



**Down's Syndrome
Association**

A Registered Charity No. 1061474

Health Series



Children – Vision, eye tests and glasses



The
Down Syndrome
Medical Interest
Group

A Down's Syndrome Association publication

Our resources and Information Team are here to help

Please see our website for up-to-date information: www.downs-syndrome.org.uk

If you would like to talk about any of the issues raised in this resource, then please get in touch with our helpline by calling 0333 1212 300 or by emailing us on info@downs-syndrome.org.uk.

Helpline Monday - Friday 10am-4pm | Telephone: 0333 1212 300

This publication brings together articles written for DSA's Journal and Blog by Dr J Margaret (Maggie) Woodhouse (Senior Lecturer at the Down's Syndrome Vision Research Unit School of Optometry & Vision Sciences at Cardiff University) and Simon Berry (Optometrist)

We have produced a separate resource about eye conditions in children which can be downloaded from the health section of our website (under 'vision')

Vision in children with Down's syndrome

By Maggie Woodhouse

Our research team has been studying visual development in children with Down's syndrome for over 20 years. We have a study group of more than 250 children and young people with Down's syndrome, and the older members have been with us since the beginning. Our oldest member is now 25; the youngest to join was just 12 weeks.

The children and young people, and their parents, have shown tremendous commitment to our work, coming back time and time again for our studies and when we have needed to compare our results with typical children, brothers and sisters have joined in too.

One of our most important findings is that vision is poorer in children with Down's syndrome than in typical children of the same age, and remains poorer even when the children have glasses for any long or short sight.

How can we measure vision in children?

When you go along for an eye test, we ask you to read a letter chart. We score your visual acuity, or detail vision, as the smallest line of letters that you can read correctly. Older children with Down's syndrome may also use a letter chart. Non-readers and younger children can match letters, or identify pictures, by naming, matching or signing. For toddlers, we can use a type of test called 'preferential looking' (PL). In the Cardiff Test, we use a grey card that has a picture, either at the top or bottom. In successive cards, the outline that makes up the picture becomes finer, and the cards are designed in such a way that if the outline is beyond the child's vision limit, the picture simply disappears into the background and becomes invisible. So, if the child can reliably look at a picture, it means that he or she can see the outline. We score the finest picture that the child can see.

For tiny babies (weeks or months of age), we use a similar test that has black/white stripes rather than a picture. Stripes happen to be very attention-grabbing for a baby, but the testing principle is the same, we simply hold up the card and watch where the child looks.

Another aspect of a child's vision that we measure is contrast sensitivity. This is the ability to see faint (rather than fine) objects. If we use a letter chart for this, the letters fade down the chart rather than get smaller. We have preferential looking versions of contrast sensitivity tests too.

Whichever aspect of vision we are measuring, and whatever type of test we use, we find that children with Down's syndrome don't score as well as typical children. Staff in eye clinics must have noticed this for many years, and certainly it has been reported in the scientific literature, but in general parents and teachers are unaware of this.

Why don't children with Down's syndrome see as well as other children?

One obvious explanation of the low scores (and, I suspect, the reason that eye clinics don't point it out to parents) is that the children have a learning disability and they don't try hard when tests get difficult. When we test vision, we start with easy targets and make them harder; perhaps the children just give up when the letter or picture gets difficult to see. To check this possibility, we measured vision in children in a way that didn't require the children to try at all.

Visual Evoked Potentials (VEPs) are brain signals that arise when a subject looks at a target. We can detect these tiny signals by placing sensors on the scalp, and recording the electrical activity. In our study, we asked the children to look at black/white (for acuity) or dark/ light grey (for contrast sensitivity) stripes on a screen. Nothing uncomfortable or demanding – all the child had to do was watch a TV screen for 10 seconds. Easy! During those 10 seconds the stripes got finer or fainter and we knew when they disappeared to the child, because the brain signals disappeared too. This was one of the times when we asked brothers and sisters to join in too, as we needed comparisons between the children with Down's syndrome and typical children.

Figure 1. Visual acuity measured by conventional tests

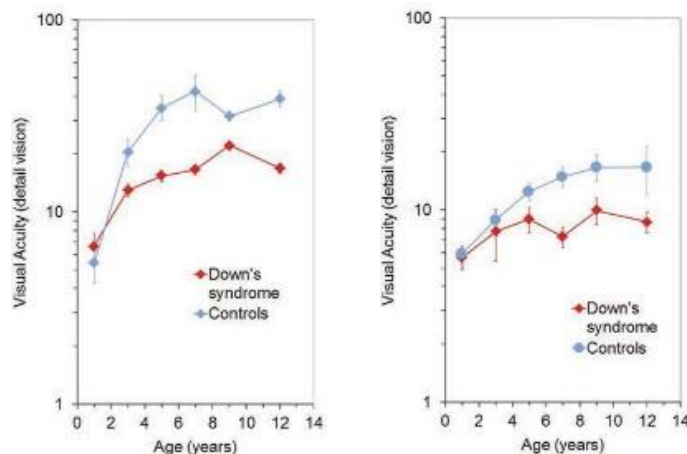
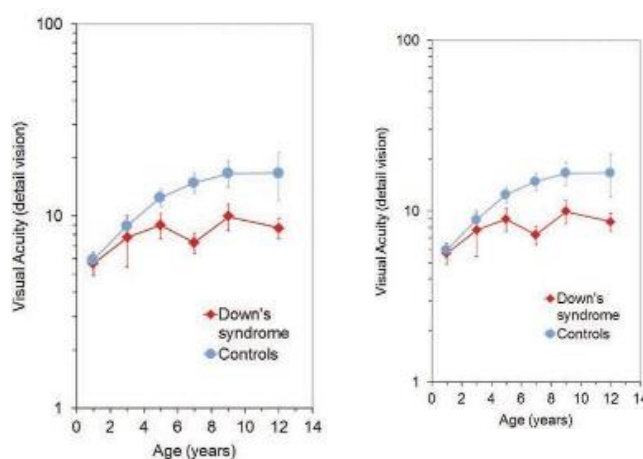


Figure 2. Visual acuity measured by VEP



Figures 1 and 2 show the results. Figure 1 shows the visual acuity results for conventional tests, when children named or matched pictures or letters, or used PL. Figure 2 shows the results for our objective VEP study. Both show the same; children with Down's syndrome have poorer scores, even when we have removed the need to concentrate or try. (Scores differ between the two techniques; this is simply because we are recording in different ways). We found similar results for contrast sensitivity too. In other words, it is not lack of motivation or attention that gives the children with Down's syndrome poorer scores – they really are trying when they do the tests, but they have a genuine visual deficit that mean they do not see as well as other children.

What does this mean for the way children with Down's syndrome see the world?

The difference in vision scores is fairly small (equivalent to 1-3 lines on a letter chart) and not enough for parents to notice in everyday life. After all, toys are generally big and bright and easily seen. But the difference has huge implications for the classroom, when the children's sight is pushed to the limit.

When children are young, they learn to read with big print and the vision deficit probably won't stop children with Down's syndrome learning to read. But it is worth remembering that the children have to work considerably harder than other children to read or to do any school tasks, because they are not seeing their work as easily. As children's reading skills progress, the print gets smaller. There may come a time when a child with Down's syndrome can't make the next step in the reading scheme, not because he or she can't manage the cognitive step to more complex text, but because he or she simply can't see the smaller text.

Little children generally learn to write in pencil. Pencil is faint and very hard for children with Down's syndrome to see. The children should obviously be encouraged to use a pen right from the start. One early writing task is to learn to form letters on the line. To be able to do that, the child must be able to see the line – many children with Down's syndrome can't.

What can we do about this poor vision?

It is sometimes difficult for teachers to appreciate that a child with Down's syndrome in their classroom sees the world differently to the other children.

Their world lacks fine detail and sharp contrast. Teachers are expecting the child with Down's syndrome to have learning problems; after all, that's part of the syndrome. The danger, when a child struggles with a task, is that the teacher puts the failure down to the learning disability and doesn't realise that the child can't see the task. Making the task bigger and bolder can mean the difference between success and failure, and everything that this implies for the child's learning.

It is, therefore, essential that all teachers, at every level of education are aware that every child with Down's syndrome has a genuine visual problem. This is the case even if the child doesn't need glasses or is wearing the correct glasses. Furthermore, the visual deficit MUST be recorded in the Education, Health and Care Plan (EHCP) and, ideally,

every child with Down's syndrome should be supported by the Visual Impairment Service. A Qualified Teacher of the Visually Impaired can check out the visibility of the material in the classroom and advise on any modifications that might help, as well as ensure that, as the child progresses through school, all teaching staff are aware of their needs.

Email from a Mum:

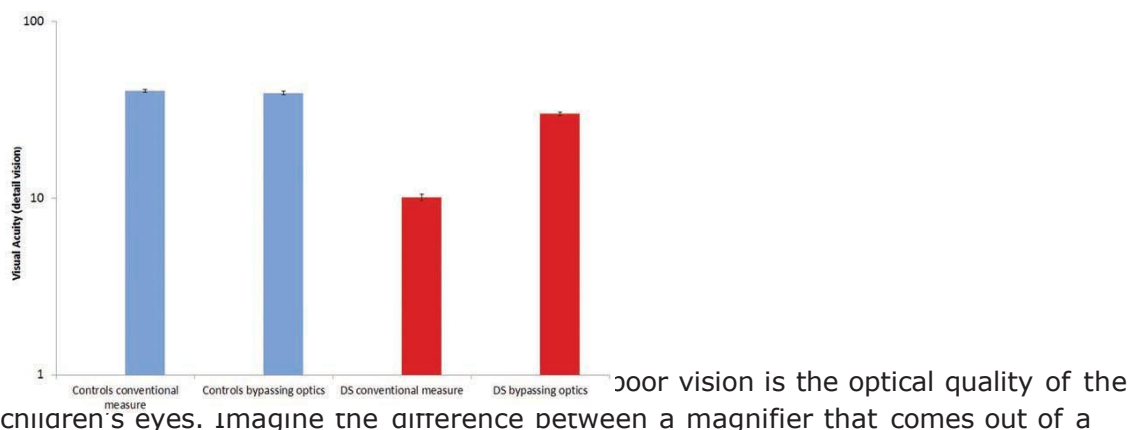
"I know what a difference this [providing information to the school] will make to Ben as one of his targets at school was to write on the line which he couldn't do. It turned out the line was in pencil so I suggested that perhaps he couldn't see it. His TA then drew the lines in pen and instantly he could write on the lines!!"

The DSA's material for schools contains advice about the visual deficit and stresses the importance of modifying materials. My advice to teachers is that if you make all classroom materials big and bold enough for a child with Down's syndrome, it won't do any harm to the other children. So maybe you don't need to do anything special for one child – just make all your classroom materials **BIG** and **BOLD**.

What causes this poor vision?

My colleagues Kathryn Saunders and Julie-Anne Little, from the University of Ulster in Northern Ireland, devised a neat experiment to determine what might be causing the problem. First, we asked children with Down's syndrome and typical children to do a vision test in a conventional way. We asked the children to tell us whether black/white stripes were vertical (standing up) or horizontal (lying down), as the stripes became finer. This was equivalent to our usual vision tests and showed the expected difference between the two groups of children. Then we used a technique called diffractometry that shone a laser light (very weak, completely harmless) into the eye, that created dark/ light stripes within the eye. Again the stripes were vertical or horizontal. This technique bypasses the eye's optics (the cornea and the lens). This time, there was much less difference between the two groups – with this technique children with Down's syndrome had greatly improved vision (see Figure 3).

Figure 3. Visual acuity measured with a conventional technique and with diffractometry that excludes the quality of the optics



Christmas cracker and one bought from a craft shop. The image seen through the cheap cracker magnifier is not clear, compared to the expensive magnifier.

Can the children's vision be improved?

If we are right, and it is the optics that limits the children's vision, we don't have a remedy right now. However, science is moving forward, in developing 'adaptive optics' that can compensate for distortions. The technique is already in use for astronomical telescopes (at astronomical cost, of course). We are a very long way from developing spectacle lenses that compensate for the eye's distortions, but I am confident that they will come.

In the meantime, the best we can do is compensate for the poor vision by making print, pictures etc. easier for the children to see, and by educating all professionals who come into contact with children with Down's syndrome to do the same.

Finally, I believe there is always a bright side and in this case, it's this: the easiest way to envisage how the world looks to a child with Down's syndrome is to picture it in soft focus. There are no sharp edges in your child's world and that's quite a romantic idea isn't it?

Eye Examinations for Children

by Simon Berry

New research has meant that we now understand a lot more about the difficulties that some children with Down's syndrome have with their eyesight. An eye examination is an important part of a general health check and should be a regular occurrence for all children.

There are some specialist areas for Optometrists (Opticians) to think about when examining a child with Down's syndrome. It can sometimes be difficult for parents to know if their Optometrist has the relevant experience and knowledge in this area.

This guide is designed to help you discuss with your Optometrist any concerns you may have. It is a general guide and can never completely include all situations and all children. It should be used as a starting point for any discussion and does not override professional advice.

The Eye Examination

Many parts of an eye examination are as relevant to a child with Down's syndrome as they are any other child. In general, an eye test will always include the following:

- Measuring the optical prescription
- Examining the health of the front and back of the eye
- An assessment of the alignment and movements of the eyes (ocular muscle balance)

There are however some other some aspects of examining a child with Down's syndrome that might differ from a standard eye examination and these are discussed below:

Appropriate Vision Testing

Measuring what someone can see is the basic measurement in any eye test. It allows the Optometrist to decide whether a child has the expected level of vision for their condition, and remains a useful measure to check whether the eyes are developing normally.

The standard way of testing vision is by using a letter chart set 6 metres away from where the patient is sitting. There are different types of test chart but the most common used in the UK are a Snellen or Logmar chart.

If a child is not able to complete one of the standard tests there are other tests available as an alternative way of measuring vision. Some of these charts use pictures and are designed for use with children. They are not reliant on the child's reading ability. Some of the tests match symbols or use a technique called preferential looking to gather the information needed. Examples of alternative test charts include 'Kay pictures', 'Allen pictures' or 'Cardiff Acuity Test'.

It is important that the Optometrist measures your child's vision using a method that is appropriate to their level of understanding. Many of these alternative tests are not standard issue and not all Optometrists will stock all tests. You can discuss testing

requirements with your Optometrist before the eye test and ask about the alternative testing methods that they have.

Dynamic Retinoscopy

It is thought that up to 70% of children with Down's syndrome have a focussing problem called an accommodative lag. This means that they may not be able to bring close objects into focus for any length of time. This can be corrected by prescribing bifocal or varifocal lenses. The technique that Optometrists use to look for this problem is called dynamic retinoscopy. This is not a standard technique and not all Optometrists will use the technique. It would be useful to ask your Optometrist if they are familiar with this examination before any eye test.

Cycloplegic Refraction

Sometimes it is difficult to complete an eye examination if the patient is not able to fully cooperate with the Optometrist. This is when a cycloplegic examination is very useful. It involves instilling an eye drop into the patient's eye. This relaxes the focusing muscle and dilates the pupil. This enables the Optometrist to obtain a very accurate optical prescription and makes it easier to examine the back of the eye. Whilst this may not be necessary for all children, it is a test that should be considered and is included here so that you can discuss with the Optometrist whether it is appropriate for your child.

Reasonable Adjustments

If your child has a learning disability this term may be familiar to you. Healthcare workers should be willing to make reasonable adjustments to the way in which they work to make sure that patients with a learning disability receive the care they deserve. This might be as simple as having a longer appointment, or using alternative testing methods. It will always mean that the Optometrist communicates in a way that the child can understand. If you are concerned that the Optometrist may need to make reasonable adjustments, then you can discuss your child's requirements before an eye test.

Summary

You can print this page to remind yourself about any issues you would like to discuss at your child's eye examination:

Eye Examinations for Children with Down's syndrome

Children with Down's Syndrome Vision checklist

It is recommended that my child receive an eye test that:

1. Considers the use of **C**ycloplegic refraction
2. Includes **D**ynamic retinoscopy
3. **S**peaks to your child in a way they can understand (including *reasonable adjustments*)
4. Uses a **V**ision testing method that is appropriate to their level of understanding

Frame Fitting

By Simon Berry, Optometrist

Spectacle frames these days tend to all be designed and produced in the same way. They have a particular standard set of dimensions that fit most of the population. For people with Down's syndrome it can become a challenge to find frames that fit correctly.

It is a common sight to see a pair of glasses perched on the end of the nose of someone with Down's syndrome. This is because people with Down's syndrome typically have a flat, broad bridge to their nose and the standard nose fitting on that average spectacle frame tends not fit properly.

To try and keep costs as low as possible many spectacle frames are mass-produced in factories on large production lines. This is particularly true for children's frames because in the UK it has become expected that children's glasses should be paid for by the National Health Service. For the frame designers the only way to do that and maximise their profits is by churning out thousands of generic, inflexible, middle-of-the-road frames.

It is to be expected that mass-produced frames don't fit everyone, although there are things we can do to improve the situation. This short guide will give you an introduction to spectacle frame fitting and give some practical suggestions on how to obtain a more comfortable frame fitting for people with Down's syndrome.

What Does the Frame Do?

The whole point of a spectacle frame is to ensure that the optical lenses are held in front of the patient's eyes so they can see better. The frame should be balanced correctly with the weight of the frame evenly distributed between the points of contact with the face. This makes it most likely that the frame will be comfortable to wear and not cause any irritation.

Most spectacle frames achieve this ideal fit by balancing the front of the frame on the nose and using the ears as points to anchor the frame to the face. The glasses will only fit correctly if the points of contact on the nose are in alignment enough to achieve a good balance and the anchor points on the ear are in the correct place and properly fitted.

We also want the spectacle frame to hold up the lenses so that the centre of the optical lens is exactly at the point that the person is looking through. An optical lens has a "sweet spot" in the centre of the lens where the prescription is perfectly correct. This is why when we prescribe a pair of glasses we measure the distance between the eyes so that we can balance the lenses correctly. If the frame slips down, then the eye is not looking through that sweet spot.

The nosepieces on the front of the frame are crucial to maintaining the fit of the frame. They are designed to keep the frame angled in the correct position, to maintain the distance from the eyes, and to help keep the frames balanced on the face. For people

with Down's syndrome the frame typically slips down because often these nosepieces do not fit properly.

What Can Go Wrong?

If glasses don't fit properly, or slide down regularly, they are more likely to work loose and fall off. This increases the chances of breaking the frame. It also means that the frame is less comfortable to wear and children are less likely to tolerate wearing it.

For patients with Down's syndrome a poorly fitted frame also means that it tends to sit on the cheeks, meaning that the frame is uncomfortable and the lenses get dirtier quicker.

The most important problem is that the vision may be compromised. We prescribe optical lenses to fit in a specific place. If the frame slips down constantly then the prescription may not be correct, for various reasons.

- The optical prescription is set at a defined distance from the eye. If the glasses slip down, then the distance from the eye to the lens is longer and the prescription is not correct. This effect is very subtle for small prescriptions, but can be significant for stronger prescriptions.
- The centres of the optical lenses are the "sweet spot" in the lens where the prescription is perfect. Away from this centre the prescription is compromised and there are some induced distortions. If the glasses slip down, you do not get the full advantage of the prescription optical lens.
- If bifocals are prescribed then the top of the bifocal is placed in an optimal place so that it does not affect the distance vision, but is in a convenient place for reading vision. If the frame slips down the nose, the bifocal is not in that optimal place.

How to Achieve a Good Fit

To achieve a comfortable and sturdy fit, we need to fit the spectacle frame so that it is balanced correctly on the nose and anchored securely to the ears, or the head. The weight of the glasses should be spread evenly between the nose and ears.

Standard Frames

We can make adjustments to more traditional frame designs to help them fit smaller flat noses and if we can get a better fitting nose piece, then everything else slots into place.

Metal frames are easier to adapt because they come with more adjustable nosepieces. These nosepieces can be manipulated and angled to fit the shape of a flat nose better. The nose pads themselves can also be changed to slightly more slip-resistant pads to give a little more friction and stop the frame moving so much.

If it is not possible to achieve a good balanced fit on the nose, sometimes by adjusting the arms of the glasses to take more of the weight we can still obtain a reasonable fit. This reduces the need for the nose to hold up the weight of the lenses. This can be done by altering the curvature of the arms so that they grip around the head a little more. Or,

we can also use alternative arms that add more stability such as curl sides or headbands.

It is important when picking frames to check that the length of the arm of the frame can be adjusted.

Specialist Frames

There are also manufacturers that produce frames specifically for a range of face shapes and some that are solely produced for people with Down's syndrome.

Tomato Glasses produce a frame with adjustable curl sides and a moveable adjustable bridge. This gives many more options and ways of achieving a correctly fitted comfortable frame.

Erin's World frames are specifically made for people with Down's syndrome. They feature a lowered bridge, extra-wide frame fronts and shortened temples.

There are also frame manufacturers that produce spectacle frames made specifically to fit flatter faces with a small nose. These are sometimes referred to as Asian-Fit frames. These will tend to have narrower, deeper bridges and longer nose pad arms. Companies such as Swiss-flex will produce alternative nose pieces for their frames, or other companies such as Charton Eyewear produce frames solely for this niche market.

Conclusion

We should not put up with a poorly fitting spectacle frame. We need to make sure that glasses fit correctly for all people with Down's syndrome so that their vision is as good as is possibly can be.

There are alternatives out there that cater for people with Down's syndrome.

NHS Optical Voucher

From 1 April 2016, parents and carers of children for whom a basic spectacle frame will not fit correctly and a more expensive, specially-made frame is clinically required, and who therefore qualify for the Special Facial Characteristics Voucher, will be able to claim their voucher from both Hospital Eye Services (HES) and General Ophthalmic Services (GOS). GOS covers NHS treatment at high street opticians.

Before 1 April 2016, the voucher was only available if a child received their care from HES but not from GOS providers.

More information can be found at:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/509601/Sight_test_fee_associated_fees_and_vouchers.pdf

Why is my Child Wearing Bifocal Lenses?

By Simon Berry, Optometrist

Your child has been prescribed glasses with bifocal lenses to help them to read. They have been found to have a problem with the way in which their eyes focus on close objects. The bifocal lens enables them to bring near tasks into sharp focus. The medical term for describing this problem is an **accommodative lag**. It needs to be corrected using a bifocal lens because the prescription for viewing near objects is different to the prescription for viewing distance objects.

Things to watch out for

It is important that the bifocal lenses are used correctly. Please check that your child is looking through the bifocal part of the lens when reading or viewing close objects. It is particularly important that the glasses are adjusted properly to enable them to do this.

If this is their first pair of bifocal lenses, there will be an initial period of adaption. They may move their head position more than normal as they experiment with different points of focus. They may find the "line" of the bifocal initially annoying.

One disadvantage of a bifocal lens is that when walking around wearing glasses and looking down, the ground will be blurred. This is especially important to note if your child has any problems with their mobility. If this proves to be a problem, it is possible to use a single vision lens for playing outside and a bifocal lens in the classroom. However, this does complicate the treatment because your child will need to remember to swap glasses depending on what they are doing.

Generally, children adapt very well to bifocal lenses within a few days. Most children find they do not need separate glasses for different tasks.

The bifocal lens will make it significantly easier for your child to see close objects. You should notice an increase in your child's concentration and attention for near tasks. You may notice an improvement in reading ability.

Once they begin to see the benefit of the bifocal part of the lens they may make a conscious effort to look through this part of the lens when asked to view near objects. This is a good sign that the bifocals are working. You may notice they adjust their head position to ensure they are looking through the bifocal part of the lens.

Please report back any observations good or bad. An accommodative lag is a dynamic condition and can change. All observations are useful and will be taken into account when prescribing further glasses.

Frequently Asked Questions

What exactly is an Accommodative Lag?

It is a descriptive name for the condition.

Accommodation is the term used to describe our eye's ability to change focus. The ability to do this means we can view all objects clearly no matter what distance they are from us. The effort it takes to accommodate becomes greater the closer the object is to the eye.

A **lag** in the accommodation means that the eye is not correctly focused at the correct point. There is an under-accommodation that gets worse the closer the object is to the eye.

The effect of this is that the object your child wants to look at will be blurred. If they can't see it, their attention and reading ability will be affected.

My child cannot read. How can the Optometrist be sure that my child has this condition?

This condition is measured using an objective technique. This means that it does not rely on the answers of the child and they are unable to give any wrong answers.

What is the connection between Down's syndrome and Accommodative Lag?

Current research suggests that around 70% of children with Down's syndrome have an accommodative lag. Such a high number means that all children with Down's syndrome should be screened to see if they have the condition.

Will the bifocals cure the condition?

The bifocal lens means that your child will be able to properly focus on close objects. Some research has suggested that the bifocals can help to "teach" the eye to focus and that for some children they may only be needed for a short length of time. This research has not been fully validated yet and it is likely that all children are different. It is important that any child wearing bifocals has regular eye checks to measure whether any alteration to the prescription is needed.

Can Varifocals be used as an alternative?

A varifocal lens has a much smaller reading area than a bifocal and can affect peripheral vision. For these reasons it is preferable to use a bifocal lens. However, every child is different. If you have a specific reason to request a varifocal please discuss your concerns.

What do I need to tell the teacher?

Please give them a copy of this information. Your teacher's observations are very important because they will see your child working with the bifocal lenses. We are happy to discuss the condition with your child's teacher but we will need your permission to do so before they contact us.

Encouraging your child to wear glasses

By Maggie Woodhouse

Why does my child need to wear glasses?

Glasses are prescribed to correct a refractive error. Refractive error can mean long or short-sight, with or without astigmatism. 'Long-sight' means that distance vision is clearer than near vision and is caused by the eyeball being slightly too small. 'Short-sight' means that near vision is clearer than distance vision and is caused by the eyeball being slightly too large. Astigmatism results from irregular curvature of the front of the eye and distorts vision at all distances.

When does my child need to wear his/her glasses?

Your Optometrist will tell you when your child should wear his/her glasses. If your child needs to wear his/her glasses in school, it is important that the class teacher knows when the glasses should be worn. The Optometrist will send a copy of your child's report directly to the school (with your consent). You can help by mentioning the glasses to the teacher when you next visit the school.

Why won't my child wear his/her glasses?

There can be several reasons for a child's reluctance, and it is important that you consider each one. Are your child's glasses fitting properly?

Are the glasses too tight against the side of the head or behind the ears? Are they too loose and keep slipping down your child's nose? A child will not want to wear glasses that feel uncomfortable. Glasses can be adjusted to fit your child properly and you should insist that the Optometrist/Optician takes time to do this when you collect the glasses. If the glasses become bent or stop fitting properly get them adjusted again. Your Optician will be happy to do this for you.

If your child is reluctant to wear his/her glasses at first this may be because they are adjusting to the prescription. When we make the world clearer with glasses, we may think this means 'better' – your child may just think 'different'. This difference can sometimes take a little while to get used to.

Some children do not like objects on or near their face. Others do not like change. Once your child learns that the glasses will not harm them and gets used to the glasses they will be happy to wear them.

How do I persuade my child to keep his/her glasses on?

We find a simple 'programme' works well. Choose an activity that your child enjoys doing with you, and one for which the glasses will help – discuss this with your Optometrist. It may be reading a story, or watching a favourite video, for example. Make it a 'special time' together - this way your child learns to associate wearing glasses with a pleasant experience. Put the glasses on at the start of the activity (don't forget to put yours on if you need them too!) and make the activity short at first. If your child takes the glasses

off, simply stop the activity. Persevere, increasing the length of time and/or introducing a second 'spectacle-wearing' activity. Don't worry if it takes a long time (weeks or even months) before your child is happy to keep his/her glasses on.

Most importantly, do NOT turn it into a battle – your child will win! Children learn very quickly that throwing glasses across the room gets more attention than almost anything else!

If your child won't wear his/her glasses at home, then perhaps he/she will wear them at school. Chat to the class teacher and ask for help in trying to persuade your child to wear the glasses. Give them a copy of this hand-out. There may be other children in the class who wear glasses and this may encourage your child to wear his/hers. What do I do if my child WILL NOT wear his/her glasses? Some few children will not wear their glasses, even after all of the above has been tried. Don't panic. It is common for children to grow out of their reluctance to wear glasses. It may be that if you wait for a few weeks and then try again it will be more successful. Glasses will improve your child's vision and this benefit will eventually motivate him/her to want to wear his/her glasses.

Annual health checks for people with Down's syndrome (aged 14 years plus)

In the past people with learning disabilities have not had equal access to healthcare compared to the general population. This, amongst other reasons, has given rise to poorer mental and physical health and a lower life expectancy for people with learning disabilities. Free annual health checks for adults with learning disabilities, with their GP, were introduced in 2008 as a way to improve people's quality of life.

The annual health check for people with learning disabilities is a Directed Enhanced Service (DES). This is a special service or activity provided by GP practices that has been negotiated nationally. Practices can choose whether or not to provide this service. The Learning Disability DES was introduced to improve healthcare and provide annual health checks for adults on the local authority learning disability register. To participate in this DES, staff from the GP practice need to attend a multi-professional education session run by their local Trust. The GP practice is then paid a sum of money for every annual health check undertaken.

Who can have one?

Annual health checks have been extended to include anyone with learning disabilities aged 14 years or above. So anyone with Down's syndrome aged 14 years or over can have an annual health check.

The benefits of annual health checks

- additional support to get the right healthcare
- increased chance of detecting unmet, unrecognised and potentially treatable health conditions
- action can be taken to address these health needs.

How to get an annual health check

- The GP may get in touch with the person with Down's syndrome to offer an annual health check but this doesn't always happen.
- A person with Down's syndrome and/or a supporter can ask their GP for an annual health check. You do not need to be known to social services to ask for an annual health check.

Not all GPs do annual health checks for people with learning disabilities but they should be able to provide details of other GPs in your area who offer this service.

What happens next?

- The GP practice may send out a pre-check questionnaire to be filled out before the annual health check takes place.
- The GP may arrange for the person with Down's syndrome to have a routine blood test a week or so before the annual health check.

Who attends the annual health check?

If the person with Down's syndrome (age 16 years or over) has capacity and gives their consent, a parent or supporter can attend the health check as well.

How long should an annual health check be?

Guidance from the Royal College of GPs suggests half an hour with your GP and half an hour with the Practice nurse.

What areas of health should be looked at as part of the annual health check?

We have produced a check list for GPs which contains information about what should be included as part of a comprehensive and thorough annual health check. This includes a list of checks that everyone with a learning disability should undergo as part of an annual health check and a list of checks specific to people with Down's syndrome. You can find the health check list at the 'annual health checks' section of our website under 'families and carers and 'health and wellbeing'.

Eyes should be checked as part of a comprehensive and thorough Annual Health Check.

Ophthalmic problems such as cataract, glaucoma, keratoconus and refractive errors need to be checked:

- **Full assessment by optician/optometrist at least every 2 years**
- **If examination difficult, refer to specialist optician or ophthalmologist for assessment.**

Source: Annual health checks for adults with Down's syndrome check list (amended 2017,

What happens after the annual health check?

Your GP should tell you what they and the nurse have found during the annual health check. You should have a chance to ask any questions you have. Your GP may refer you to specialist services for further tests as appropriate. Your GP should use what they have found during your annual health check to produce a health action plan. This should set out the key actions agreed with you and (where applicable) your parent or carer during the annual health check. Your GP has to do this as part of the annual health check service.

Information about health issues for GPs

There is information at our website for GPs about some of the more common health conditions seen in people with Down's syndrome. You will find this information at the 'annual health checks' section of our website under 'families and carers and 'health and wellbeing'.

GPs learning disability register

People with learning disabilities experience poorer health compared to the rest of the population, but some ill health is preventable. Over one million people in the UK have a learning disability but only 200,000 are on their GPs learning disability register.

We know that people with a learning disability often have difficulties accessing health services and face inequalities in the service they receive. The Government is asking parents and supporters to speak to their GP and ensure their sons/daughters or the people whom they support are registered. It is hoped that this drive will ensure better and more person centered health care for people with learning disabilities.

The Learning Disability Register is a record of people with a learning disability who are registered with each GP practice. The Register is sometimes referred to as the Quality Outcomes Framework (QOF) Register.

If you are not sure you are on the Register, you can ask the receptionist at your GP Practice to check for you.

The doctor may have made a note on the record that a person has Down's syndrome but this does not automatically mean they have been put on the Register. When you speak to the GP about being registered, the needs and support of the person in health settings can be discussed. This information can be entered on the person's Summary Care Record (SCR) so that all health professionals at the practice know about their needs and how best to support them.

If the person is over 16 years of age or older, they must give their consent (see section in this resource about the Mental Capacity Act 2005):

- for information about their support needs to be added to their SCR
- to which information can be shared and with whom

It's never too early (or late) to join your GP's Learning Disability Register; you can join at any age. It's a good idea for children with a learning disability to join the learning disability register at an early age. This means adjustments and support can be put in place before they reach adult

Reasonable adjustments in health care

You may have heard of the term 'reasonable adjustments' and wondered what it meant. Since the Disability Discrimination Act (1995) and the Equality Act (2010) (this does not apply to Northern Ireland) public services are required by law to make reasonable adjustments to help remove barriers faced by people with disabilities when trying to use a service. The duty under the Equality Act to make reasonable adjustments applies if you are placed at a substantial disadvantage because of your disability compared to people without a disability or who don't have the same disability as you.

So for people with physical disabilities reasonable adjustments may include changes to the environment like ramps for the ease of wheelchair users. For people with learning disabilities 'reasonable adjustments' may include easy read information, longer appointments, clearer signs at the practice, help to make decisions, changes to policies, procedures and staff training.

If a patient with Down's syndrome is NOT on their GP's Learning Disability Register then reasonable adjustments to care for that person cannot be anticipated and made.

Reviewed and updated 2018

Stuart Mills – Information Officer (DSA)

Publication date 2016

The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome.

We also work to champion the rights of people with Down's syndrome, by campaigning for change and challenging discrimination.

A wide range of Down's Syndrome Association publications can be downloaded free of charge from our website.

Contact us

Down's Syndrome Association

National Office

Langdon Down Centre,
2a Langdon Park, Teddington,
Middlesex, TW11 9PS

t. 0333 1212 300

f. 020 8614 5127

e. info@downs-syndrome.org.uk

w. www.downs-syndrome.org.uk

Wales

t. 0333 1212 300

e. wales@downs-syndrome.org.uk

Northern Ireland

Unit 2, Marlborough House,
348 Lisburn Road,
Belfast BT9 6GH

t. 02890 665260

f. 02890 667674

e. enquiriesni@downs-syndrome.org.uk



WorkFit® is a registered trade mark of the Down's Syndrome Association. Photographs courtesy of the Cheshire Down's Syndrome Support Group.



www.dsactive.org



www.dsworkfit.org.uk



www.langdondownmuseum.org.uk



www.langdondowncentre.org.uk



© Down's Syndrome Association 2017