

Belzutifan for treating tumours associated with von Hippel-Lindau disease

Information for the public

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Belzutifan (Welireg) is available during the [managed access](#) period. It is a possible treatment for tumours associated with von Hippel-Lindau (VHL) disease in adults when localised procedures such as surgery are unsuitable or not wanted. These tumours include renal cell carcinomas, central nervous system hemangioblastomas or pancreatic neuroendocrine tumours.

More evidence on belzutifan is being collected. After this, NICE will decide whether to recommend belzutifan for use on the NHS and update the guidance. It will be available with managed access until then.

If you are not eligible for belzutifan but are already having it, you should be able to continue until you and your healthcare professional decide when best to stop.

Is this treatment right for me?

Your healthcare professionals should give you clear information, talk with you about your options and listen carefully to your views and concerns. Your family can be involved too, if you wish. See [our webpage on making decisions about your care](#).

Questions to think about

- How well does it work compared with other treatments?
- What are the risks or side effects? How likely are they?
- How will the treatment affect my day-to-day life?
- What happens if the treatment does not work?
- What happens if I do not want to have treatment? Are there other treatments available?

Information and support

These organisations can give you advice and support:

- [VHL UK/Ireland](#), support@vhl-uk-ireland.org
- [Action Kidney Cancer](#), 0800 121 8721

You can also get support from your local [Healthwatch](#).

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

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