



You and Eye

A film about eye care for
people with learning disabilities

This book accompanies the film **You and Eye – A film about eye care for people with learning disabilities**

Developed by SeeAbility's eye 2 eye Campaign



SeeAbility House
Hook Road
Epsom, Surrey, KT19 8SQ

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information on eye care and vision
for people with learning disabilities

www.lookupinfo.org
0800 121 8900

Text by Leigh Harris and with contributions from
Paula Spinks-Chamberlain, Gill Levy, David Melling, Laura Christie,
Michael Loftus, Elaine Wharton and Stephen Kill.

Photographs by Ian Olsen, Andy Forman and Profile Vision.
Designed by Clifford Singer at Edition

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Contents

Page 2	Introduction
Page 4	Having an eye test and getting new glasses
Page 4	What the story on the DVD is about
Page 6	Things to do before you go to the optometrist
Page 7	What the optometrist needs to know
Page 9	Planning the appointment
Page 10	At the optometrist – what happens in the eye test?
Page 15	At the optometrist – what happens at the end of the eye test?
Page 16	Getting used to wearing glasses – things to consider
Page 20	‘Telling the optometrist about me’ form
Page 28	‘Feedback from the optometrist about my eye test’ form
Page 32	Having a cataract operation
Page 32	What the story on the DVD is about?
Page 32	What is a cataract?
Page 33	What signs to look for?
Page 35	The eye hospital appointment
Page 37	Consent to treatment
Page 37	Having a cataract operation
Page 39	‘Eye Surgery Support Plan’ form
Page 55	Ignoring the signs
Page 55	What the story on the DVD is about?
Page 55	Looking after our eyesight
Page 56	Eye Poking
Page 57	What you can do to help
Page 58	Glossary – what does it mean?

Introduction



Sight helps us to learn things and move around.



1 in 3 people with a learning disability has a sight problem.



People with learning disabilities may not know they have a sight problem and may not be able to tell others.



No one is too disabled to have his or her eyes tested.



Everyone needs regular eye tests.



Eye tests are health checks, not just about getting glasses.



You need an eye test every two years, or more often if your optometrist says you need it.



You don't have to be able to read or talk to have an eye test.



Lots of people with learning difficulties have to get used to wearing glasses.



Lots of people with learning disabilities have eye operations to make their sight better.



People with learning difficulties need the same help as everybody else with a sight problem.

This book accompanies the film **‘You and Eye’ – A film about eye care for people with learning disabilities**. The film and book were developed by SeeAbility’s eye 2 eye Campaign in conjunction with the Misfits Theatre Company in Bristol.

The film and book aim to provide information for people with learning disabilities and their carers about the importance of eye care and vision. Regular and effective sight tests are rare among people with learning disabilities therefore visual impairment often goes undetected – leading to poor eye health; dependence; and in some instances preventable blindness.

About the eye 2 eye Campaign

In 2005 SeeAbility launched the eye 2 eye Campaign with the aim of improving eye care and vision for people with learning disabilities. The eye 2 eye Campaign aims to achieve this goal via:

- A number of eye 2 eye **Community Development Projects** across the UK – we currently have projects in Bristol; Sheffield; Birmingham; London, West Sussex with many more planned.
- A national Information service named **Look Up** (in collaboration with RNIB). The service, for adults with learning disabilities; family carers; eye care professionals and health and social care staff; is delivered via a website www.lookupinfo.org, publications, a telephone line 0800 121 8900 and an email forum.
- **Lobbying and Campaigning** activities designed to influence government policy on eye care and vision for people with learning disabilities.

If you would like further information about SeeAbility’s eye 2 eye Campaign please email eye2eye@seeability.org, visit www.seeability.org or phone 01372 755000.



Having an eye test and getting new glasses

What the story on the DVD is about



- The story shows you what happens when you visit the optometrist.



- It will show why you might have problems seeing well.



- It will show you that it is important to get your eyes tested.

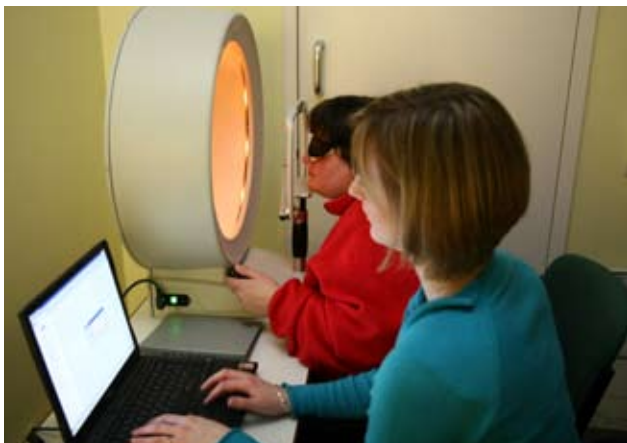


- It will show you what happens when you have an eye test.

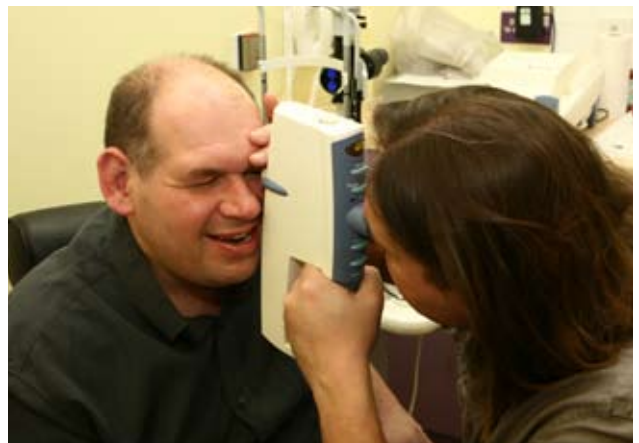


- We hope that after you watch this video you will be happy to have your eyes tested.

This story was made to help people with learning disabilities and their carers understand why they need to get their eyes tested and what will happen at the optometrist. The DVD shows a basic eye test. However, different optometrists may use different methods to obtain the results they need. There are some other tests not shown in the DVD which you need to be aware of such as:



- Visual field test.



- Glaucoma test.



- Having eyes drops put in the eye.



- Having a torch light shone in the eye.

These tests are explained in the **‘What happens in the eye test?’** section.

In the film our actors refer to people who test your eyes as opticians as many people find this word easier to say than optometrist.

An **optometrist** is a person who is qualified to carry out eye examinations, advise on eye care and recognise eye problems. They prescribe and fit glasses, contact lenses and low vision appliances (such as magnifying aids). They work in private practices in high streets, hospital eye departments or health centres/community clinics.

An **optician** (sometimes called dispensing optician) is a person who is qualified to fit and adjust glasses. Some are also qualified to fit contact lenses. They also give out low vision appliances from a prescription supplied by an ophthalmologist or optometrist. They work in high street premises or hospital eye departments.

In the book we refer to people who test your eyes as optometrists.

I. Things to do before you go to the optometrist



It is important for carers to know the individual being tested and what parts of the test are they able to do well. Are there parts of the eye test that they may be frightened of – such as having drops inserted or somebody coming up close to them.

It can be useful to prepare people for some of the tests they may find difficult, for example:

- Practice matching pictures. Your local social services visual impairment rehabilitation team may have Kay Picture tests you can borrow to practice. Alternatively contact SeeAbility's eye 2 eye team.



- Familiarize the person with air being blown on their face. This will help them to be prepared for the 'puffer' test which tests for glaucoma. This can be done simply by using a biro casing or a straw.
- Practice shining a small torch in the person's eye to get them used to someone being up close and having a light shone in their eyes.



2. What the optometrist needs to know

It is important for carers to tell the optometrist information that will help them complete a satisfactory eye test. This information can be recorded on our **'Telling the optometrist about me'** form which is included in this pack. You can photocopy this form from the book or the form can be downloaded from our website www.lookupinfo.org.

The information that the optometrist needs to know is:

- The person's date of birth.
- Do they receive benefits which would entitle them to a free eye test and a voucher towards the cost of glasses? If yes, take evidence with you to the eye test (people in Scotland and Wales get free eye tests).
- Does the person have an identified eye problem?
- What medication is the person taking?
- Has the person ever been seen by an ophthalmologist (eye doctor), optometrist, orthoptist or low vision clinic before and when were they seen?
- Does the person have glasses? When were they prescribed and what are they for? Do the glasses help and when does the person wear them?
- Does the person have any magnifiers or low vision aids?
- Make sure that you take all current glasses and any other low vision aids such as magnifiers to the appointment.



- Has the person ever had a severe eye infection, head injury or stroke?
- Does the person have any condition that might affect their vision, for example
 - diabetes, epilepsy, high blood pressure, sickle cell disease, cerebral palsy etc.
- Is there any family history of eye problems for example glaucoma.
- How does the individual use their vision?
 - Do they recognise people – at what distance?
 - Do they make eye contact?
 - Do they gaze into the distance?
 - Do they hold objects close to their eyes? Can they focus on near (for example food) or distant objects?
 - Do they do anything to see better
 - for example, put their head on one side, peer closely at things?
 - What is their field of vision? Can they see all around?
 - Does their sight seem to vary according to the time of day?
 - Has their behaviour changed recently?



3. Planning the appointment

If you need help finding an optometrist then go to our website www.lookupinfo.org or ask staff or friends to recommend an optometrist.



Plan the appointment at a time of day when the person functions best.

It is important that the sight test and eye health check is carried out in an unhurried way – people with learning disabilities may take longer to test. If you think you may need a longer appointment then tell the receptionist when you make the appointment.



If necessary, check that the optometrist's practice is accessible for wheelchair users.



Ensure that the person is accompanied on the day by someone who knows them well.



Remember this is a medical appointment – often optometrists find that appointments for people with learning disabilities are cancelled at short notice. This sometimes happens because of good reasons, for example illness. However, sometimes appointments are cancelled because of poor staff planning. Each cancelled appointment costs the optometrist money. Consider whether you would be as likely to cancel a GP, dental or hospital appointment.

4. At the optometrists – what happens in the eye test?

Make sure that the optometrist knows how the person likes to communicate and any special needs, likes and dislikes they may have.

- Can they say yes or no?
- Can they understand and say the words 'better' or 'worse'?
- Can they match pictures.



Be prepared to help during the test by encouraging and supporting the person or interpreting their responses – and don't be offended if the optometrist tells you that you are in the way.



There are many different parts to an eye test, and all should ideally be carried out, but not necessarily in the order given below:

1. The optometrist will **ask about the person's history, symptoms and medication.**



2. The optometrist will do an **eye health check** – to look for eye diseases or damage inside and outside the eye. An eye health check is made up of a lot of different tests so be aware that:

- This will include a torch light being shone into the eye so the optometrist can get a clear look at the back of the eye.
- The optometrist may need to turn out the lights to get the best view, so you need to tell them if this is likely to upset the person having their eyes tested.
- The optometrist may have to get close to the individual to get the best view.



- Eye drops may need to be put in the person's eye to widen the pupil. It is important to be aware that eye drops can blur vision for a short period and the eye drops take 15/20 minutes to work. You may need to go back and wait in reception while the eye drops start to work. Eye drops may take a couple of hours to wear off and during that time people can have problems with bright light and moving around.



- The optometrist may also do a test to check the pressure within the eye, especially in an older person. This test involves air being puffed into the eye.



- Many optometrists will also screen for diabetes by taking a photograph of the inside of the eye. This involves the person keeping very still and looking straight ahead into a special camera.



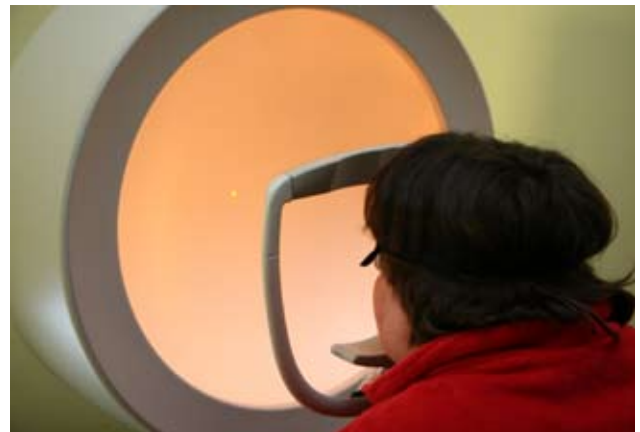
- An evaluation of eye movement control (a 'binocular vision check') will take place to assess how the two eyes work together and a test to check how the eyes react to changes in light may also take place.



- The optometrist will also test the person's level of vision for both distance and near tasks and they will check for shortsight, longsight and/or astigmatism and the need for glasses or contact lenses for near or distance.



- A visual fields test – to assess 'all round vision' will take place. It is important that the optometrist tests a person's visual field, which is the extent to which a person can see around them without moving either their eyes or head. This test should establish whether a person has full all-round vision, loss on one side or the other, has lost their central vision or has tunnel or 'patchy' vision. This test can be done by asking the person to look at a central dot of light in a machine and then count the dots of light that appear around it.



3. The optometrist will **test the level of vision ('visual acuity')**. Testing visual acuity can be enjoyable and you can practice this part of the test at home so that the person is prepared. The following tests may be used to check the level of vision:

- **Letter charts and adapted letter charts**

The Snellen chart – commonly seen in GP surgeries, optometrist/opticians and hospital eye clinics, involves reading the letters down the chart, starting with the largest one at the top.



There are simple charts for people who cannot identify letters but can match the letters. The optometrist holds up a booklet containing one letter, or a row of letters, on a page. The person responds by pointing to letters on a card held on their lap.



- **Kay Picture Test**

The optometrist presents a single black picture or a row of pictures (boot, clock, duck etc) and the person responds by naming, or pointing at a picture on their card. Alternatively, the person might sign in Makaton to identify the picture. Different sized pictures are held up by the optometrist to establish the limit of a person's vision.



- **Cardiff Acuity Test**

This test was originally devised for young children and an adult version is now available. It uses the 'preferential looking' principle. The person being tested does not need to name or match, but simply look at a picture either at the top or the bottom of a card. The optometrist holds the card at eye level and watches for the person's eye movements towards the picture.



The optometrist will also use **trial frames to help them decide what lenses would help the person see best.** The optometrist may place a trial frame on the person's face. This may be a strange experience and people may find it uncomfortable.



Other optometrists may simply hold a lens up to the person to look through it. The person is then asked if the lens makes things better or worse. Many people (of all levels of ability) find it hard to answer, so you may want to practice before the appointment and use phrases such as 'nearer' or 'far away' until you are clear that a consistent response is being given.



5. At the optometrist – what happens at the end of the eye test?

It is important that you find out as much information as possible about what the optometrist found during the eye test. Sometimes this can be confusing as optometrists use words that you may not understand.

At the end of the eye test ask the optometrist to fill out our **'Feedback from the optometrist about my eye test'** form which is included in this pack. You can photocopy this form from the book or the form can be downloaded from our website www.lookupinfo.org.



Alternatively, ask for a written report about their findings, and ensure this contains advice on what action should be taken. If a report cannot be obtained, make notes of what the optometrist says about the person's eye problems.

If glasses have been prescribed, asked whether they are for near or distance, or both, and when they will help the person with specific tasks. Consider labelling different pairs of glasses with discreet colour spots – such as blue for TV, red for magazines, eating and other close work.

With the person's agreement, this information should be distributed to other staff members and key people in the individual's life and included in:

- their care plan.
- their person-centred plan.
- their health action plan.
- their medical note.



6. Getting used to wearing glasses – things to consider

If the individual requires glasses the optometrist will write a prescription which tells you what type and strength of glasses are needed.

You do not have to buy your glasses at the same optometrist where you had your eyes tested, but if you are comfortable there it saves visiting another unfamiliar environment.

If you are tired you can always go back another day to have your glasses fitted.

1. Choosing glasses:

- Most people on income support will get a voucher towards the cost of their glasses. Most glasses cost more than this so be aware you may need to pay more for the pair you like most.

- Most people like to look good. So if individual chooses their pair of glasses, and likes how they look in them, they will be more likely to wear them.

- Who helps the person choose the frames? Are they going to be encouraged to buy expensive glasses with expensive coatings?

- Does the person need to have a parent or particular staff member around to help them decide which frames will be best for them?



2. Fitting glasses:

- It is important that glasses fit properly, if they are uncomfortable, they are more likely to be rejected.
- Glasses must fit on the nose, not slide up or down. Some people with small, flat noses may have problems if they have a large prescription, as heavy lenses may pull the glasses down their face.
- Glasses must fit on ears, not hurt them. It is important to check that people don't have skin problems on or around their ears.
- Glasses must not cut into the side of a person's face.



3. Wearing glasses:

- People need to know what glasses are for. Are they for near, distance or both? Will it help to label what glasses are for?
- Lots of people take time to get used to new glasses – not just people with learning disabilities.



- Looking through glasses can feel very strange to begin with, especially if you have never had glasses before. Sometimes the optometrist will give a weaker pair, so that person can get used to wearing them.
- Some people will not want to wear glasses, and may need to be gradually introduced to wearing them. What is known as a adaptation programme may help.



An adaptation programme

- This programme is designed to introduce the person to the new sensations of wearing glasses gradually and in a positive way.
- Don't start the programme until you are certain that the glasses fit well and are comfortable.
- Choose an activity that the person enjoys and one for which the glasses will help. If they are short sighted, glasses improve distance vision, so the activity may be watching TV.
- If the person is long sighted, the greatest benefit will be for near tasks, so the activity may be drawing, looking at magazines, or eating.
- The activity chosen should be safe and not involve any risk to the person who may have initial problems in judging depth or distance (e.g. mobile activities).
- Put the glasses on at the start of the activity and make the activity very short at first. If they take the glasses off, simply stop the activity without

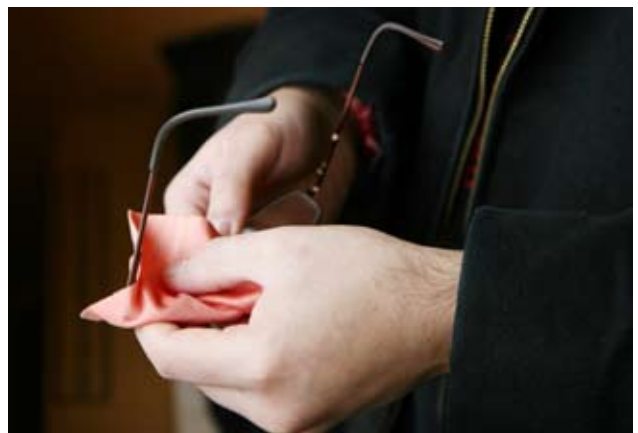


comment, if this is appropriate. Alternatively, encourage them to put the glasses back on for a short time with lots of encouragement.

- Persevere slowly, increasing the length of time, and/or introduce a second “glasses-wearing” activity. Don’t worry if it takes a long time.
- Remember that the ultimate choice of whether to wear the glasses has to lie with the individual. Although we believe that improved vision improves the quality of life, it is unlikely that an adult will do harm by rejecting glasses. If you are concerned about long-term consequences discuss this with the optometrist.

4. Taking care of glasses:

- You need to keep them clean, using a soft cloth.



- You will need to lie them down so lenses aren’t scratched.
- Glasses and nose pads may need to be adjusted regularly to ensure they continue to fit.
- Nose pads can get brown and mucky-looking and may need to be replaced.
- Although there is no entitlement under the NHS to provide a spare pair of glasses if they become damaged, if an individual is reliant on glasses, it may be best to buy a spare pair as it will be distressing if there is long wait to have the main pair repaired.
- Some individuals will be more likely to break their glasses (intentionally or accidentally), and may benefit from ‘unbreakable’ memoflex frames. These cost more but may benefit a person who is likely to throw their glasses.





information on eye care and vision
for people with learning disabilities

Telling the Optometrist About Me

Your name: _____

The name you like to be called: _____

Date of Birth: _____

NHS number: _____ National Insurance number: _____

Address for letters: _____

Phone number: _____

GP's name and address: _____

Most people on benefits get a free eye test and money towards the cost of glasses. You must bring something that shows you get benefits to the eye test. Please write down any benefits you get e.g. Income Support: _____

About your eyes:

When was your last eye test? _____

Where did you go to have your eyes tested? _____

What were the results of the eye test? _____

Do you have any problems seeing?

Yes ☐ No ☐ Don't know ☐ Sometimes ☐

If yes, please write what the problems are:

Do you have glasses?

Yes ☐ No ☐ Don't know ☐

If yes, please take your glasses with you to the eye test

When did you get them? _____

When do you wear your glasses? _____

Do you have a copy of the prescription for these glasses?

Yes ☐ No ☐ Don't know ☐

If yes, please take the prescription with you to the eye test

Are you registered Blind/Severely Sight Impaired?

Yes ☐ No ☐ Don't know ☐

Are you registered Partially Sighted/Sight Impaired/?

Yes ☐ No ☐ Don't know ☐

Have you ever been to the hospital about problems with your eyes?

Yes ☐ No ☐ Don't know ☐

If yes, why did you have to go? _____

Which hospital did you go to? _____

Has anyone in your family had serious eye problems?

Yes ☐ No ☐ Don't know ☐

If yes please write below:

Person:
(for example, mum, dad, sister)

Eye Problem:
(for example, glaucoma,
cataracts, diabetes)

About you:

Do you use a wheelchair? (if you do, check that it will fit into the optician's shop and eye test room)

Yes ☐ No ☐

If you do use a wheelchair can you move safely from it to another?

Yes ☐ No ☐ Don't know ☐

Do you have any health problems or disabilities? Yes ☐ No ☐

If yes, what are they?

Do you take any medication? Yes ☐ No ☐ Don't know ☐

If yes:

What is it called?

How much do you take?

What is it for?

<hr/>	<hr/>	<hr/>
<hr/>	<hr/>	<hr/>
<hr/>	<hr/>	<hr/>

Are you deaf or hard of hearing? Yes ☐ No ☐

Do you find it hard to communicate? Yes ☐ No ☐

What helps you communicate?

About the eye test:

When you have your eye test the optometrist will need to look in your eyes and do some tests to see how well you can see. To help the optometrist do the eye test:



Please tick the box with the right answer:

I can say the names of letters on a chart on the wall (like A, E, X, O)

Yes ☐ No ☐ Don't know ☐

I can say the names of pictures on a chart on the wall (like a fish, house or flower)

Yes ☐ No ☐ Don't know ☐

I can point to a letter on a card that is the same as the letter on the chart on the wall

Yes ☐ No ☐ Don't know ☐

I can point to a picture on a card that is the same as the picture on a chart on the wall

Yes ☐ No ☐ Don't know ☐

I understand the words "better" or "worse"

Yes ☐ No ☐ Don't know ☐

I will be OK going to a new place with new people

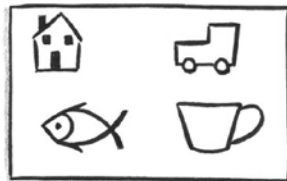
Yes ☐ No ☐ Don't know ☐

I will be able to wait for more than 20 minutes before having my eyes tested.

Yes ☐ No ☐ Don't know ☐



Haunor



I will be able to keep looking at a letter or picture on the wall for a few minutes.

Yes ☐ No ☐ Don't know ☐

I will be able to keep looking at a letter or picture on the wall for a few seconds.

Yes ☐ No ☐ Don't know ☐

I will be ok if the optometrist were to cover my eyes one at a time and ask me to look at the letters or pictures on the wall.

Yes ☐ No ☐ Don't know ☐



Haunor

I will be able to wear test frames on my face.

Yes ☐ No ☐ Don't know ☐

I can say which ones make the letters or pictures on the wall easier to see.

Yes ☐ No ☐ Don't know ☐

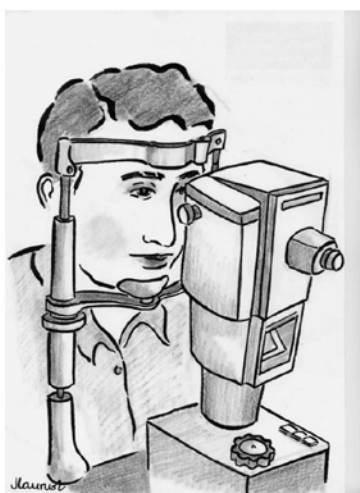


Some people need to have drops put in their eyes during the eye test, would this be ok?

Yes ☐ No ☐ Don't know ☐

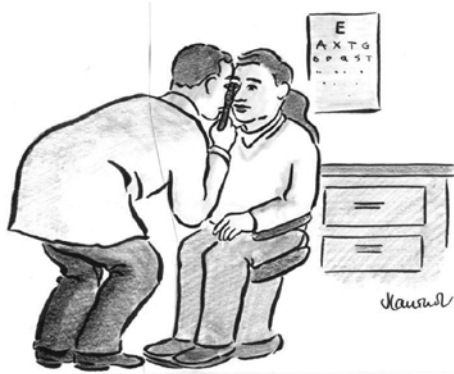
(Some eye drops may sting for a bit or make it hard to see, so make sure you ask the Optometrist what will happen first)

I will be ok if the lights in the room were turned off for a few minutes. Yes ☐ No ☐ Don't know ☐



I would be able to put my chin on a shelf in front of a machine. I can keep my head still so that the optometrist can shine a light into my eyes.

Yes ☐ No ☐ Don't know ☐



I would be ok if the optometrist came very close to me.

Yes ☐ No ☐ Don't know ☐

I would be ok if the optometrist came close to me and shone a bright light in my eye.

Yes ☐ No ☐ Don't know ☐

It would be ok to hold a glass up to my eye and shine a bright light into my eye from far away.

Yes ☐ No ☐ Don't know ☐

It would be ok for a gentle puff of air to be blow into my eye from a from a machine that will measure my eye pressure.
(This will not hurt but it will make you jump)

Yes ☐ No ☐ Don't know ☐

Is there anything that needs to be done to make your eye test easier and more fun?

Things to take to your eye test:

Remember to take these things to your eye test:

- A filled in copy of this eye test form
- Evidence of the benefits you get (if you get any)
- Your glasses (if you have any)
- The prescription for these glasses (if you have one)
- Your Health Action Plan (if you have one)



information on eye care and vision
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Feedback From The Optometrist About My Eye Test

To be completed by eye care professional and given to person with their prescription (GOS 2).

Name of practice

Name of eye care professional

Practice contact details

Name of person

Date of birth

Date of eye test

Was full examination possible?
(may be limited due to communication difficulties, lack of co-operation, boredom, lack of specialist equipment etc)

If not, does another test need to be carried out?

What alternative testing methods were used? Please tick.

Cardiff Acuity Test ☐ Sheridan Gardiner Test ☐

Kay Picture Test ☐ Other ☐

Were parts of the eye test **not** performed? Please tick.

External eye examination ☐ Colour vision ☐

Looking at back of the eye ☐ Eye pressure ☐

Visual fields / all round vision ☐ Contract sensitivity ☐

Visual sharpness / seeing detail ☐

Why?

Are further examinations required in near future? If yes, when and where?

Glasses issued? Yes ☐ No ☐

First pair for: near ☐ distance ☐ both ☐

Second pair for: near ☐ distance ☐ both ☐

If worn will glasses fully correct vision? Yes ☐ No ☐

If person will not wear glasses how well can they see?

Person sees best with –

Left Eye ☐ Right Eye ☐ Both Eyes ☐

How clearly do they see?

Left Eye

Right Eye

Both eyes

At what distance can person best see pictures / writing in an A4 book?

Have any significant sight problems been detected?

Please describe

Have any other health problems been detected in this eye test?

Is person to be referred on to –

Low Vision Clinic ☐

Rehabilitation Worker for Visually Impaired People ☐

Community Team for People with a Learning Disability ☐

Why?

Who needs to make this referral?

Does the person use a Low Vision Aid? Yes ☐ No ☐

Type

Used for

Does the person need increased lighting? Yes ☐ No ☐

Type

Used for

How can person be helped to use their vision at home/in day activities? (e.g. Large print, positioning for TV, eating, colour contrast, protection from glare etc.)

Will person's vision vary according to time of day?

Any other comments/recommendations?

Next eye test due when?

Will a reminder be sent? Yes ☐ No ☐

Practitioner's signature.....

Having a cataract operation

What the story on the DVD is about

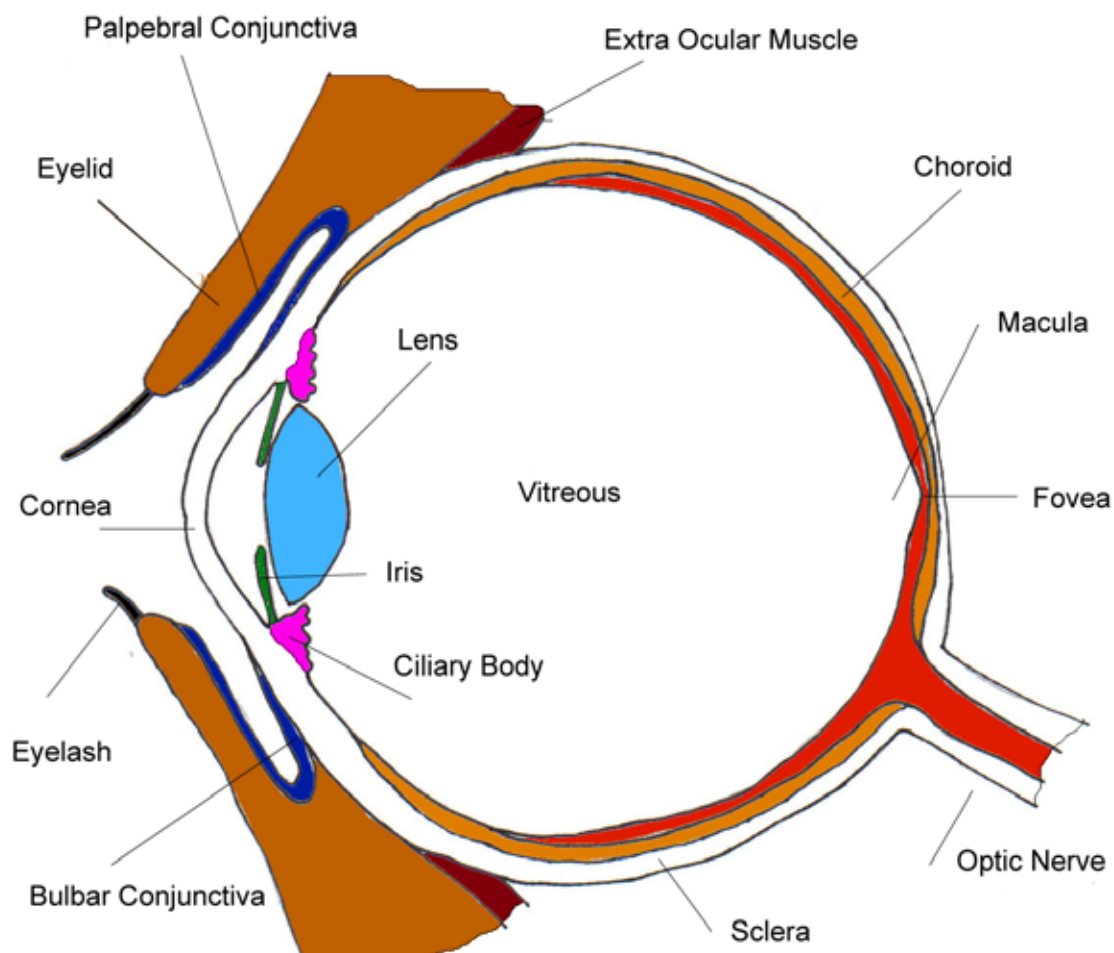
- The story shows you what happens when you have a cataract.
- A cataract is something inside the front of the eye that stops light going into the eye.
- A cataract will stop you seeing well and doing the activities that you enjoy.
- If you have a cataract you may need an operation to make your sight better.
- The operation will be carried out by an ophthalmologist – who is an eye doctor.
- After your operation you may need to get your eyes tested again, and wear glasses if needed.

This story was made to help people with learning disabilities and their carers understand what it may be like to have a cataract operation. In the film our actors refer to people who do operations on your eyes as an ophthalmologist.

An **ophthalmologist** or **ophthalmic surgeon** is a medically qualified doctor. They are eye specialists who treat eye problems. Some of them do eye operations and they may prescribe glasses. They work in hospital eye departments, health centers, community clinics or in private practice.

1. What is a cataract?

A cataract is a clouding of part of your eye called the lens. Your vision becomes blurred because the cataract is like a frosted glass, interfering with your sight and preventing light reaching the back of your eye.



2. What signs to look for

People with learning disabilities can often lack the communication skills to explain that their sight is getting worse. While most eye diseases will be picked up in a routine eye test, there are some things that carers should look out. They are:

1. The appearance of eye:

- In the most advanced cases of cataracts the centre of the eye (the pupil), will be appear to be coloured white.
- In a healthy eye when pen torch light is shone at eye, the pupil will get smaller to stop light entering the eye. If the eye is healthy, this reaction will only take a few seconds. If a person has a cataract or other eye disease the pupil may stay the same.



2. Behavioural changes:

- People with cataracts often **dislike bright light**. They may:

- Shield their eyes in bright sunlight
- Be reluctant to go out when it is sunny.
- Hold on tightly to supporter when previously able to walk unaided.
- Draw curtains when indoors.
- Turn off lights when indoors.



- People with cataracts **may display confused behaviours**. They may:

- Regularly put things down and not be able to find them.
- Regularly rub or wipe their eye. This has been described as trying to wipe the mist away.
- Inability to recognise familiar faces.



It is important to recognise that some behaviour associated with the onset of dementia could also be attributed to developing sight loss. People with Down's syndrome are more prone to dementia and certain eye conditions such as cataracts, earlier than the general population. If it is suspected that a person may have a dementia related condition, it is important that they get their eyes tested.

- People with cataracts **may display withdrawn behaviours**. They may:
 - Be reluctant to engage in activities they previously enjoyed.
 - Be reluctant to engage in activities that requires good sight.
 - May withdraw to a quiet area in the day centre or at home, when previously very sociable.
 - May withdraw or refuse to take part in familiar journeys.

3. The eye hospital appointment

When a person has been diagnosed with cataracts, he or she will be referred to their local eye hospital to see an ophthalmologist. The referral is usually made via their GP, following recommendation from the optometrist. In some cases an optometrist may refer you directly to the eye hospital. It usually takes about 3 months to get an appointment at the eye hospital.



On the day of your hospital appointment you will have to check in with the receptionist and you will have to wait until the eye doctor is ready to see you.



During the appointment the ophthalmologist will:

- Need to look into your eyes and put some drops in your eyes. The eye drops may make your eyes hurt in bright lights and sometimes they sting. Things may also look fuzzy after you have eye drops but this will only last for a short time.
- Use a special torch to see right into the back of your eye.
- Ask you to put your chin on a machine. They will have to get very close to you and touch your eyes. This may feel strange. It is important to sit very still when the doctor looks into your eyes.
- Tell you if you should have an operation.



Preparing for your eye operation:

Most people go into hospital for just one day to have their eye operation. Some people stay one or two nights in hospital. You will go home soon, as hospitals want to send people home to get better.

Lots of people worry about operations. There will be many things you need to know. You can visit the hospital before your operation. You might want to go two or three times. You can talk to the staff at the hospital. They will answer your questions.

You can take a friend or someone from your family with you when you go into hospital. They can stay with you all the time till you go home.



Before your eye operation you will have some tests at the hospital:

- You will have a **blood test**. The nurse will put a tight band around your arm and tell you to sit still. They will put a needle into your arm and take some of your blood.

You will see the blood flow into a needle. Lots of people don't want to look. The blood is then put into a special bottle and the nurse takes the band off your arm. The little bottle of blood will be sent away and tested. This is to make sure you are well enough to have the operation. Blood tests can hurt a bit.

- The nurse will take your **blood pressure**. They will put a strap around your arm and pump air into the strap. You only have the strap on your arm for a minute or two. It doesn't hurt but it can feel strange.
- You will be given a **form to sign**. This is to say you agree to have the operation.



Included in this pack is our '**Eye Surgery Support Plan**' which will help you plan for your hospital visit and your eye surgery. You can photocopy this form from the book or the form can be downloaded from our website www.lookupinfo.org.

4. Consent to treatment

Some adults with learning disabilities have refused to have eye surgery because they did not fully understand that they would be returning home soon afterwards. They associated hospital admission with permanent institutional care.

Frequent pre-operative visits to the prospective ward may be necessary, with hospital staff becoming familiar with an individual and stressing that he/she will only be admitted for a very short period to a 'go home hospital' – as against a 'long-stay hospital'.

Supporters need to understand the law on consent. Where people with learning disabilities are not able to consent to surgery, a multi-disciplinary 'best interests' meeting should be convened.

The ophthalmologist should be invited to attend – or more usually, the meeting can be held at an eye clinic to enable hospital staff to be there.

The area of consent for people with learning disabilities is complex. Therefore, we would recommend that readers in England, Wales and Northern Ireland obtain information on consent from the Department of Health website:

<http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Consent/ConsentGeneralInformation/fs/en>

Readers in Scotland may wish to obtain advice from ENABLE Scotland Information Service, 6th Floor, 7 Buchanan Street, Glasgow, G1 3HL. The telephone enquiry line 0141 226 4541 is open Monday-Friday.

5. Having a cataract operation

Before the operation:

On the day of the operation you must not eat or drink anything. The nurse will tell you when you must stop eating and drinking.

When it is time for the operation, you will be given an injection to make you sleepy, or your might have a mask put over your face and asked to breathe deeply.

You will be in a deep sleep when you have the operation. The doctor will make a little slit in your eye. They will take



the cloudy lens out of your eye and fix a new plastic one in your eye. The doctor will sew up the slit with stitches that you can't see. The doctor won't take your eye out.

After the operation:

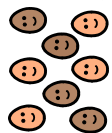
- You will wake up with a pad over your eye. This is to stop you from bumping it by mistake or rubbing it.
- You may feel a bit sick when you wake up. But you will soon feel better.
- Most people see well when the pad is taken off. Other people do not see very clearly to start with, but you should see better after a few days.
- Your eye shouldn't hurt after the operation. Talk to someone if it hurts.
- You should tell someone if you can't see well or feel worried.
- You will have eye drops.
- You may have to sleep with a patch over your eye. Don't rub your eye. It will get better quicker if you don't touch it.
- You may need to take it easy after the operation. The doctor will tell you what to do.
- After a few weeks you will see the ophthalmologist or the optometrist. They will look into your eye to make sure it is getting better. You may have to put your chin on special equipment while they check your eye. There are lots of ways to check your eye, so ask them to explain what they are going to do.
- The ophthalmologist will talk to you about new glasses. Lots of people need glasses after a cataract operation.



Eye Surgery Support Plan

Name of Individual:		Person responsible for this Action Plan:	
Date Action Plan Form completed:		Date of surgery:	

While this suggested Support Plan covers many of the areas that you should consider when supporting a person with learning disabilities through eye surgery, it should not be regarded as exhaustive. The needs of the individual through the surgery process will obviously vary greatly. This document therefore, should be used flexibly and those of you who know the above named individual well should make additions and alterations to meet his/her unique needs.



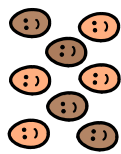
Significant People

Requirement	Who	How	When	Outcome (if applicable)
Identify a key worker to co-ordinate the action plan and attend all visits to hospital.				
Identify a core group of people to support before/during/after.				
Prepare a rota to cover hospital stay and any extra support necessary after surgery.		(Make this photographed if appropriate to individual)		
Identify external support (Rehab Worker, Community Nurse, District Nurse, etc.)				
Ensure all key people have relevant information regarding individual's eye condition/history. See Appendix 1.				

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Can individual consent to treatment?					
Is best interest meeting required to facilitate this decision (this will ideally include Consultant Ophthalmologist, and so will probably need to be held at hospital).					
Who needs to be invited to this meeting?					

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Significant People

Requirement	Who	How	When	Outcome (if applicable)
Inform all significant others involved with individual.				
Identify (if possible) who surgeon and anaesthetist will be.				
Identify (if possible) key nurses who will be working at time of surgery.				
Take photos of key people at hospital if appropriate.				



Exchanging Information

Requirement	Who	How	When	Outcome (if applicable)
Prepare a comprehensive summary of the individual's care needs. See Appendix 2.				
Key worker to visit hospital initially without individual.				
Identify (if possible) a named nurse in advance. Ensure the named nurse knows of possible support from Learning Disability Link Nurse (where one is employed)				
Agree how individual's care needs will be met on the ward.				
Find out hospital routine. See Appendix 3.				

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Exchanging Information

Requirement	Who	How	When	Outcome (if applicable)
Identify best position in ward for individual to be, based on his/her needs.				
Take a photograph of the hospital and the ward if appropriate?				
Establish what the surgical procedure and after care will entail. See Appendix 4.				

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Preparing the individual

Requirement	Who	How	When	Outcome (if applicable)
Prepare the individual for a visit to the hospital in whatever way is meaningful?		(e.g. object of reference, photos, symbolised calendar etc.)		
Key worker to visit hospital with individual (possibly more than once) to meet key people and do some orientation.				
Prepare the visit so that the individual will find it as enjoyable as possible.				
Prepare activities for the individual to do whilst in hospital and on his/her return home.				
Prepare the individual for his/her admission to hospital in whatever way is meaningful?		(e.g. object of reference, photos, symbolised calendar etc.)		

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Information about the individual's vision

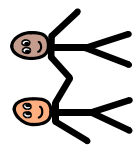
(refer to Look Up factsheet 'Eye tests for adults with learning disabilities')

Appendix 1

This should include:

<ul style="list-style-type: none"> • What the eye condition is. • Whether the individual was born with it or acquired it. • What medication the individual is on. • Whether the individual has been seen by any ophthalmic professionals in the past and if so when. • Whether the individual wears glasses and if so are they helpful. • What are the glasses for and how long has the individual has had them. • Whether the individual has a hearing loss and if he/she wears a hearing aid. • What the individual's expressive and receptive communication skills are. • Whether the individual has ever had a severe eye infection or a head injury. 	<ul style="list-style-type: none"> • Whether the individual has any condition that may affect his/her vision. • Whether the individual is at risk of damaging his/her eyes. • Whether there has been any change in his/her behaviour. • Whether there is any family history of eye conditions. • Whether the individual does anything to help them see better. • How the individual responds to sensory stimuli – touch, sound, heat, cold, wet, dry, light, colour, taste, smell. • What the individual uses his/her sight for. • Whether he/she uses their field of vision. • Whether the individual vision varies in different environments.
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Care Needs

Appendix 2

This should include the following areas:

- Support required to understand what people say to them.
- Support required to express themselves.
- Support required to eat and drink.
- Support required to manage any health issues.
- Support required for bathing.
- Support required with dressing.
- Support required for mobility.
- Support required for continence.
- Support required around medication.
- Support required to manage emotional health.
- Support required to manage any 'behaviours' that may present difficulties
- Support required to meet any cultural needs.
- Support required to participate in activities of their choice.

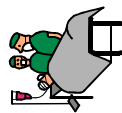
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Ward Routine

Appendix 3

What is the hospital policy on staff/relatives staying with the individual overnight?	
Where are the toilets?	
What time are baths?	
What time are meals and where will they be served?	
Where is the TV located?	
What time is visiting?	
How many people can visit at any one time?	
What time do the doctors do their ward rounds?	



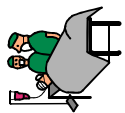
Surgical Procedure

(refer to Look Up factsheet 'Minimising problems in eye surgery')

Appendix 4

How long will the individual be required to stay at the hospital?	
What anaesthetic will be required?	
Can the individual eat or drink before arrival at the hospital?	
What will the procedure entail?	
<i>(For lens transplant op only)</i> What kind of lens will be implanted? (e.g. long distance, mid distance, short distance)	
Will there be any pain or discomfort?	

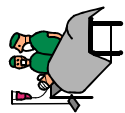
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Surgical Procedure (Continued)

Will the individual be required to rest or be still following the surgery?	
Will additional sedation be required?	
Will the individual require stitches and if so how will they be removed?	
Will the individual be required to wear a patch or dressings, what sort and is so for how long?	
Is there any post-operative treatment involved? (e.g. drops)	
Who will need to be involved in post-operative care? (e.g. administer drops, change dressings etc.)	

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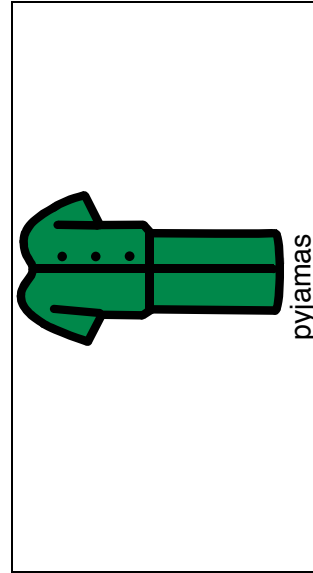
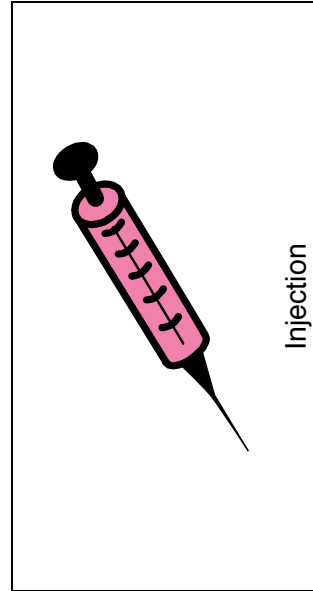
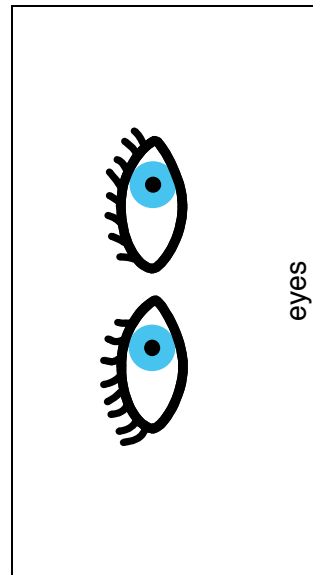
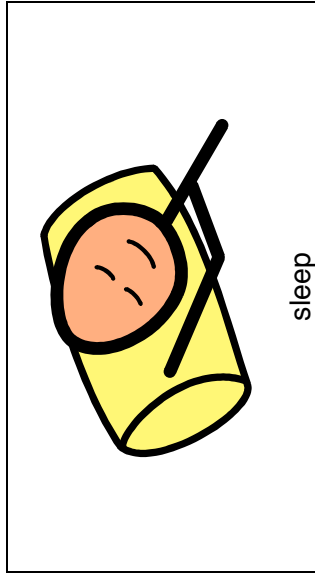
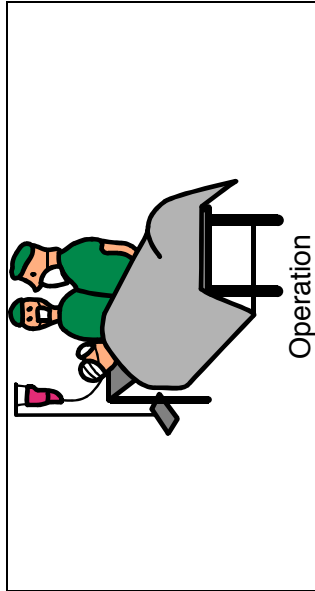
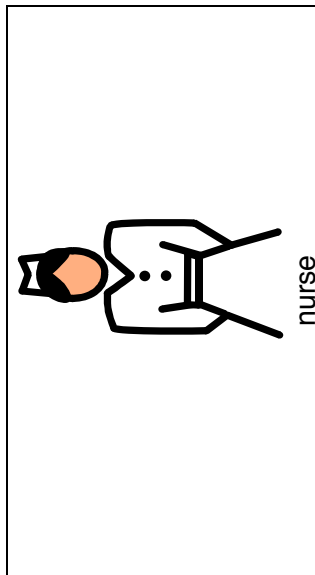
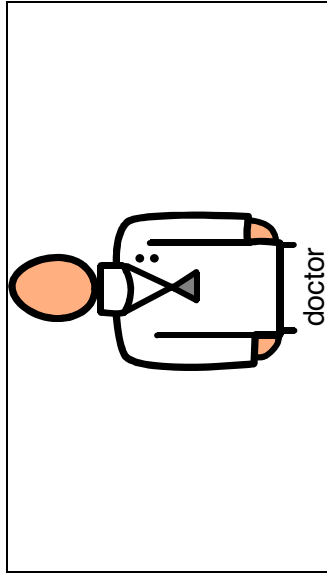
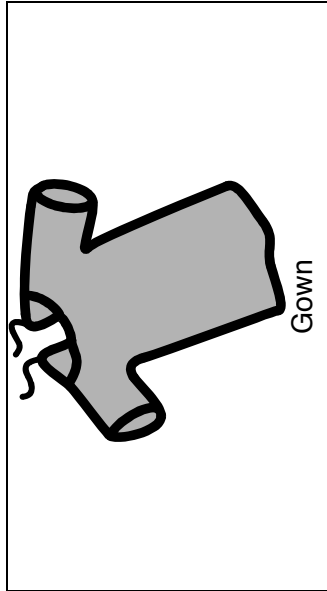
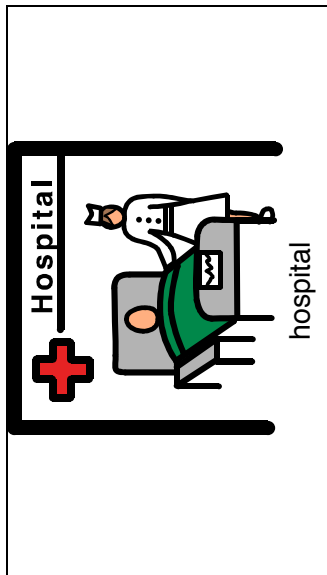
Surgical Procedure (Continued)

What period of convalescence will be necessary?	
How can the risk of infection be minimised? (e.g. ensuring the individual doesn't try to touch his/her eye, method of hair washing etc.)	
How may the individual's sight be improved? What will it be like long/short term or will it fluctuate?	
Will the individual require glasses after surgery if so what for and when should he/she wear them?	
How could the individual best be supported in his/her environments after the surgery?	

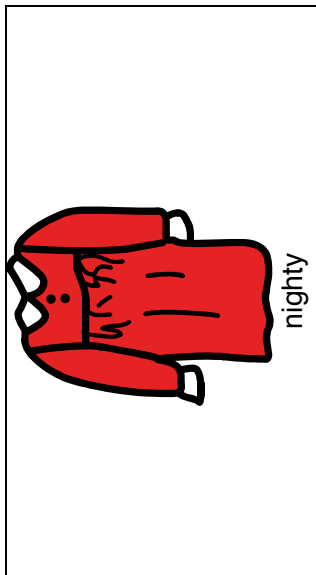
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Appendix 5

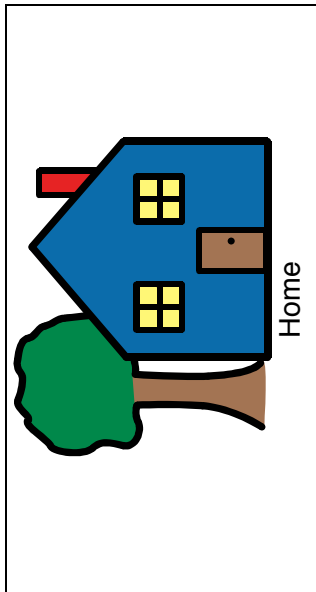
If the individual has symbol recognition the following may be useful tools for giving information about a pending hospital visit. These may be photocopied and enlarged as appropriate.



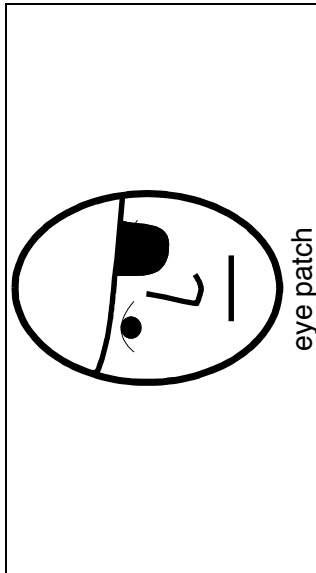
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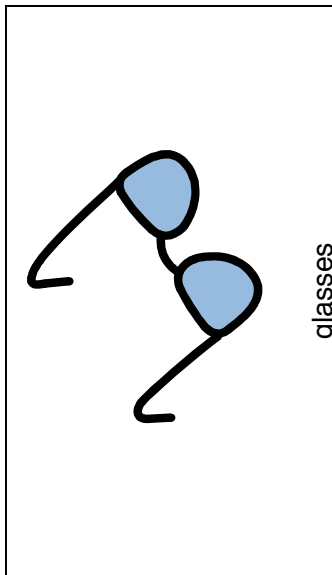
nighty



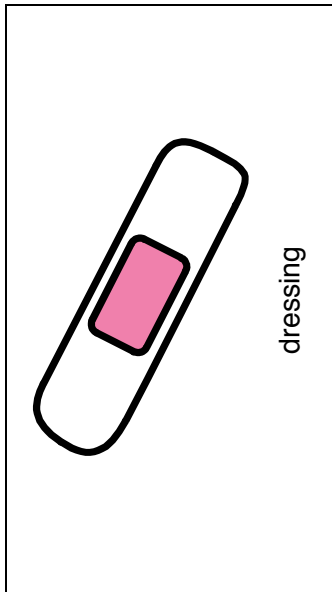
Home



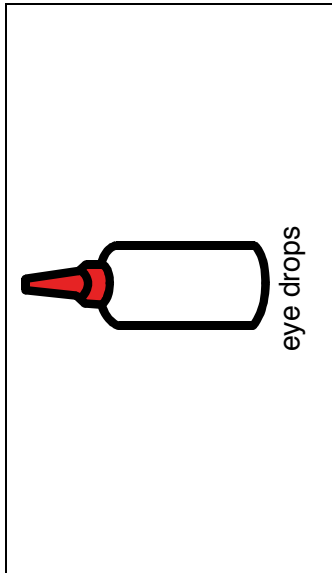
eye patch



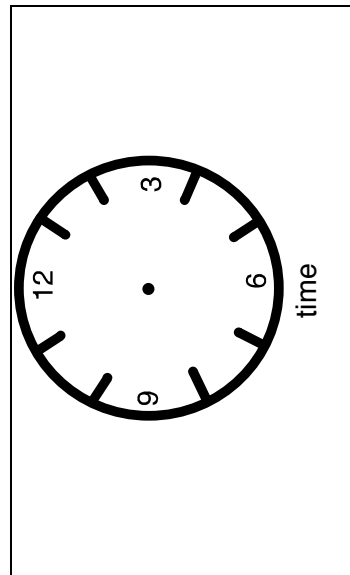
glasses



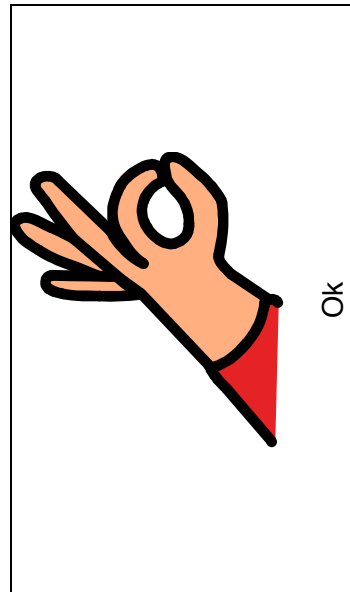
dressing



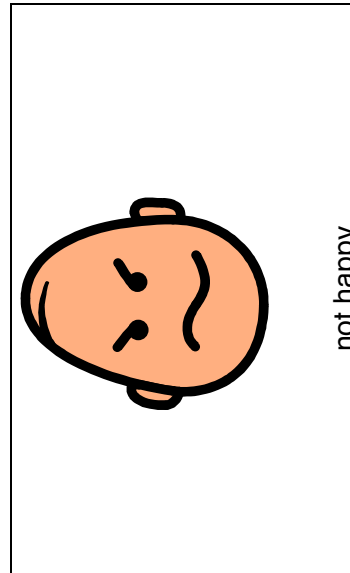
eye drops



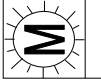




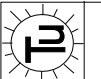




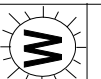




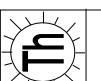




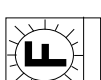














time



Ok



not happy

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Ignoring the signs

What the story on the DVD is about

- The DVD tells a story about Michelle who has problems with her eyes.
- She was not able to tell people she had problems with her eyes.
- Her eyes hurt her and she would rub and poke her eyes to make the pain go away.
- Eventually she totally lost her sight.
- This would not have happened if she had been helped to have a proper eye test and medical treatment earlier.

This story was made to help people with learning disabilities and their carers understand the importance of having good eye tests and getting the right medical help if needed. It talks about how to look for signs of sight problems in people with learning disabilities, and how they can change people's behaviours. It talks about why some people eye poke and what can be done to help them.

1. Looking after our eyesight

All adults, not just adults with learning disabilities, need to have their eyes tested at least every two years. A eye test is not just about getting glasses it is about having an eye health check so we can keep our eyes healthy and prevent eye disease.

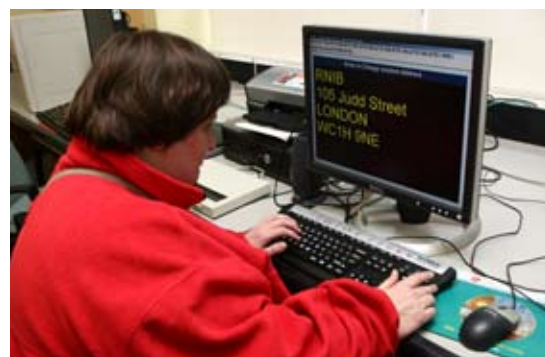
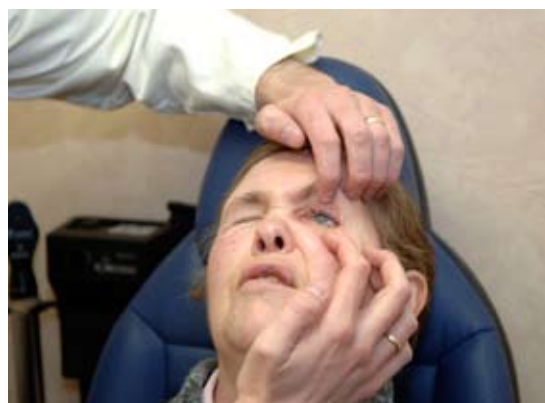
Eye tests are important as they can:

- **Show undetected eye diseases.** Some of these eye diseases are able to be treated and sight can be restored if appropriate medical intervention is sort. These eye diseases include cataracts and keratoconus.
- **Halt further deterioration of sight.** If the eye condition is identified and appropriate treatment is obtained then it can halt further deterioration of sight. These eye diseases include glaucoma, diabetic retinopathy, and retinal damage.
- **Be an early detector of other health problems.** These health problems may include diabetes, high blood pressure, high cholesterol levels, vitamin deficiencies, usher's syndrome, and brain tumours.

2. Eye Poking

There are many reasons why everybody, but especially people with learning disabilities, may poke their eyes. Reasons include:

- People with little or no vision, may get a light stimulation response by pressing or poking their eye.
- Boredom. Many people may be in environments that don't stimulate them or under-stimulate them. Eye poking may be an activity they can do to control there environment and provide them with visual stimulation.
- Tiredness. An instinctive behaviour especially when sleepy.
- Undetected sight problems that may require treatment for example Keratoconus.
- Itchy eyes due to hay fever or other allergies. Does the person eye rub more between May to September?
- Some people, especially people with Down's syndrome, are more prone to eye infections. These require medical treatment or eye drops.
- Scaly eye-lids, bumps or cysts on the eye-lid can all be annoying. People often need help to clean their eyes-lids and apply eye ointment.
- People may also have skin problems on or close to their eye-lids, such as psoriasis, eczema, dermatitis for which they need treatment.
- Dry eyes due to other factors such as air conditioning, long hours of computer use etc.
- They may be trying to see better.
- They may be using eye rubbing as a method of communication – if when they rub their eyes they get a response.
- The person's sight may be deteriorating and they are unable to communicate this to their carers.



3. What you can do to help

There are a range of things that can be done. For example:

- Consider hand hygiene for people with learning disabilities. If people regularly touch their eyes, it is especially important that their hands are kept clean. Fingernails need to be kept clean and short, with rounded 'corners' to reduce the risk of people scratching their eyes.
- Carers also need to keep their hands clean if touching people's eyes especially after cooking spicy food, cleaning or smoking.
- Regular eye tests will often spot many reasons for eye poking. For example red or sore eyes may be sign of a sight threatening condition such as glaucoma and appropriate treatment, for example eye drops, can alleviate this.
- Eye rubbing due to itchy eyes may be due to allergies and hay fever and again can be reduced by accessing appropriate medical treatment.
- Protecting eyes in environmentally aggravating situations e.g. keeping shampoo out of eyes when hair washing and wearing goggles when swimming.
- If communication is poor, eye poking may be a means of calling attention; therefore a referral to a Speech and Language Therapists may be useful as they can devise more effective ways to communicate.
- Assistance from a clinical psychologist or challenging needs/behavioural support specialist may be needed in order to help carers understand the reason for the behaviour and prevent the individual from habitual eye rubbing and self-blinding.



Glossary – what does it mean?

Acuity tests	Is a test to find how well or badly a person can see.
Astigmatism	When there are two points of focus for the eye, causing blurred vision. Usually because the front of the eye is rugby ball shaped, rather than soccer ball shaped.
Binocular vision	This is the ability to have single vision when both eyes work together – as against the two eyes seeing different things.
Cardiff Acuity Test	Cards with the outline of everyday images that help decide whether a person with little or no communication can see or not.
Cataract	This is something inside the front of the eye that stops light going into the eye.
Cerebral palsy	People with cerebral palsy may have a variety of different problems. It often affects their movement. Some people have learning disabilities. They may also have communication problems and epilepsy. People with cerebral palsy often have sight and hearing problems.
Diabetes	This is a complicated condition that can damage someone's sight.
Diabetic Retinopathy	When there is damage to the retina at the back of the eye from diabetes.
Down's Syndrome	Downs syndrome is a condition resulting from a chromosomal abnormality. People with Down's syndrome share a number of physical characteristics. They usually have learning disabilities, although the degree of learning disability can vary widely. Lots of people with Down's syndrome have eye problems and need glasses. Lots of people with Down's syndrome have problems with their hearing too.
Eye drops	These are drops that are placed on the eye. The drops might be used by the optometrist in a sight test. Some drops might stop the eye from focussing. Some drops might make the pupil bigger so the optometrist can see into the back of the eye.

Kay Picture Test	Cards with simple bold drawings of everyday objects. The cards help decide whether a person with little or no communication can see or not.
Keratoconus	When the cornea of the eye is shaped like a cone. This affects the way a person sees.
Longsight	When a person can see things far away better than things up close.
Magnifiers	Pieces of glass or plastic that make objects look bigger. Objects that look bigger are easier to see. Magnifiers come in lots of different shapes and sizes.
Makaton	A language that uses signs and symbols to communicate. It is a language that is used by people with learning disabilities.
Ophthalmologist	Ophthalmologists/ophthalmic surgeons are medically qualified doctors. They are eye specialists who treat eye problems. Some of them do eye operations. They may prescribe glasses. They work in hospital eye departments, health centres/community clinics or in private practice.
Pupil	The black circular disc that can be seen at the front of the eye. The pupil is in the centre of the coloured bit of the eye.
Shortsight	When a person can see things up close better than things far away.
Sickle cell	This is a complicated illness that sometimes can be detected by having an eye test.
Snellen chart	This is a test that uses a Snellen Chart. The chart has letters from the alphabet on it that get smaller as they go down the chart. This test shows what a person can see.
Usher's Syndrome	Usher syndrome causes moderate to severe hearing impairment. People with this condition are born with hearing problems and later get eye problems which can get worse over time.
Visual field	This is the area of what a person can see. The area includes what a person can see in front of them and what they can see off to their sides.

You and Eye

This book accompanies the film
**You and Eye – A film about eye care
for people with learning disabilities.**

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SeeAbility House
Hook Road
Epsom, Surrey, KT19 8SQ

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www.lookupinfo.org
0800 121 8900