

What else can I do to help my glaucoma?

I am often asked by patients after we have discussed their eyedrops and follow-up plan, “But what else can I do to help my glaucoma?”

There is also a small group of patients where their glaucoma appears to be getting remorselessly worse despite apparently well controlled eye pressures. For these people we want to pull out all the stops, and so give the sort of advice that follows.

The most important point is that we want to keep your eye pressure at a safe level all day every day: never forget your eyedrops, be sure that they are getting in your eyes, and make sure you are having regular checks. But there is more: diet and lifestyle choices may alter eye pressure, alter blood flow to the optic nerve, and alter apoptosis (the process of loss of nerve fibres). The evidence for what follows is variable; with some pieces of advice having better evidence to support them than others.

I recommend regular exercise: there is good evidence that this is beneficial for your glaucoma. There is soft evidence that leading a

generally healthy life, what for instance is good for your heart, may help with glaucoma. Eat a diet rich in fruit and vegetables, omega 3 fatty acids rather than omega 6, lower your cholesterol, and maintain a healthy weight. Do not drink a lot of (any) fluid over a short period of time, as this can cause spikes in your eye pressure.

In advanced glaucoma avoid sleeping on your worst side, don't sleep face down, and consider raising the head end of your bed on blocks. Don't have more than two cups of coffee a day. Maintain a healthy blood pressure: not too high but also not too low. Avoid weightlifting, head down yoga

positions, and prolonged playing of wind instruments.

There is evidence that nutritional supplements may be helpful, particularly ginkgo biloba and nicotinamide (3g per day). There is also evidence supporting taking the following: forskolin, PEA, anthocyanins (blackcurrant or bilberry extracts), and erigeron breviscapus. In NZ the most accessible options are Clinician's Optisight tablets and Blackmore's Insolar.



*Dr. James Stewart Ophthalmologist,
Counties Manukau Health*

Your Support Matters



It's my pleasure to share the latest updates with you on how your loyal support is helping people affected by glaucoma.

Earlier this year, thanks to a generous grant from the Freemason's Foundation, we initiated our community education & support programme, which enabled us to double the number of education sessions delivered in retirement villages and at community organisations. Thanks to your generous support, we have established eight new support groups, however Covid has delayed the start of these until early next year.

The Auckland patient symposium, Love your Eyes, was able to go ahead with a large audience hearing from four Ophthalmologists on a range of glaucoma topics. We are hopeful that restrictions will be lifted to enable us to deliver future symposiums in other regions.

I am truly grateful to the glaucoma specialists, who generously volunteer their knowledge & time to keep us up to date with the latest treatments, surgeries & research. In this issue Dr James Stewart and Professor Helen Danesh-Meyer present evidence that suggests vitamin B3 (nicotinamide) could play an important role in protecting against retinal ganglion cell damage that leads to blindness in glaucoma.

Childhood glaucoma is a rare type of glaucoma and there is little research out there that tells us about how the condition may impact on someone's life. A team of researchers in Adelaide are dedicated to putting the spotlight on childhood glaucoma. They are asking for your help to create better support systems and promote awareness of this rare condition

I would like to thank Elsa and Kellie for sharing their story. Covid has shown us all that life is full of unexpected twists and turns and adds a level of uncertainty to living with a progressive disease. However, we have also witnessed the power of communities pulling together and the difference it makes to know that you are not alone on this journey.

We can't thank YOU enough. Your generous contributions make it possible for us to be there with a free service to make a real difference in the lives of people affected by glaucoma.

I hope you enjoy this newsletter. Please feel free to get in touch at any time; we really value your feedback.

Warm regards,

Pippa

General Manager

Eyedrop Aids

Using eye drops can be a challenge for many patients, young or old. AutoDrop® and AutoSqueeze™ have been developed to make self-administration as simple as possible – helping to improve patient compliance and reducing reliance on others to help with this task.

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New Evidence for Neuroprotection

A clinical trial led by Melbourne researchers suggests vitamin B3 (nicotinamide) could play an important role in protecting against retinal ganglion cell damage that leads to blindness in glaucoma.

Vitamin B3, or nicotinamide, is a precursor of NAD+ (nicotinamide adenine dinucleotide) and is a critical co-enzyme found in every cell in the body. It is involved in hundreds of metabolic processes. There is some research that has indicated that glaucoma patients are low in NAD+ serum.

The nerve fibres of retinal ganglion cells are the cells that form the optic nerve, the nerve of sight. The retina is the part of the body with one of the highest metabolic demands. Therefore, retinal ganglion cells are normally under significant stress. In glaucoma, the retinal ganglion cells are under more stress than in a healthy eye. The theory is that B3 supplementation provides protection.

Recent work has indicated that

patients with primary open-angle glaucoma (POAG) have reduced serum levels of nicotinamide (NAM, the amide of vitamin B3 and precursor for NAD+).

The dosage used in this three-month study was very high – increasing to 3 grams of nicotinamide per day. Patients were given 1.5 grams/day for six weeks, then 3 grams daily for a further six weeks in addition to their regular glaucoma drops. The control group of patients received a placebo. The study design was a cross-over study. This means that after 12 weeks the patients in the treatment group were given a placebo while the patients in the placebo group were given the B3.

In order to avoid the side-effects of vitamin B3, patients were given nicotinamide which is the amide of

vitamin B3 and the precursor of NAD+. Patients only experienced mild gastro-intestinal side-effects with nicotinamide.

To measure success, patients had visual field testing and electroretinography. Electroretinography is a test that measures the electrical conduction of the retina and optic nerve. It is analogous to how an ECG measures the conduction of the heart.

The results the researchers found was that 23% of participants who took B3 showed improvement in their electrical conduction. There was a trend towards improvement for visual fields as well.

If you are interested in using nicotinamide, please discuss with your GP and ophthalmologist.



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Dietary supplements are not a replacement for a balanced diet. Always read the label, and use as directed. Do not exceed the recommended daily dose. If symptoms persist, see your healthcare professional. Douglas Pharmaceuticals Ltd, Auckland

Sleep and Glaucoma

Sleep is an essential part of everyday life. Though generally a time for healing, there are changes to the body's physiology and positioning that can have a negative effect on glaucoma and eye pressure.



This article highlights how sleep can affect eye pressure, optic nerve blood flow and glaucoma progression.

Intraocular pressure during sleep

Eye pressure is affected by the rate of aqueous fluid production and drainage. Although aqueous fluid production decreases during sleep, intraocular pressure actually increases due to blocking of the drainage system when lying flat. Overall, eye pressure increases 10-20% when both effects are considered.

Blood flow to the optic nerve during sleep

Blood pressure generally decreases during sleep and stays low throughout the night. This long duration of relative hypotension has been linked to worsening of glaucoma. However, lower night-time blood pressure in some hypertensive patients may decrease certain cardiovascular risks. In patients whose glaucoma is worsening despite what appears to

be good eye pressure control, either the patient or the ophthalmologist should have a discussion with the primary care doctor or internist to see if decreasing night-time blood pressure medicines could be safely undertaken.

Sleep Apnoea

Another process that can occur during sleep and could negatively affect glaucoma is sleep apnoea. Some individuals, especially those who are overweight or who snore heavily, may be prone to episodes of partial or complete cessation of breathing that happen during sleep. The patient may be totally unaware of these episodes, but the sleeping partner may notice the choking or gasping sounds. During these periods of reduced or absent breathing, there is a reduction in the oxygen going to the optic nerve causing further damage in glaucoma patients.

Also, these night-time episodes may be accompanied by daytime fatigue and sleepiness. Patients with sleep apnoea have a greater

likelihood of having glaucoma and, although not common, patients with glaucoma are more likely than the general population to have sleep apnoea. Because sleep apnoea can cause worsening of glaucoma, it is particularly important to recognize its presence and to appropriately treat it.

In any of the above conditions, close collaboration between the eye doctor and the primary care doctor can be both a vision saver and a life saver.

Adequate Sleep Benefits

Finally, too little, or too much sleep has been linked to worsening visual field defects in glaucoma patients and a higher rate of glaucoma. The ideal amount of sleep is different for each individual but varies from five to nine hours. In addition, adequate sleep has also been shown to benefit patients with conditions such as Alzheimer's disease, heart disease, kidney disease, high blood pressure, diabetes, stroke, and obesity — conditions which may also be present in glaucoma patients.

Love your Eyes

In August we held the Auckland Love your Eyes Symposium to inspire, inform, and educate glaucoma patients and their caregivers, providing a unique forum for learning about the latest treatment options and practical tips for living with glaucoma.

We would like to thank Dr Hussain Patel, Dr Sonya Bennett, Dr Divya Perumal, Dr Jim Stewart and Jas Walia, who generously volunteered their time to speak on a range of topics from effects of coffee & exercise to the types of glaucoma surgeries available.

Our audience also heard from Wendy Wrapson, a patient member who bravely shared her glaucoma story, highlighting the benefit of support

& friendship that she receives from her local glaucoma support group.

The symposium provided a unique opportunity for our speakers to provide in-depth explanations to questions from patients that they ordinarily may not have time to discuss during scheduled appointments. Further discussion continued over coffee, with the chance to review low vision aids



Symposium photos by Focal Point Photos

or book an escorted tour with Moa Tours.

This event was funded by Trillian Trust, Moa Tours & donations like yours. Thank you, as your ongoing commitment means we can continue to offer education events to support people living with glaucoma.

Mailbox Q & A



Why do some people only get Glaucoma in one eye and not in the other?

Most people with primary open angle glaucoma develop glaucoma in both eyes (although it is often asymmetrical, and in some people one eye may be significantly worse than the other). However, secondary glaucoma (glaucoma caused by a precipitating factor) is much more likely to occur in one eye only. Examples include trauma induced

glaucoma, neovascular glaucoma, uveitic glaucoma (in patients who have had inflammation in the eye) or glaucoma induced by surgery. As the precipitating factor is in one eye, then the glaucoma is in that affected eye only. If you are found to have glaucoma in one eye only, the optometrist or ophthalmologist will do a careful examination and ask you certain questions to help determine the underlying cause.



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Putting the spotlight on childhood glaucoma:

Childhood glaucoma is a rare type of glaucoma that is diagnosed before someone turns 18 years old. Living with childhood glaucoma can be challenging, and there is little research out there that tells us about how the condition may impact on someone's life.

A team of researchers at the Australian and New Zealand Registry of Advanced Glaucoma (ANZRAG) at Flinders University, Adelaide, are dedicated to putting the spotlight on childhood glaucoma. They want to help create better support systems, promote awareness of this rare condition, and give a voice to those living with childhood glaucoma.

Over the past 18 months, the ANZRAG researchers interviewed almost 50 adults with childhood glaucoma and asked them about the impact of the condition on their lives.

From these interviews, they report that adults with childhood glaucoma are resilient and adaptable to the challenges of living with the condition. It was also found that adults form a strong bond with their ophthalmologist and often rely on family and friends for emotional and social support.

Because childhood glaucoma is rare, it was common for research participants to sometimes feel lonely and misunderstood by their



Lachlan Knight

friends, family, or workplace. It was also very common for adults to feel worried and protective of their eye health because they did not want their vision to deteriorate or their eye pressures to increase.

The researchers also found that childhood glaucoma can impact on someone's decision-making when planning to have a family, for a variety of reasons. Adults often sought genetic testing to understand their risk of passing on their glaucoma to their child, and to seek peace of mind.

From these interviews, the ANZRAG researchers have made a questionnaire to measure the impact of childhood glaucoma.

They need as many adults with childhood glaucoma as possible to complete the questionnaire so that they can make sure that it is accurate.

The results of this research will help support groups and healthcare providers to better understand how

to support adults with childhood glaucoma wherever they are in their journey.

Can I complete this questionnaire?

If you are an adult and were diagnosed with any type of glaucoma before the age of 18 years, the ANZRAG would be greatly appreciative if you could complete this questionnaire. It only takes 10-20 minutes and is accessible to people with vision impairment.

To receive an electronic or hard copy of the questionnaire, or to complete it over the phone, please contact Lachlan or Karon for more information on how. You can also request a copy of the study results.

Contact information:

Lachlan (Flinders University)
Email: Lachlan.WheelhouseKnight@flinders.edu.au

Karon (Glaucoma New Zealand)
Phone: 0800 452 826

6 Ways You Can Help GNZ

If you are not able to donate today have you thought about leaving a legacy gift to support education & research to reduce the incidence and impact of glaucoma in Elsa's lifetime?

Imagine the world perhaps 50 years from now when Elsa is 63, managing her glaucoma without the fear or uncertainty of looming sight loss, and living her life with the confidence that her grandchildren will not be impacted as she was. What a special gift.

We do not publish the names of those who have indicated they have left a legacy gift to Glaucoma NZ; however, we do appreciate the opportunity to acknowledge your gift and extend the invitation to join us for special events. If you have left a bequest/legacy gift or would like more information to do this, please tick the box or contact us to find out more.

- 1 Volunteer your skills. We need an army of friends with a range of skills including events administration, facilitating support groups, photographers, interviewing & writing stories of our patients, researchers, or health professionals.
- 2 Arrange a community fundraising event in your area or suggest to your work colleagues that they hold a

special event to support the importance of eye health.

- 3 Think of us when preparing or updating your Will. No amount is too small.
- 4 Tell everyone about Glaucoma NZ and its services.
- 5 Tell us what you need. We want to hear your feedback and questions, and we will always do our best to provide the answers.
- 6 Donate regularly – no amount is too small.

On behalf of members like Elsa and her family –who will directly benefit from your support – we thank you for considering our appeal for help.

Do you know someone who is looking for a healthy distraction a few hours a month – let me put them to good work.

Please get in touch with Karon info@glaucoma.org.nz or 0800 452 826 if you can offer help in anyway.



Thank you!

We can't say thank you enough for the generous support we receive from these funders. Their kindness and contribution make it possible for us to support our volunteers & you, or others like you on your journey with glaucoma.

- Allergan
- Ara Lodge No 348 I.C
- Blue Sky Community Trust
- Blue Waters Trust
- Broderick Printing
- Community Organisation Grant Scheme
- Denton Kensington Swan
- Foundation North
- Freemasons Foundation
- HPCA Ltd
- KA Charitable Research Trust
- Lion Foundation
- Lottery Support for Volunteering
- Maurice Paykel Community Trust
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- Trillian Trust
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GLAUCOMA NZ

Department of Ophthalmology, The University of Auckland

Private Bag 92019, Auckland 1142, New Zealand

Donations over \$5 are tax deductible.



I'm lucky nothing major has happened

You can do something special today to help other families, like Elsa's, affected by glaucoma. Like many of you, GNZ has been affected by the crisis and we've suffered a severe drop in income & reduced our ability to provide education and support in your community.

We aim to raise \$30,000 from this appeal to continue this programme. Please consider donating to help us be there throughout Elsa's lifetime. We simply can't do what we do without you!

Glaucoma NZ is a registered charitable trust and receives no government funding. We rely solely on donations, sponsorship, grants and fundraising. All the information available and provided to members of Glaucoma New Zealand and the general public is free.

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