What to expect at your annual review - thalassaemia and rare inherited anemias

What is an annual review?

Your specialist centre may offer an annual review- this is a longer appointment, once a year, that is different in purpose from your usual clinic visits.

Most appointments are about how you are now – your haemoglobin, your transfusions (if you are on them), your regular medications, how you have been feeling, anything that has gone wrong recently. An annual review steps back from all that. It is about the long term: the things that build up quietly over years, and what can be done to stop them. It's also about planning your long-term health.

In some places, your annual review lasts about 40 to 45 minutes. It is the one apopintment in the year with enough time to talk about everything - not just your bloods.

Because it is longer, it is worth preparing for – and worth arranging time off work or childcare for, if you need to. Coming in rushed, or having to leave early, can make this appointment less useful.

Why does it exist?

People with thalassaemia and inherited anaemias are living longer than ever before – which is genuinely good news, and it has changed what we need to worry about.

As people live longer with these conditions, we have become aware of complications that arise later in life. They tend to accumulate silently. Nothing hurts, nothing feels wrong, and by the time something does, damage has often already been done, and often can't be reversed.

The reason that matters is what follows from it: **if good prevention is put in place, and if you work with your medical team in sticking to those plans, in most cases the chance of these complications arising can be reduced**. That is why your team sets aside a longer appointment once a year, rather than trying to fit this around a routine visit.

This is also why an annual review can feel strange when you feel perfectly well. Feeling well is not evidence that nothing is happening. It is precisely when you feel well that this appointment is worth most.

Who will I see?

Usually a doctor and a specialist nurse, together or one after the other. In some services a psychologist is also part of the team.

If you meet a psychologist, this is not because anyone thinks there is something wrong with you or that you are not coping. Living with a lifelong condition – the appointments, the medicines, the tiredness, the way it shapes decisions about work and family – is a lot to carry, and it is treated as a normal part of your care rather than an add-on for when things go badly.

The specialist nurse is often the person you will have most contact with during the year, and the person easiest to reach when something comes up. The annual review is a good opportunity to make sure you know how to contact them.

What gets talked about?

This is the part people do not expect, and it is the reason for the extra time. An annual review is a conversation, not just a set of tests.

Your medicines, honestly Not just what you are prescribed – whether you are actually taking it, and what gets in the way. This is a review of whether the plan is working for you, not a test of whether you "have been good". If your chelation makes you feel sick, if the routine has fallen apart, if you have quietly stopped, this is the appointment to say so. Nobody is going to tell you off. Chelation is genuinely hard to keep going with, it is one of the most common things people stop, and there are usually options – different medicines, different doses, different timing. None of them can be offered for a problem nobody knows about.

Pregnancy and contraception Whether you are thinking about a pregnancy now, might be one day, or want to make sure you do not have one yet. For these conditions there is a lot worth planning in advance rather than sorting out afterwards – some medicines need changing before a pregnancy rather than during it, and there are things worth knowing about how your condition and pregnancy affect each other. Contraception choices can also be affected by your condition. Whatever your situation, this is the appointment to raise it. If you want to talk about testing for a future child, our leaflet on preimplantation genetic diagnosis (PGD) covers the options.

Work, education and money. Whether your condition is affecting your job, your studies, or your finances. Time off for transfusions and appointments, tiredness affecting your work or exams, and the practical business of benefits and support all come up here. Your team can advise and refer, and CAN can help too – please ask. People often assume this is not what the appointment is for. It is.

Staying well generally Diet, exercise, alcohol, smoking, vaccinations, and travel plans. Not lecturing – these things genuinely interact with your condition, and there is time to discuss them properly.

Anything you have been meaning to ask The things too small for a busy clinic, but too persistent to forget. Write them down and bring them.

What gets checked?

Not everything applies to everyone – it depends on your condition and your treatment. Your team will tell you which apply to you.

Your diagnosis, in detail Your exact condition, including your genetic result where known. This matters more in rare anaemias than it sounds: knowing precisely which condition and which gene changes what should be monitored and what treatments are options.

Your transfusions, if you have them How many units, how often, and your red cell antibodies. Having your antibody list recorded matters enormously if you are ever transfused somewhere new.

Iron overload Iron builds up from transfusions or from the anaemia itself, and causes no symptoms for years. Ferritin is checked with a blood test, and iron in your liver and heart measured directly by MRI – a T2* or Ferriscan. Ferritin alone is not enough, which is why the scans matter. See our leaflets on iron overload.

Bone health These conditions make osteoporosis more likely – thinning of the bones – which onscan be prevented with calcium, vitamin D and exercise. Your vitamin D level is checked, and you may have a DEXA scan.

Your heart An echocardiogram – an ultrasound of the heart – is usually done every 3 to 5 years.

If you are on iron chelation Your kidneys are checked with a urine test, and your eyes and hearing checked too, because chelation medicines can occasionally affect them. These checks catch problems while they are still reversible.

Your spleen Whether it is enlarged, and whether it has been removed. If you have had a splenectomy, infection prevention becomes a major part of your review. See our splenectomy leaflet.

Parvovirus status Whether you have had this virus, which can cause a sudden severe drop in blood counts in people with inherited anaemias. Once you have had it, you are immune.

Vaccinations Flu and COVID for everyone; if you have had your spleen removed, also pneumococcal, Hib/MenC, and meningitis B and ACWY.

An examination Weight, oxygen levels, pulse, blood pressure, and an examination of your chest, heart and abdomen.

What happens afterwards?

You will receive a copy of the letter summarising what was discussed, your results and the plan. **Keep it.This letter is the single most useful document you can have.**

If you are ever treated somewhere new – on holiday, at university, in an emergency, after a house move – it tells a team who has never met you what your diagnosis is, what antibodies you have, what you take, and who looks after you. A photograph of it on your phone takes a minute and can save hours at a difficult moment.

If a follow-up test, scan or referral is arranged and you have not heard within the timeframe you were given, chase it. Things do occasionally get lost, and it is easier to ask than to find out a year later.

You do not have to wait for your annual review to raise something. If something changes or worries you before then, contact your team.

When to seek medical advice

Do not wait for your annual review if you notice:

- Increasing tiredness or breathlessness
- Palpitations or an irregular heartbeat
- Abdominal pain, particularly on the upper right side
- Joint pain, or increased thirst and passing more urine
- Changes in your vision or hearing, if you are on chelation
- Fever, if you have had your spleen removed – this needs immediate attention
- Any side effect making it hard to take your chelation

Can we help?

CAN (Congenital Anaemia Network) is a charity specifically for patients with inherited anaemias. It was started by a group of patients and doctors, working together to tackle some of the problems of having an inherited anaemia – the lack of information and the loneliness of not knowing anyone else with your condition. We run events for patients to meet each other, as well as provide some additional information, support and services for patients who need that extra bit of help.

If you want to know more visit www.togetherwecan.uk or email us: info@togetherwecan.uk

Do you know your care should involve a specialist centre for inherited anaemias? These conditions are rare enough that few doctors see many of them and all patients with rare inherited anaemias should be under the care of a haemoglobinopathy specialist. Please read our 'How red cell services are organised in England' information sheet. If you don't know who your specialist service should be, please get in touch with us so we can help you find out.