



## Eye Surgery Preparation and Post Op Planning for Individuals with Intellectual Disability

Post-surgical concerns should not be a deterrent to eye surgery. Proper preparation for both pre- and post-eye surgery is a critical part of successful recovery and involves clear communication and collaboration among the individual with intellectual disability, caregivers, the eye surgeon and the medical team. This brochure offers suggestions, question lists and considerations that will be helpful to members of the care team who will help to prepare and care for an individual with intellectual disability through all stages of eye surgery.

- Pre-Surgical Visits with the Eye Surgeon
- Preparing the Individual and Team for Eye Surgery
- Staffing for Post-Operative Care
- Considerations for Eye Protection and/or Supportive and Protective Devices
- Eye Drops and Eye Ointments
- Additional Resources for Information and Support

## Pre-Operative Planning

Focusing on the needs from the perspective of both the individual with intellectual disability and the caregivers helps tremendously in pre-operative planning. Pre-planning and clear communication can reduce anxiety and assist caregivers to feel confident in their ability to care for an individual post operatively.

Often following eye surgery, eye surgeons may order eye protection along with medications and physical limitations for the individual. These medical orders may feel overwhelming for the individual and the caregivers, but with proper planning, pre and post-operative concerns can be eased.

## Preparing for All Visits with the Eye Surgeon

It is helpful if two caregivers accompany the individual to all appointments. In this way, one person can be sure that the individual's needs are met, while the other can document information and instructions from the eye surgeon.

If possible, schedule the initial and all pre-surgery eye exams on days when familiar caregivers, preferably two, can accompany the individual. Supportive companions can help the individual relax and feel as comfortable as possible so that all eye exams can be completed. Knowledgeable caregivers will be able to assist the individual to answer questions the eye surgeon may have.

Consult with the surgeon's office to reduce waiting time as much as possible, this may mean calling ahead on the day of the appointment to verify if the eye surgeon is running on time. Inquire what records are needed.

Prepare the individual based on needs. It may be helpful to talk about the upcoming appointment as a way to reduce anxiety about the exam. Consider scheduling a pre-visit to the office. For others, the opposite may be true and it may be best to inform the person just before the exam. Whichever approach is used, planning for how the visit will be addressed is an important step for a successful exam.

## What to Bring

- All important information including: medical diagnoses, medications, allergies, environmental sensitivities, guardianship information, previous eye reports, prior reactions to eye exams, functional vision information, and any questions or concerns.
- An item or quiet activity that is reinforcing and/or comforting to the individual. This may be helpful to have along if there is time to be spent in the waiting room.

# Questions for the Eye Surgeon: “Big Picture”

1. What problem is the eye surgery addressing?
2. If the goal is visual improvement, how will the individual’s visual ability change after surgery, and at what rate?
3. If the goal is pain alleviation, will relief be immediate or gradual?
4. What appointments, exams and blood work will be needed before surgery? Will any of these appointments require sedation?
5. What type of sedation will be used for the eye surgery?
6. What are the risks of the surgery?
7. How long is recovery from surgery? Will an overnight at the hospital be needed and if so, for how many days?
8. What will happen to the individual’s vision and/or eye pain if the surgery does not occur?
9. For the long term after the surgery, will the individual need to wear prescription eyeglasses or sunglasses?
10. For the long term after surgery, will eye medications need to be taken either by mouth, by eye drop or eye ointment?





# Meeting with the Eye Surgeon: What Happens Post-Surgery?

From the caregiver perspective, one of the most daunting aspects of eye surgery for an individual with intellectual disability is what happens after surgery. The suggested **Questions for the Eye Surgeon Regarding After Surgery** will help caregivers feel better prepared. Based on the particular needs of the individual, be sure to ask any other questions that reflect other concerns about the eye surgery and recovery.



**REMEMBER:**

It is helpful to have 2 caregivers at each appointment. One can take notes on what the eye surgeon is saying, and the other can assist the individual as needed.

# Questions for the Surgeon Regarding After Surgery

1. What precautions, if any, will need to be taken to protect the eye immediately after surgery?
2. Will a bandage or patch or protective glasses be needed? If yes, obtain multiple sets of these items to accustom the individual for its use. Should a supervised demonstration be practiced at the eye surgeon's office?
3. If anticipated that the individual will have a difficult time tolerating the eye protection what precautions will need to be taken to assist the individual to prevent self-inflicted injury and/or surgical site disruption?
4. What medications will need to be administered during the recovery period?
5. Will frequent eye drops or eye ointment be needed daily and for how long?
6. If the individual has not regularly received eye drops would the doctor prescribe a saline eye drop trial to accustom the individual to drops in general?
7. Will there be any physical limitations during recovery?
8. For how long after surgery days, weeks will these limitations need to be in place?
9. Will there need to be efforts undertaken to prevent constipation and/or straining during the post-operative period?
10. Is there any anticipation of pain following the eye surgery? What comfort measures and/or medications are available to help with pain?
11. Will there be any limitations with bathing or showering following eye surgery?
12. What are the risks during recovery?



# Preparing the Individual and Caregivers for Eye Surgery

With answered questions from the eye surgeon in hand, it is now time for the lead caregiver to prepare the individual and the team of caregivers for what to expect in terms of eye care after surgery. The meeting should take place as soon as possible after the pre-surgical visit to provide detailed information gathered from the surgeon and provide an opportunity for training and discussion of individual and caregiver concerns.

## For the Caregivers

- Assess which caregivers will be assigned to administer the eye medications if the individual cannot self-administer, and if any training is needed.
- Assess which caregivers will be responsible for maintaining eye protection, and provide a training opportunity for how to apply, change and clean the shield, glasses, or bandage. Initial training from medical staff in the surgeon's office is best.
- If the individual will have a reduction in functional vision, even for just a short period of time, ensure that caregivers are prepared and sensitive to the needs of the individual with vision loss. This includes training on how to safely use the Human Guide technique, how to be sensitive when pushing the individual in a wheelchair, how and where to position materials so the individual can make the most of their functional vision.
- See the Resources section for helpful training resources.







## For the Individual

- Communicate to the individual with words and gentle touch to the eyebrow and temple which eye is going to be operated on. If current functional vision is limited, additional description/demonstration may be needed.
- If a saline eye drop trial was ordered, this will accustom the individual to receiving drops and will aid in determining how the individual reacts. This trial will allow time to plan accordingly with the medical team.
- Well ahead of the surgical date present any protective bandages or glasses that will be worn during recovery.
- In a comfortable, familiar environment, assist the person to practice putting the eye protection on. If helpful through role play, a caregiver could put on an eye shield and/or protective glasses first to show the individual, and then take turns. This exercise will also aid in determining how the individual may react and will allow time to plan accordingly.
- If any physical limitations will be imposed during recovery, strategies for safety should be addressed prior to surgery by talking to the individual, using demonstration, or role-play. Activity limitations may include a specific head position, no touching of the eye, no bending down to tie a shoe or pull up pants, or no work and household tasks that require heavy lifting or carrying.

## Post-Operative Staffing

It is critical for caregivers to meet and discuss staffing for post-operative care well ahead of the surgical date. A plan is especially important when the individual may have difficulty tolerating post-operative bandaging, receiving eye medication, and/or any physical limitations required immediately after surgery. The goal is to plan for all post-operative needs given what is known about the individual's reactions and the information obtained from the pre-surgical appointments with the eye surgeon. Planning should include staffing and strategies at relevant locations for initial and long-term recovery, such as recovery room, hospital, respite and/or home.

### Staffing Needs for Initial Recovery in Recovery Room

Although the time period in the recovery room may be brief, it is a critical time for keeping the eye safe following surgery.

#### Questions to Consider Regarding the Recovery Room

1. In the recovery room will the individual need assistance from familiar caregivers for positioning, and reassurance while coming out of sedation?
2. Will supportive and protective devices be immediately necessary in the recovery room to maintain eye bandages?







## Staffing Needs for Hospital Overnight Stay

If the individual needs to spend overnight(s) in the hospital, representatives from the medical team, who may not know the person very well, should be present at the planning meetings, or at a minimum be made aware of any communication considerations or behavioral challenges.

## Questions to Consider Regarding a Hospital Overnight Stay

1. During the hospital stay will the individual need assistance from caregivers around the clock to monitor for positioning, reassurance and effectiveness of any supportive and protective devices?
2. Will the hospital be able to supply staff to assist with safety monitoring?
3. How long will the hospital stay be after surgery?
4. Are there any items or quiet activities that could be brought to the hospital to make the stay more comfortable for the individual?
5. Will activation of the hospital TV and telephone add to the individual's comfort?

## Staffing Needs for Recovery at Home or Respite

Following day surgery or a hospital stay, everyone involved in the individual's care should meet to ensure effective communication of plans and concerns regarding post-surgical care. Although this team may have met before surgery it should again be mobilized upon completion of the surgery and/or following a hospital stay to plan for any unanticipated changes in care.



**REMEMBER:**

- Include the individual who is having surgery in as much of the planning as possible.
- Be sure to also address his/her questions and concerns.

# Questions to Consider About the Recovery at Home or Respite Home

1. What is the name of the eye surgeon who will be available or on call for post-operative questions? Post contact numbers where visible for all caregivers.
2. What indications (fever, excessive drainage, bleeding, eye pain) necessitate transport to the emergency room? Ask the eye surgeon to write the specific indications on paper.
3. Will training for caregivers be needed about eye care after surgery regarding:
  - eye protection, its use and cleaning
  - use of protective and supportive devices
  - physical limitationsIf so, who will provide training and monitoring of care?
4. Is someone needed to oversee and/or administer the medications? If staffing support is needed, exactly who will provide?
5. Will the individual need support from familiar caregivers around the clock to monitor for safety and the use of any supportive and protective-devices? Monitoring is important for effectiveness, skin integrity and circulation as recommended by medical oversight and/or regulation.
6. The term “support” should be clearly defined for all who are providing it.
  - Does it mean within arm’s length or across the room?
  - Does the definition change when the individual is asleep?
  - Does the definition change when the individual is in a vehicle?
7. If required, will the individual tolerate staying in bed without being monitored?
8. Will the individual be able to use the bathroom independently?
9. How many days will the individual need to remain “quiet” during this stage of recovery?
10. Are there activities or items that should be provided to make this phase of recovery more comfortable for the individual?
11. Are there activities or items that should that can’t be used for safety reasons, or due to any required physical limitations during the initial recovery phase?
12. Is the eye surgeon fully aware of what the individual does at work and/or at the day program with regards to lifting, stacking, etc.
13. What is the anticipated time for returning to work or day program?
14. What is the timeline for visual and/or pain improvement?



## Bandages and Eye Patches

Most often following surgery, eye protection, for some period of time, is needed and exceptions cannot be made. Caregivers should be encouraged to address in detail with the eye surgeon and medical team questions and considerations regarding all aspects of wearing, cleaning, and schedule for wearing the device. For individuals who will be predictably, or even questionably disruptive of the surgical eye site, caregivers must develop a plan for eye protection with the eye surgeon and medical team before surgery.



## Supportive and Protective Devices

In extreme cases of concern for the integrity of the surgical site, during the post-operative recovery period the eye surgeon may order supportive and protective devices, such as face shield and/or helmet and/or elbow splints. In this situation a detailed plan and medical order will be necessary for use.

All systems of care have regulatory guidelines for use of these devices. They must be followed and incorporated into the written plan. Human Rights Regulations on use of Supportive and Protective Devices must always be considered. The plan should include all staff training of device application, frequent documentation observing that it is not causing harm, and assignment of support persons needing to be present when devices are worn and removed. Anticipatory planning should take place when these devices need to be removed for activities such as bathing, eating and/or administering eye medications. Training should include hands on demonstration, a binder of photographs, and written accompaniment of how protective devices and/or shields are properly placed and/or changed, and/or cleaned.

Plan effectiveness should be reviewed frequently and all changes reviewed with the entire team of caregivers with the goal to achieve the least restrictive protection of the eye during the recovery period. This stage of recovery may be intense for both the individual and the caregivers so extra support and attention must be provided.

# Questions to Consider About Eye Protection

1. Will it be possible for the individual to wear the least intrusive protection available? For example, some individuals will tolerate wearing clear safety glasses, but will not tolerate wearing either the clear plastic or pinhole type metal shield that is taped to the face to cover the eye.
2. Will a desensitization program prior to surgery help the individual relax and be able to tolerate wearing the eye protection?
3. Who will work with the individual through this process and evaluate its effectiveness?
4. Will an anti-anxiety medication be of benefit, pre operatively and/or post operatively?
5. Who will administer and evaluate the medication's effectiveness and duration of use?
6. Will a cotton bandage be needed under the shield or protective eyeglasses? How often should this be changed? How long will it need to be worn?
7. Is there a point in time during recovery when the individual will be required to wear the shield or protective glasses, without the cotton bandage?
8. Will the individual be able to see through the eye shield if a bandage is not needed?
9. If yes, train caregivers not to cover center pinholes with the tape.
10. If tape is needed with the style of eye protection, does the individual have a latex tape allergy? Should an alternative tape be used?
11. How and how often should the eye protection be cleaned?
12. Will the eye surgeon order supportive and protective devices, such as face shield/helmet and/or elbow splints?



photo courtesy: [www.hilcovision.com](http://www.hilcovision.com)

# Eye Drops and Eye Ointments

Most often eye drops and/or ointments are needed and exceptions cannot be made. Discuss with the eye surgeon and medical team all aspects of the administration of eye medications.



## Instructions for Administration of Eye Drops and Ointment

1. Person administering the drops/ointment should have freshly washed clean hands and preferably be wearing sterile gloves.
2. The individual receiving the drops/ointment should be in a comfortable position; this may be sitting or lying down with head tilted back.
3. Gently pull down the lower lid with the index finger, or thumb and index finger, to form a “pocket”.
4. Encourage the individual to keep his/her eye open and to not squeeze eyelids tight.
5. Avoid touching the dropper/tube to the eyeball.
6. Apply the prescribed medication into the open lower lid.
7. If lying down, slightly turn head to side, so the affected eye is up, gently pull down lower lid and instill medication into the outer aspect of the “pocket”.
8. Encourage the individual to close eye gently after the medication has been administered. NOTE: Squeezing eyes tightly immediately after drops are administered may reduce the amount of medication getting into the eye.
9. Gently wipe away excess with a clean tissue.
10. Store medication as indicated.

### **REMEMBER:**

There are also many online resources regarding administering of eye medications that can be helpful such as American Academy of Ophthalmology, Prevent Blindness America, and WebMD. Please see the **Resources** section.



# Questions to Consider About Eye Drops/Eye Ointments

1. Has there been an assessment to determine if the individual can self-administer eye medications? If the individual cannot self-administer eye medications, a written plan should include specific instructions for medication administration with consideration for the individual's tolerance.
2. What physical position is the most comfortable for the individual to receive eye medications?
3. In addition to the caregiver administering the eye medication, is assistance of others needed during this process? Use of favorite caregivers, visual aids, or enjoyable sounds to distract the person as the eye medication is administered may be helpful.
4. If more than one type of eye drop/ointment is ordered is there a time interval between administering these medications?
5. What are the storage requirements for the medication?
6. What should be done if not all of the drops or ointment have gone into the eye?



# Long Term Recovery

Caregivers should discuss considerations for long-term recovery with the eye surgeon so that the individual and team can prepare. It is important for the team of caregivers to understand and be sensitive to a person's new level of functional vision and offer support as needed.

In most cases, eye surgery helps to restore, stabilize or improve a person's functional vision. If worn, eyeglass prescriptions may change, necessitating new eyewear. Donation of old eyeglasses is recommended so that the individual does not wear the old prescription by mistake.



In rare cases, vision is not improved. If functional vision is not improved, an assessment and training in use of orientation and mobility techniques may be helpful for safe travel. A Certified Orientation & Mobility Specialist (COMS) evaluates what techniques best support travel, and teaches the individual, as well as caregivers in use of the techniques.





# Questions to Consider About Long Term Recovery

1. Will visits to the eye surgeon be more frequent than previously?
2. Will the individual be more sensitive to light (photophobic), requiring the use of sunglasses for use both indoors and outdoors?
3. If the individual needs light protection, but does not tolerate the wearing of sunglasses, would use of a hat with a wide brim, an umbrella, or positioning to reduce glare and exposure to bright light be helpful?
4. What environmental modifications will increase safety and function?

Environmental Assessments can also be provided by Certified Orientation & Mobility Specialist (COMS) as part of the assessment with the goal of increasing independence and preventing injury. Suggestions can be made for how best to adapt environments to make it safe and functional for individuals. This may include use of color contrast, lighting, furniture placement, handrails, and grab bars.





## Additional Resources

There are several online resources that can offer more information and support. Please always seek professional medical advice in an emergency.



## Administration of Eye Drops and Eye Ointment

- American Academy of Ophthalmology  
<https://store.aao.org/eyedrop-information-pad.html>
- Prevent Blindness America  
[https://www.preventblindness.org/sites/default/files/national/documents/fact\\_sheets/MK17\\_EyedropMeds.pdf](https://www.preventblindness.org/sites/default/files/national/documents/fact_sheets/MK17_EyedropMeds.pdf)
- WebMD  
<https://www.webmd.com/eye-health/how-insert-eye-drops?print=true>

## Standards to Promote Dignity, Supports and Health-Related Protections

- Massachusetts Department of Developmental Services  
<https://www.mass.gov/eohhs/gov/laws-regs/dds/115-cmr-100-1000.html>
- Massachusetts Department of Developmental Services  
<https://www.mass.gov/files/documents/2016/07/st/reg-115cmr005.pdf>

### “Focus” Resources

For a downloadable copy of this brochure, the Question List for Eye Surgery Preparation and Post Op Planning for Individuals with Intellectual Disability, and for more information regarding the full array of MCB/DDS Partnership Project resources, videos, eye care provider list by town, and events including the annual “Focus” on Vision Impairment and Blindness Conference: Meeting the Needs of Individuals with Intellectual Disability and Vision Loss, please visit the “Focus” website: [www.focusonvisionandvisionloss.org](http://www.focusonvisionandvisionloss.org)

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A resource of the MCB/DDS Partnership Project  
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