Should I have surgery to remove part or all of my kidney for my kidney tumor?

A decision aid to discuss treatment options with your urologist

This decision aid was created to educate patients with kidney tumors and to encourage them to think about different parts of treatment that are important to them. All patients are unique. There are no wrong decisions. This decision aid will hopefully help you discuss treatment choices with your urologist when determining how to best manage your kidney tumor.

This decision aid is for you if:

- You have a tumor in one of your kidneys that is large in size or located in a challenging part of the kidney.
- You are considering surgery to remove part or all of the kidney to treat the tumor.

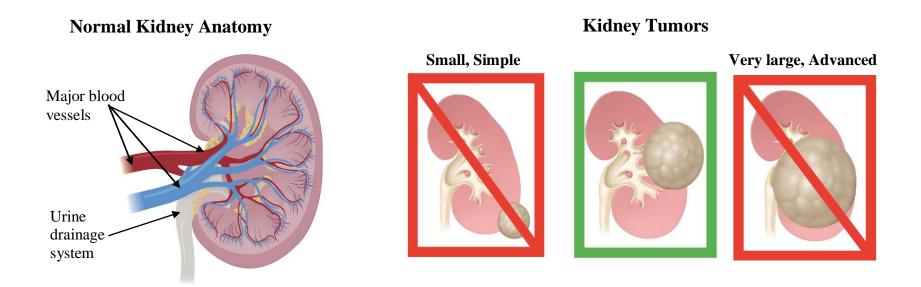
This decision aid may not be for you if:

- You have a small kidney tumor or an advanced, very large kidney tumor.
- You have more than one kidney tumor.
- You only have one kidney
- You have two kidneys but your kidney function is poor.

If you are not sure if this decision aid applies to you, please ask your urologist.

What is a kidney tumor?

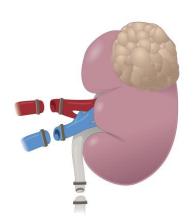
- Kidney tumors are abnormal areas of tissue growth that may be cancerous. Sometimes the diagnosis may be confirmed with a biopsy before tumor removal. Sometimes the diagnosis can only be known after tumor removal. The risks and benefits of a biopsy can be discussed with your urologist (see page 3).
- The standard treatment for many kidney tumors is surgery.
- Surgery may involve removal of the entire kidney or just the tumor.
- A kidney tumor may be considered challenging to remove without the rest of the kidney due to its **size** or **location** in the kidney. Tumors that are deeper in the kidney may be harder to remove without removing the whole kidney because they are near the urine drainage system and/or major blood vessels.



What are the surgical treatment options for kidney tumors?

Minimally-invasive total nephrectomy (laparoscopic radical):

- Surgery to remove <u>all of one kidney</u> including the tumor.
- <u>Minimally-invasive (laparoscopic) surgery</u> is done with 3-4 small incisions, a camera and small surgical tools. One bigger cut (6-8cm) is needed to take the kidney out.
- You usually have a general anesthetic (asleep with breathing tube) for this surgery.



Open partial nephrectomy (open sub-total):

- Surgery to remove part of one kidney including the tumor, leaving the normal kidney tissue in place.
- Open surgery means one large cut (15-40cm) in the side or middle of the abdomen is made for the surgeon to remove part of one kidney, including the tumor.
- You usually have a general anesthetic (asleep with breathing tube) for this surgery.



Minimally-invasive partial nephrectomy (laparoscopic or robotic sub-total)*:

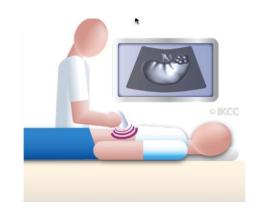
- Surgery to remove part of one kidney including the tumor, leaving the normal kidney tissue in place.
- Minimally-invasive (laparoscopic or robotic) surgery is done with 3-4 small incisions, a camera and small surgical tools.
- You usually have a general anesthetic (asleep with breathing tube) for this surgery.
- *Some tumors are too complex to be taken out with this approach. Ask your urologist if this is an
 option for you.



What are other treatment options for kidney tumors?

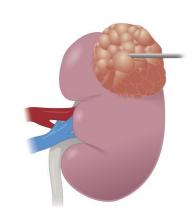
Observation/active surveillance (No surgical treatment):

- No surgery. Regular follow-up with CT (CAT) scans or ultrasounds to make sure the tumor is not growing too quickly or spreading.
 - *This decision aid was created to help patients with kidney tumors decide on which surgery to receive. Observation may be a good option for some patients with kidney tumors. Please discuss with your urologist.



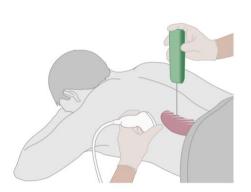
Tissue ablation:

- Energy applied with needles to kill the tumor by heating or freezing it.
- This procedure is usually done with skin freezing (local anesthetic) with the patient awake, and is
 not a surgery. At some hospitals, it is done with laparoscopic surgery and a general anesthetic.
 Please discuss this with your urologist.
 - * This decision aid was created to help patients with kidney tumors decide on which surgery to receive. Tissue ablation may be a good option for some patients with kidney tumors. Please discuss with your urologist.



Kidney tumor biopsy:

- A biopsy is a sample taken from the abnormal kidney tissue with a needle through the skin.
- A biopsy is done to find out if the tumor is cancer or not.
- The biopsy is done by a radiologist (doctor who reads x-rays) with freezing (local anesthetic) with the patient awake, and is not a surgery.
- A biopsy is not always able to tell if a tumor is cancer or not, so in some cases it may not help.
- The main risks of a kidney biopsy are bleeding and pain.



What other health factors may affect your options?

Circle yes or no and discuss your other health factors with your surgeon.

| Do you have | Yes or No | | Comment |
|---|-----------|----|---------|
| Diabetes? | Yes | No | |
| High blood pressure? | Yes | No | |
| Genetic disorder affecting the kidneys? | Yes | No | |
| Renal failure / Kidney disease? | Yes | No | |
| Family members with kidney problems? | Yes | No | |
| Other medical or personal issues? | Yes | No | |
| Are you over the age of 80 years? | Yes | No | |
| Previous kidney surgery? | Yes | No | |
| Kidney stones? | Yes | No | |
| None of these apply to me | Yes | No | |

| Other comments related to your health: | | |
|--|--|--|
| | | |
| | | |
| | | |

Working through the 4 steps of this decision aid may help you consider the options.

Step 1: What are the benefits and disadvantages of each treatment option? What does the research show?

Every patient is unique. No one can predict the exact outcome of your decision. These diagrams have blocks of 100 faces that show a 'best estimate' of what happens to **100 people** with large or challenging kidney tumors who undergo each treatment option over **10 years.** Each face (②) stands for one person. The shaded areas show the **average** number of people affected based on current research, although there is a range of values for each outcome reported by different studies. There is no way of knowing in advance if you will experience these benefits or disadvantages, however, individual factors may help your physician predict your risk. These outcomes could happen at any time, but research has not been done to show what the estimates are beyond 10 years.

Benefits: Patients who benefit from the given treatment highlighted in green

Minimally-invasive total

nephrectomy

Benefit – Likelihood of survival at 10 years

After treatment, the likelihood of survival at 10 years is¹:

(1) (2) (3) (4) (5) (7)

Minimally-invasive total nephrectomy

78 are alive

999999999

90 have no evidence of cancer

Open partial nephrectomy

Open partial nephrectomy

90 have no evidence of cancer

Minimally-invasive partial nephrectomy

Minimally-invasive partial nephrectomy

90 have no evidence of cancer

Observation (No surgical treatment)

Observation (No surgical treatment)

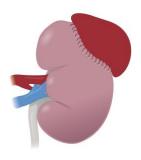
o are free of tumor that may be cancer

After treatment, the chance of having no evidence of kidney cancer is¹:

Disadvantages: Patients with side effect of the given treatment highlighted in blue.

Risk – Post-operative bleeding

After treatment, the chance of having bleeding requiring a blood transfusion is^{2,5,7,12}:



Minimally-invasive total nephrectomy



Open partial nephrectomy



bleed

Minimally-invasive partial nephrectomy



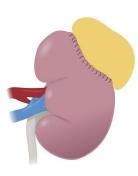
8 have a post-op bleed

Observation (No surgical treatment)

have a post-op
 bleed

Risk – Post-operative urine leak

After treatment, the chance of having a urine leak requiring a temporary drainage tube through the skin or between the kidney and the bladder is^{2,5,6,10}:



Minimally-invasive total nephrectomy

bleed

| 999999999 |
|-----------|
| 999999999 |
| |
| |
| |

have a urine leak

Open partial nephrectomy

| 999999999 |
|-----------|
| 999999999 |
| 999999999 |
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| |
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| |

10 have a urine leak

Minimally-invasive partial nephrectomy



6 have a urine leak

Observation (No surgical treatment)

have a urine leak

Disadvantages: Patients with side effect of the given treatment highlighted in blue.

The following risks are related to the kidney function after treatment in patients with normal kidney function before surgery.

A patient with poor kidney function before surgery, or other health factors that affect their kidney, may be at higher risk of these harms over 10 years.

Risk - Poor Kidney Function

After treatment, the chance a person with normal kidney function develops poor kidney function (stage 3 kidney disease = moderate kidney damage) over 10 years is ^{2,6}:

Poor kidney function may increase the risk of heart attack, stroke and future medical problems⁹.

Minimally-invasive total nephrectomy



36 have kidney failure

Open partial nephrectomy



3 have kidney failure

Minimally-invasive partial nephrectomy



3 have kidney failure

Observation (No surgical treatment)

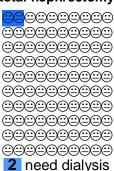


3 have kidney failure

Serious Harm – Kidney failure with need for dialysis

After treatment, the chance a person with normal kidney function develops severe kidney failure requiring dialysis over 10 years is^{3,7}:

Minimally-invasive total nephrectomy



Open partial nephrectomy



1 needs dialysis

Minimally-invasive partial nephrectomy



1 needs dialysis

Observation (No surgical treatment)



0 need dialysis

Average length of stay in hospital after surgery

Average number of days8:

Minimally-invasive total nephrectomy



3 days

Open partial nephrectomy



5 days

Minimally-invasive partial nephrectomy



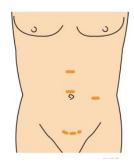
0 days

Observation

(No surgical treatment)

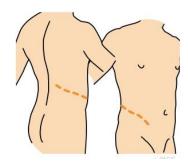
Expected scars after surgery¹³

Laparoscopic total nephrectomy



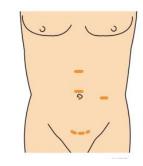
- 3-4 small incisions
- One larger incision in the lower abdomen to remove the kidney

Open partial nephrectomy



- 1 large incision
- 15% of patients notice a lump at the incision up to 2 years after surgery. It is rarely harmful but can be bothersome or painful for some patients.

Minimally-invasive partial nephrectomy



No Incisions

Observation

(No surgical treatment)

- 4-5 small incisions
- One larger incision is made to remove the tumor

Step 2. What matters most to you?

Common reasons to choose each treatment option are listed below.

Check ✓ how much each reason matters **to you** on a scale from 0 to 5.

'0' means the reason is **not** important to you. '5' means it is **very** important to you.

| Reasons to choose: Minimally-invasive total nephrectomy | Not Importar | nt | | | lm | Very portant | |
|---|-----------------|----|---|---|----|------------------|--|
| How important is it to you to have a short recovery? | 0 | 1 | 2 | 3 | 4 | (5) | |
| How important is it to you to avoid complications around the time of the operation? | 0 | 1 | 2 | 3 | 4 | (5) | |
| Reasons to choose: Open partial nephrectomy | Not Importar | nt | | | lm | Very portant | |
| How important is it to you to avoid decreased kidney function and dialysis? | 0 | 1 | 2 | 3 | 4 | (5) | |
| How important is it to you to keep as much of your kidney tissue as possible? | 0 | 1 | 2 | 3 | 4 | (5) | |
| Reasons to choose: Minimally-invasive partial nephrectomy | Not Importar | nt | | | ln | Very nportant | |
| How important is it to you to avoid a lump or bulge at your incision after the surgery? | 0 | 1 | 2 | 3 | 4 | (5) | |
| How important is it to you to have a short hospital stay after surgery? | 0 | 1 | 2 | 3 | 4 | (5) | |

Now, think about which option has the reasons that are most important to you. Please remember that not all options may be recommended or available for you depending on your medical history and kidney tumor.

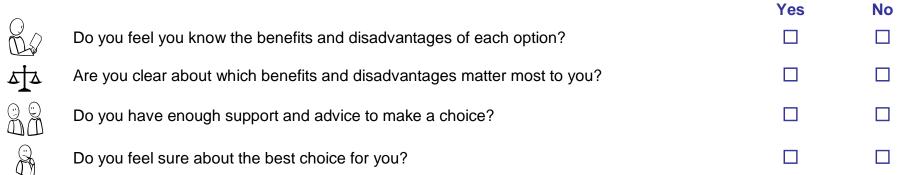
| Which option do you prefer? |
|--|
| Check ☑ one. □ Total (laparoscopic radical) nephrectomy |
| ☐ Open partial (sub-total) nephrectomy |
| ☐ Minimally-invasive partial (sub-total) nephrectomy |
| ☐ Observation (no surgery and follow up only) |
| ☐ I have not decided yet |
| |
| Are there other questions you have for your urologist? If so, please write them down here. |
| |
| |
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| |

Step 3: What else do you need to prepare for decision making?

Find out how well this decision aid helped you learn the key facts.

Check \square the best answer(s).

| | | Laparoscopic total nephrectomy | Open partial nephrectomy | Minimally-invasive partial nephrectomy | They are the same | Not sure |
|----|---|--------------------------------|--------------------------|--|-------------------|-----------|
| 1. | Which option has the best chance of having no evidence of cancer in 10 years' time? | | | | | |
| 2. | Which option has the lowest risk of complications around the time of surgery? | | | | | |
| 3. | Which two options have the lowest risk of kidney failure or need for dialysis? | | | | | |
| 4. | Which two options have the shortest average hospital stay? | | | | | |
| | | | | Check your answers a | at the bottom of | the page. |
| F | ind out how comfortable you feel ab | out deciding | | | v | |



If you answered 'No' to any of these, discuss with your urologist (The SURE Test © O'Connor & Légaré, 2008)

Answers for the key facts: 1. They are the same, 2. Total, 3. Open partial and Minimally-invasive partial, 4. Total and Minimally-invasive partial

Step 4: What are the next steps?

| CI | heck ☑ what you want to do next. |
|----|---|
| | ☐ I have decided to receive a total (laparoscopic radical) nephrectomy. |
| | ☐ I have decided to receive an open partial (sub-total) nephrectomy. |
| | ☐ I have decided to receive a minimally-invasive partial (sub-total) nephrectomy. |
| | □ I need to discuss the options with my urologist and family. □ |
| | ☐ I need to read more about my options. |
| | □ Other, please specify |

This information is not intended to replace the advice of a health care provider.

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SMOG readability rating: 8.6 (Ninth grade)

The level of evidence for studies referenced in this decision aid varied. Although randomized controlled trials and systematic reviews were included for many of the outcomes, others are based on database values (length of stay) and cohort studies (rates of flank bulge).

Benefits and harms data take from:

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