

Factsheet

Cataracts and dementia

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Vision UK Learning Disability, Dementia
& Sight Loss Committee

1. Introduction

This factsheet will be useful for people with dementia, their families, carers and professionals. There are other factsheets about 'Dementia and low vision', 'Eye examinations for people with dementia' and 'Wearing spectacles with dementia'.

Cataracts are a very common eye condition in older people. Most people with cataracts are over the age of 60 and they become more common as people age. Dementia is also a condition that mainly affects people over the age of 65 and becomes more common as people get older. It is thought that there are at least 100,000 people in the UK with both dementia and sight loss. Not everyone with dementia has cataracts nor do all patients with cataracts have dementia, but a significant number will have both conditions. Because of this many people may face having a cataract operation while also dealing with dementia.

The information in this factsheet covers:

- what a cataract is and its effect on vision;
- how to tell if you or someone you care for has a cataract;
- cataract surgery and the difference it can make to a person's quality of life;
- how to prepare for surgery;
- how to help someone with dementia cope with surgery; and
- what happens after surgery.

Hopefully this information will be useful for people with dementia, their families, carers and medical professionals.

"I perform cataract surgery on many hundreds of patients each year. I have seen many patients with dementia experience great improvement in the quality of their lives after the surgery and they really appreciate having the operation." Paul Ursell, Consultant Ophthalmologist

"My father has dementia and he had cataract surgery. His vision was better the next day and he is much more confident walking around the house as a consequence. Also watching the subtitles on TV is easier as he is deaf and cannot hear it and he is looking forward to having the second eye operated on." Jenny, daughter of patient

2. What is a cataract?

Cataracts are a very common eye condition. As we get older the lens inside our eye gradually changes and becomes less transparent (clear). A lens that has turned misty or cloudy is said to have a cataract.

As a cataract gets worse it can interfere with your everyday life. It may:

- make things harder to see;

- make reading difficult;
- make colours seem washed out;
- cause problems when getting around, as stairs and steps become more difficult to see;
- cause problems with bright light and glare; and/or
- affect your ability to drive safely.

Most people have their cataract removed by a straightforward operation. This operation removes the cloudy lens and replaces it with an artificial lens implant. This makes sight clear again and removes the vision problems caused by the cataract. Cataract surgery is one of the most common procedures performed by the NHS.

3. How can I tell if I or someone I care for has a cataract?

The best way to know if you have a cataract is to have your eyes examined by an optometrist (optician). Everyone should have their sight tested at least once every two years, or once every year if you are 70 years old or older. An optometrist will be able to tell you how often you need to have your eyes tested. Eye examinations are important to ensure you have the right pair of spectacles (if you need them), but also to detect eye diseases such as cataracts that may affect your sight. If you or someone you care for finds it difficult to leave the house, then you can arrange for an optometrist to visit your home to perform an eye examination – this is called a domiciliary eye examination. Your GP or your optometrist should be able to tell you who to contact to arrange an eye test in your home.

If you have dementia you should still have your regular eye examination. When you go for your examination it is worth telling your optometrist about your dementia and any problems it may cause. They may then adapt some of their tests to take account of your dementia and it will also help them make decisions about when to refer you to the hospital for a cataract operation.

Cataracts can be removed at any time. You do not have to wait for them to be ripe. Someone with dementia may benefit from having them removed sooner rather than later, because it may be easier to deal with the cataract operation before their dementia symptoms get worse.

If you seem to be having problems with your sight between your regular eye examinations, then you should arrange for another test with your optometrist as soon as you can.

If someone has difficulties with their speech or explaining things, then there are signs you can look out for that may indicate they have a sight problem. If someone

you care for has difficulties with any of the following, then they should be checked out by an optometrist.

- Recognising familiar faces.
- Reading facial expressions.
- Needing more light to do tasks.
- Being in bright light, low light or both.
- Finding things.
- Reading the newspaper or enjoying familiar hobbies.
- Playing cards or doing crosswords.
- Watching TV.
- Managing in unfamiliar surroundings.
- Locating food on the plate.
- Managing current spectacles (perhaps saying “I need new specs.”).

If your optometrist detects a cataract that is affecting your sight, they should refer you to an ophthalmologist (hospital eye consultant) for further examinations and possible cataract surgery.

4. What does cataract surgery involve?

A cataract can only be treated by surgery. This surgery normally takes place as a day case (you do not usually stay overnight in hospital) using a local anaesthetic, so that you are awake but unable to feel pain during the surgery.

Although the surgery itself takes around 20 minutes you may find that you have to be at the hospital for most of the day. This is because some time is needed for the medical team to prepare you for the surgery and you may also need some time to recover once the surgery is finished. Following the surgery, you or your carers will be expected to care for your eye while it heals at home. This will include using eye drops and taking steps to avoid infection.

Usually people develop cataracts in both eyes, but you normally only have one cataract removed at a time, with a gap of 6 to 12 weeks between operations. However, the length of time may change depending on your individual needs.

Most people will have both of their cataracts removed so that, after their second operation, their sight will be balanced, but it is possible for someone to gain a lot of benefit by just removing one. You and your ophthalmologist should discuss what would be best for you.

5. Is cataract surgery safe for someone with dementia?

In most cases there are no physical reasons which make cataract surgery more difficult if you have dementia. Usually the decision to perform the operation is

made by judging the benefits you will gain from having the surgery against the risks it involves. Often this decision will take into account how your dementia may affect your ability to cope with the surgery and the aftercare. The decision needs to be made by you, with help from your ophthalmologist and your family or carers. Whether you have surgery or not may depend on how your dementia affects your everyday life.

If you have dementia and are living in your own home – coping with most things on your own or just need some help with a few things – then removing your cataracts will probably be of benefit as it will help you with day-to-day things like:

- reading;
- orientation – recognising people and places;
- confusion – better sight may help with your understanding; and
- getting around safely – improved vision will help you avoid trips and falls when you are out and about.

If you have mild or moderate dementia then you will still be able to cooperate with the tests before your surgery, during the surgery and with the treatment you will need after surgery.

If you or someone you care for has dementia that is more severe – meaning they have difficulties communicating and co-operating – then cataract surgery needs to be more carefully assessed. It is important to consider whether the risk of the operation itself, the stress it may cause and the difficulties of aftercare, will outweigh the benefits gained from the surgery.

Sometimes the benefits of removing cataracts are not as obvious as the risks, but they should still be considered. Often many of the things that people with dementia enjoy are visual, such as watching television, for example. Or if dementia has made someone isolated, sight problems caused by cataracts is likely to limit their activities, making them feel even more confused or isolated.

6. Should I tell the eye clinic staff about my dementia?

If you have dementia then let the staff at the eye clinic know. The ophthalmology team will be used to seeing lots of older people, so they should be experienced in helping people with dementia. If staff at the clinic know you have dementia then they can take this into account throughout your treatment.

It is always best to let them know of any problems you have before your appointment, so that they can be prepared for your visit. If it is hard to get in touch with the eye clinic before your appointment, you could ask your carers or your GP to let them know on your behalf. If you usually have help from family or carers

then it may be best for them to be involved and attend the eye appointments with you.

7. What happens before a cataract operation?

If you decide to have a cataract operation, then you will have an assessment appointment at the eye clinic first. This will include a thorough eye examination and some tests to measure your level of vision and to decide the lens implant to be used.

If you have dementia you may need more time to undertake these tests, or the tests may need to be adapted to suit you.

If you or someone you care for has more severe dementia and/or communication difficulties it is still possible to assess their vision and make decisions on what would be the best way of dealing with their cataract.

Once these tests and assessments are complete you will be given a date for your operation.

8. How do I give my consent for the operation?

Before anyone has any medical treatment, they need to give informed consent. This usually means being told of the risks of the surgery and signing a form to say that you accept these risks and consent to having the surgery. This is usually signed by the person having the operation. If there are any concerns about you or someone you care for having the capacity to give consent for the operation, then there are systems in place to help with this. You or your carers can discuss this with your ophthalmologist or your health care team. More information on capacity and consent is available from the Alzheimer's Society. Visit their website www.alzheimers.org.uk or call 0300 222 11 22.

9. What anaesthetic will be used for my surgery?

Cataract surgery is usually performed using a local anaesthetic. This means that although you will be awake for the operation you will not feel any pain.

Local anaesthetic is generally preferred to a general anaesthetic because you will recover more quickly and there is a much smaller chance of having any serious side effects. If a local anaesthetic is used you will be fully awake for the operation. You will need to be able to keep very still and calm while the surgery is happening.

If you or your carers have any worries about this then you need to tell the ophthalmologist as soon as possible. They can make adjustments to the surgery such as allowing extra time to make sure you are comfortable or allowing you to move at certain times during the operation. They may also suggest you take a sedative before the operation to help keep you calm.

Most people with mild or moderate dementia are, with a little more communication or a slight sedative, able to cope with local anaesthetic.

If you have more advanced dementia, then it is possible to perform the surgery with general anaesthetic. This means you will be unconscious during the surgery. General anaesthetic can be very useful for someone with moderate to severe dementia because you will not be expected to stay still and co-operate during the operation. Although general anaesthetic is not usually used for cataract operations, your ophthalmologist should be able to arrange for this if they think it is the best way for you to have the operation.

10. Will a general anaesthetic make my dementia worse?

There is some concern, among professionals that provide medical care to older people that general anaesthetic may affect your dementia in the long term. Many older people may have a short period of confusion following a general anaesthetic but most fully recover.

However the amount of general anaesthetic used for cataract surgery is very small and the amount of time you are under the anaesthetic is very short, so the risk of a permanent change in your dementia is thought to be very slight. You should discuss with your ophthalmologist and your anaesthetist any question you may have about the anaesthetic.

11. What happens after my cataract surgery?

There are four main issues that you will need to consider following your cataract operation:

- coping with eye drops;
- helping your eye to heal;
- your level of vision; and
- your need for spectacles.

12. Will I have to take eye drops after my surgery?

Most people will need to take eye drops following their operation. Usually these are antibiotics to help prevent infection and a steroid drop to help calm

inflammation in your eye. Usually they will need to be taken two to four times a day for about two to three weeks.

If you or your carers do not think that you will be able to manage the drops on your own, then you or your carers may need to arrange for someone to put the drops in for you. If you think you will need help you should ask your GP about this well in advance of your operation.

If you and your ophthalmologist are worried that you will not be able to manage taking drops, then they may choose to use an injection at the time of your surgery, which will mean you will not need drops at all.

If you do need to use drops, then the following may help you to manage them.

- Having clear and simple instructions for when you need to take the drops, written in large print which can be kept near your drops and shared with anyone that helps with your care.
- A chart with a timetable when the drops should be used. This could include photographs of the bottles of drops and a space for you to tick when they have been taken.
- It may be useful for you to ask your family or carers to help remind you about the drops and to check if you have taken them everyday.

If you have problems with your hands because of arthritis or any other physical problems, then aids are available to make the eye drop bottles easier to use. Your pharmacist, district nurse or GP should be able to supply these for you, but they can also be bought from organisations such as RNIB.

13. Will I have stitches in my eye?

Modern techniques for removing cataracts make very small cuts to your eye, which are designed to heal quickly, meaning that usually stitches are not needed. The tiny wound usually heals quicker and with less discomfort without a stitch. Occasionally a stitch may be required, especially if there is a worry that you may not be able to stop rubbing your eye just after the operation.

Following the operation, your eye may be a little uncomfortable for a couple of days but you can take a pain-killing tablet for this. You may have some bruising around the eye and the eye itself may look a little red, but this redness should clear up in two to three days. If your eye becomes very painful or starts to look very red or hot to touch or the sight in the eye gets suddenly worse these may be signs of infection. If you suspect an infection, then you should let the hospital know as soon as possible as treatment for any infection needs to start quickly.

14. What will my sight be like after the operation?

Most people will notice an improvement in their vision within about two or three days, once the eye has started to recover from the operation. The overall change in your vision once the eye has recovered can depend on how developed your cataract was when you had it removed. If your sight was badly affected by your cataract then you will probably notice more of a change than if your cataract was not causing much of a problem.

15. Will I need spectacles after the operation?

The lens implant used during the surgery will mean that your sight is slightly different than it was before the operation. Usually this means that if you needed spectacles for distance then you may not need them after the operation. This is because the lens implant used in the surgery can correct your vision for distance. However, most people will need a new pair of reading spectacles. Some people prefer to have the lens implant correct their vision so that they do not need reading spectacles after surgery, especially if their dementia means they forget to wear their spectacles, or they misplace or remove them often. Although they may need to have spectacles for seeing things in the distance.

It is possible to correct your vision in lots of different ways using the lens implant and you and your ophthalmologist can discuss which lens implant to use so that your vision is best for you following your operation.

Most people will need to have the cataract operation on both eyes. This can mean that between the operations, sight may not be quite right, but once both operations have been completed your sight will be balanced. It is possible to only have one cataract removed and if this is the plan for you then the ophthalmologist will choose a lens implant that will work best for you.

16. Summary

Cataract surgery for people with dementia is very successful and usually results in good vision. However, there are some important things to be considered.

- Cataracts that are not removed will eventually affect someone's day-to-day life.
- Getting your cataracts diagnosed early through regular eye examinations by an optometrist is important so that you get the treatment you need at the best time for you.
- Deciding if and when you have your cataract removed will depend on how badly they are affecting your sight, how advanced your dementia is and the difficulties it may cause in your day-to-day life.

- Making sure that everyone involved in your care knows about your dementia and any difficulties it causes for you can help make your cataract surgery go more smoothly.
- Your ophthalmologist and their medical team can make changes to how they perform the cataract operation to make things easier for you.
- Knowing what to expect after your cataract operation and organising any support you might need before the operation can make a real difference to how well you and your carers manage your aftercare.

17. Are there any other sources of information and support?

RNIB and The Royal College of Ophthalmologists produce information on cataracts. This is available from RNIB's website www.rnib.org.uk or you can order a copy in print, audio or braille by calling their helpline on 0303 123 9999. RNIB can also offer information and support on making the most of your sight and all aspects of living with a sight problem.

18. Useful contacts

Alzheimer's Society

43-44 Crutched Friars

London

EC3N 2AE

Helpline: 0300 222 1122

Email: enquiries@alzheimers.org.uk

Web: www.alzheimers.org.uk

Royal National Institute of Blind People (RNIB)

105 Judd Street

London

WC1H 9NE

Helpline: 0303 123 9999

Email: helpline@rnib.org.uk

Web: www.rnib.org.uk

19. About the Vision UK Learning Disability, Dementia & Sight Loss Committee

The information in this fact sheet was produced by the Learning Disability, Dementia & Sight Loss Committee. The committee was formed to promote better understanding of the issues facing people affected by learning disability and autism, dementia and sight loss. It also seeks to develop and disseminate materials resources and tools that contribute to good practice.

Visit www.visionuk.org.uk to find out more.

20. Glossary of terms

Optometrists or ophthalmic opticians

Optometrists or ophthalmic/dispensing opticians (often called opticians) usually work in high street practices or shops, or hospital eye departments.

They are qualified to test sight, prescribe spectacles and detect eye conditions. They can also refer you, if necessary, to your GP (family doctor) who may in turn refer you onto a hospital.

Most optometrists are not qualified to diagnose, treat or operate on your eyes, although they will often discuss your eye condition with you. They can also provide advice on looking after your eyes and may help you with your low vision aids.

Ophthalmologists

Ophthalmologists are specialist eye doctors who diagnose, treat and monitor eye conditions with medication and surgery. They usually work in hospital eye departments or clinics (often called ophthalmology departments).

They may prescribe spectacles although they do not fit and supply them.