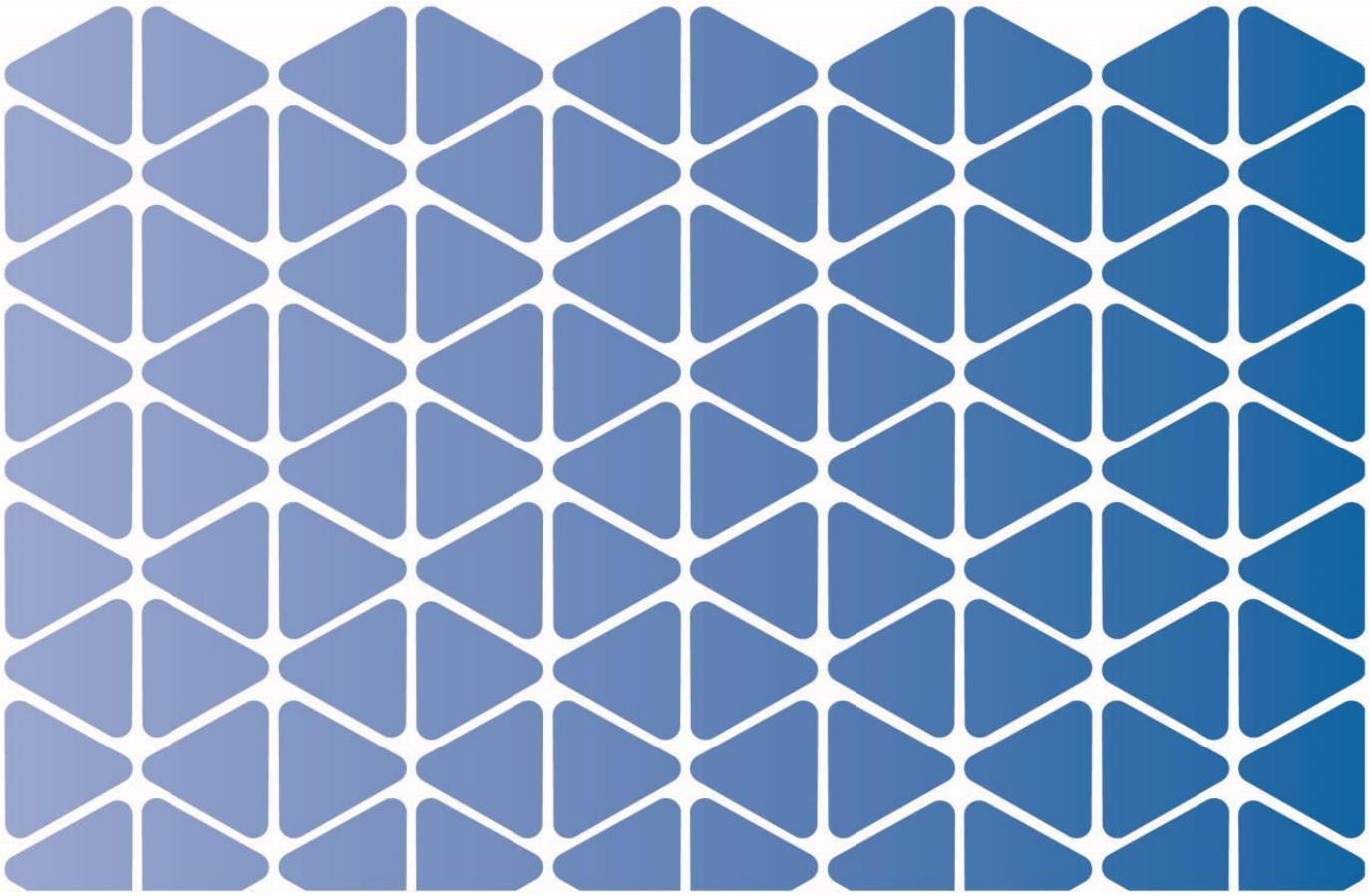
Worcestershire Acute Hospitals NHS Trust

PATIENT INFORMATION

AGE-RELATED MACULAR DEGENERATION (AMD) AND EYE INJECTIONS

If you need help to read or understand this leaflet, please ask a nurse to help you.



Age-related Macular Degeneration (AMD) and Eye Injections

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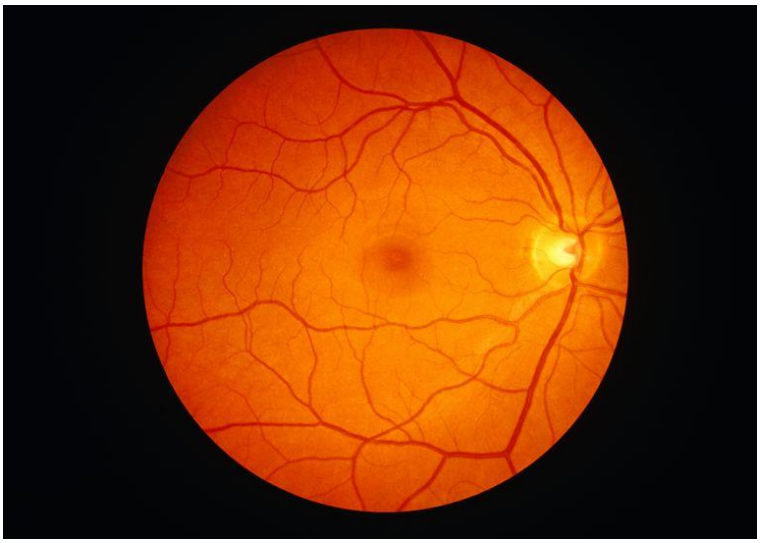
Introduction - What is the Macula?

The back of the eye contains the retina, which is a light sensitive layer, like the film in an old camera. The retina sends signals along the optic nerve to the brain to give us vision. The central part of the retina is called the macula. The macula is used for fine detail vision, such as reading and recognising faces.

Healthy Retina

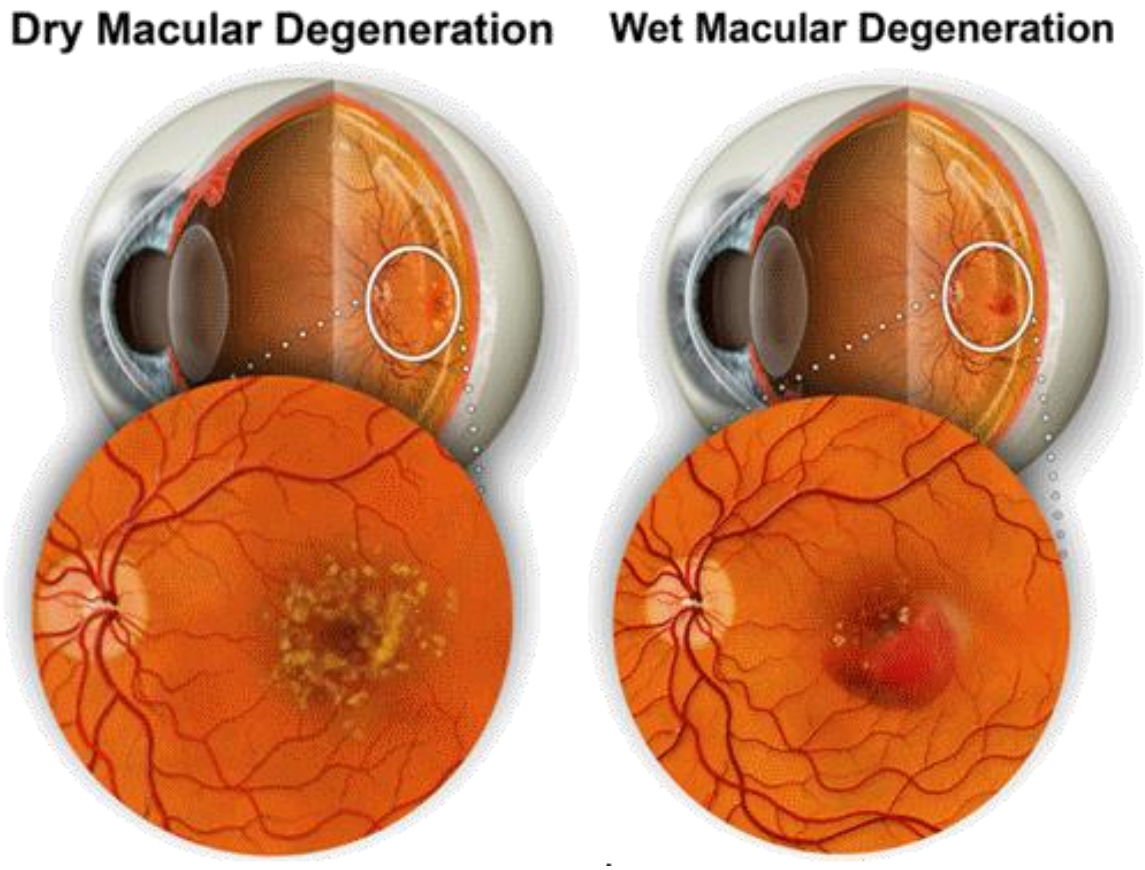


In this picture, the central area is the macula. The yellow disc with the pale centre is the optic nerve.

What is AMD?

Age-related Macular Degeneration (AMD) is a condition that can cause blurring and distortion of the central eyesight. It makes reading, watching television and recognising people's faces more difficult. It usually occurs after 60 years of age but can happen earlier. Some people who lose the centre of their vision get 'Charles Bonnet Syndrome'. This means that they sometimes see patterns, objects or people that are not really there. Please tell a nurse if you are concerned about this.

There are two types of AMD: **Dry and Wet**.



Dry AMD is a gradual deterioration of the retinal cells of the macula. The condition varies in how fast it progresses but usually develops slowly, over a period of months or years. There is currently no treatment for Dry AMD.

Wet AMD generally causes more rapid deterioration or distortion of the eyesight. It is due to abnormal blood vessels growing in the macula area. These blood vessels leak fluid or blood and result in scarring. There is treatment for Wet AMD, which is currently in the form of injections of medication into the eye. Treatment outcomes are generally better if the condition is treated in the earlier stages. If wet AMD is advanced, treatment may not be helpful.

Wet AMD is more common in people who smoke tobacco. It may be less common in people who have a diet that includes plenty of green-leafed vegetables, such as spinach, broccoli or kale.

Diagnosis is based on symptoms of blurred or distorted eyesight, and examination of the eye. We also use special pictures of the eye that are taken with the OCT (Optical Coherence Tomography) scanner, and often also taken with an OCT-a (non-invasive angiography) or Fundus Fluorescein Angiogram (FFA).

Treating Wet AMD

If we find wet AMD that is suitable for treatment, we will advise a course of eye injections. The purpose of the treatment is to try to stabilise the eyesight. Further regular injections are usually required in order to try to keep the condition under control, in order to maintain your eyesight.

The eye condition and your eyesight are likely to worsen if you do not have treatment when it is appropriate. This deterioration is likely to be permanent.

At the moment, the only wet AMD treatment approved for use in the NHS is injections in the eye.

Your Treatment Plan and Your Consent

There are several medicines available for treating wet AMD, such as Ongavia®, Eylea®, Vabysmo® and other similar preparations. In our departments, eye injections are sometimes given by doctors but are mostly given by Nurse/Specialist Practitioners. Before you start the treatment we give you information so that you are able to give consent for the injections. The risks of injections are described in Appendix 2. Please ask if you have any questions. Please tell us if you need more time to think about whether to have the treatment. However, we generally advise starting treatment fairly urgently.

You will have one injection per month for three months. This is called ‘induction’. Six to eight weeks later, you will receive the fourth injection. At that time, we will also test your eyesight and repeat the OCT scan(s) in order to check the response to the treatment. The results of these tests will be

reviewed later and the next appointment will be sent to you. If further treatment is needed, you will continue to have injections. For most people, treatment does not cure the condition, but it helps to control it. We will continue to give you treatment for as long as is helping.

Your treatment plan is managed by the AMD Admin team (see Appendix 1 for the telephone number). Please contact us if you are expecting an appointment and have not received one.

The AMD Diagnostic Clinic

This clinic is run by trained ophthalmic staff at the Princess of Wales Community Hospital (POWCH) in Bromsgrove. At the clinic your eyesight will be tested. (Please bring the most up-to-date glasses that you have been prescribed for television or driving - unless none have been prescribed for you.) You will also have an OCT and OPTOS scans. You do not need to have dilation drops for these scans. You will not see a doctor during your appointment, but after the clinic, your results will be checked by a consultant, a senior doctor or an ophthalmic nurse/specialist practitioner. If you need further treatment, further appointments will be booked; if you need monitoring only, this appointment will also be booked. We will send a copy of the letter to both you and your GP.

In most cases, patients who drive a car can drive to and from the clinic because we can get good images without using eye drops to make the pupils big. On rare occasions we may ask a patient to return on a later date for eye drops before the tests are done. If you need to return for these drops please make sure that you do not have to drive during the four-hour period after the drops.

‘Treat and Extend’ Pathway

After the induction course of injections, it is likely that you will continue to have more injections in order to try and maintain your eyesight. These

injections will be given every few weeks. Over a period of time, we will aim to increase the time between injections, usually by two weeks at a time – this is the “Treat and Extend” pathway. Each time you have an injection, we will test your eyesight and repeat the OCT scans to guide us when the next injection should be. While you are on this pathway, you should also expect to have your notes and scans reviewed by a doctor once a year.

While you are being treated, it is important for you to self-monitor your own eyesight, checking each eye separately (if appropriate). Use the Amsler Grid, which is shown in Appendix 4. We recommend you use the Amsler Grid at least once a week. If you see any **definite changes** to your vision, telephone the Worcestershire Hospitals AMD Service within 1 to 3 days, using one of contact numbers listed in Appendix 1. Please be advised that this telephone line is busy, therefore, please leave your name; date of birth and/or hospital number; your contact number; a short message and someone will get back in touch with you.

If the gap between the injections can be extended to 12-16 weeks, and your eyesight and OCT scans remain stable, the treatment will be stopped. We will then continue to test your eye in the AMD diagnostic or face to face clinic.

Sometimes the disease becomes ‘active’ again and treatment needs to be restarted. In this case, the gap between injections is usually reduced until the eye condition is stable before starting to extend the gap again.

Stopping Treatment

If your eyes remain stable for a period of time without treatment, you will be discharged back to your optometrist (optician) for annual review. It is important to continue to use the Amsler Grid to self-monitor your eyesight and report any rapid deterioration to your optometrist (optician). Further treatment might be appropriate in the future.

Occasionally, the injections are stopped because there is a poor response to treatment. Sometimes the disease advances to the point where further

injections will not be helpful. If your treatment is being stopped, you should get a telephone call and a letter to explain why.

Low Vision Clinics and Sight Impairment

We offer Low Vision Clinics at Sight Concern in Worcester where staff can offer practical advice to help with daily living, and magnifying glasses to help with reading. If you would like an appointment, please telephone the Worcestershire Hospitals AMD Service using one of contact numbers listed in Appendix 1, or speak to a member of the AMD team.

If appropriate, we can arrange a certificate of vision impairment. (This may be appropriate if both eyes have poor vision.) This would lead to you being put on the register of people who are either 'sight impaired' or 'severely sight impaired'. This can help you access further support. Please speak to a doctor or nurse if you would like this.

You can find a list of Support Services in Appendix 3.

Your Eye Injection Appointment

The injection procedure itself is very quick but please allow 1-2 hours for your appointment in case of any delays. You may also need to have your vision checked and have OCT scans before treatment if you are on the Treat and Extend pathway. Please bring your glasses to each appointment.

A nurse will take you into a clean room or operating theatre and your identity will be checked. You will be asked to sit or lie down on the procedure trolley and you will be made comfortable. If you are unable to lie down, the procedure can be done with you sitting up.

Your forehead will be marked above the correct eye. You will then be given local anaesthetic eye drops in order to numb the front of your eye. The skin around your eye will be cleaned (with iodine) and a little clip inserted to hold your eyelids open so that you do not have to worry about blinking.

You will be asked to look up or down and the injection will be given from the side (not at the front). You may feel a pressure in your eye. It is normal to notice ‘patterns of fluid’ or ‘bubbles’ in your vision during and shortly after the injection but these will settle.

After the injection, the skin around the eye will be cleaned again and we will make sure that you have your Aftercare Instructions (see Appendix 2) before you go home.

Appendix 1

Worcestershire Hospitals AMD Service

Contact Numbers

AMD service coordinator: **01562 828853**

Senior medical secretary: **01562 828852**

Support medical secretary: **01562 828860**

PLEASE CALL ONE OF THE ABOVE NUMBERS IF YOU WILL NOT BE ABLE TO ATTEND A HOSPITAL APPOINTMENT (FOR EXAMPLE DUE TO ILLNESS).

PLEASE CALL AND LET US KNOW IF YOU HAVE HAD A HEART ATTACK, STROKE OR MINI STROKE WITHIN THE PAST 3 MONTHS AS WE MAY NEED TO DELAY YOUR INJECTION.

PLEASE ALSO CALL IF YOU ARE EXPECTING AN APPOINTMENT AND YOU HAVE NOT RECEIVED IT.

Do not rely on messages being sent via reception or nursing staff.

PLEASE NOTE: these telephone lines are often busy and the answerphone may be on. In this case, please leave a message with your name and hospital number or date of birth. If an appointment is required, one will be made once you have left your message.

If you are ringing because you have problems with your vision, a telephone call will be made back to you.

Appendix 2

Risks of Eye Injections and Aftercare Instructions

Risks of Eye Injections:

Our Trust has a good safety record for these injections. The risk of an eye becoming blind due to an injection is less than 1 in 1200.

Some common side effects

- Foreign body sensation (gritty eye) and excess tears (watery eye), which should settle in a few days.
- A red patch on the white of the eye, which usually settles within two weeks.
- Small specks in your vision called ‘floaters’ or ‘spots,’ which should settle in a few days.

Some possible complications of injections

- Corneal erosion or abrasion (loss of some of the skin at the front of the eye) – your eye may be painful and watery. These symptoms usually settle within 48 hours. You may find lubricating eye drops helpful.
- Raised eye pressure – you may get a headache or pain above the eye, which does not settle with your usual pain relief medication.
- Infection inside the eye – this is a rare but a very serious complication of treatment. Your eyesight may get worse and your eye may become increasingly red, painful and sticky, with swelling of the eyelids.
- Bleeding inside the eye.
- Retinal tears or detachment, which is rare but may need surgery.
- Cataract (a clouding of the lens), which may need surgery.
- We do not know whether injections might slightly increase the risk of heart attack or stroke. However, if there is a risk, it must be very small. Please let us know if you have had a heart attack or a stroke within the last three months.

Aftercare Instructions (after an injection)

Please telephone for advice immediately (using one of the numbers below) if you have any of these:

- A decrease in your vision and/or the ‘floaters’ get worse
- Increasing pain or discomfort
- Increasing redness of the eye or swelling of the eyelids

Emergency Contact Telephone Numbers –

For help and advice following treatment:

During Office Hours (Monday to Friday 9.00am to 5.00pm) -

- Kidderminster Hospital Eye Department
  01562 512382

Outside Office Hours (5.00pm to 9.00am, weekends and bank holidays) -

- either contact your own GP or optometrist

- or contact Birmingham & Midland Eye Centre (BMEC) **0121 507 4440 and ask for the Eye Casualty department**

Appendix 3

Other Support Services

(These are mostly charities and they are separate from the NHS)

Sight Concern
Bradbury Centre, 2, Sansome Walk, Worcester, WR1 1LH
01905 723 245
info@sightconcern.co.uk

Sight Concern Worcestershire is your local charity supporting people to live well with sight loss. If you would like to know more about the wide range of support and equipment available, have questions about your sight loss or need to talk to someone about it, please phone **01905 723 245**, email info@sightconcern.co.uk or visit the website www.sightconcern.co.uk

Macular Society
PO Box 1870, Andover, SP10 9AD
01264 350 551
www.macularsociety.org
info@macularsociety.org

Royal National Institute for the Blind (RNIB)
Helpline: **0303 123 9999**
www.rnib.org.uk

Talking News Federation
Craven House, 145, Victoria Road, Swindon
Wiltshire, SN1 3BU
01793 497 555
www.tnf.org.uk

Local Macular Society Support Groups

Barnt Green
Meets on the last Friday of each month (except December)
2.00pm – 4.00pm
The Parish Centre (behind St Andrew's church)
Sandhills Road, Barnt Green, B45 8NR
For more information, call the Macular Society helpline on **0300 3030 111**

Bridgnorth & District
Meets on the last Thursday of each month
2.00pm – 4.00pm
The Peoples Hall, Evangelical Church
7, St John Street, Bridgnorth, WV15 6AG
For more information, call the Macular Society helpline on **0300 3030 111**

Kidderminster Macular Support Group
Meets on the 2nd Wednesday of each month
10.30am – 12.30pm
The Museum of Carpet (entrance next to Morrison's supermarket)
Green Street, Kidderminster, DY10 1AZ
For more information, call Jane Johns on
01562 700 802

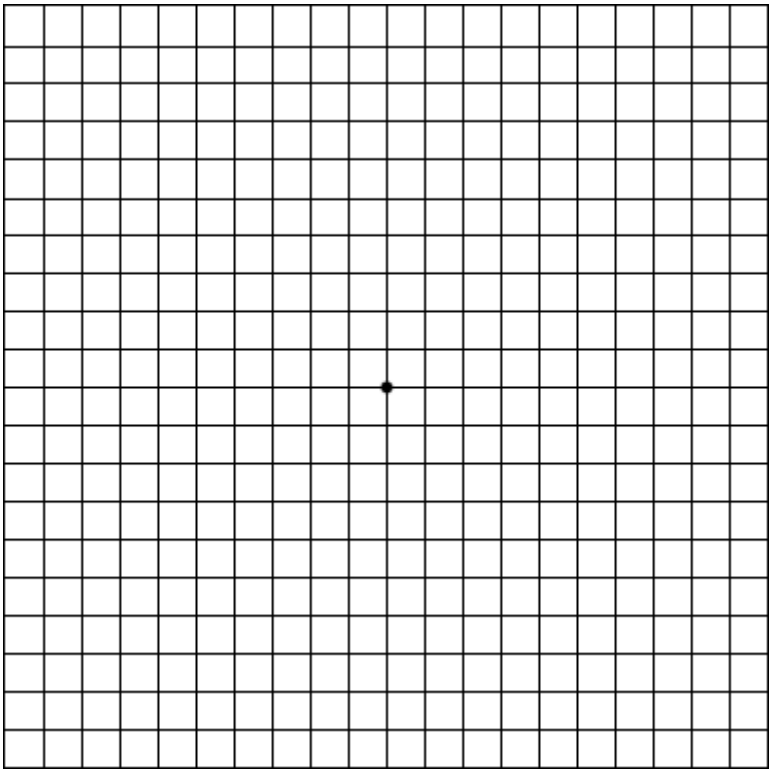
Malvern
Meets on the 2nd Monday of each month
2.00pm – 4.00pm
Malvern Cube
Albert Road North, Malvern, WR14 2YF
For more information, call the Macular Society helpline on
0300 3030 111

Worcester Macular Support Group
Meets on the 3rd Thursday of each month
2.00pm – 4.00pm
Bradbury Centre
2, Sansome Walk, Worcester, WR1 1LH
For more information, please call Bill Dawson on
01386 792 270

Please use the space below for any questions you may have.

Appendix 4

Amsler Grid



- Wear any glasses you normally use for reading.
- Hold the grid about 30 to 40 cm (12 to 15 inches) from you, where it is best in focus.
- Test each eye separately by covering the other eye.
- Keep your eye fixed on the central dot and think about the appearance of the rest of the grid.
- If you have AMD, the lines of the grid may appear wavy or distorted. Parts of the grid may be blurred, faded or missing.
- Please contact the eye department, using one of the numbers above, if you notice that your eyesight is getting worse.

General Advice from Worcestershire Acute Hospitals Trust

If your symptoms or condition worsens, or if you are concerned about anything, please call your GP, 111, or 999.

Patient Experience

We know that being admitted to hospital can be a difficult and unsettling time for you and your loved ones. If you have any questions or concerns, please do speak with a member of staff on the ward or in the relevant department who will do their best to answer your questions and reassure you.

Feedback

Feedback is really important and useful to us – it can tell us where we are working well and where improvements can be made. There are lots of ways you can share your experience with us including completing our Friends and Family Test – cards are available and can be posted on all wards, departments and clinics at our hospitals. We value your comments and feedback and thank you for taking the time to share this with us.

Patient Advice and Liaison Service (PALS)

If you have any concerns or questions about your care, we advise you to talk with the nurse in charge or the department manager in the first instance as they are best placed to answer any questions or resolve concerns quickly. If the relevant member of staff is unable to help resolve your concern, you can contact the PALS Team. We offer informal help, advice or support about any aspect of hospital services & experiences.

Our PALS team will liaise with the various departments in our hospitals on your behalf, if you feel unable to do so, to resolve your problems and where appropriate refer to outside help.

If you are still unhappy you can contact the Complaints Department, who can investigate your concerns. You can make a complaint orally, electronically or in writing and we can advise and guide you through the complaints procedure.

How to contact PALS:

Telephone Patient Services: 0300 123 1732 or via email at:

wah-tr.PALS@nhs.net

Opening times:

The PALS telephone lines are open Monday to Friday from 8.30am to 4.00pm. Please be aware that you may need to leave a voicemail message, but we aim to return your call within one working day.

If you are unable to understand this leaflet, please communicate with a member of staff.