



## Birdshot Survival Guide

compiled by Fiona Gee  
with help from members of the  
Birdshot Uveitis Society

### **Birdshot Uveitis Society**

a support group for people with the rare, hard to treat  
autoimmune posterior uveitis called Birdshot Chorioretinopathy

*...you are not alone.....*

## 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 a birdshot patient using input from many fellow birdshotters (as we call ourselves) and reviewed by medical professionals.

The purpose of the guide is to share handy tips that other patients have discovered on their birdshot journey. The hope is that this booklet will help others to survive the many challenges of being a birdshotter.

Sources of further support and advice are listed in the 'Useful sources of information' section ([see page 40](#)).

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# Diagnosis

## 1. What is it?

Birdshot is a rare form of 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 colour 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.*

After some time, an ophthalmologist may be able to see cream or orange oval-shaped spots in the retina in the distinctive scattered pattern which gives this condition its name.

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 oedema, 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 where 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

### 3. What treatment is available to me?

Initial treatment for birdshot is usually with high doses of corticosteroid (steroid) to get the inflammation in the eye under control, after which the dose will gradually be reduced to as low as possible. Long-term treatment with an immunosuppressant is added to help stop the immune system attacking the eyes. Once the eyes have 'quietened', the steroid may be further reduced very slowly and stopped if possible.

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

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.

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.

Newer treatments are becoming available, such as steroid implants placed in the back of the eye, or biologic immunosuppressants, some of which are designed for self-injection under the skin.



**TOP TIPS:** *If you are taking steroids, make sure that your pharmacist gives you a steroid card to carry. Keep it up to date with your changes in steroid doses. It is also helpful to carry this card for a year after you stop taking steroids.*

*Reducing your steroid, especially below 7.5mg prednisolone 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.*

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

# Monitoring and managing birdshot

## 4. 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 examine 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. If you start to feel like this, the first thing you need to tell yourself is...

***Every test that you are asked to do has the single goal of assisting your medical professionals to treat you. All the tests help your doctors understand what is going on in your eyes, and what medication might be best for you.***

## 5. What tests can I expect?

### ***Blood tests***

Blood tests are to help keep you well. They 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 ciclosporin, you will also have what's called a 'trough level test' which measures how much of the drug you are absorbing. You are asked to have your blood taken 12 hours after you have last taken that medication and the result is a simple numeric reading.

The frequency of all these blood tests varies according to what stage of treatment you are at. Ask your doctor what their schedule is for the different tests, so you know what to expect and when.

### ***Urine tests***

You will be asked to give urine samples so your kidney function can be checked regularly. As with the blood tests, ask your doctor what their policy is on how often these urine tests should be done.

## ***Scans and pictures***

More detailed information on each of these tests can be found in the BUS factsheets section at [www.birdshot.org.uk/factsheets](http://www.birdshot.org.uk/factsheets)

### ***Optical Coherence Tomography (OCT) scan***

Although it sounds scary, the OCT scan is actually very simple. It looks under the top layer of the retina and detects problems early before they affect your vision.

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.

OCT scans particularly check for fluid building up under the part of your eye called the macula. Any fluid build-up there is called cystoid macular oedema (CMO).

Further information can be found in the BUS Factsheet [\*\*\*Optical Coherence Tomography \(OCT\) scan\*\*\*](#)

[\*\*See the TOP TIP\*\*](#) on the next page.

## ***Fluorescein angiography (FA, also called FFA) and Indocyanine green angiography (ICG)***

These yellow and green dye tests examine the blood circulation of the [retina](#) and [choroid](#) layers of the eye respectively.

The dye is injected into your arm or the back of your hand and then a technician takes a series of pictures of your eyes at set times, up to 20 minutes after the dye first starts to circulate.

The fluorescein dye appears in your urine, causing it to turn the same colour as a yellow highlighter pen. Your skin also goes a pale yellow. These effects wear off within 24 hours.

Further information can be found in the Moorfields Eye Hospital patient information leaflet:

**['Fluorescein angiography and Indocyanine green angiography patient information'](#)**

**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.*

## ***Visual field test (also called 'fields' or perimetry)***

This test is to check your peripheral (side) vision to see whether this has been affected by your birdshot. You are asked to look inside a large bowl-like instrument, 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.

**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.*

## ***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 and the retina in your eyes. The tests are carried out under both light and dark conditions. The results from these tests are called an electroretinogram.

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

NB: not all hospitals use this test, so do not be alarmed if it is not offered to you.

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

See the BUS factsheet [\*\*\*Electroretinography \(ERG\) testing\*\*\*](#)

**TOP TIP:** *You need to stay focussed and keep your eyes still to ensure the ERG test produces good data:*

- *Keep both your feet firmly on the ground or foot rest*
- *Make sure you are comfortable*
- *Focus your thoughts on breathing in and out*
- *Breathing in through mouth – for a count 6*
- *Breathing out through nose – for a count of 10*
- *Practising Mindfulness at home may help*

## ***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 GP or consultant should assess your fracture risk. As part of that assessment, your doctor may want to arrange for your bone density to be measured with a DEXA (DXA) scan. Repeat scans may be performed, generally every one or two years, to monitor the state of your bones. If you are not offered this test, don't forget to ask about it.

Further information about DEXA scans can be found in the BUS Factsheet: [\*\*\*DEXA \(DXA\) scan – measuring bone density\*\*\*](#)



## 6. Medicines, your pharmacist and your prescriptions

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 is your medicines expert. They can help you with your birdshot journey.

Choose a pharmacy convenient for your home or work. They may have computer links to your GP's surgery, so your prescriptions can be electronically transmitted to the pharmacy, saving you time. Ask what systems are available.

Speak to your pharmacist about birdshot. You could take along a copy of the BUS factsheet. They are not likely to have heard of birdshot, but they will be familiar with the medications, as these are used for several other conditions. Most pharmacies have a private consultation room, so your briefing on birdshot does not need to be in front of a crowd.

If your GP is prescribing your medicines, your chosen pharmacy will probably have to order them specially for you. Allow time for this.

Your pharmacist will understand the effects your medicines might be having on you and they may be able to help you manage side-effects.

### ***Prescription charges***

You are likely to need frequent prescriptions for your birdshot. If you live in England and you have to pay prescription charges, you can save money by buying an NHS prescription charges prepayment certificate. See <https://www.nhs.uk/NHSEngland/Healthcosts/Pages/PPC.aspx> for details.

### ***Prescription forms***

There are several kinds of NHS prescriptions, and there are rules on where they can and cannot be dispensed. Save yourself possible time, trouble and frustration and find out which forms may or may not be accepted at hospital or community pharmacies by looking at <https://birdshot.org.uk/wp-content/uploads/UK-information-about-prescription-charge-top-tip.pdf>

**TOP TIPS:** *If you have your medicines prescribed by your hospital doctor, you need to keep an eye on your supplies, especially if your next appointment is moved or delayed. If you are going to run out of medicine before your next visit, find out and make a note of who you need to contact to arrange an extra supply. You then need to ask them: is my prescription going to be on the kind of form that I can take to a community pharmacy, or do I have to come back to the hospital to get it dispensed?*

See <https://birdshot.org.uk/wp-content/uploads/UK-information-about-prescription-charge-top-tip.pdf>

## 7. Your GP – where do they fit in?

Your GP (general practitioner) is a key player in your treatment plan. They can:

- if the hospital clinic agrees, arrange for your blood tests to be taken locally, rather than travelling to the eye clinic
- prescribe antibiotics if they are needed to fight an infection
- support your treatment and help advise you if any of the side-effects are becoming too much.

**Here are some questions frequently raised by birdshotters.**

***“Why can’t my GP provide me with my prescriptions? Why do they need to be done at the hospital?”***

*Treating birdshot is a specialised matter, so your GP may prefer to leave the prescribing and monitoring of your treatment with the hospital consultant’s team who examine you and provide your eye care. Also, NHS funding and supply of some of the newer and more expensive uveitis treatments is made only through specialist hospital centres.*

*However, having your prescriptions from the hospital can cause you problems if your appointment is postponed,*

meaning you may not have enough medicines to last you till the rearranged appointment – [see TOP TIPS page 19 for advice](#). If having hospital prescribing and long dispensing waiting times causes you particular difficulties, eg, if you live a long way from the hospital and you have return public transport times deadlines, ask at your eye clinic if it is possible for them to help you to receive your medicines from your GP or if they have some other solution to your problem.

***“I have a nightmare getting my blood results – it all takes so long.”***

*The length of time you wait for blood test results depends not only on how long it takes to do the test, but also where you live and where the blood is going for testing. Some tests, such as a trough test for tacrolimus or ciclosporin, will take longer than routine blood tests because they have to be sent to specialised laboratories.*

***“My GP does not seem to care about me.”***

*Does your GP know enough about your condition? Taking along the [BUS factsheet](#) on birdshot could help build up your relationship.*

*Set yourself up with ‘patient access’ or any equivalent service at your GP surgery to help with repeat prescriptions and appointment bookings. Maybe the GP is just not the right one for you. You could change GP to someone with whom you feel more comfortable.*

## Getting the most out of hospital visits

*Adapted from information provided by RNIB in their ['Ask and Tell' leaflet](#).*

### 8. Timely appointments

Your eye clinic must ensure that your appointments fall within the timeframe recommended by your eye doctor. Contact the eye clinic if your appointment is cancelled or delayed beyond this timeframe. Your sight depends on it.

### 9. Knowing what to expect

Where possible, your eye clinic should tell you beforehand of any tests or treatment you'll have at your next appointment. These details matter. For example, you need to know if your eyes will be dilated or not, as this may affect how you get to and from clinic and whether or not your eyes will have recovered enough to enable you to go back to work after the appointment. You may not be told this, so you need to ask if your next appointment is solely for a blood test (this can happen early on in your treatment, when blood testing is frequent) or if you have to see the doctor as well, which is likely to involve having dilating drops put in your eyes.

## 10. Time to ask

You should be given time to ask questions at each appointment. If there is anything you don't understand, it's OK to ask again.

## 11. Contact information

Your eye clinic should make it clear who to contact if you're worried about changes in your vision, or if you are having problems taking your prescribed medication. If you are not given this information, ask for it. Make a note of the names and contact details on the ['Your contacts' space on page 37.](#)

## 12. Appointments

Get details of how to contact your appointments team and keep a note of them on the ['Your contacts' space on page 37.](#) There may be a special telephone number for uveitis clinic appointments.

## 13. Accessible information

Your eye clinic must provide appointment letters and test reminders in an accessible format.

## 14. Access to support

Your eye clinic should offer you access to emotional and practical support if needed. Don't be put off if the service offered has the word 'blind' in the title – they deal with all kinds of vision problems, and they may be able to signpost you to further help.

**TOP TIPS:** *Any birdshot old-timer will tell you that ensuring you get the most out of your hospital visit is crucial. Take notes, ask questions and 'own' your medical history.*

*Use the 'Checklist' [on page 39](#) to help you prepare.*

- *Take a written summary of your medical and eye history to your appointments because your brain will go blank during consultations.*
- *Keep a notebook or computer file to write down dates of each appointment, what tests were done, any medication changes and the main points of the consultation. Update it after each appointment and take the notebook or printout to each clinic visit. You will find this a very useful reference to help you keep track of what happened when, and also help the doctor navigate what can become a rather large file of notes.*
- *If you wear spectacles, keep a copy of your optical prescription with your notebook or printout and take it to your appointments. This may help the technician to set up your visual field tests without them having to measure the correction on your spectacles first. Also, your doctor may need to know details of your current optical prescription.*



## Getting practical

### 15. Be your own advocate

You must take charge of your own case. You are the only person who will know if appointments are not being made when they should be, and you have to speak up if things seem to be slipping.

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, as you may not always see the same doctor at your clinic visits.

### 16. How will I know if I am having a flare-up?

You will often know that your symptoms are getting worse long before this becomes evident to your specialists. 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 arrange an earlier appointment. Your sight depends on it.

You may find using an Amsler grid is helpful. [A link to an Amsler grid can be found here](#). It is a good idea to print off a copy and keep it somewhere handy, so you can check your sight regularly and know what is right for you. If you notice that the grid lines are getting more bent or wobbly, you know that you need to be seen quickly by your eye doctors.

## 17. My eyes are sore and inflamed

You need to get this checked promptly by your eye doctor or your optometrist. There could be many reasons for this, including eye infections, and the treatment will depend on the cause.

## 18. 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 sufferers 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.

[The Birdshot Uveitis Society factsheet, About Birdshot Chorioretinopathy](#), will help you explain your condition. or [see BUS contact details on page 40.](#)

### **You could try the approach that one of our members uses:**

*'My immune system has decided to attack and inflame the circulation at the back of my eyes. Nobody knows what sets this off, but I have inherited a genetic marker which is known 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. Because of where it is in my eyes, it can't be treated with eyedrops. 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.'*

## 19. What do I tell my employers and colleagues?

Talking about your diagnosis in the early stages may be difficult, especially at work. Some people may worry that their employer will make them redundant or discriminate against them.

Birdshot is overwhelming and scary, and so you may not fancy 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.

### *Employers*

**Firstly, the serious bit.** If you live and work in the UK, you are protected against discrimination by the Equality Act 2010 in England, Scotland and Wales. The Disability Discrimination Act 1995 protects people who live in Northern Ireland.

Talking to your boss also helps them to understand if you were perhaps not yourself recently and to give them the notice that they may need to make work adjustments, like time off for appointments or re-thinking aspects of your role if you are unable to complete certain tasks.

You could take someone with you when you have the conversation. You could also ask that the conversation takes place in a private place and that it is not rushed.

## *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.

You could give people a short explanation of your treatment and its side-effects. Tell them if tiredness is a problem if your concentration is affected, or if you're at risk of infection.

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 behaviour that something's wrong, and they may feel uncomfortable if they don't know what it is.

## 20. Driving

You are still allowed to drive if your corrected sight is within the legal limits. Your consultant will tell you if you should not drive.

However, please note that UK law says that you must tell the DVLA if you have a visual impairment. Telling the DVLA will result in you having the special periodic eye and visual field tests the DVLA order so you can keep your driving licence current. [See page 41](#) for contact details for the DVLA.

## 21. Alcohol

Can I still drink alcohol? This will depend on which medications you take; what the doctors say; and the results of your liver function tests. You should check this with your consultant.

## **22. Am I being treated at the right hospital?**

This is hard to answer, but because birdshot is a rare condition, it is usually best treated at one of the specialist (tertiary) uveitis clinics which are in larger hospitals. These clinics will have a team of ophthalmologists whose sole job is to treat uveitis. They are likely to be looking after several people with birdshot.

Your local eye hospital may refer you to one of these specialist centres for your treatment, or you may ask for a referral there. However, you have to consider the time and the costs of getting to a specialist centre for what can be frequent appointments. Your local eye clinic consultant may be willing to treat you with advice received from a specialist uveitis clinic consultant. Ask if this could be an option for you.

## **23. Private medical insurance: will I be covered?**

Sadly, this can become a problem in the UK. It is likely that your insurers will stop paying for private medical care because birdshot is a chronic condition. Problems usually happen sometime after you are stabilised and on the right medication. You can try to argue that you should be treated like a diabetic, for whom many insurance companies give an annual allowance in case they need urgent medical care. This usually has to be done via an appeal process, which can add to your stress, but it is worth taking forward if you are very keen to keep private medicine open as an option.

# Coping - keeping healthy and happy

## 24. What can I do to help myself?

Here are some suggestions which birdshotters have found helpful.

**Move often** – regular exercise 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, aiming for at least 30 minutes of exercise a day.

- **TOP TIP:** *For booklets with exercises you could try, see: <https://www.laterlifetraining.co.uk/llt-home-exercise-booklets/>*
- *Don't be put off because this website provides exercise training material for use with older people. The chair-based exercises could all be done at home or in your office!*

## **Nutrition**

- **Try to follow a 'rainbow diet'**, which means eating a good variety of foods daily, encompassing foods of different colours. <https://drchatterjee.com/wp-content/uploads/2017/12/Rainbow-Chart.pdf>
- **Try and say no to processed food** and reduce the sugar (sucrose) in your diet. Read the labels! Sugar is added to a surprising number of foods that aren't sweet.
- **Doing your own cooking** where possible means you have a better idea of what's in your food.
- **Try a Mediterranean diet**, including lots of fruit and veg, whole grains, fish, pulses, nuts, seeds and olive oil. This fits 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.

**Look** at the ['Immunosuppression and lifestyle Q &A's'](#) on the BUS website.

**Dentist** – gum disease can contribute to inflammation in the body. Clean 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**

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
- **Screens** – switch off all electronic devices at least 90 minutes before bedtime
- **Avoid stimulants** like caffeine and nicotine before going to bed.

**Manage stress – this helps your general wellbeing and** also to cope with birdshot and its medications. Taking up practices such as T'ai chi, qi gong, yoga, Mindfulness and meditation could be beneficial.

**Supplements, vitamins and herbal medicines,** for example, CoQ10, probiotics, tart cherry juice, omega 3, turmeric, resveratrol, biotin, magnesium and zinc. These and others have been tried by birdshotters for their claimed effects.

**TOP TIPS:** *Always check with your doctor or pharmacist if any supplements, vitamins or herbal medicines are OK for you to take because many can interact with your prescribed medicines.*

*Quite a few birdshotters report that they are found to be deficient in Vitamin D and B<sub>12</sub>. It's a good idea to ask your GP if your blood tests can include a check on your Vitamin D and B<sub>12</sub> levels.*

## 25. How do I cope with the tricky times?

Everybody gets these! Life with birdshot can be hard. The Birdshot International Facebook group

<https://www.facebook.com/groups/Birdshot/>

is a wonderful place where you can chat to others who really understand how you're feeling. There are always friends there to support you, give you good advice, and help you feel less alone.

Nearly every one of us experiences long hospital waiting room times. These waits can be boring. When your eyes are dilated it is hard to read, and listening to music is not a good idea as you might miss hearing your name called. One way to pass the time is by chatting to others in the waiting area. You can meet many interesting people and hear inspiring stories. It also helps others to know that they are not alone.

## 26. How to distract yourself

Get yourself a 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, and to help you to relax and reduce stress. Try creating some 'me' time. This isn't being selfish: it's being sensible. In the Birdshot International Facebook group, you will find birdshotters who do all sorts of things, from sports to arts and crafts.

The key is to try to continue to have as normal a life as possible and aim never to use your birdshot as an excuse for not doing something.

So, lean into the birdshot fellowship, use the Facebook group to ask all those questions you need to have answered, and remember:

***“You should never view your challenges as a disadvantage. Instead, it's important for you to understand that your experience facing and overcoming adversity is actually one of your biggest advantages. “ Michelle Obama***

## Your contacts

Keep a note of all your useful contact information here:

- **Eye consultant and other members of team**

- **Eye hospital main switchboard phone no.**

- **Eye appointments phone no.**

- **Consultant's secretary phone no and email address**

- **Eye emergency department phone no.**

- **Eye clinic phone no.** (in case you are delayed getting there)

- **Other useful numbers**



## Checklist for your appointments

### Take with you:

- **Your appointment letter** or appointment card.
- **A note of any new symptoms** since your last appointment and any questions you want to ask.
- **An up-to-date list of all your medicines**

### For each item, your list should say:

- Name of medicine
- Strength (mg, grams, percentage if it's an eye drop)
- How many tablets/capsules/ml/drops you take each time
- How many times a day you take those doses, and when.
- **Be ready to tell the doctor about any changes** to your treatments that have happened since your last appointment.
- **Your own record of your eye clinic visits** (useful for checking quickly during a consultation about what last happened, and when).
- **Your latest eye test report** or spectacles prescription.
- **This Survival Guide** of information and contact details.

## Useful sources of information

### Birdshot Uveitis Society

PO Box 64996, London SW20 2BL

[www.birdshot.org.uk](http://www.birdshot.org.uk)

[info@birdshot.org.uk](mailto:info@birdshot.org.uk)

### Useful links on the BUS website

- About Birdshot <https://birdshot.org.uk/birdshot-overview>
- Factsheets <https://birdshot.org.uk/factsheets/>
- Immunosuppression and lifestyle advice Q&As <https://birdshot.org.uk/birdshot-overview/immunosuppression-and-lifestyle-advice-q-as>
- Prescriptions <https://birdshot.org.uk/wp-content/uploads/UK-information-about-prescription-charge-top-tip.pdf>
- Interactions: some Q&As <https://birdshot.org.uk/interactions-some-q-as/>

### Video and audio talks and interviews

- BUS also has short videos and audio recordings on YouTube of talks and interviews given at our Birdshot Days

**Video** <https://www.youtube.com/user/Birdshot100>

**Audio** <https://audiomack.com/artist/birdshot-recordings>



**Centre for Rare Diseases, Queen Elizabeth Hospital,  
Birmingham**

<https://www.uhb.nhs.uk/centre-for-rare-diseases.htm>

**Moorfields Eye Hospital NHS Foundation Trust**

[www.moorfields.nhs.uk/condition/birdshot-chorioretinopathy](http://www.moorfields.nhs.uk/condition/birdshot-chorioretinopathy)

**Scottish Uveitis Network**

[www.sun.scot.nhs.uk](http://www.sun.scot.nhs.uk)

**Royal National Institute of Blind People (RNIB)**

<https://www.rnib.org.uk>

Helpline 0303 123 9999

Email: [helpline@rnib.org.uk](mailto:helpline@rnib.org.uk)

**PIC Society**

[www.pic-world.net](http://www.pic-world.net)

**Driver and Vehicle Licensing Agency (DVLA)**

<https://www.gov.uk/browse/driving/disability-health-condition>

Tel: 0300 790 6806

## ***Acknowledgements***

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Further copies of this Birdshot Survival Guide are available from the Birdshot Uveitis Society, PO Box 64996, London SW20 2BL

## **BIRDSHOT UVEITIS SOCIETY**

A charity providing support and information for people with this rare and hard to treat autoimmune, posterior uveitis.

### **DONATE**

Your donation will help us achieve our aims. 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.

You can make your donation online <https://birdshot.org.uk> or by cheque or postal order payable to Birdshot Uveitis Society and send to:

**Birdshot Uveitis Society**  
**PO Box 64994**  
**London SW20 2BL**

Registered Charity Number 1145349  
Company Number: 7716343  
Registered in England and Wales

***You are no longer alone.....***

For help and support please contact the  
Birdshot Uveitis Society at:  
[info@birdshot.org.uk](mailto:info@birdshot.org.uk) and join the Facebook  
group at:

<https://www.facebook.com/groups/Birdshot/>

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