

Tolvaptan for treating autosomal dominant polycystic kidney disease

Information for the public

Published: 28 October 2015

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What has NICE said?

Tolvaptan (Jinarc) is recommended as a possible treatment for people with autosomal dominant polycystic kidney disease if:

- they have chronic kidney disease stage 2 or 3 at the start of treatment and
- there is evidence of rapidly progressing disease.

What does this mean for me?

If you have rapidly progressing autosomal dominant polycystic kidney disease with chronic kidney disease stage 2 or 3 at the start of treatment, and your doctor thinks that tolvaptan is the right treatment, you should be able to have the treatment on the NHS.

Tolvaptan should be available on the NHS within 3 months of the guidance being issued.

If you are not eligible for treatment as described above, you should be able to continue taking tolvaptan until you and your doctor decide it is the right time to stop.

Why has NICE said this?

NICE looks at how well treatments work in relation to how much they cost compared with other treatments available on the NHS.

Tolvaptan was recommended because the benefits to patients justify its cost.

The condition and the treatment(s)

Autosomal dominant polycystic kidney disease is an inherited condition that causes cysts (small, fluid-filled sacs) to grow in the kidneys. Over time these cysts get bigger and affect the way the kidneys work.

Tolvaptan (Jinarc) slows the growth of cysts and helps the kidneys work properly.

NHS Choices (www.nhs.uk) may be a good place to find out more.

Sources of advice and support

- British Kidney Patient Association, 01420 541 424, www.britishkidney-pa.co.uk
- Kidney Research UK, 0845 070 7601, www.kidneyresearchuk.org
- Polycystic Kidney Disease (PKD) Charity UK, 0300 111 1234, www.pkdcharity.org.uk
- National Kidney Federation, 0845 601 0209, www.kidney.org.uk

NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

ISBN: 978-1-4731-1486-9

Accreditation

