as kidneys from deceased donors.

## Benefits to the donor include:

- Many donors report great emotional benefit in giving the gift of transplant to a loved one or friend. Transplants can improve the recipient's quality of life, allowing him/her to return to normal activities.
- Because the recipient of a live donor kidney is removed from the national transplant waiting list, the next patient on the list gets the next available deceased donor kidney; therefore, the donor is directly and indirectly giving the gift of life to more than one person.

## Risks to the donor include:

- **Pain:** While the procedure may be less invasive when performed laparoscopically, like any surgery, you will experience pain, usually in the abdominal area. The surgical team will ensure you receive enough pain medication so you are comfortable.
- Other complications that can occur when undergoing any surgery include:
  - **Infection:** The wound from the incision may become infected. This may delay the healing process but can be easily treated with antibiotics.
  - **Hernia:** Due to a weakness of the muscles at the incision scar, a bulging of the incision area may occur. This can be treated with surgical repair and does not happen to everyone.
  - **Pneumonia:** Surgery increases the risk of developing pneumonia. The nurses will instruct you on



techniques to decrease this risk, such as coughing, deep breathing, and using an incentive spirometer (breathing tool).

- **Blood clots:** Clots can occur after any surgery due to decreased activity. To prevent this, the nurses will encourage you to sit up at the side of the bed the night of surgery, and to start walking around the unit the next day.
- **Injury to surrounding tissue or other organs:** This could occur during the surgery and may contribute to blood loss that could require blood transfusions and the possibility of a larger incision.
- **Collapsed lung:** Because our kidneys are close to the lungs, the space around the lung may be inadvertently opened during surgery. If this happens, the lung may collapse. In the event of this complication, a chest tube may be inserted until this heals.
- **Allergic reaction:** In the event you have an allergic reaction to anesthesia or any other medication administered, the doctors will take immediate corrective action.
- **Death:** Although exceedingly rare, death is a risk of any surgical procedure. One study indicates the risk to donor surgery at three-hundredths of a percent, which is three deaths for every 10,000 procedures.

Some other negative symptoms the donor may experience after surgery include nausea, vomiting, constipation, fever and urinary pain related to the placement of a catheter in the bladder. Some donors may experience anxiety that the transplant will be unsuccessful or even sadness if the donated kidney fails. It is not well known if the emotional symptoms from donation continue long after the healing process is over. The transplant team can help you through this process and will continue to be available long after donation.

## Transplant Complications

Although living donor transplants generally have better outcomes, you should prepare yourself for the possibility that the kidney might fail. There are many reasons this could happen. The kidney may fail due to a technical problem during surgery. The recipient's immune system may reject the kidney. This could happen immediately or over several years. The original disease that caused the person's kidney failure may attack the transplant. This could also happen immediately or over several years.

Failure of a transplant can be very disappointing for not only the donor but the recipient as well. If this happens, be assured you did everything possible to help your relative or friend. Keep in mind that if the donated kidney fails, the recipient still has options. They can return to dialysis or can choose to try another transplant. Second transplants are frequently successful. We will provide you with our most updated statistics and national data provided by the Scientific Registry and Organ Procurement and Transplant Network.

## Surgery

The procedure used for kidney donation, also known as a "donor nephrectomy," is done laparoscopically at the AdventHealth Transplant Institute. For most patients, we are able to complete the procedure via a single "key-hole" incision in the belly button. There is a small percentage of donors who may need a larger incision to make the procedure safer for the donor and/or preserve the function of the donated kidney.

The surgeon will evaluate your kidney anatomy and discuss the procedure that is right for you and the risks involved.

## Recovery

Living donors are generally in the hospital for about two to three days. Upon discharge, all donors are prescribed medication for pain management at home and generally do not need any other medications. Sometimes a stool softener is needed to prevent constipation caused by prescription pain medications. You may not be able to drive for up to two weeks. You may have lifting and bending restrictions for at least six weeks. Most kidney donors can resume normal activities after four to six weeks, depending on the physical demands of daily living and work tasks.

If you work, consider talking with your employer before donation about existing leave policies and the use of short-term disability insurance. The coordinator can assist in completing these forms once the surgery is scheduled and complete return-to-work forms after surgery.

## Financial Information/ National Living Donor Assistance Center (NLDAC)

The recipient's insurance typically covers the medical evaluation, except for age-related cancer screenings such as a pap smear, mammogram and colonoscopy. Insurance will cover the surgery, hospitalization and the initial follow-up care lasting usually 60 to 90 days after the donation. Unfortunately, insurance may not cover long-term follow-up care if medical problems occur from the donation. Your own insurance may not cover these expenses either. The recipient's insurance typically does not cover transportation costs, lodging, child care or lost wages.

Some transplant candidates have Medicare, which may provide coverage for donors who have donation-related complications. For more information, contact Medicare by calling 800-MEDICARE or visit [Medicare.gov](http://Medicare.gov).

If there are financial concerns relating to transportation and lodging costs for evaluation and donation, there is a program that may help. The National Living Donor Assistance Center (NLDAC) provides funds to potential living donors to cover the cost of travel, lodging, meals and other non-medical expenses related to appointments for evaluation, surgery and follow-up care. Applications for this can be obtained at the Transplant Institute. The approval of your application is based on the income of both the donor and recipient and will be reviewed within 15 days of submission.

Some donors have reported difficulty in getting, affording or keeping health, disability and/or life insurance. It is important that you check with your current provider on how donation could affect your coverage. Your premiums could increase. If you do not have health insurance, undergoing kidney donation could be considered a pre-existing condition if you apply for insurance later. If you are unable to donate because a medical condition is uncovered, this could also be considered a pre-existing condition when trying to get health insurance.

All transplant centers are required to follow up with donors at a minimum of two years. These visits are required at six months, one year and two years post-donation. For all living donors, this service is provided at the AdventHealth Transplant Institute at no cost to the living donor. All donors are contacted to arrange appointments, but can complete this follow-up appointment with their own physician under their own insurance coverage if they choose.

## Common Concerns

### Relationships

When things go well and the transplant is successful, this tends to have a positive impact on the relationship between the donor and recipient. If there are complications or the transplant fails, this could have a negative impact on the donor-recipient relationship. Also, if the donor decides not to donate or is not eligible to donate for any reason, this could also affect the relationship. We encourage all living donors to talk with their recipient directly about their decision and feelings. If the donor doesn't feel comfortable, the living-donor advocate or social worker can be a resource. Other relationships that should be considered before deciding to donate is the donor's own family, especially parents or children and work relationships.

### Scars

Some potential donors are concerned with the scar from the incision. The procedure for kidney donation has changed over the years, and the AdventHealth Transplant Institute offers a surgical technique utilizing a small incision and resulting in less scarring. This could still have an impact on the way the donor views his/her body. Some donors have considered it their "badge of honor" for being a live donor.

### Family Planning

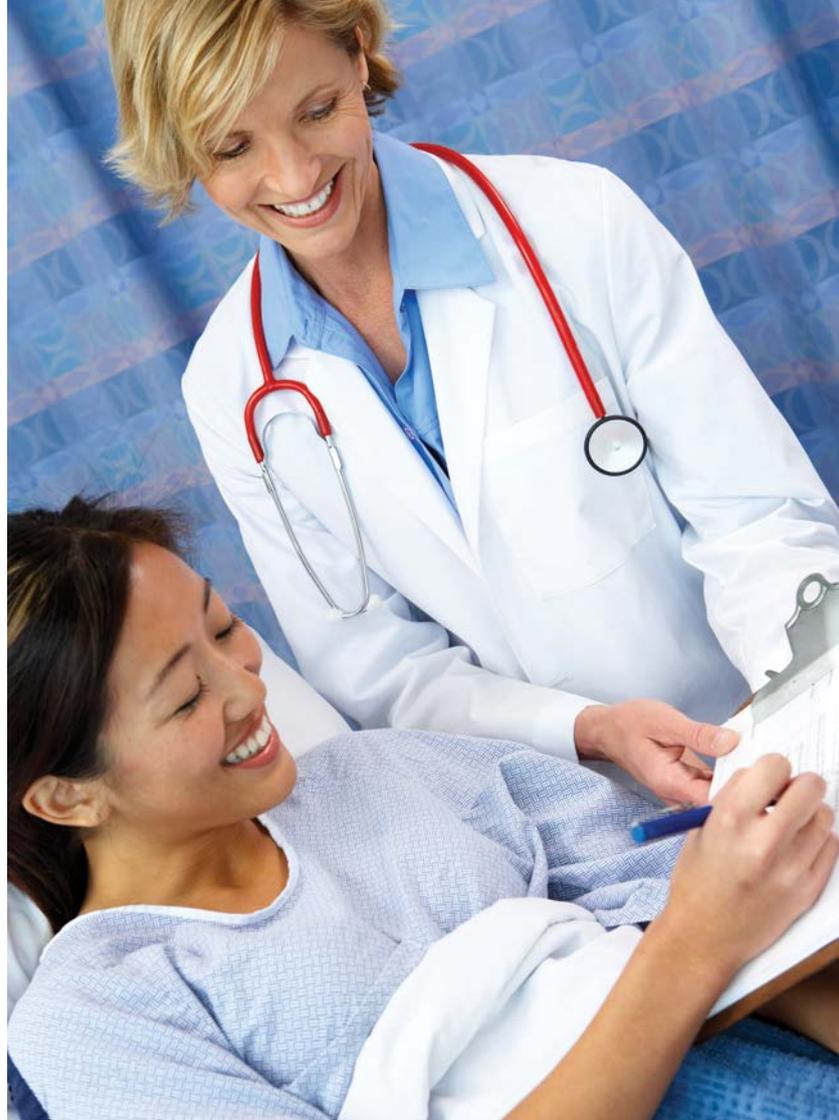
Many donors have gone on to have normal pregnancies after kidney donation. We do advise that you wait at least six months after you donate so the body has plenty of time to recuperate. If you do become pregnant, make sure your obstetrician or gynecologist knows you donated a kidney. That way, he/she can monitor your remaining kidney.

### Time Off

Your recovery time will depend on how well your body reacts to the surgery. Good timing and a well thought-out plan can help to diminish these concerns. Living donation is never considered an emergency and can be scheduled at the convenience of the donor. An open discussion with the recipient may help them to understand your needs as his/her donor.

### Insurability

Not being able to obtain insurance is a real concern for anyone being evaluated for donation. If you experience any rejections for life insurance, disability or health insurance, the Transplant Institute physicians can help appeal these decisions by writing a letter to the insurer's medical director.



## Paired Donation

Unfortunately, not all potential living donors are compatible with the person in need of a transplant. This could happen if your blood type is not a match or if there is another incompatibility, such as antibodies, that prevent a compatible transplant. Programs have been developed to help patients in the same situation to swap living donors if a match can be made with another pair in the same situation. This is called paired donation or paired exchange. Once the living donor has been evaluated and deemed a suitable living donor, he/she is entered into two databases for potential matching. Oftentimes if a match is found, it is a swap between multiple pairs. The donation and transplant usually occur on or around the same day so there is an equal exchange of donors.

The benefit to paired exchange is that the living donor is still able to help his/her relative or friend receive a living donor transplant by donating to someone else. Our program currently collaborates with the Alliance for Paired Donation and OPTN/UNOS Kidney Paired Donation Pilot Program as our paired-exchange databases. More information about paired donation will be discussed with you when you meet the team.

# Glossary of Terms

## *Anesthesia*

Medicines given intravenously to put someone to sleep during a surgical procedure.

## *Anti-rejection medications*

Medicines given to decrease the body's natural response to an infection or transplant.

## *Body mass index (BMI)*

This is a calculation using a person's height and weight to determine if he/she is at a healthy weight.

## *Compatibility*

Testing to determine if you match the recipient.

## *Dialysis*

Life-sustaining treatment for kidney failure usually performed in three weekly treatments at a dialysis center or daily at home. Dialysis can be done by filtering the blood (hemodialysis) or by putting fluid into the abdomen and draining it after a period of time (peritoneal).

## *Immune system*

The body's natural defense against infection.

## *Independent living-donor advocate*

A person at the Transplant Institute who advocates for the living donor and is not involved in the transplant recipient's care.

## *Laparoscopic*

Minimally invasive surgery performed using a camera and small instruments to prevent a large incision.

## *Paired donation/exchange*

Type of living donation where the donor, who is not compatible, donates to another patient when another living donor donates to his/her recipient.

## *Pre-existing condition*

Medical condition or surgery that occurred prior to obtaining an insurance policy.

## Additional Resources

**Organ Procurement and Transplantation Network (OPTN):** [OPTN.Transplant.HRSA.gov/](https://optn.transplant.hrsa.gov/)

**National Living Donor Assistance Center (NLDAC):** [LivingDonorAssistance.org](https://LivingDonorAssistance.org)

**Scientific Registry of Transplant Recipients (SRTR):** [SRTR.org](https://SRTR.org)

**Transplant Living:** [TransplantLiving.org](https://TransplantLiving.org)

**United Network for Organ Sharing (UNOS):** [UNOS.org](https://UNOS.org)

**Alliance for Paired Donation (APD):** [PairedDonation.org](https://PairedDonation.org)

**American Society of Transplantation:** [myast.org](https://myast.org)

**Coalition on Donation:** [DonateLife.net](https://DonateLife.net)

**National Kidney Foundation:** [LivingDonors.org](https://LivingDonors.org)

**AdventHealth Living Donation Program:** [AHLivingDonor.com](https://AHLivingDonor.com)



# CREATION Health: Our Philosophy of Health and Wellness

CREATION Health is a whole-person lifestyle that helps people live a healthier, happier life, no matter what stage of life they might be in. Each letter of the word CREATION stands for one of the eight principles of health found in the Bible's creation story — Choice, Rest, Environment, Activity, Trust, Interpersonal Relationships, Outlook and Nutrition. You can use this philosophy as a guide to personal fulfillment and recovery.

## CHOICE

Choice inspires personal fulfillment and well-being. Establishing control over your life through conscious decision-making leads to improved health and longevity. Choose the most important thing for you each day and share it with friends and loved ones

## REST

Rest rejuvenates the mind, body and spirit, empowering you to function at your best. Proper sleep and relaxation can lower blood pressure and reduce stress. Rest is important to your recovery. Take time to relax. Listen to soothing music, read and meditate.

## ENVIRONMENT

Environment influences your overall health. Creating pleasant surroundings that energize the senses can lead to inner peace and happiness. Keep things around you that make you feel comfortable. Adjust lighting and temperature as needed.

## ACTIVITY

Activity strengthens the body, sharpens the mind and invigorates the spirit. Regular physical and mental exercise can greatly improve your quality of life. Maintain the level of activity that your healthcare team recommends. Puzzles, word searches and other games are a fun way to stimulate your mind.

## TRUST

Trust promotes healing and security in your relationship with God or a higher power, family, friends and coworkers. Nurturing trust in all your relationships creates inner stability and confidence, which leads to wellness. Talk to your pastor, friends and family about your spiritual and emotional needs. Pray, read scripture or journal about your experiences.

## INTERPERSONAL RELATIONSHIPS

Interpersonal relationships can spark health and healing. Social connection fortifies resolve and nourishes the mind, body and spirit. Stay connected through emails, blogs, letters and phone calls. Encourage friends and family to visit.

## OUTLOOK

Outlook creates your reality. A positive attitude can strengthen the health of your mind, body and spiritual life. Begin a gratitude journal and write down what you are thankful for each day. Keep a list of how you are integrating CREATION Health principles into your life.

## NUTRITION

Nutrition is the fuel that drives you. Small changes to your diet can produce profound improvements to your overall health. Follow your diet plan to feel better and more energized.

# Our Health Equity Promise

## Patient Protection and Affordable Care Act: Section 1557

AdventHealth complies with applicable federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability or sex. This facility does not exclude people or treat them differently because of race, color, national origin, age, disability or sex.

AdventHealth provides free aid and services to people with disabilities to communicate effectively with us, such as:

- Qualified sign language interpreters
- Written information in other formats (large print, audio, accessible electronic formats, other formats)

AdventHealth provides free language services to people whose primary language is not English, such as:

- Qualified interpreters
- Information written in other languages

**If you need these services, please call 407-303-5600 x1106707.**

If you believe that this facility has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability or sex, you can file a grievance or request that someone assist you with filing a grievance at 407-200-1324 or [FH.Risk.Management@AdventHealth.com](mailto:FH.Risk.Management@AdventHealth.com).

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically, through the Office for Civil Rights Complaint Portal, available at [ocrportal.hhs.gov/ocr/portal/lobby.jsf](http://ocrportal.hhs.gov/ocr/portal/lobby.jsf), or by mail or phone at:

### U.S. Department of Health and Human Services

200 Independence Avenue, SW

Room 509F, HHH Building Washington, D.C. 20201

1-800-368-1019, 800-537-7697 (TDD)

Complaint forms are available at [hhs.gov/ocr/office/file/index.html](http://hhs.gov/ocr/office/file/index.html).

## The statements below direct people whose primary language is not English to translation assistance:

**ATENCIÓN:** si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al número siguiente.

**CHÚ Ý:** Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi theo số điện thoại dưới đây.

**注意:** 如果您使用中文, 您可以免费获得语言协助服务。请拨打下面电话号码。

**Atansyon:** Si ou pale kreyòl Ayisyen, gen sèvis asistans nan lang ou ki disponib gratis pou ou. Rele nimewo ki anba an.

**주의:** 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 아래의 번호로 전화하십시오.

**UWAGA:** Jeżeli mówisz po polsku, możesz skorzystać z bezpłatnej pomocy językowej. Zadzwoń pod numer podany poniżej.

ملحوظة: إذا كنت لتتحدث اللغة الإنجليزية فإن خدمات الترجمة متوفرة لك مجاناً. الرجاء الإتصال بالرقم أدناه:

**ATTENTION:** Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le numéro ci-dessous.

**PAUNAWA:** Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tawagan ang numero sa ibaba.

**ВНИМАНИЕ!** Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Для этого позвоните по нижеуказанному номеру.

**ACHTUNG:** Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufen Sie die untere Nummer an.

**सुचना:** जे तमे गुजराती बोवता हे, तो निःशुल्क भाषा सहायता सेवां तमारा माटे उपलब्ध हे. नीचेना नंबर पर फोन करे.

**ATENÇÃO:** Se você fala português, disponibilizamos serviços lingüísticos gratuitos. Ligue para o número abaixo.

**ध्यान दें:** यदि आप हिंदी बोलते हैं तो आपके लिए मुफ्त में भाषा सहायता सेवाएं उपलब्ध हैं। नीचे लिखे नम्बर पर सम्पर्क करें।

اگر شما فارسی زبان هستید، خدمات کمکی زبان بطور مجانی در دسترس شما قرار دارد. تو شماره زیر زنگ بزنید.

توجه فرمائیں۔ اگر آپ اردو بولتے/بولتی ہیں تو آپ کے لئے لسانی خدمات مفت میسر ہیں۔ ذیل میں دئیے گئے نمبر پر کال کریں۔

**注意:** 日本語でお話になりたい場合には、無料の通訳サービスをご利用いただけます。下記の番号にお電話してください。

**ໄປດຊາບ:** ຖ້າວ່າ ທ່ານເວົ້າພາສາ ລາວ, ການບໍລິການຊ່ວຍເຫຼືອ ດ້ານພາສາ, ໄດຍບໍ່ເສັຽຄ່າ, ແມ່ນມີພ້ອມໃຫ້ທ່ານ. ກະລຸນາໃຫ້ນໍ້າເບິ່ງຊ່າງລຸ່ມ

**LUS CEEB TOOM:** Yog tias koj hais lus Hmoob, cov kev pab txog lus, muaj kev pab dawb rau koj. Hu tus xojtooj hauv qab no.

**ATTENZIONE:** Se parlate italiano, sono disponibili dei servizi di assistenza linguistica gratuiti. Chiamare il numero sotto indicato.

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