



Birdshot Survival Guide

**Birdshot Uveitis Society
of North America**
www.busna.org

Who is BUSNA?

Birdshot Uveitis Society of North America (BUSNA) is a volunteer-led organization of birdshot uveitis patients determined to raise awareness and research funds for our rare autoimmune eye disorder. We also offer support for fellow patients. BUSNA is registered as a 501(c)(3) tax-exempt nonprofit organization with the Internal Revenue Service (IRS). We maintain a broad social media presence designed to create an active patient community and a website to share news, events, and resources. See the Resources section for links.

BUSNA partners with other organizations around the world who share our mission. We are grateful to these groups for bringing birdshot patients together in the search for a cure.

Acknowledgements

Portions of this guide and its format are adapted, with permission, from the *Birdshot Survival Guide* created by the UK-based Birdshot Uveitis Society.

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Introduction

When you are first diagnosed with any medical condition, it comes as a shock, it is worrying, and it provokes the inevitable anxiety caused by anything that rocks your life. When the medical condition is a rare one like birdshot, which is sometimes hard to diagnose and can be even harder to treat, then you need all the help you can get.

This guide has been compiled by birdshot patients using input from fellow patients. Its purpose is to share information that other patients have found helpful. The hope is that this guide will help others to survive the many challenges of living with birdshot.

Additional sources of support and other information are listed in the Resources for information and support section.

Please note: BUSNA does not provide medical advice. Nothing in this guide should be considered medical advice. Ask your doctor about your specific birdshot case, and whether you should make any lifestyle changes.

Diagnosis

Birdshot is sometimes difficult to diagnose because many forms of uveitis present with similar symptoms. Typically, birdshot is diagnosed by ruling out other possibilities.

1. What is it?

Birdshot is a rare form of noninfectious posterior uveitis – an inflammation of the uvea, the part of the eye that provides the retina with most of its blood supply. The retina is the light-sensitive layer of cells at the back of the eye necessary for vision.

It is not known exactly how many people have birdshot, but it is more common in Caucasian people and in those who are aged 45 to 50 years old. However, it can also affect people who are much younger or older.

Birdshot often starts with floaters and/or blurred vision. These are symptoms of many other eye conditions, so this can make birdshot difficult to

diagnose early on. People with birdshot may go on to experience other symptoms including

- “Night blindness” or difficulty seeing in low light levels
- Delayed light to dark adaptation
- Problems with color vision
- Sensitivity to bright lights
- Seeing flashing lights
- Distortions in vision
- Loss of depth perception and/or peripheral (side) vision



A photographic impression to show what it is like seeing with birdshot eyes. Photo credit: Annie Folkard, BUS

Your ophthalmologist may be able to see cream colored oval-shaped spots in the retina. These spots appear in a scattered pattern like birdshot from a shotgun, which is how the condition got its name. These spots might not be present in early stages.

The severity of birdshot symptoms varies from person to person, but most people will experience flare-ups of inflammation in the eye. If uncontrolled, flare-ups can lead to macular edema, a swelling in the region of the eye responsible for central vision, causing potential reduction of sight.

2. How did I get it?

The exact cause of birdshot is unknown, but it is thought to be an autoimmune disease. An autoimmune disease is one in which the body's immune system gets confused and begins to attack its own tissues.

More than 98% of people with birdshot have the HLA-A29 genetic marker. A blood test for HLA-A29 is usually done if a birdshot diagnosis is suspected.

Top Tip:

It is natural to want to know exactly why you have birdshot. Although this is understandable, in reality it is unlikely that you will get an answer. It is probably best to get on with managing your birdshot rather than worrying about how you came to get it.

Treatment

Every birdshot patient is different and not all treatments help all patients. Frequently, there is a period of trial-and-error to find the right “cocktail” of medications that will control your birdshot.

The goal of treatment is to reach and sustain “quiet eyes” on minimal, or no, medication. This takes time.

3. What type of doctor treats birdshot?

Birdshot is treated by an ophthalmologist. However, other doctors may help with your care, such as a rheumatologist and your Primary Care Physician (PCP).

Choose an ophthalmologist who has experience in treating uveitis. This is important because the signs and symptoms of birdshot can be subtle. You want to work with a doctor who can recognize how birdshot appears in the back of the eye.

4. What treatment is available?

Initial treatment for birdshot is usually with high doses of corticosteroid (steroid, typically prednisone) to get the inflammation under control, after which the dose will gradually be reduced to as low as possible. Long-term treatment with an immunosuppressant is typically added to help stop the immune system from attacking the eyes. Once the eyes have become “quiet” (meaning no active disease), the steroid may be further reduced very slowly and stopped if possible.

Some patients are not able to tolerate immunosuppressants, or prefer not to take them. These patients may choose to use a steroid implant. Implants are tiny capsules of medication that are surgically inserted into the eye by an ophthalmologist. Over time, they gradually release medication directly to the area affected by birdshot. Implants need to be replaced after a while because the medication depletes. How long an implant lasts depends upon the type of implant used. There are a number of types available. Your doctor will discuss and select the best option for you.

Unfortunately, long-term steroid and immunosuppressant use can have side-effects like bone thinning or stomach complaints, so you will be closely monitored and may receive other medications to manage these side-effects. Your doctor will use lab tests to evaluate the impact of medication on your body.

There is no single treatment regime that suits all people with birdshot, so you will need to work with your doctors to find one that works best for you. Remember to be patient; it takes time.

5. Where can I find medication information?

Your doctor is your main source of information about your medications. For details, read the information pamphlets that come with your prescriptions.

Some people like to wear a bracelet or pendant ID, which identifies the medications they are taking.

TOP TIP:

Reducing your steroid, especially below 7.5mg prednisone daily, may make you feel unwell.

Symptoms can include muscle or joint pains and mood changes. These usually pass as your body adjusts to the lower dose, but seek your doctor's advice if symptoms are severe or persist.

6. Will my health insurance cover my medication?

In the US

To see if your medication is included in your health insurance company's formulary, or drug list, check the company's website or call the customer service number on the back of your health insurance ID card. This applies to both private and Medicare Part D plans.

If your medication is not covered by your plan, or your prescription is denied, contact your insurance company to find out how to request an exception or to appeal the denial decision.

Some pharmaceutical companies offer savings programs to persons who have private insurance. Contact the company that manufactures your specific drug. Your doctor may also be able to point you to resources in your state or province that provide prescription assistance.

In Canada

In Canada you can contact your health insurance plan, if applicable, and individual provincially run health plans.

Monitoring and managing birdshot

Birdshot requires regular monitoring for two important reasons:

- To ensure that medications are working and not damaging your system,
- To ensure that no active disease is present.

7. Why do they need to monitor me?

You may feel bombarded with requests when you are first diagnosed. You will be told that you need blood taken; that they need to dilate your eyes; take different types of pictures of the eyes and every now and then someone will ask you strange questions before a test, such as: are you allergic to seafood? It can all seem overwhelming, complicated, and quite intrusive.

Top Tip:

If you start to feel overwhelmed with testing, remind yourself that every test has the single goal of preserving your vision. All the tests give your doctor information about what's going on in your eyes, what treatment is working, and what may not be working. Share your concerns with sympathetic birdshot patients on the Facebook support groups. See the Resources section.

8. What tests can I expect?

Your doctor may request an array of tests. But not every patient gets every test at every appointment.

Angiography

Angiography is the process of injecting dye to observe the blood flow in the eye. Two types of angiography are typically used in birdshot:

- Fluorescein angiography (FA)
- Indocyanine green angiography (ICG)

These yellow and green dye tests examine the blood circulation in the retina and choroid layers of the eye, respectively.

The dye is injected into your arm or the back of your hand. You look into a machine as a technician takes a series of pictures of your eyes at certain times after the dye first starts to circulate. The technician will give you instructions on how to move your eyes. Electronic images of your eye are created that can tell your doctor whether birdshot is active.

Later in the day, you may notice your urine appears bright yellow, like a highlighter. This is normal. It's your body eliminating the dye, which is bright yellow. This effect wears off in a few hours.

For more information about these tests, see these articles:

- [Fluorescein angiography](#)
- [Indocyanine green angiography \(ICG\)](#)

TOP TIP:

Keep your eyes wide open and do not blink while the pictures and scans are being taken. Listen to the instructions given by the technician

Blood tests

Blood tests measure your liver and kidney function and check the levels of your different blood cells. Special blood tests for some medications measure how you are reacting to them. So, if you take tacrolimus or cyclosporine, you will also have what's called a "trough level test" which measures how much of the drug you are absorbing. Your doctor will tell you how often to get blood tests and if there are any specific instructions.

DEXA (DXA) scan

People taking corticosteroids (steroids) by mouth have an increased chance of developing osteoporosis. This is a condition where the bones lose density – they become thinner – which makes them more likely to break.

If you are going to be taking steroids for some time, your Primary Care Physician (PCP), your rheumatologist, or your birdshot specialist should assess your fracture risk. As part of that assessment, your doctor may want you to have a DEXA (DXA) scan to measure your bone density. If your doctor doesn't mention this test, you might want to ask about it.

Electroretinography (ERG)

This test examines the function of the retina. Electroretinography works by using patterns and flashes of light which induce responses from the photoreceptors in the retina. The tests are carried out under both light and dark conditions. The results from these tests are called an electroretinogram. Contact lenses, placed on your eye, are used to take the electronic measurements.

The ERG testing will take anywhere from 40 minutes to two hours, depending on the range of tests you are having.

Ask any birdshot patient and they will say that this test is quite a challenge.

For more information, see this article from the [American Academy of Ophthalmology](#).

TOP TIPS:

- Stay focused and keep your eyes still to ensure the ERG produces good data.
- Keep both your feet firmly on the ground or footrest.
- Make sure you are comfortable. Focus your thoughts on breathing in and out.
- Breathing in through mouth – for a count of 6.
- Breathing out through nose – for a count of 10.
- Practicing mindfulness at home may help.

Optical Coherence Tomography (OCT)

Although it may sound scary, the OCT scan is actually very simple. It looks under the top layer of the retina and measures the thickness of the retina. This tells your doctor whether any edema or other aspects of active birdshot are present. The test produces an electronic image of your retina that your doctor will view on a computer screen.

OCT scanning takes only a few minutes but may need dilating drops to be put in your eyes first.

OCT normally takes place at the beginning of your

appointment. It doesn't hurt, is non-invasive (no needles) and does not involve radiation or X-rays.

For more information about OCT, see this article from the [American Academy of Ophthalmology](#)

Urine tests

You may be asked to give urine samples so your kidney function can be checked. As with the blood tests, ask your doctor for instructions.

Visual field test

The visual fields, or “fields,” test checks your peripheral (side) vision to see whether it has been affected by your birdshot. There are two types of machines that can be used, one is manual and the other electronic.

You are asked to look inside a large bowl-like instrument (or into an electronic machine) with a forehead and chin rest to hold your head steady. You stare at a source of light straight ahead and tiny lights of different intensities are flashed from random points in your visual field. Each time you see one of these lights, you immediately press a button or use some other means to indicate your response.

For more information about the visual fields test, see this article from [American Academy of Ophthalmology](#).

TOP TIP:

It may sound silly, but remember to breathe during your field test. It is also OK to blink occasionally during this test. Your tester should explain this to you.

9. What medications are used?

Before your birdshot diagnosis, you may not have been taking any medication. You now have to learn to manage your medicine supplies and understand how the different parts of the prescribing and dispensing process work.

Your pharmacist can answer questions about your medications, their side effects, and how they may interact with other medications you may be taking.

In the US

Choose a pharmacy that is included in your health insurance company's network. You can find in-network pharmacies by searching on your health

insurance company's website, or by calling the customer service number on the back of your insurance ID card. Insurance carriers typically give you a choice in using either a retail, or local, pharmacy or a mail-order pharmacy (where you may get a larger supply of your medicine at a lower price). Your doctor should be able to transmit your prescriptions to either pharmacy type electronically.

In Canada

Consider choosing a local pharmacy and if possible get all ongoing prescriptions from the same pharmacy for continuity of care and pharmacist support.

Most Canadians have some access to insurance coverage for prescription drugs through a patchwork of public and/or private insurance plans. For more information, see this article from the Government of Canada:

[Prescription drug insurance coverage](#)

Getting practical

Being a birdshot patient comes with its own set of responsibilities. This section offers suggestions on how to deal with some day-to-day experiences.

10. **Be your own advocate**

You must take charge of your own case. You must keep track of your appointments and make sure you are seen regularly. Always contact your doctor if you notice a negative change in your vision.

You also need to be well-informed about where you are with your condition, your treatment, and your tests. This is particularly important as you progress on your birdshot journey.

11. **How will I know if I am having a flare-up?**

Every birdshot patient is different. You may know that your symptoms are getting worse long before this becomes evident to your doctor. Your vision may become more blurred, the number of floaters may

increase, you may feel that your vision has become less good, or that seeing in the dark is more difficult. Trust your instincts and get your eye doctor's advice or ask for an earlier appointment. Your sight depends on it.

12. What do I tell my family and friends?

Most people who have a long-term health condition will tell you of the constant support that they get from their loved ones. Although most birdshot patients live pretty normal lives, it is important to ensure that your family and friends understand some of what you are going through.

One of the important things for them to know is what this disease actually is. You could try the approach recommended by a birdshot patient:

“My immune system has decided to attack and inflame the tissue in the back of my eyes. Nobody knows what sets this off, but I have inherited a genetic marker that is believed to be linked with developing birdshot uveitis. Birdshot affects both my eyes, it is slowly progressive and potentially blinding if it is not

diagnosed and treated promptly. Because it occurs in the back of the eyes, it can't be treated with eye drops, surgery, or corrective lenses. I have to take medications to suppress my immune system. This means I pick up infections more easily, and the medications can sometimes make me feel unwell."

13. What do I tell my employers and colleagues?

Talking about your diagnosis in the early stages may be difficult, especially at work. This is a personal decision that all birdshot patients must make for themselves. Some workplaces are more supportive and open-minded than others.

Birdshot is overwhelming and scary, and so you may not like the idea of telling all your work colleagues in the early stages. However, you spend a lot of your week at work with your colleagues and it is an important hurdle to get over.

Use the Facebook support pages to learn how other birdshot patients have dealt with the work issue. Other patients will be happy to share their experiences with new patients.

Employers

You may want to talk with your manager and describe your condition. If you find that you need to make a change in your work environment—for example, changing the lighting to reduce glare—talk it over with them.

In the US

The Americans with Disabilities Act (ADA) prohibits discrimination against people with disabilities and guarantees equal opportunities for them in a multitude of daily activities. For more information about this law, see the [ADA website](#).

In Canada

In Canada the Accessible Canada Act recognizes the existing human rights framework which supports equality for people with disabilities in Canada. For further information see the [Summary of the Accessible Canada Act](#).

Colleagues

Talking to the people you work with about your diagnosis can be difficult. You may decide first to tell the people you feel closest to. They may be able to help you plan how to tell others.

Telling people can have benefits:

- it gives them the chance to support you and know what to expect
- you can let them know when you need help
- they may suggest helpful ways for you to cope with your work
- it may make you feel closer to the people you work with
- there may be people who have similar experiences who could support you.

If some people avoid you, it is usually because they don't know what to say or are worried about saying the wrong thing. Showing them that you're willing to talk openly about your illness may help.

Some people may prefer not to tell colleagues so that they can keep one area of their life as normal as possible. This is a good way of coping for some people.

However, sometimes the effects of treatment and the need to take time off for eye clinic visits or infections can make it difficult or impossible not to tell your colleagues.

Your colleagues may also be aware from your behavior that something's wrong, and they may feel uncomfortable if they don't know what it is.

14. What about driving?

Many birdshot patients continue driving. Visual acuity requirements can vary from state to state and province to province. Your doctor will tell you if you should not drive.

15. What about alcohol?

Many birdshot patients wonder if they can drink alcohol while taking medications. You must ask your doctor about your particular situation.

Coping, keeping healthy and happy

Here are some lifestyle suggestions that other birdshot patients have found helpful. Be sure to ask your doctor before making any lifestyle changes.

Move often

Regular exercise helps improve your overall fitness, health, and quality of life. It may reduce the body's levels of inflammatory chemicals. Brisk walking, cycling and swimming are examples. If you are not used to exercise, get your eye doctor's approval, and start slowly.

Eat well

Try following a "rainbow diet," which means eating a good variety of foods daily, encompassing fruits and vegetables of different colors.

Try avoiding processed foods and reducing the sugar (sucrose) in your diet. Read the labels! Sugar is added to a surprising number of foods that are not "sweet."

Doing your own cooking where possible means you have a better idea of what's in your food.

Try following a Mediterranean diet, including lots of fruits and vegetables, whole grains, fish, nuts, seeds, and olive oil. This is thought to fit the anti-inflammatory bill. It is high in polyphenols, which are plant chemicals that are also found in dark chocolate, coffee, tea, and red wine.

Maintain dental health

Gum disease may contribute to inflammation in the body. Brush and floss twice daily. Visit your dentist regularly and always tell them what medicines you are taking, as your gums may need special care.

Sleep well

Disturbed sleep may contribute to inflammatory conditions. If high doses of oral steroids are disrupting your sleep, get advice from your doctor on how to cope, and rest as much as you are able.

There are a number of very simple things you can do that may improve your chances of getting a good night's sleep. This is sometimes referred to as "sleep hygiene":

- Go to bed and get up at the same time every day (even at weekends).
- Make sure your bedroom is a calm space that's quiet, dark, and tidy.
- Take time to relax or wind down before bed (have a bath or meditate).
- Choose food or drink that is rich in the amino acid tryptophan, such as a milky drink before bedtime.
- Switch off electronic devices at least 90 minutes before bedtime.
- Avoid stimulants like caffeine and nicotine before going to bed.

Take care with supplements

If you are taking or plan to take any vitamins or supplements, ask your doctor if the products will be safe. Some substances can interact with prescribed medications.

Manage stress

Managing stress can help your general wellbeing and help you cope with birdshot and its medication challenges. Taking up practices such as T'ai chi, qi

gong, yoga, Mindfulness, or meditation could be beneficial.

Distracting yourself can help you reduce stress. Get a new hobby or learn a new skill. It helps to find something that will take your mind away from the ever-present issue of your eyes. Try reserving some time for yourself, for self-care. This isn't being selfish: it's being sensible. In the Facebook support groups, you will find birdshot patients who participate in all sorts of activities, from sports to arts and crafts. The key is to try to continue to have as normal a life as possible and never to use your birdshot as an excuse for not trying something.

Resources

Your main source of information is your doctor. However, there are many resources out there to help you feel that you are not alone in this journey.

16. **BUSNA website**

[Home page](#)

[The Wellness Room](#)

[Birdshot resources](#)

[Research projects we support](#)

[Our blog](#)

[Subscribe](#)

17. **Social Media**

Facebook pages and support groups

[BUSNA Facebook page](#)

[Birdshot Uveitis \(USA\) Facebook support group](#)

[Birdshot Uveitis Society \(International\) Facebook support group](#)

[Birdshot Uveitis Society, UK page](#)

[Birdshot Association, France](#)

Instagram

[BUSNA Instagram page](#)

Twitter

[BUSNA Twitter feed](#)

LinkedIn

[BUSNA LinkedIn profile](#)

18. Other Resources

[American Academy of Ophthalmology \(AAO\)](#)

[American Council of the Blind](#)

[American Uveitis Society \(AUS\)](#)

[Autoimmune Association](#)

[Birdshot Uveitis Society, UK](#)

[CNIB Foundation](#)

[Medscape](#)

[National Institutes of Health](#)

[National Eye Institute](#)

[Ocular Immunology and Uveitis Foundation \(OIUF\)](#)

19. Find a Specialist

[Canadian Ophthalmological Society \(COS\)](#)

[Uveitis Specialist Directory \(AUS\)](#)

[Uveitis Specialists in the US \(OIUF\)](#)

20. **Support BUSNA**

Your donation will help us achieve our mission. We want to prevent needless sight loss and find better ways of treating this aggressive eye condition.

By making a single donation or a regular donation you can help us bring about a change in the lives of the people with birdshot. Donations can be made on our website or by check.

[Birdshot Uveitis Society of North American Donations](#)

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