

VHL questions to ask



**NeuroEndocrine
Cancer Australia**

It can be difficult to know what questions to ask during an appointment with a medical specialist. Asking questions can help you better understand von Hippel-Lindau (VHL), your risk or type of associated conditions, and about treatments options.

It is okay if you do not know where to start. This fact sheet can help guide you.

General VHL Questions

- How is VHL diagnosed?
- What are the risk factors for developing VHL?
- Which specialists will I see for ongoing care of my VHL?
- How often should I see each specialist?
- Will I have a main specialist responsible for my care?
- Which symptoms should prompt me to seek medical attention?
- Who is the best contact person if I'm experiencing symptoms related to VHL?
- How does VHL typically progress over time?

Cyst/tumour/cancer questions

- Where is my tumour/cyst located, and are there any other tumours/cysts in my body?
- When should I be concerned about this cyst or tumour?
- Is my case discussed in a multidisciplinary meeting?

Diagnosis, screening, and investigations

- How often will I need to have blood tests, urine tests, or scans to monitor my VHL?
- Where do I get these tests done? At my local hospital or elsewhere?

Treatment and management of VHL

- What are my treatment options for VHL?
- Why have you chosen this treatment option for me?
- What are the possible side effects that I might experience (short term and long term)?

- How long will I be having this treatment for?
- Are there any considerations to be aware of whilst having this treatment (e.g. work, travel)?
- Is there a cost for my treatment?
- How will the treatment affect my day-to-day life?
- Are there less invasive treatment options available?
- Is belzutifan a potential treatment that I could access?

Ongoing management

- What will be the ongoing plan in terms of monitoring and investigations?
- Can I have a written care plan (a plan that outlines my follow-up care, ongoing monitoring, long-term health management etc.)?
- What lifestyle changes can help support my ongoing health?
- Are cysts and/or tumours likely to return or spread to other organs?
- What symptoms might suggest that a cyst/tumour has returned or progressed?
- Will VHL or treatment affect my fertility? If so, who can I speak to for fertility counselling?

Genetics

- Was VHL passed down in the family (inherited) or a new genetic change (sporadic)?
- Who do I see for genetic counselling and testing?
- How do I access a genetic counsellor?
- Are my family members at risk of developing VHL?
- How do I talk to my family about getting genetic counselling and testing?



Support



Education



Research



Awareness



Advocacy

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- What potential risks could this have for my children or future children (e.g. can they develop VHL)?
- What do I need to consider when thinking about starting a family?

Clinical trials (if available)

- What clinical trials are currently on offer for VHL?
- Where can I find out more information about VHL clinical trials?
- Is there a cost associated with these clinical trials?
- How do I find out if I'm eligible for a clinical trial?

Support and resources

- Where can I find out more information regarding VHL?
- Is there a support group where I can connect with others who have VHL?
- Are there resources for explaining VHL to my family or employer?
- Who can I talk to if I'm feeling anxious or overwhelmed?
- Is there a nurse or care coordinator who can help me navigate me through this?

Finance

- What are the costs associated with my treatment, scans, or tests?
- Are my scans and treatment covered by Medicare or private health insurance?
- Is there any financial aid available to support me?
- Can a social worker or financial counsellor assist with navigating costs?
- Are travel and accommodation support available for specialist appointments or treatment if I live in a rural or regional area?

Contact NeuroEndocrine Cancer Australia

If you need further support or information about neuroendocrine cancer, contact the NET nurses at NeuroEndocrine Cancer Australia on 1300 287 363, Monday–Friday, 9am–5pm.

NET Nurse 1300 287 363

netnurse@neuroendocrine.org.au

[Schedule a time that suits you](#)



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