

Plain English Summary

Tolvaptan for treating autosomal dominant polycystic kidney disease

What does the guidance say?

Tolvaptan is not recommended for government subsidy for patients with autosomal dominant polycystic kidney disease.

What is polycystic kidney disease?

Polycystic kidney disease (also called PKD) – is a genetic disorder that causes cysts to grow in the kidneys. If too many cysts grow, they can damage and change the shape of kidneys. Over time, this can cause the kidneys to lose their ability to filter waste from the blood, leading to a gradual decline in kidney function.

There are two main inherited types of PKD, autosomal dominant PKD and autosomal recessive PKD. Autosomal dominant PKD is the most common type, with each child of an affected parent having a 50% chance of inheriting the disease. Symptoms usually develop in adults between 30 to 40 years of age, but they can also begin in childhood.

People with PKD who have lost up to 75% of their kidney function may have few or no symptoms. As PKD worsens, patients may experience symptoms such as abdominal pain, high blood pressure, blood in the urine, kidney stones, and urinary tract infections.

What is tolvaptan?

Tolvaptan belongs to a group of medicines called vasopressin antagonists. It slows the growth of kidney cysts and the decline in kidney function. It is taken orally.

Why was tolvaptan not recommended for subsidy?

ACE evaluates how well a treatment works in relation to how much it costs compared to other treatments. Tolvaptan was not recommended for government subsidy because its benefits do not justify its cost. If you need tolvaptan for treating autosomal dominant PKD, you can speak to a medical social worker to find out if there is other financial assistance available to help with the cost of treatment.



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Is this the right treatment for me?

Your doctor may recommend you have tolvaptan if other treatments cannot adequately control your condition. Your doctor should give you clear information, listen to your views and concerns, and talk to you about your treatment options. Some of the questions you may want to ask your doctor when making decisions about your care are:

- How will the treatment affect my day-to-day activities?
- How well does it work compared to other treatments?
- What are the side effects and risks of treatment, and how likely are they?
- How much does the treatment cost?
- How long will I need to be on the treatment for?
- What happens if the treatment stops working?
- What happens if I do not want to have treatment?

Published: 4 June 2024

Agency for Care Effectiveness - ACE in Agency for Care Effectiveness (ACE)

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This summary is not, and should not be regarded as, a substitute for professional or medical advice.

Please seek the advice of a qualified healthcare professional about any medical condition.

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