Aneurysm

What is an aneurysm?

- An aneurysm is a dilation or bulge of the fistula or graft

Am I at risk for an aneurysm?

- The longer you have your fistula or graft, the more likely it can develop an aneurysm
- If the fistula or graft is poked in the same places every time you have dialysis, that can increase the risk of getting an aneurysm in that place

How do I know if I have an aneurysm?

- You may see a bulge over your fistula or graft

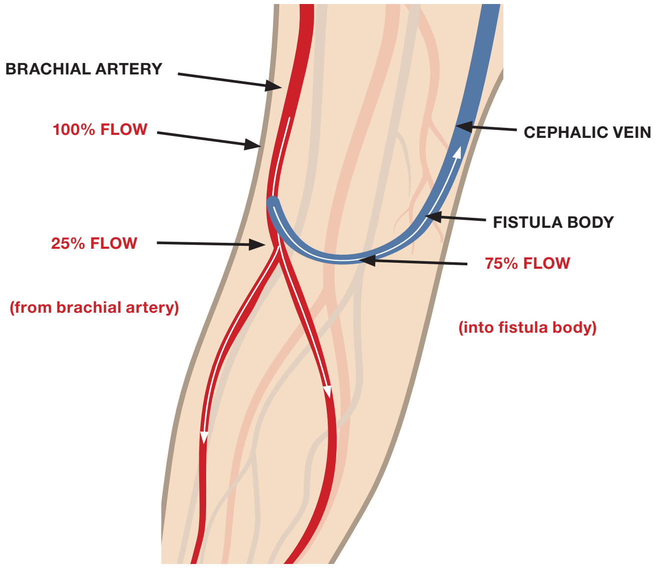
If I have an aneurysm, what happens next?

- Your nurses and doctors will monitor the aneurysm
- Small aneurysms that have healthy skin over them are not dangerous and do not need an operation
- The aneurysm could become infected (see page 28 for more information)
- As the aneurysm becomes larger, the skin over it may become unhealthy and thin and possibly develop a scab. If the skin becomes unhealthy, there is a risk that the aneurysm could rupture and bleed a lot. This can be life threatening.
- Your doctor will decide when the skin over the aneurysm has become unhealthy. At that time, your doctor will probably recommend an operation to fix the aneurysm.
- If an aneurysm starts bleeding at home, you should hold pressure directly over the site that is bleeding. Keep holding pressure and call for an ambulance. (see page 35 for more information)

Steal Syndrome

What is steal syndrome?

- Arteries carry blood down your arm to your hand and fingers. When creating a fistula or graft, we redirect some blood flow from the artery to the fistula or graft.
- Sometimes, too much blood goes into the fistula or graft and not enough blood goes to the hand and fingers. This is called "steal."



Am I at risk for steal syndrome?

- Steal happens in about 10-15 people for every 100 people
- Females, people with smaller arteries, and older people are at higher risk for steal
- If a very large vein is used to create a fistula, that can increase the risk of steal
- Fistulas and grafts in the upper arm (above the elbow) have a higher risk of steal than those in the forearm

How do I know if I have steal syndrome?

- In mild cases, your fingers may feel cool, or a little numb. Sometimes the symptoms only happen when you are having dialysis.
- In more severe cases, your hand may feel weak
- In the most severe cases, the tissue in the fingertips can die because there is not enough blood

If I have steal syndrome, what happens next?

- In mild cases, you may not need any treatment

- In more severe cases, your doctor may recommend an operation to repair the steal
- In the most severe cases, your doctor may recommend removing the fistula or graft

Central venous occlusion and stenosis

What are central veins?

- Central veins are large veins in the chest that drain the arms

What is central venous occlusion?

- Central venous occlusion is when one of the large veins in the chest is completely blocked

What is central venous stenosis?

- Central venous stenosis is when one of the large veins in the chest has a narrowing

Am I at risk for central venous occlusion or stenosis?

- Anyone who has ever had a catheter in their neck or chest that goes into the central veins can get central venous occlusion and stenosis
- More catheters and a longer amount of time that the catheter stays in increases the risk of having central venous occlusion and stenosis
- People who have never had a catheter but have a fistula or graft in their arm can also get central venous occlusion and stenosis. However, this is much less common.

How do I know if I have central venous occlusion or stenosis?

- If you arm or your face is swollen, you might have central venous occlusion or stenosis

What happens next if I have central venous occlusion or stenosis?

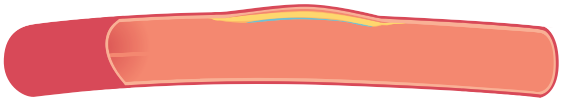
- Your doctor may recommend an imaging test to look at the central veins
- The test could be a CT scan, MRI or a venogram

What is a venogram?

- A venogram is where a doctor puts a catheter in a vein, usually in your arm
- The doctor injects contrast dye in the catheter and takes pictures with an X-ray. This shows the doctor if there is an occlusion or stenosis of the central veins.

How is central venous occlusion or stenosis treated?

- If your doctor recommends treatment, the most common procedure is done through a catheter placed in your arm, and sometimes the leg. This can be done at the same time as the venogram.



ANGIOPLASTY

- Depending on where the occlusion or stenosis is, the doctor may be able to open it with a balloon. This is called angioplasty.
- Sometimes the doctor may need to put a stent to hold the vein open (a stent is a metal mesh tube)
- Less commonly, a major surgery can be performed to repair the central venous occlusion or stenosis

If I have the central venous occlusion or stenosis treated, can it come back?

- It is very common that the central venous occlusion or stenosis comes back after it is treated
- It is especially common if it is treated using the balloon and/or stent

Bleeding

Am I at risk for bleeding?

- Anyone with a fistula or a graft can have bleeding from the fistula or graft
- If the fistula or graft has an aneurysm (see page 31), that can increase the risk of bleeding
- If the skin over the fistula or graft is not healthy, that can increase the risk of bleeding

How do I know if I am at increased risk for bleeding?

- The nurses and technicians at your dialysis facility and your doctors should check the health of your fistula or graft every time they see you

What should I do if my fistula or graft starts bleeding?

- Hold pressure directly over the bleeding area with one finger or two fingers
- Do not apply a large amount of gauze or a towel or any other absorbent material
- If you have a bottle top you can use this to help control the bleeding. Apply the hollow side of the bottle top over the bleeding site. Press firmly to stop or slow down the bleeding. Secure the bottle top firmly with a bandage wrapped around your arm and the bottle top.
- Call 911. Tell the operator you have uncontrolled bleeding from your dialysis fistula or graft.

Apply hollow side over bleeding site

Maintain pressure

Secure firmly with a bandage

CALL 911

Tell the emergency services you have uncontrolled bleeding from your dialysis fistula/graft

Adapted with permission from Kidney Care UK

Part 3: Discussing choices for managing my kidney disease

Best Case Worst Case tool

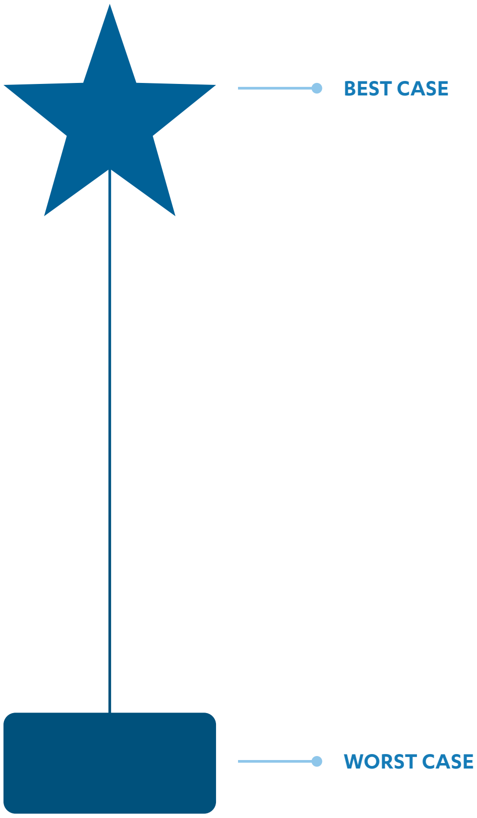
1. Your trusted healthcare profession will discuss the options available to you for managing your kidney disease.
2. Use the tool below to discuss the best case, worst case and most likely stories for each of the options that you discuss.
3. The most likely outcome for each option should be marked along the spectrum between best case and worst case scenarios.

To learn more about how the Best Case Worst Case tool works, visit **patientpreferences.org/best-case-worst-case/**

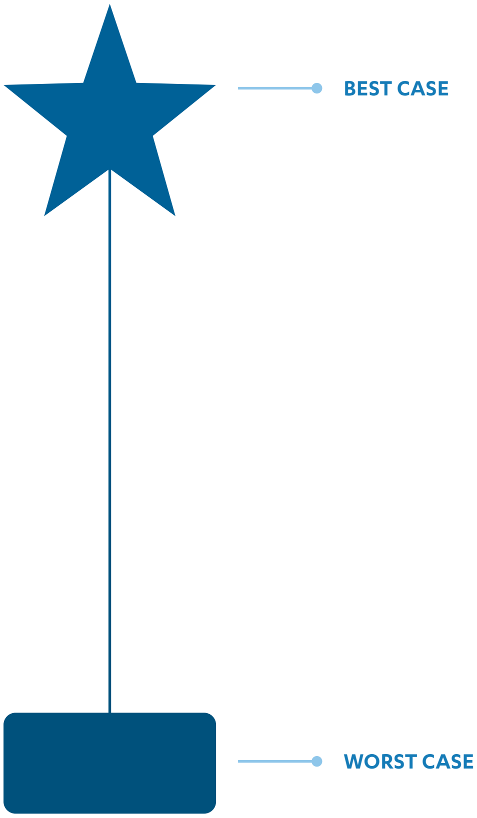
To hear about how the Best Case Worst Case tool works, visit:

Dr. Schwarze, Scenario Planning: youtu.be/eBgPRuRaiPw

ESKD Management Strategy or Access Type Discussed



ESKD Management Strategy or Access Type Discussed



Part 4: Identifying my care team

You may have doctors or other healthcare professionals who understand your goals, values and preferences very well. If so, and if you would like them involved in conversations about managing your kidney disease, please list them in this section.

Filling out this section can also help healthcare professionals identify who needs to be notified if there are any changes in your health.

Remember also to discuss your goals, values and preferences with your doctor(s) and provide them with a copy of your ESKD Life Plan.

Facility information

Dialysis Facility:	Phone #:
Facility Nephrologist:	Facility Charge Nurse:
Facility Social Worker:	Facility Dietician:

Non-Facility information

Non-facility Nephrologist:	Phone #:	Transplant Nephrologist:	Phone #:
Other Nephrologist:	Phone #:	Vascular Access Coordinator:	Phone #:
Interverntionalist:	Phone #:	Vascular Access Surgeon	Phone #:
Transplant Surgeon:	Phone #:	Cardiologist:	Phone #:
Primary Care Doctor:	Phone #:		

Part 4: Identifying my care team (continued)

Are there family members, friends, or other people that you want to be involved in helping you make decisions?

Name:	Role:	Phone #:
Name:	Role:	Phone #:
Name:	Role:	Phone #:

In the event of an emergency, who would you like to be called?

Name:	Role:	Phone #:	Alternate Phone #:
Name:	Role:	Phone #:	Alternate Phone #:

Part 5: Making my ESKD Life Plan

What is the Life Plan?

- The Life Plan is your individualized treatment strategy for living with kidney failure
- The Life Plan details multiple treatments for kidney failure for you
- The Life Plan includes your preferred treatment for your kidney failure- HD, PD or transplant (see section 2: Learning about choices for managing my kidney disease)
- The Life Plan also includes what you would like to do next if your preferred treatment method does not work out
- The Life Plan describes how you will protect your blood vessels for future vascular access
- Your Life Plan will also include your preferred vascular access
- The Life Plan will include what you would like to do next if your preferred vascular access does not work out

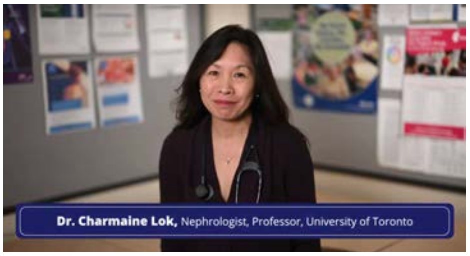
Who makes my Life Plan?

- You make your Life Plan with your care team

What if I want to change my Life Plan?

- You can change your Life Plan any time you want
- You and your care team will review your Life Plan at least once a year to make sure it still fits with your preferences

To hear about the ESKD Life Plan, visit:



Dr. Lok, ESKD Life Plan: youtu.be/SGqsTbx71WI

My ESKD Life Plan

Today's date:

About Myself

Full name:	What I prefer to be called:
How old I am today:	My pronouns:
Languages I speak:	My preferred language:
The arm I use most: right/left	What I want my ESKD Care Team to know about me:

Your ESKD Life Plan Coordinator

Which health care professional from Part 4 would you like to be in charge of coordinating your ESKD care? They will keep a record of your ESKD Life Plan and make sure it gets updated regularly.

Name:	Role:	Phone #:

My ESKD Life Plan

Treatment type 1	Treatment type 2	Treatment type 3
Access strategy	Access strategy	Access strategy

Questions I want to ask my doctor

Index of terms

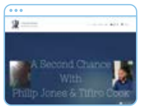
Additional Resources

MyHealthPriorities.org: A process that will help you identify what matters most to you- your Health Priorities.

mydialysischoice.org: My life, My Dialysis Choice. This tool helps you link your values to the options for dialysis. (It does not include non-dialysis options)

Kidneyschool.org: Kidney School is a detailed online education program for people who want to learn how to manage and live with ckd.

ckmcare.com/ckmpathway/pathwayintroduction: Decision aid to assist with the choice between conservative kidney management (no dialysis) and dialysis.



philipjones17scta.wixsite.com/asecondchance: The purpose of A Second Chance is to spotlight people and their story of fighting difficult life situations as well as being an instrument for the people. The other side of A Second Chance is bringing awareness to organ transplantation and organ donation.

youtube.com/c/hopewithjonathan: Hope with Jonathan highlights kidney patients' personal journeys—from battling kidney disease and dialysis to awaiting transplants and beyond. Their mission is to inform, educate, and inspire through podcasts, interviews and stories of hope.

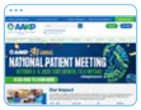
facebook.com/groups/IHateDialysis: Facebook group for anyone affected by kidney disease. It is a fellowship comprised of patients, caregivers and the medical community. It is a meeting place for people to unload their frustrations about being on dialysis.

facebook.com/groups/DialysisUncensored: Private Facebook group for support, information, and sharing experiences among dialysis and kidney disease patients, transplant recipients, dialysis staff, and those with affected loved ones.

reddit.com/r/kidneydisease: A supportive Reddit community to share personal stories and experiences about how kidney disease has impacted your life or the life of a loved one.

reddit.com/r/dialysis: A Reddit forum for asking questions, sharing experiences, and discussing topics related to kidney failure and dialysis treatment.

Organizations



aakp.org: American Association of Kidney Patients (AAKP) is dedicated to improving the lives and long-term outcomes of kidney patients through education, advocacy, patient engagement and the fostering of patient communities. AAKP fights for early disease detection and the appropriate diagnosis of rare/genetic conditions; increased kidney transplantation and pre-emptive transplantation; full patient choice of either in-center or home dialysis; protection of the patient/physician relationship; promotion of research and innovation including artificial implantable and wearable kidneys; and the elimination of barriers for patient access to available treatment options.

asn-online.org: The mission of the American Society of Nephrology (ASN) is to create a world without kidney diseases. The ASN Alliance for Kidney Health elevates care by educating and informing, driving breakthroughs and innovation, and advocating for policies that create transformative changes in kidney medicine throughout the world.

kidney.org: Fueled by passion and urgency, National Kidney Foundation (NKF) is a lifeline for all people affected by kidney disease. As pioneers of scientific research and innovation, NKF focuses on the whole patient through the lens of kidney health. The mission of the NKF is to enhance lives through action, education and accelerating change.

kidney.org/professionals/guidelines: Kidney Disease Outcomes Quality Initiative (KDOQI) continually updates a selection of its original clinical practice guidelines. Updates are initiated when enough new evidence becomes available of high enough quality to change current recommendations, e.g. a recommended intervention causes previously unknown substantial harm, a new intervention is significantly superior to a previously recommended intervention, or a recommendation can be applied to a new population.

khi.asn-online.org: The Kidney Health Initiative (KHI) was established in September 2012 under a Memorandum of Understanding between the ASN and US Food and Drug Administration (FDA). The mission of the KHI is to establish a deeper knowledge of disease states and forge multi-disciplinary collaborations to find safe and effective new therapies.

niddk.nih.gov: National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) research creates knowledge about and treatments for diseases that are among the most chronic, costly, and consequential for patients, their families, and the nation.