# **MY CHOICE FOR MY KIDNEYS**

Booklet 1: Information Guide for Elderly People with Kidney Failure







**The objective of this booklet:** To provide information about treatment options for elderly people with Kidney Failure (End-Stage Kidney Disease, ESKD) to help them and their family caregivers make informed treatment choices.

This booklet does not replace talking to your medical team. Please talk to them about your concerns and treatment options.

# **CONTENTS**

#### What this booklet includes:

1. What Kidney Failure is	3
1.1. What healthy kidneys do	3
1.2. When do kidneys fail	4
1.3. What the symptoms of Kidney Failure are	5
2. What your treatment options are	6
2.1. Dialysis	8
2.1.1. Peritoneal Dialysis (PD/Water Dialysis)	8
2.1.2. Hemodialysis (HD/Blood Dialysis)	12
2.2. Kidney Supportive Care (KSC/Conservative Management)	14
3. How to choose a treatment	16
3.1. Comparing your treatment options	18
3.2. What if you want to stop dialysis	24
4. Advice for family caregivers	25

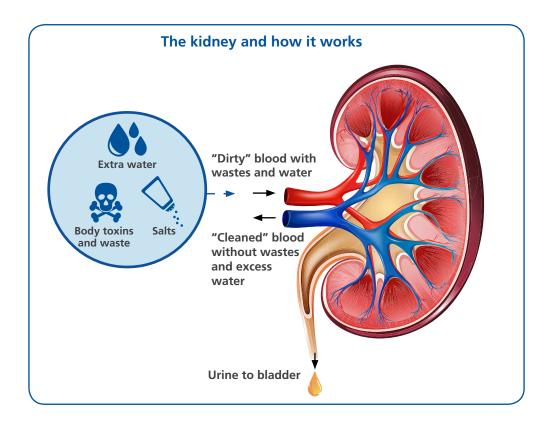
Please complete "Booklet 2: Decision guide for Elderly People with Kidney Failure" to help you understand:

- 1. Which treatment option is best for you.
- 2. How to discuss your concerns with your loved <u>ones and doctor.</u>

# 1. What Kidney Failure is

## 1.1. What healthy kidneys do

Your kidneys are important to your body. Here are some of the things they do for you...



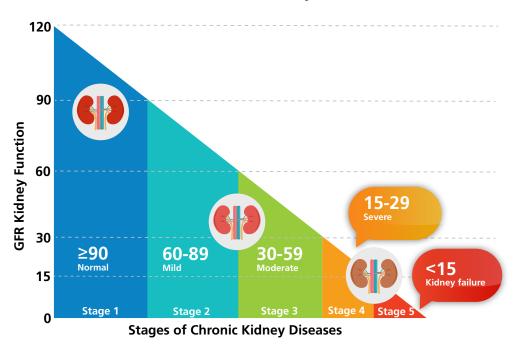
#### Kidneys...

- Clean your blood by taking out waste and extra water.
- Help you maintain your mineral levels such as sodium and potassium.
- Help control blood pressure and red blood cell count.
- Control your calcium and phosphate levels and keep your bones healthy.

## 1.2. When do kidneys fail

- The estimated Glomerular Filtration Rate (eGFR) is a measure that is used to check how well the kidneys are removing waste from the blood.
- Healthy people with normal kidneys have an eGFR higher than 90, although it may be lower in the elderly.
- When eGFR is below 15, the kidneys begin to fail. This is called Stage 5 Chronic Kidney Disease or **Kidney Failure**.

# Glomerular Filtration Rate (GFR) can be estimated from a blood test and is a measure of kidney function



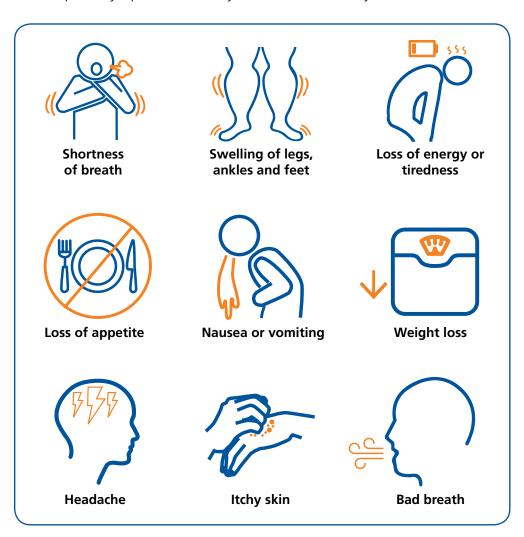
#### YOU ARE NOT ALONE

In Singapore,

- Over 11,000 people have Kidney Failure<sup>1</sup>.
- Every year, about 1,800 new cases occur<sup>1</sup>.

## 1.3. What the symptoms of Kidney Failure are

You may have symptoms at later stages of Kidney Failure. Not everyone develops all symptoms but they become more likely over time.



There is no cure for Kidney Failure. There are treatments that may help extend life and control symptoms. However, treatments may not help everyone live longer or improve quality of life. This depends on age, other health conditions and how well people respond to treatment.

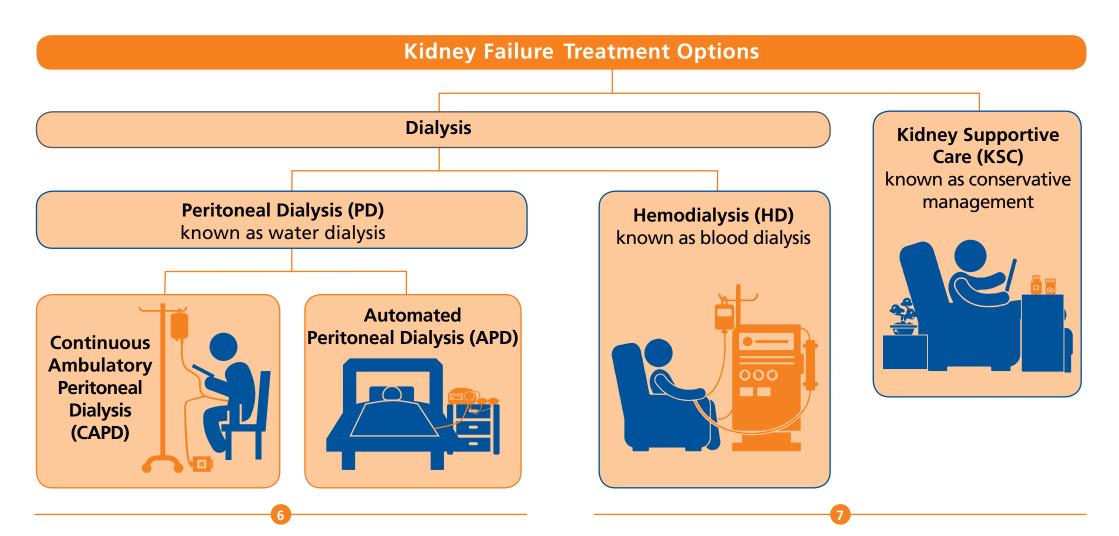
## 2. What your treatment options are

As your kidneys become weaker, you will be asked how you want to manage your Kidney Failure. The decision should be made based on both medical and non-medical factors and should be discussed with those who are involved in your care.

The first decision is to choose between:

- 1. Dialysis (a treatment to clean your blood and do some of the work that healthy kidneys do), and
- 2. **Kidney Supportive Care (KSC)** (a treatment focused on managing your Kidney Failure symptoms).

If you choose dialysis, the second decision is to choose a type of dialysis.



## 2.1. Dialysis

There are two main types of dialysis:

- Peritoneal dialysis (PD), also known as water dialysis, and
- Hemodialysis (HD), also known as blood dialysis.

#### 2.1.1. Peritoneal Dialysis (PD/Water Dialysis)

#### **Features**

- A daily home-based treatment.
- Can be done by yourself or your caregivers.

#### **Getting started**

- You will need a minor surgery at your belly to create an access point.
- A small, soft plastic tube called a catheter will be inserted through this access point.
- You will spend at least one night in the hospital for this surgery.
- A nurse will teach you or your caregiver how to do PD.

#### **Treatment process**

- Cleansing fluid flows into your body and removes toxins through the catheter.
- This exchange happens a few times to reduce the toxin levels in your blood.
- Can be done manually or by a machine.

#### **Logistics**

- Need space to store the machine and water bags for PD.
- Need to keep the machine and house clean to avoid infection.

There are two types of PD in Singapore:

- Continuous Ambulatory Peritoneal Dialysis (CAPD) where the exchange is done manually.
- Automated Peritoneal Dialysis (APD) where the exchange is done by a machine.

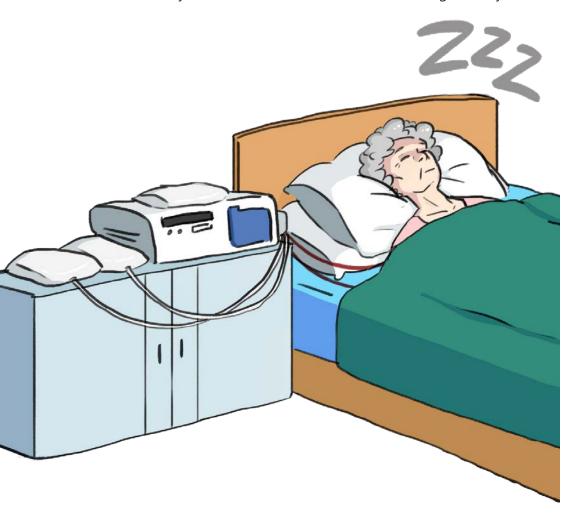
#### a. Continuous Ambulatory Peritoneal Dialysis (CAPD)

- Done manually at home.
- Done on a daily basis.
- 3 to 5 times a day, with each exchange taking 20 to 30 minutes.
- Patients can usually continue with normal daily activities between exchanges.



#### b. Automated Peritoneal Dialysis (APD)

- Done by a machine at home.
- Done on a daily basis.
- Once a day, for 8 to 10 hours, typically during sleep.
- Patients can usually continue with normal activities during the day.



#### **Key Factors to consider for PD**

- Requires a minor surgery before starting dialysis
- Daily treatment
- Done at home
- You or your caregivers need to learn how to do PD
- Requires space at home for PD machine and water bags
- Can be done when it is convenient for you
- Your sleep may be disturbed if you do APD during sleep
- Less strict diet and fluid intake than HD
- Risk of infection
- On average, less expensive than HD
- You need to bring PD equipment when you travel abroad

### 2.1.2. Hemodialysis (HD/Blood Dialysis)

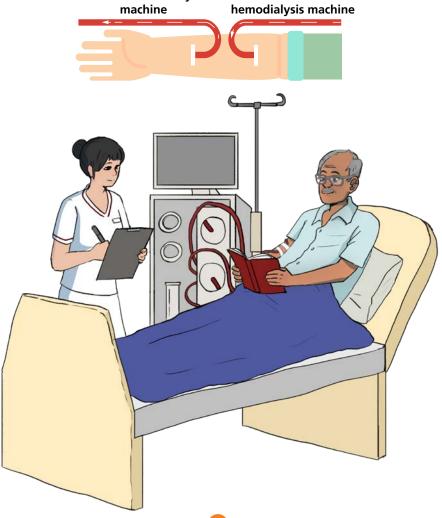
#### **Features**

• Usually done at a dialysis centre in Singapore.

**Blood to hemodialysis** 

- About 3 times a week.
- Each session takes around 4-6 hours.
- Most patients can go on with normal daily life when not receiving dialysis.

**Blood from** 



#### **Getting started**

- You will need a minor surgery at your arm to create access to your blood.
- However, the blood vessel needs 2-3 months after the surgery to be ready for dialysis.
- During this time, you can receive HD via a temporary access point through a plastic tube around your neck or chest.

#### **Treatment process**

- Every time you receive HD, needles will be placed in your arm.
- An artificial dialysis filter in the HD machine will clean your blood.

#### **Logistics**

- You will need to travel to a dialysis centre to get HD.
- There are centres all over Singapore. A healthcare provider can connect you with a suitable dialysis centre.

#### **Key Factors to consider for HD**

- Requires a minor surgery before starting dialysis
- About 3 sessions per week, 4-6 hours per session
- Have to travel to and from dialysis centre
- Nurses at the dialysis centre will perform dialysis for you
- Chance of meeting other patients at dialysis centre
- Needles will be used every time you get dialysis
- May feel tired after a dialysis session
- Stricter diet and fluid intake compared to PD
- Risk of infection
- On average, more expensive than PD
- You need to arrange with a dialysis centre when you travel abroad

# 2.2. Kidney Supportive Care (KSC/Conservative Management)

#### **Features**

- KSC is an alternative to dialysis, especially for elderly people aged 75 and above with multiple health problems and limited life expectancy.
- Not meant to extend life.
- The focus of care will be to maintain your quality of life.
- Use medicine to control symptoms and problems related to Kidney Failure.
- Less time spent on treatment will allow you to spend time with your loved ones and do activities that you enjoy.

#### **Getting started**

- Your doctor will discuss a care plan with you.
- No other preparation is needed.



#### **Treatment process**

- You should take your medicine as prescribed to prevent or reduce symptoms.
- You should follow the diet that your medical team recommends.
- A community nurse can visit you at your home if needed.

#### **Logistics**

• You will need to travel to the hospital or clinic for your doctor's appointments.



- More suitable for elderly aged 75 and above with other health problems
- Not a life-extending treatment
- Does not replace the functions of kidneys
- Medicine will be used to manage symptoms
- No need for surgery or needles
- Your doctor will monitor and follow up with you
- You can request for a community nurse to visit you at home
- More free time compared to undergoing dialysis
- No risk of infection related to treatment
- Least expensive treatment
- You may travel depending on how well you are

## 3. How to choose a treatment

You can follow the steps below to guide you...

#### **Step 1: Clear your doubts**

- Make sure that you understand your current condition and how it will change over time.
- Be familiar with all available treatment options. (Refer to pages 6 to 15)
- If anything is unclear, ask your doctor.

#### Step 2: Think about....

- What is important to you?
- What are your values and treatment goals? (Refer to Booklet 2)
- Think about how involved you want to be in choosing a treatment.



## Step 3: Discuss with your loved ones and doctor

(Refer to Booklet 2)

- Share your thoughts with your loved ones and doctor.
- If making a treatment decision is too stressful, ask your loved ones and doctor for help.
- You can choose someone to help you talk to your doctor. When there are conflicts, this person can also speak on your behalf.

#### **Step 4: After making a decision**

- If you decide to get dialysis, follow your doctor's instructions about preparing for it.
- If you decide to choose kidney supportive care, talk to your doctor about a care plan for you.
- You can change your treatment later if you decide to do so. (Refer to page 24)
- No matter what your decision is, you should always discuss about Advance Care Planning (ACP) with your medical team. You can find out more here: https://www.livingmatters.sg/

# 3.1. Comparing your treatment options

## Use this table to consider the factors that may help you choose a treatment:

Your Kidneys, Your Plan	Dialysis		Kidney Supportive Care
four Kiulleys, four Flam	Peritoneal Dialysis (PD/Water Dialysis)	Hemodialysis (HD/Blood Dialysis)	(KSC/Conservative Management)
Your treatment	Dialysis at home, done daily.	Dialysis at a centre, done 3-4 times a week.	Medicine and monitoring by your medical team.
Getting Started	You need a surgery to create an access point on your belly.	You need a surgery to create an access point on your arm.	No preparation.
Treatment process	Clean dialysis fluid flows into your belly to remove toxins and fluids.	An artificial dialysis filter in the HD machine cleans your blood.	Manage your symptoms through diet and medicine.
Your suitability	May not be suitable if you had major surgery in or around your belly.	May not be suitable if you have a weak heart or poor blood vessels.	More suitable for people aged 75 and above with multiple health conditions or limited life expectancy <sup>2</sup> .
Your treatment risks	Chance of infection. You need to keep the access points clean.		No treatment-related risks.
Your daily activities	Flexible dialysis schedule.	Fixed dialysis schedule.	Take medicine as prescribed.
Your diet	There are some food and fluid limitations.		
Your travel plan	You need to bring your PD equipment when you travel.	You need to arrange to go to a dialysis centre for HD wherever you travel. Insurance may not cover overseas dialysis cost.	You can travel if you feel well.
Your home	You need to store the dialysis bags and a small dialysis machine at home. You need to keep your home clean.	No impact.	No impact.
Your support	You may need help to do dialysis at home. Your caregiver will need training on how to do it. Nurses can be contacted 24 hours a day for support.	You may need someone to help you travel to and from the dialysis centre.	Your medical team can support you and your family when needed. You can request a community nurse to visit you at your home.

18

# Here is a summary of what is known about the survival rates regarding each treatment option:

Vous Kidnove, Vous Dlan	Dialysis		Kidney Supportive Care			
Your Kidneys, Your Plan	Peritoneal Dialysis (PD/Water Dialysis)	Hemodialysis (HD/Blood Dialysis)	(KSC/Conservative Management)			
Survival	<ul> <li>Current age</li> <li>Overall health and other health problems (e.g., diabetes, heart disease, obesity)</li> </ul>					
Median Survival <sup>3</sup> : The length of time when half of patients under a treatment are no longer alive.						
Age 70 – 74	<b>4.4</b> Years	<b>5.1</b> Years	<b>1.3 – 2.5</b> Years			
Age 75+	<b>3.8</b> Years	<b>3.6</b> Years	<b>1.3 – 2.5</b> Years			
5 year survival rate <sup>3</sup> : Each diagram has 10 people. The blue people are the number out of ten expected to be alive in 5 years. Alive Dead						
	<b>4</b> in 10 (40%) PD patients are expected to be alive in 5 years.	<b>5</b> in 10 (50%) HD patients are expected to be alive in 5 years.	1 in 10 (10%) KSC patients are expected to be alive in 5 years.			
Age 70 - 74	40% <b>TṛTTTTTT</b>	50% TTTTTTTTTT	10% TTTTTTTTTT			
	<b>3</b> in 10 (30%) PD patients are expected to be alive in 5 years.	<b>4</b> in 10 (40%) HD patients are expected to be alive in 5 years.	1 in 10 (10%) KSC patients are expected to be alive in 5 years.			
Age 75+*	30% TTTTTTTTT	40% TTTTTTTTTT	10% TTTTTTTTT			

<sup>\*</sup> For all Singaporeans aged 75+, 9 in 10 (90%) people are expected to be alive in 5 years.

## Here is a summary of what is known about the benefits, risks and costs of each treatment option:

Your Kidneys, Your	Dialysis		Kidney Supportive Care	
Plan	Peritoneal Dialysis (PD/ Water Dialysis)	Hemodialysis (HD/Blood Dialysis)	(KSC/Conservative Management)	
	Dialysis may help manage your symptoms. However, the side effects of treatment may lower quality of life. Dialysis also does not help with other serious health problems (such as diabetes or heart problems).  Getting dialysis also reduces time for other activities.		KSC may help manage your symptoms. Usually quality of life remains stable until the last 1-2 months of life, when it begins to drop steadily.  You can go on with your daily activities.	
Quality of Life	A study with elderly (aged 75 and above) people with Kidney Failure in Singapore showed the following <sup>2</sup> :  • Dialysis and KSC patients had similar physical and mental well-being.  • The effect of kidney disease on daily life was higher among dialysis patients than among KSC patients.			
Side effects	If PD is done well, you will have few side effects. If PD machine is not kept clean, it may lead to infection.  Your sleep may be disturbed if you do APD.	<ul> <li>After a dialysis session, you may:</li> <li>Feel tired.</li> <li>Have low blood pressure.</li> <li>Feel dizzy.</li> <li>Need a few hours to fully recover.</li> </ul>	You will likely have the symptoms of Kidney Failure. Medicine and lifestyle changes can help reduce these symptoms. However, the medicine may have some side effects.	
Treatment risk	You may face:  Bleeding at surgery site. Intestinal injury. Painful infection around catheter. Other problems with catheter (e.g. blockage).  These problems may be solved with medicine or minor surgery.	<ul> <li>You may face:</li> <li>Vein blockage.</li> <li>Blood infection.</li> <li>Painful infection and clotting around catheter.</li> <li>Other problems with graft or catheter (e.g. blockage).</li> <li>These problems may be solved with medicine or minor surgery.</li> </ul>	There are no treatment-related risks.	
Total expected cost (SGD) of dialysis without medication and consultation (before subsidy)	You can use Medishield Life and Medisave to pay for dialysis.  You can check with your medical social worker if you qualify for aid from the Voluntary Welfare Organisations (e.g. NKF, KDF).  CAPD: \$1,100-\$1,300 per month.  APD: \$1,600-\$1,800 per month excluding electricity bill.  \$2,500-\$3,000 per month excluding transport cost.		There will be costs for medicines and consultations. There are no costs related to dialysis.	

## 3.2. What if you want to stop dialysis

After getting dialysis for a while, some patients may feel that they do not want to continue with dialysis anymore.

Some reasons a patient might want to stop dialysis are:

- To reduce hospitalizations due to complications related to dialysis,
- To reduce care burden related to dialysis,
- To focus on maintaining quality of life,
- To focus on spending quality time with family and friends towards the end of life.

The decision to stop dialysis is a personal one as patients have different needs and preferences. If you are considering stopping dialysis, talk to your family and doctor about your concerns and discuss a plan for Kidney Supportive Care.



# 4. Advice for family caregivers

It can be hard to help your loved one. Here are some insights on how to support them:

- 1. Try to understand what is most important to your loved one when managing his/her disease
- 2. Try to understand what kind of fears and concerns your loved one has
- 3. Ask your loved one what kind of treatment he/she wants
- 4. Respect the preferences of your loved one
- 5. Help your loved one communicate what he/she wants to his/her doctor
- 6. Do not hesitate to discuss your questions with your loved one's medical team

#### Remember...

- It is important to make a timely decision. If no decision is made and your symptoms get worse, you may need emergency care and go through a treatment you do not want. So, plan ahead and choose a treatment in time.
- There is no right or wrong choice.
- You may be able to change your treatment if you wish. Talk to your loved ones and doctor about it.
- Caring for your health is an ongoing process. You don't have to finish the conversation all at once.

If you have further questions, please ask your doctor.

If you need to talk to someone about how you feel or worry about the treatment cost, please ask to see a social worker.

If you need more information about Kidney Failure, please visit these sites:

National Kidney Foundation: https://www.nkfs.org/ Kidney Dialysis Foundation: www.kdf.org.sg/

To contact us about this booklet, email: lcpc@duke-nus.edu.sq

To cite: Ozdemir S, Choong LHL, Gan SSW, Yee ACP, Lim LWW, Jafar TH, Malhotra C, Vishwanath P, Tan SNG, Lee JJ, Finkelstein EA. My Choice for My Kidneys: Information Guide for Elderly Patients with Kidney Failure. Lien Centre for Palliative Care: Singapore (2019). https://www.duke-nus.edu.sg/lcpc/research/projects-by-themes/retreat.

The authors have no conflict of interest.

The development of this booklet was funded by the National Medical Research Council (NMRC/HSRG/0080/2017) and the Lien Centre for Palliative Care. This study has been approved by the Central Internal Review Board (2018/2350) of SingHealth.

We would like to thank the following persons and institutions for their participation and support in the development of this booklet:

- Department of Renal Medicine, Singapore General Hospital
- National Registry of Diseases Office
- RETREAT Research Team members
- RETREAT Advisory Panel members

This booklet was last updated in June 2020.

- Incidence, Prevalence, Patient Characteristics, and Treatment Modalities. Retrieved from https://www.usrds.org/2018/view/v2\_01.aspx
- Seow, Y., Cheung, Y. B., Qu, L. M., & Yee, A. C. (2013). Trajectory of Quality of Life for Poor Prognosis Stage 5D Chronic Kidney Disease with and without Dialysis. *American Journal of Nephrology*, 37(3), 231-238. doi:10.1159/000347220
- 3. National Registry of Diseases Office, Health Promotion Board

#### The following documents were referenced during the development of the booklet:

- Singapore Renal Registry Annual Report 2016 NRDO. Retrieved from https://www.nrdo. gov.sg/docs/librariesprovider3/default-document-library/singapore-renal-registry-annual-re-port-2016\_1999-till-2016\_v5\_online\_final.pdf?sfvrsn=0
- Carson, R. C., Juszczak, M., Davenport, A., & Burns, A. (2009). Is Maximum Conservative Management an Equivalent Treatment Option to Dialysis for Elderly Patients with Significant Comorbid Disease? *Clinical Journal of the American Society of Nephrology,4*(10), 1611-1619. doi:10.2215/cjn.00510109
- 6. De Biase V, Tobaldini O, Boaretti C, et al. Prolonged conservative treatment for frail elderly patients with end-stage renal disease: the Verona experience. *Nephrol Dial Transplant. 2008*; 23(4):1313–1317. doi:10.1093/ndt/qfm772
- Silva-Gane, M. D., Wellsted, D., Greenshields, H., Norton, S., Chandna, S. M., & Farrington, K. (2012). Quality of Life and Survival in Patients with Advanced Kidney Failure Managed Conservatively or by Dialysis. Clinical Journal of the American Society of Nephrology, 7(12), 2002-2009. doi:10.2215/cjn.01130112
- 8. Thorsteinsdottir, B., Murad, M. H., Montori, V., & Prokop. (2013). Ageism vs the technical imperative applying the GRADE framework to the evidence on hemodialysis in very elderly patients. *Clinical Interventions in Aging*, 797. doi:10.2147/cia.s43817
- Seow, Y., Cheung, Y. B., Qu, L. M., & Yee, A. C. (2013). Trajectory of Quality of Life for Poor Prognosis Stage 5D Chronic Kidney Disease with and without Dialysis. *American Journal of Nephrology*, 37(3), 231-238. doi:10.1159/000347220
- 10. Murtagh, F. E., Addington-Hall, J. M., & Higginson, I. J. (2011). End-Stage Renal Disease: A New Trajectory of Functional Decline in the Last Year of Life. *Journal of the American Geriatrics Society, 59*(2), 304-308. doi:10.1111/j.1532-5415.2010.03248.x
- 11. Tan Tock Seng Hospital, Ministry Of Health, Dialysis Counselling Booklet Kidney Research UK, Dialysis: making the right choices for you
- 12. Murtagh, F. E., Marsh, J. E., Donohoe, P., Ekbal, N. J., Sheerin, N. S., & Harris, F. E. (2007). Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5. *Nephrology Dialysis Transplantation*, 22(7), 1955-1962. doi:10.1093/ndt/gfm153
- Chandna, S. M., Silva-Gane, M. D., Marshall, C., Warwicker, P., Greenwood, R. N., & Farrington, K. (2010). Survival of elderly patients with stage 5 CKD: Comparison of conservative management and renal replacement therapy. *Nephrology Dialysis Transplantation*, 26(5), 1608-1614. doi:10.1093/ndt/gfq630



