

GENETIC TESTING IS A COMPLEX PROCESS AND THE INFORMATION YOU RECEIVE MAY FEEL OVERWHELMING



**Macular
Disease
Foundation**
AUSTRALIA

This is a free checklist of questions you could ask when first diagnosed with a genetic eye condition. The questions may be directed to your ophthalmologist and/or the genetic counsellor if you're having genetic testing.

Disease Characteristics

- ☐ What is this disease? (explanation of the disease)
- ☐ How common is it?
- ☐ What is the genetic cause of the disease? How/why did I get it?
- ☐ Is it genetic/inherited? Can I pass it on to my children?
- ☐ Is the disease curable?

Impact of Disease

- ☐ What does this disease mean for me?
- ☐ How will it affect me and my vision? What will be the impact on my daily life?
- ☐ What are the symptoms? Will this change over time?
- ☐ What is the progression of the disease?
- ☐ Is it likely to get worse?
- ☐ What is the prognosis?
- ☐ What can I expect? What does the future hold for me?
- ☐ What is the likely outcome?
- ☐ What quality of life can I expect?
- ☐ Am I at risk of developing disease elsewhere in my body because of the genetic change?

Treatment

- ☐ What are the treatment options available? What are the alternatives?
- ☐ What will the outcome of treatment be?
- ☐ How do I find a specialist to treat my disease?

Support

- ☐ Is there a support group for my disease? If so, what is the name of the support group?
- ☐ How can I connect to other people who have this disease?
- ☐ What support, help and advice is available and how do I access it?
- ☐ What financial/income help is available?
- ☐ Where else can I get good information from? Any websites? Printed information?
- ☐ Where can I get counselling?

Self-management

- ☐ What do I do now?
- ☐ How can I manage the disease? How do I live with the disease?
- ☐ How can I manage my day-to-day living?
- ☐ What changes should I make to my lifestyle?
- ☐ How do I avoid or delay the onset of symptoms?

Research

- ☐ What research is being conducted on my disease?
- ☐ How can I access research such as clinical trials?

Eye health checklist

- ☐ have regular eye examinations, including a check of the macula
- ☐ don't smoke
- ☐ live a healthy lifestyle, control your weight, and exercise regularly
- ☐ make sure your diet includes two-three servings of fish (oily fish is preferable) per week, daily serves of dark green leafy vegetables, daily serves of fruit, and a handful of nuts a week
- ☐ limit your consumption of fats and oils
- ☐ choose low glycemic index (GI) carbohydrates instead of high GI, whenever possible
- ☐ ask your doctor about taking a dietary supplement if food intake is inadequate
- ☐ protect your eyes from sunlight with sunglasses and a wide-brimmed hat
- ☐ use an Amsler grid regularly to check for changes in your vision.

Important: Check with your doctor before making any changes to your diet or lifestyle.



Need more information?

Learn more about macular disease at www.mdfoundation.com.au.

How's your macula? Take the quiz at www.CheckMyMacula.com.au.

You can also access our free, personalised support services and order information kits and Amsler grids by calling our National Helpline on **1800 111 709**.

MDFA has a free newsletter and you can sign up to receive invitations to education sessions and events in your area.

Macular Disease Foundation Australia is committed to reducing the incidence and impact of macular disease, by providing up-to-date information, advice and support.

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