

**“LET’S TALK  
CKD”**

# CKD Discussion Companion



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**Start**





# CKD Disclosure Companion

Suggestions to help disclose a CKD diagnosis to a range of patients

**This disclosure companion has been developed by physicians and behavioural scientists, and validated by a patient panel.**



## BENEFITS OF EARLY DISCLOSURE

Click here to learn more about the benefits of an early CKD diagnosis disclosure.



## GENERAL GUIDANCE

Click here if you want to feel more prepared for disclosure conversations in general.



## DIFFICULTY UNDERSTANDING THE DIAGNOSIS

Click here for help with a patient who:

- Struggles to understand English
- Has low health literacy
- Has hearing, vision or cognitive impairment



## DIFFICULTY COPING WITH THE DIAGNOSIS

Click here for help with a patient who:

- Has other long-term health conditions
- May struggle to cope with the diagnosis, either mentally or practically
- Has a diagnosed mental health condition



## DIFFICULTY ACCEPTING THE DIAGNOSIS

Click here for help with a patient who:

- May be shocked or surprised by the diagnosis
- May underestimate the seriousness of the diagnosis



# CKD Disclosure Companion

## Benefits of disclosing a CKD diagnosis early



Avoiding (or delaying the time to) dialysis



Slowing progression to advanced stages of CKD



Improving survival with better quality of life

## Learn more about the benefits in the Disclosure Matters videos as part of this toolkit



Disclosure Matters...  
To You



Disclosure Matters...  
To Your Patients



Disclosure Matters...  
To Your Healthcare System



# CKD Disclosure Companion

## General guidance



### Explain what CKD is and that symptoms may not appear until later stages



Explain CKD in simple terms and add details if you feel the patient understands



Be clear that CKD is a disease and not just a risk factor for further kidney issues



Highlight that people can lose up to 90% of their kidney function without showing any symptoms<sup>1</sup>

Your kidneys are not working as well as they should be, which we call CKD, or chronic kidney disease

You may not notice any symptoms until your kidney function is dangerously low, so it's important to keep managing this, even if you feel well<sup>1</sup>



### Explain that early diagnosis means your patient may be able to delay progression with proper management



Reassure your patient that you can work together to make sure CKD is manageable



If you explain how CKD relates to other chronic condition(s), they could be motivated to manage their health better



Keep your language non-judgemental: your patient may become defensive if they feel scolded

We can't cure your CKD with medicines, but, if we work together, we can help slow down further damage to your kidneys

CKD is more common in people who have diabetes/high blood pressure/CVD<sup>2</sup> so it's important that we work together to manage your conditions



# CKD Disclosure Companion

## General guidance



**If your patient appears shocked/upset, or has difficulty understanding the diagnosis, consider a follow-up appointment**



If your patient is shocked or upset, they may not be able to concentrate



Allow your patient to ask questions and reassure them that you can discuss managing CKD when they are ready



Suggest resources that your patient can access for more information



If needed, ask for support from your practice nurse to help manage follow-up appointments

**I see that you are upset/angry and that's OK. It can be upsetting to hear about this diagnosis. When you are ready, I will answer any questions**

**Do you want me to call someone for you?**

**Please make an appointment to come back in a few weeks so we can discuss any more questions that come up**



**Provide options for positive action and agree on a plan together**



Help your patient feel involved in the decision-making process. They may be more likely to adhere to any treatment or lifestyle changes



Ask your patient for suggestions and help them come up with a realistic plan for positive action



If you create a plan and set goals together they are more likely to feel accountable for their self-management

**How are your current medications working for you?**

**What challenges are you facing with your eating/exercise habits?**

**What do you think is realistic based on your current lifestyle?**

# CKD Disclosure Companion

## Difficulty understanding the diagnosis



### How to identify this type of patient



Difficulty speaking or understanding English



Hearing, vision or cognitive impairments



Difficulty understanding health issues/advice you have discussed in the past



Difficulty explaining their health condition(s) or treatment(s)



Asking the same questions again, even when you have given an answer



Follow your instincts – if you feel that the patient doesn't understand, they probably don't



### Action points



**Reassure your patient** that CKD is sometimes difficult to understand but that you can try to answer any questions



**Arrange multiple follow-up visits** and consider including colleagues who also have a relationship with the patient



**Consider including a care partner or a translator** if your patient has impairments or language difficulties



**Ask them to repeat** what you said if you are unsure if they understood you



**Point out useful resources**, such as video explanations and leaflets, to help them understand CKD in their own time



### Example phrases

CKD is difficult to understand and that's OK. We can work together to make sure that you know what to do to manage it

If you don't understand, please tell me. I want to make sure you know what this disease means for you and how we can manage it

Please can you tell me what you understand about what I've explained?



### Scenario video: trouble understanding the diagnosis





# CKD Disclosure Companion

## Difficulty coping with the diagnosis



### How to identify this type of patient



May struggle to cope with the diagnosis, either mentally or practically



Has long-term health conditions that are not well managed



Has limited family/social support to help cope



May have a diagnosed mental health condition



Gets upset, angry or stops interacting with you



Says that these types of things always happen to them, that they do not know what to do, or statements such as ‘Why me?’



### Example phrases

I see that you are upset/angry and that’s OK/normal/understandable. When you are ready, I can try to answer any questions you have

Do you want me to arrange your next appointment with your nurse?

Do you want me to call someone for you?



### Action points



**Consider referring to a mental health professional** if they have a diagnosed mental health condition or their reaction concerns you



**Give them time** to consider what you have said and express their emotions



**Wait** until you are sure they are ready to listen



**Arrange a follow-up appointment**, this could be with a nurse that they are familiar with



**Assure them** that they are not alone and recommend they connect with other CKD patients for support



### Scenario videos

Existing long-term health conditions



Perceived as being unable to cope



Diagnosed mental health condition





# CKD Disclosure Companion

## Difficulty accepting the diagnosis



### How to identify this type of patient



Young and/or no other chronic health concerns



Appear shocked, surprised or concerned, as they are unlikely to expect the CKD diagnosis



May say that the diagnosis must be wrong as they feel fine or argue that the numbers must be wrong



Appear dismissive and appear to underestimate the seriousness of the diagnosis



### Example phrases

I see that this has come as a shock. It can be upsetting to hear about this diagnosis. I can try to answer any questions that you have when you are ready

If we work together to make a plan, we can try to slow progression and stop further damage to your kidneys

Not everyone with CKD has obvious symptoms; you could even get down to 10% kidney function before having symptoms



### Action points



**Keep your language non-judgemental:** your patient may become defensive if they feel they are being scolded



**Allow your patient** to express their concerns



**Focus on positive action** and that they have control over the choices they make



**Reassure the patient** that CKD is manageable and that you can work together to make sure they have the right guidance and treatment



**Reinforce that being symptom free isn't disease free.** However, with the proper management, you both can stop progression



### Scenario video: difficulty accepting the diagnosis

