# Discussing Prognosis with Patients on Dialysis Resource for healthcare providers

## **Disclosing prognosis**

Advanced chronic kidney disease (CKD) is a serious illness. In alignment with Choosing Wisely Canada (2014), it is recommended that treatment decisions (including initiating dialysis) reflect the patient's wishes, values, and beliefs for their care. In order for the patient (or, if the patient is incapable, the Substitute Decision Maker [SDM]) to engage in meaningful conversations about their current and future care, nephrologists should disclose prognosis and the risks and benefits of dialysis, as a part of informed consent (Cohen, Ruthazer, Moss & Germain; 2010). Depending on the patient's preference and risk for mortality, disclosure of prognosis can also lead to the early identification of individuals who may benefit from palliative care.

## Survival data

While a simple, reliable formula for predicting survival in individual patients on dialysis remains unavailable, there is survival data demonstrating the 1-, 3- and 5-year average survival estimates for patients within different age groups. Studies that identify clinical features predicting shorter survival (e.g., co-morbidities) are also available, and can be used to further engage the patient (or SDM) in a conversation on their illness understanding.

Using this data, nephrologists can stratify patients into those who are at a low, medium, or high risk for mortality within the first three years after initiating dialysis.

### **Quick facts**

Ontario Renal Reporting System data from a 2007–2011 incident dialysis patient cohort indicate:

- The median overall survival time on dialysis is approximately 5 years.
- For patients starting dialysis in Ontario, the approximate overall 1-year survival is 88%, 3-year survival is 70%, and 5-year survival is 52%.
- Survival on dialysis varies substantially with age. For patients starting dialysis at under 50 years of age, the approximate overall 1-year survival is 95%, 5-year survival is 80%, and 10-year survival is over 50%.
- In contrast, for patients starting dialysis at over 80 years of age, the approximate overall 1-year survival is 80%, 5-year survival is 33%, and 10-year survival is 8%.

# Survival estimates for patients on chronic dialysis

Using data from the Ontario Renal Reporting System, two cohorts of incident chronic dialysis patients (2007–2011 cohort to estimate 1-, 3- and 5-year survival, and 2001–2005 cohort to estimate 10-year survival) in Ontario were analyzed. The tables on page 2 demonstrate the 10-year survival estimates by age. As diabetes is a significant factor underlying early mortality in patients who are on dialysis, the cohort was further stratified by diabetic status.

Note that the estimation of 10-year survival probability was determined using data from The Renal Disease Registry and represents mainly Toronto Central region data.



#### Table 1: 10-year survival in chronic dialysis patients, non-diabetic, Ontario, 2001-2005 with follow-up 2001-2016

Age group	Survival estimates: non-diabetic*				
	1 year	3 year	5 year	10 year	
20–40 years (n=347)	98.5%	97.3%	95.2%	80.9%	
41–50 years (n=361)	96.0%	92.2%	87.9%	71.1%	
51–60 years (n=461)	91.5%	83.3%	78.1%	51.3%	
61–70 years (n=541	88.0%	77.6%	66.9%	36.0%	
71–80 years (n=910)	83.9%	65.0%	48.9%	16.8%	
>80 years (n=632)	79.9%	54.1%	34.2%	10.9%	

\*Confidence intervals for survival estimates are available upon request from the Ontario Renal Network.

## Table 2: 10-year survival in chronic dialysis patients, diabetic (type 1 or type 2), Ontario, 2001-2005 with follow-up 2001-2016

Age group	Survival estimates: diabetic (type 1 or type 2)*				
	1 year	3 year	5 year	10 year	
20–40 years (n=113)	95.3%	85.1%	78.1%	39.6%	
41–50 years (n=231)	94.7%	83.2%	71.6%	34.7%	
51–60 years (n=548)	92.8%	78.1%	64.5%	28.8%	
61–70 years (n=830)	89.8%	70.6%	55.3%	21.4%	
71 –80 years (n=843)	82.7%	61.4%	43.6%	13.4%	
> 80 years (n=323)	79.8%	48.0%	30.1%	4.1%	

\*Confidence intervals for survival estimates are available upon request from the Ontario Renal Network.

## Guideline recommendations for discussing risks and benefits with patients

As indicated in the Person-Centred Care Guideline (Cancer Care Ontario, 2015), the following principles are recommended when discussing risks and benefits with a patient (or SDM):

- Be aware that different people interpret terms such as rare, unusual and common in different ways. Use numerical data if available.
- Personalize risks and benefits, as much as possible.
- Use natural frequency rather than a percentage (e.g., 10 in 100, versus 10 percent).
- Include both positive and negative framing (e.g., treatment will be successful for 97 out of 100 patients, and unsuccessful for 3 out of 100 patients).

For more tips on how to facilitate conversations on illness understanding and prognosis with a patient (or SDM), please see: Approaches to Goals of Care Conversations: Resource for healthcare providers.

For more information about the Ontario Renal Network please visit renalnetwork.on.ca

