

HOW TO SUPPORT THE MENTAL HEALTH OF LHON COMMUNITY MEMBERS

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How Mental Health Providers can Support the Needs of LHON Community Members

Peer-to-Peer Mental Health Booklet Created by a provider, for providers

Produced by LHON Collective in partnership with
Christina Baker, PsyD

LHON Collective is a global initiative dedicated to accelerating progress toward a cure for Leber Hereditary Optic Neuropathy (LHON) while improving the lives of people living with LHON. Find out more at www.LHON.org.

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The Need for Mental Health with LHON



In 2008, the oldest of my three children suddenly became legally blind due to LHON. The emotional health aspects of LHON became evident in my own family's experience. The more people I met in the LHON community over the following years, the more its importance became clear.

In collaboration with LHON experts Rustum Karanjia and Alfredo Sadun, we documented the importance of LHON and mental health in this 2017 study: *Profound vision loss impairs psychological well-being in young and middle-aged individuals* (Garcia et al., *Clin Ophthalmol*, 2017). This research highlighted that, "While some individuals with profound vision loss may attest to a positive impact in their lives, the majority experience significant psychological morbidity."

In 2018, my daughter experienced LHON vision loss. This reinforced for me the urgent need for mental health professionals who understand the unique challenges LHON onset presents to those affected by it and those who love them.

This booklet is a tool to help meet the need for well-informed mental health assistance that was identified in the 2017 article. It takes the next step, helping the LHON community explain LHON and the LHON journey to mental health providers, not only for the individual experiencing LHON vision loss but also for those affected indirectly.

Lissa Poincenot, LHON Advocate



LHON affects more than just the visual system. The mental health challenges faced by both patients and families diagnosed with

LHON are often overlooked. This booklet provides a valuable starting point for discussions about LHON-specific mental health challenges faced by both affected and carriers of this disease with their chosen mental health professional.

Rustum Karanjia, MD, PhD



Many of our current LHON-affected patients and their family members still struggle with mental health due to this

disease. This booklet is a valuable tool to guide them towards a constructive conversation with a therapist about the LHON-specific challenges that they face.

Alfredo A. Sadun, MD, PhD

What is LHON? VISION LOSS

Leber hereditary optic neuropathy (LHON) is a rare genetic disorder that causes sudden, painless vision loss through optic nerve deterioration. In most cases, vision loss begins in one eye, with the other eye losing vision a few weeks to months later. Most people with LHON will become legally blind, thus unable to drive, read standard-sized text, or recognize faces. Blindness is often perceived as an all-or-nothing condition, so individuals with LHON frequently have to explain what they can and cannot see. They have lost central vision, but may navigate their environment and read enlarged text using their peripheral vision.

LHON is most commonly caused by one of several mutations in the mitochondria and is passed through maternal inheritance. A mother who is a "carrier," affected or unaffected by vision loss herself, passes the genetic mutation to her children. It is estimated that about 100 people in the US per year lose vision to LHON. About 25% of those affected with LHON vision loss are female and 75% are male. Due to its rarity, the medical community usually suspects other causes of sudden vision loss unless there is a family history. A genetic test can confirm an LHON clinical diagnosis.



Visualization of central scotoma (blurry blind spot) people affected with LHON often experience.

Individuals affected by LHON and those around them often face mental health challenges due to the sudden loss of vision and the associated lifestyle changes. This booklet highlights some of the different LHON community member roles and how mental health assistance may be needed based on the different relationship to LHON an individual may have.

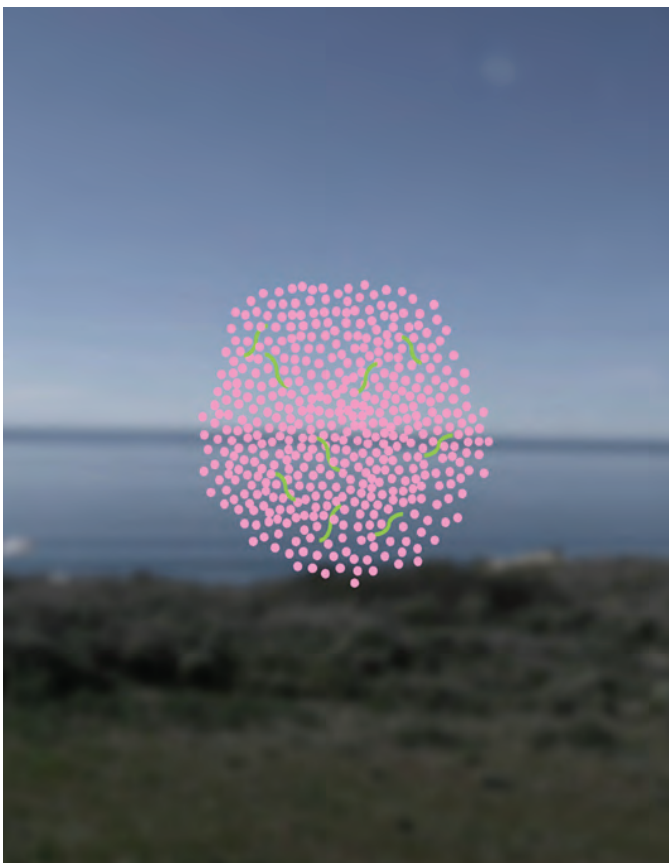
An individual may become affected by vision loss from LHON at any age. This range in age of onset diversifies the challenges each individual with vision loss may face based on whether they're in the educational system, working, have parental support, have parental responsibilities, are employed, or are retired. LHON presents significant emotional challenges to all involved.

Some individuals with LHON vision loss experience a phenomenon known as **Charles Bonnet Syndrome (CBS)**, where those affected see phantom images or hallucinations. Many medical providers are unaware of this condition, or do not discuss it with their patients with vision loss. Also, many people refrain from telling anyone about seeing these phantom images for fear of being labeled a certain way or diagnosed with a mental health disorder. It is important to provide confirmation for a person experiencing CBS that this is a normal, common side effect of any form of vision loss and that it is not associated with any form of mental decline.

**MOVEMENT
DISORDERS
CARDIAC
ABNORMALITIES
MUSCLE
WEAKNESS**

LHON PLUS

**MIGRAINE
COORDINATION
ISSUES
NUMBNESS
TREMORS**



A rendering based on a report from a patient with LHON & CBS.

In some cases, an individual carrying an LHON mutation experiences non-vision symptoms that may be associated with the LHON mutation. It is commonly referred to as “LHON Plus”, or more recently, LHON Spectrum Disorder. Since LHON Plus is a rare disease, patients may struggle to find doctors who are familiar with it, and have experience diagnosing and treating it. The diagnostic odyssey is often lengthy, and can require finding a doctor specialized in mitochondrial disease. Delays in getting access to quality care may contribute towards increased anxiety, depression and medical trauma with this ultra rare disease. This variation of LHON also may necessitate mental health support and outreach.



The loved ones closely tied to the affected individual may also be under great stress and in need of mental health support when an LHON diagnosis enters the family. These individuals include the affected individual, parent, mother or father, sibling, spouse or significant other of the affected individual.

All of these relationships to the affected individual have a unique perspective to LHON that may benefit from mental health partnership. A spouse or significant other may need to take on a greater care giving role or responsibility for income earning within the household. A sibling may have a sense of guilt as well as relief that they were not the one who became affected. A child may need to take on greater household responsibilities at an earlier age if a parent becomes affected. A mother may feel a tremendous sense of responsibility because of the mitochondrial maternal inheritance pattern that dictated how her child lost his or her vision. A father may feel a sense of loss for the life previously envisioned for the affected individual prior to this diagnosis that may seem in jeopardy based on this disease. Some of these roles also carry the risk of vision loss themselves and the unknown of when or whether that will happen to them as well and may also necessitate mental health assistance.

This booklet highlights the importance of comprehensive care that considers the mental health needs of those with LHON and those who are connected to those with LHON. To understand the mental health needs of the different roles that make up all those touched by LHON, group and individual interviews were conducted by a clinical psychologist, with each of the roles identified later in this booklet. From those interviews, the recommendation for mental health as a part of the whole person's overall care was substantiated and documented. The sudden, profound vision loss is life-altering. Despite these challenges, individuals with LHON can still achieve their full potential through resilience and adaptability.

This booklet should be considered general guidance only and should not be considered comprehensive or exhaustive. Each client will come to their mental health provider with their own personal stories and their own unique needs. This booklet is meant to give the therapist a starting point to better meet an LHON community member with a greater understanding of the unique impact this diagnosis carries for different parties.



Author Introduction and Biography

My name is Christina Baker, a clinical psychologist with many years of experience in the health psychology realm. I have had the privilege and honor to work with and know the LHON community. As such, I recognize the need to be educated in the background and needs of this unique space. I have written this booklet in the first person, speaking directly to you, my mental health colleagues, on my learnings from the LHON Community so that you may have a fuller picture of this rare disease and the various community members who are impacted by a diagnosis. I hope that with this booklet, others will feel confident in providing care to this population.

This project would not have been possible without the time and vulnerability of those in the LHON community. I conducted many interviews over the course of several months to humbly learn the needs of those affected and their family members. There are not big enough words to describe my sincerest gratitude to everyone who allowed me into their world, educated me, and guided me to greater understanding. I hope I have done everyone justice in describing their needs to future mental health providers who will have the privilege of walking alongside them in their unique journeys.

And please always remember, if you know one person with LHON, you know only one person with LHON. As mental health providers we always want to meet individuals where they are at, their personal stories, and their unique needs. This booklet is simply meant to give you a starting point so you can feel comfortable stepping into this sacred space.



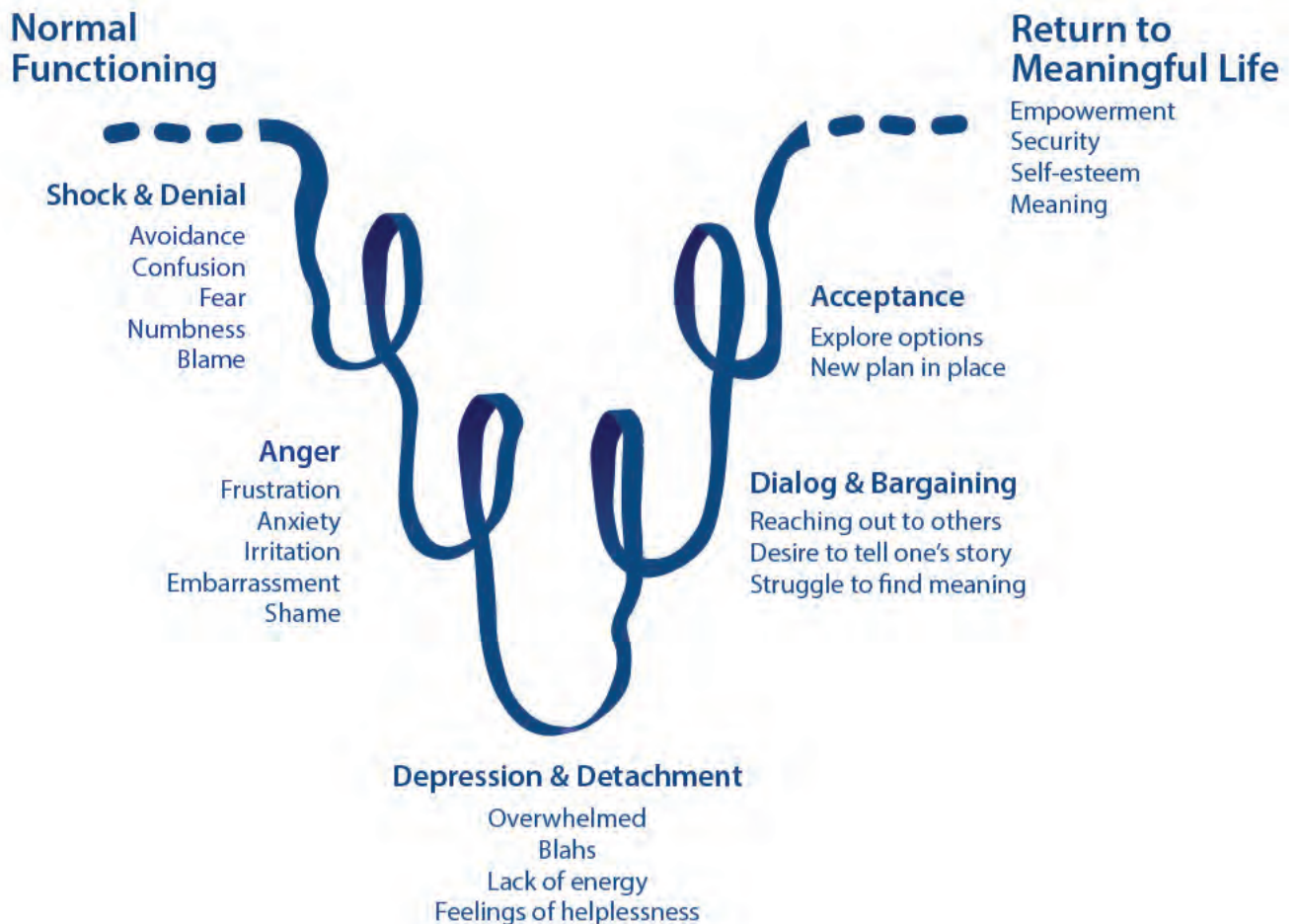
Christina Baker, Psy.D., received her undergraduate degree in Psychology from the University of New England and her doctorate in Clinical Psychology from Florida Tech. She completed her internship at Western Youth Services, and her post-doctoral fellowship at Sovereign Youth Services. She completed additional training experiences with Children's Medical Services, Sharp Mesa Vista Hospital, and in a private practice for neuropsychological testing.

Dr. Baker is a member of the society for pediatric psychology who enjoys working in the intersection of mental health and traditional medicine. She has assisted in designing the new comprehensive Sickle Cell Disease Clinic at Rady Children's Hospital - San Diego, creation of novel support groups, and community trainings to broaden the availability of community providers who have knowledge in the needs of pediatric oncology patients. She created and is the primary supervisor of the new psychology practicum program within Hematology / Oncology Pediatric Psychological Services at Rady Children's Hospital - San Diego

Grief

Put simply, grief is caused by loss. In the LHON community, there are losses everywhere. It's not just the loss of vision, but also the loss of identity, careers, relationships, independence...the list goes on. Therefore, utilizing the conceptualization of grief into therapy with your client will serve as a guiding framework for your time together. In the interviews I conducted, there was not a single person who did not mention grief and their own journey toward acceptance.

We, as therapists, know that the road to acceptance, and hopefully purpose and meaning, is not linear. It is not sequential, with one phase being fully completed before the next. Rather, it is a twisting, winding road, littered with potholes and detours. The stages of grief developed by Elizabeth Kübler Ross were simply meant to describe commonly observed sets of behaviors and emotions. We also know it is not our job to fix grief. It is our job to bear witness, without judgment, and allow processes to unfold.



Therapist Do's and Don'ts



Welcome and offer help

Offer to make client more comfortable.
Intro to navigating the office space.

Flexibility with appointments

Offer video visits.
Flexible on late or cancellation fees.

Assist in finding local resources

Encourage support groups

These may be found on page 25.

Ask the hard questions

Recognize the process is not linear

Listen over hearing

Ask reflective questions to ensure proper understanding.

Be open to the idea that not all issues will be related to LHON

Provide validation over pity

Include sighted supporters when appropriate and with consent

Caution against maladaptive coping skills such as drinking & smoking

Challenge your assumptions

Refer to client as "patient"

Reminders to difficult experiences on journey to diagnosis.

Assume the needs of client

For example, physically leading the client without asking permission.

Refer to family as "caregivers"

Raise volume of your voice

Attribute more disability than exists

Celebrate achievements following their lead.

Don't praise based on assumptions of what is "hard".

Tell clients they are "so strong"

Acknowledge adaptive choices & highlight benefits experienced.

Overgeneralize your experience in an attempt to connect

Meet client where they are at.

Be afraid of humor once rapport established

Protective Factors

POSITIVE COUNTERING EVENTS

Early
diagnosis

LHON
Affected
Family
members

Access to
therapy services
within first 2
years

Pre-existing
supportive
community

Access to
accommodations/
services at
school or work

Large support
network of
same aged
peers

Accessible
public
transportation



LHON-Affected Teen

Milestones LOSS Time in school



There is something unique about teens, as this may be their very first encounter with the idea of therapy. Education on what therapy is and is not, with a strong focus on rapport building, may serve you best.

Teens benefit from strong listeners - they are told what to do and how to do it all day long. As any good therapist would naturally do, let your client have all the space they need to openly process.

When working with adolescents and young adults (AYA), remembering the inherent resiliency of this age will serve you well. Young people tend to be more optimistic and flexible than their older counterparts. Leaning into the idea that while life will change, it may change for the better in some ways, will assist your client in their ability to adapt. Getting back to school and routine will be paramount; structure allows for a sense of control in such an uncontrollable situation.

There may be a loss of extracurriculars; assisting in connecting back to adaptive sports and arts may be a role you consider including in your work with these clients.

Focus on ensuring connection to appropriate services through Individualized Education Plans (IEPs).

It was suggested to use humor in therapy, when appropriate. Laughter, including dark humor, was a commonly reported coping mechanism. I would suggest following the patient in this, letting them lead you to their unique sense of humor.

AYA clients may benefit from a strong examination of strengths, such as memory that they may access in support of new challenges.

Unlike adults, they may need more assistance truly identifying and naming aforementioned strengths. In your sessions, topics to address include assertive communication skills and how best to educate their peers. At this age, friends are family. Ensure engagement with friends is strong and encouraging.

As a therapist, you may need to assist your client in getting access to services at school and connected to support networks of same-aged peers.

LHON-Affected Young Adult

Isolation LOSS



Young adults are a very special population in the LHON community. They are individuals about to launch into their lives, when they are suddenly jolted back to a new reality they've never known. The greatest fear in this developmental stage appears to be isolation. This stems from the idea that their peers and social circles cannot relate to their experience. Thus, ensuring they are connected to the LHON peer support groups is very important. Another important consideration is the propensity to utilize substances to cope due to propensity for risk taking and inhibition at this age.

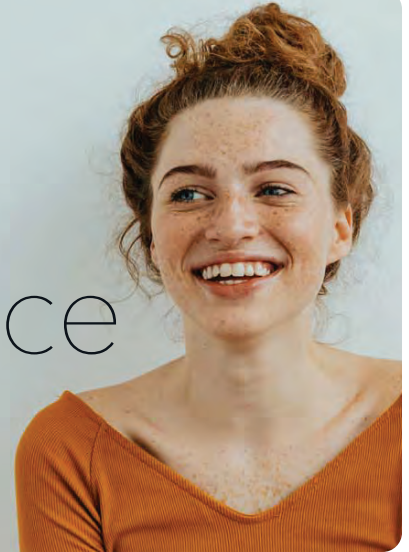
Substance use should be regularly assessed for and discussed openly. Various substances can exacerbate LHON symptomatology, making the vision loss worse, or less likely to improve. The fatalistic nature of this coping approach is common with the age group; motivational interviewing could be helpful in alerting the client to the mechanisms for these behaviors and the possibility for change.

Another thing I worry about for this population is the age of onset for other psychiatric illnesses. We know around the age of 26, we may see other concerning mood and behavior challenges start to form. Being well versed in Charles Bonnet syndrome will assist you in ruling out other types of psychiatric concerns.

With younger generations, being mindful of nuanced societal norms and terms could be useful to the therapist. In my interviews, we discussed the concept of "able-ism," the idea that people without disabilities are privileged in their experience of living. Said more simply, it's the idea that there is ignorance about the blind or LHON experience. Younger generations are impassioned; channeling some of their strife into action for the betterment of others may be a very useful coping tool.

LHON-Affected Adult

Career identity LOSS Independence



There are many factors to consider in working with an affected adult. The most salient theme was the effect of LHON on their career. At this stage of life, career is largely tied to overall identity.

Individuals affected by LHON face significant challenges in maintaining or obtaining employment. Most employers lack experience in providing appropriate accommodations to an employee with vision loss, especially when onset is sudden and profound, as with LHON. It is common for someone affected by LHON to struggle to find the tools and training required to continue working in the same or desired capacity.

In my interviews, being mindful of language such as “what you used to do” may be very hurtful; rather, focus on conceptualizing this as grief with the goal to get to adaptation. Interviewees shared the most helpful breakthrough was the development of a new identity, and allowing it to be even more powerful, eliciting pride.

An additional factor is the change in their relationship with their partner. They will need more assistance than before diagnosis, changing preexisting dynamics. Finding space to process such changes and effects on mood/behavior is important.

Ensuring a "village" around the person affected could be helpful. Assisting them in venturing out to family, friends, and neighbors may allow for them to feel less burdensome on their partner, protecting that relationship.

As a therapist, you may need to branch out and assist your client in getting connected to state-funded or other services.

Each state will have their own assistance programs that may help your client get back to autonomy & independence.

Lastly, an important consideration is that at this stage of life, LHON may not always be the greatest challenge. Those affected discussed child-rearing may be the focused stressor in session. Being open to this idea and not pigeonholing your client in an LHON bubble will serve you both best. There may be possible gender differences within this age group. Women may have a greater emphasis on family planning and the impacts of this diagnosis on those decisions.

LHON-Affected Later in Life

Future plans and Socialization



While there may be somewhat of a normative bell curve for onset of vision loss in teens and early adulthood, we must be ready for the outliers. One such group of outliers are those affected later in life.

These individuals are nearing the end of their careers and are thinking about the next Eriksonian stage of psychosocial development - when the individual will be contemplating their accomplishments as a measurement of having led a successful life.

Should such accomplishments be suddenly stripped away, it is quite possible they could fall into despair, or depression. A great piece of advice I got was to discourage your client from making any major life changes for one year. There may be a drive to DO, to change, in order to try to "fix" the problem. Rather, encourage your patient to build distress tolerance so that they may better access their expansive list of compensatory strategies to compensate for new challenges.

An attention to independence will be important. Assisting your client in determining their own autonomy and resources needed to accomplish this, will be critical. With both ideals, your client may benefit from assistance in determining new ways of making meaning in their career and retirement plans. For example, there may be a shift from a paid career to a mentorship. This, of course, will be another layer to the grief and something to readily check-in about.

In regard to coping, ensuring the individual is getting out of the house regularly and engaging with the outside world was described as most helpful for alleviating depression and anxiety.

Something to consider is the age gap effect on use of electronic equipment. There are many adaptive services available, however they require some base knowledge which older generations have had less experience with.

Becoming affected with LHON later in life, these people are more likely to have a wider repertoire of compensatory strategies, location, and access to state services.

LHON-Affected Parent

LOSS Preconceived parental identity



LHON affects individuals across the lifespan at different phases of life. Being a parent is certainly not spared by the disease. Significant visual impairment will play a role in an individual's ability to parent. Regardless, in my interviews, LHON did not appear to rob the individual of the joy (and hardships) that come with rearing children.

Rather, it encouraged flexibility and adaptability in the parenting role. When it comes to presenting for therapy services, it is best to understand the individual's unique course with LHON, supportive services received, partner dynamics, and village support. There may be different challenges in the aforementioned based on gender roles, so allowing your client to steer you will be important.

In my interviews, the younger adults appeared the most prone to resiliency - tapping into this and applying it to parenting challenges will be useful. As we know, children have very unique needs at different time points; leaving your door open for frequent check-ins to your client will also serve for appropriate adjustment to changes in children's development and corresponding parental needs.

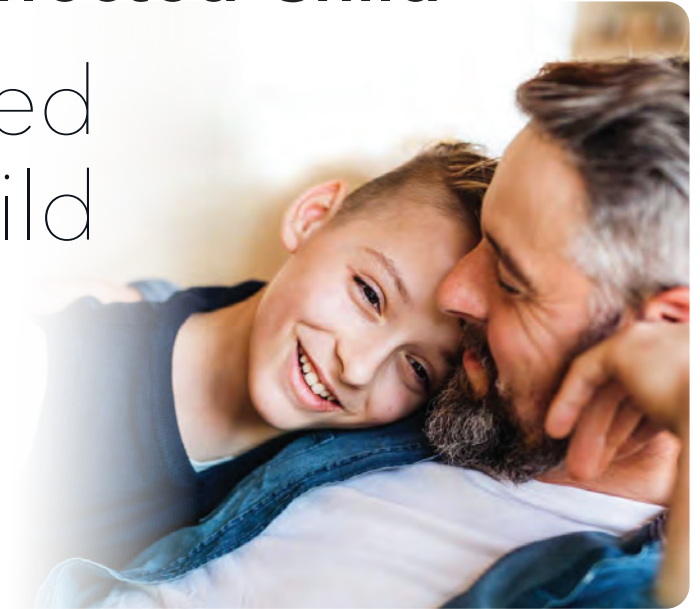
I would implore you to consider flexibility in service delivery. In-home services may be very useful in truly understanding the unique challenges faced by your client, and allow for better access to regular services.

Editor's Note: People who become vision impaired while already parents will encounter new challenges, and their children will need to adjust along with them. They may not be able to provide transportation or see their children's activities, along with other changes. This change in how the parent contributes to the overall family's needs can cause its own host of challenges.

Parent of an LHON-Affected Child

The future imagined
for their child

LOSS



Parents of a young child affected by LHON will have lots of things to work through. First and foremost, a theme was the idea that as the parent, they must have missed something - and if they had caught it earlier, maybe the outcome would have changed.

Logically, they know the aforementioned to be a cognitive distortion. Emotionally, this thought is salient and damaging. Balancing the logical and emotional may edge the parent closer to acceptance of their child's situation. Part of that process will be grieving the life they imagined for their child. While their child's life may still be beautiful and full, it will be different.

Of additional consideration, there are few of these parents. Most people are affected by the disease in adolescence and adulthood. Due to this, they may feel even more isolated, not having too many others that have walked this path ahead, with, or behind them.

It's important that session time is spent on the parent focusing on themselves and their needs. Parents running on an empty engine will impact their kids and have a cyclical effect on the wellbeing of the family. While counterintuitive to most parents, ensuring they are engaging in regular self-care will be vital in their role as a parent.

Much like with an Affected Teen, putting on a resource hat in your sessions could be very helpful. Parents who advocate for strong Individualized Education Plans (IEP) tend to fare best. It allows them to help a situation they cannot fix for their child, giving back a sense of control in an uncontrollable situation.

Parent of an LHON-Affected Teen

Losses Hopes and dreams for the future



The acute onset of profound vision loss will come as a shock. It was described to me as if life ended and slowly began again. Often there is no known family history and even when there is, onset catches the entire family off guard. This is why referrals to therapy for the whole family may be most beneficial.

In the parenting dynamic, it has been reported that the anger stage of grief will look unique. Specifically, in regard to blame. Due to the mitochondrial inheritance pattern of the disease, mothers may blame themselves and fathers may blame the mothers as well (consciously or subconsciously).

Along the stages of grief, navigating shattered dreams of future images for their child will be paramount. Many families lack experience of knowing someone who is blind and may incorrectly assume a blind life is not a good or fulfilling life. Before jumping to “fix” these distortions, a therapist may best serve their clients by sitting in this “ick” and processing the new realities and challenges a family is facing. In this processing, acceptance may follow.

Additional considerations will be the new roles the parents take on. There are many new challenges and burdens of responsibility the family must assume. In many pairings, ways problems are dealt with differ. In my interviews, there appeared to be an emotional and a practical supporter of the teen. This may push couples apart for some time.

While valid, encouraging the couple to prioritize each other as partners will be crucial. Confidence as a parent is being rocked in this process, so ensuring each is constantly providing labeled praise of the benefits they see in the actions of the other could be extremely helpful. It will be important to remember that the fear associated with this is insidious.

It follows each child and the female parent, that it could happen to them also. Sessions may need to focus on self-care and how to have difficult conversations with their maternal relatives.

Parent of an LHON-Affected Adult

Parenting a different child



A parent of an adult affected with LHON serves unique needs to the therapist. Imagine having raised your child, and then due to circumstances beyond both of your control, they suddenly need you again. The sudden and dramatic shift in roles is difficult for both parties to process, and as such, comes grief.

As with other parent roles, the loss here is the life you have imagined for your child. There is a concern that the adult child will not be independent and autonomous again - and what will this mean for the present and future of the parent? From my interviews, it was suggested that acceptance and peace come with the realization that you cannot fix it yourself.

This realization is best achieved when the parent is connected to others in the same experience, and case management is done to access state and community resources.

The concept of control comes up in this situation. With adult children, you certainly cannot control every aspect of their lives. There may be choices made regarding treatment, self-care, rehabilitation and other issues that you disagree with. Sitting in this with your client and allowing them space to discuss anger around this will assist in moving through this particular part of the grief.

Questions offered for therapeutic support include: What are your greatest fears for your child? What are the greatest things that could hurt them now? Is there anything you're feeling guilty about? Ensure the client is engaging in regular self-care and preventative coping.

As an older parent, they may not have the same capacities they did when they parented the first time, so it is vital they are working from a very full cup!

Possible Gender Differences: The guilt with women for the genetic component; males needing to do/fix, difficulties in vulnerability in session.

Mom of an LHON-Affected Child

The child before LOSS LHON



One of the most noteworthy groups in the LHON community is the moms of those affected. An LHON mutation, and thus the risk of becoming affected by LHON, passes from a woman to her children. This genetic fact can cause an incredible amount of guilt. From what I have gathered, it will not be your job to correct this narrative. Rather, sit with it and allow the waves of grief accompanying this wash over both of you until together you find ways to make the waves more manageable.

As mothers, they must come to terms with their deep desire to resolve the situation and the reality that they cannot. There will be sadness and anger - both of which require grace from all those around them. While validation will assist, mothers may ask for specific coping strategies for both of these emotions. We must remember they are wearing many hats with many responsibilities, and will feel as though the weight of the world rests solely on their shoulders.

Many mothers shared the complicated nature of their child not “looking blind”. LHON presents uniquely in the vision impaired community, with individuals having different capacities to adapt and “fit in.” This may lead to an unsupportive environment around these mothers, with many unable to understand the true loss their child is facing. These mothers may also be living in fear of losing their own vision one day. This can occur at any time in the lifespan. It may require changes in lifestyle in attempts to stave off effects (e.g., no alcohol, smoking, etc.).

The fear is compounded by the idea that should they too experience blindness, their child will no longer have their most trusted sighted supporter. As with many of the other LHON Community perspectives related to this disease, in therapy, mothers will need flexibility in service delivery. They are often overworked and overbooked, so while it is vital they carve this time out for themselves, they are more likely to engage when they know their therapist will work with and for them.

Woman Carrying an LHON Mutation-Affected or Unaffected

Freedom of family LOSS planning



Any woman who carries an LHON mutation, affected or as-yet unaffected by vision loss, is impacted by this genetic situation. LHON is caused by a mitochondrial mutation which is passed from a woman to her children.

As a therapist entering this space, keep in mind the concept of family planning. Women in this group will be dealing with the issue of passing an LHON mutation to their offspring. This can be a significant source of (anticipatory) grief. Every woman I talked to brought this up independent of one another. It is such a unique part of the female experience that is altered for these women.

Another thing I may add is the intense level of empathy in this population. This serves as a double-edged sword, where it is the women's greatest gift, and also their biggest burden. They may be so focused on the care of and concern for others that they struggle significantly to name their own challenges and ensure their own needs are met.

Helping them turn down the volume of the needs of others around them to focus on their narrative and needs can improve overall emotional and behavioral regulation. We all know the airplane air mask example - we must put on our own mask in order to best help others.

Sibling of Someone LHON-Affected

Parentified role LOSS



Siblings of those affected can easily be overlooked. The family is springing into action to support the person affected, with the sole focus on their well-being. Yet, the siblings will have their own unique needs that would benefit from therapeutic support. It may be difficult to engage the sibling initially. There is a reported sense of needing to be “strong,” minimizing their own needs in service of care to the affected sibling. However, there are important themes to work through for that sibling to get to the other side of their own grief. This may include survivor’s guilt, the “why them and not me?” mentality.

As therapists, we can see the need for control in an uncontrollable situation here. Naming this and sitting with this will be helpful for the sibling to recognize what is truly below the surface. Additionally, identifying the sibling’s pre-existing strengths, and how these may be amplified for the better after diagnosis could be a useful tool in your work. Lastly, ensuring appropriate advocacy for the sibling and their needs. They may need to find new assertive communication skills that will prevent them from getting lost in the shuffle.

Editor’s Note: Each sibling of someone affected learns (immediately or at some point) that they likely carry the same mutation that caused their sibling's vision loss. Siblings may struggle with anticipatory grief. While the affected sibling may have been surprised with an LHON diagnosis, the unaffected sibling lives knowing that sudden-onset vision loss may or may not lie ahead. Questions they may be grappling with include, “Do they make different lifestyle choices to minimize risk? Do they travel now in case they lose vision later? Do they choose a ‘blind-friendly’ career?”

Spouse/Partner of Someone LHON-Affected

Changing roles LOSS



Spouses may not come into a therapy office for some time. Their sole focus will be on ensuring their person is stable and has what they need first. This suggests that by the time they are sitting across from you, some of the grief work may have already begun. In my interviews, there was this sense of invalidation of their own emotions, as the disease “did not happen to (them).” Working through the idea that LHON did indeed happen to them too will be important in your work with spouses.

The word “trauma” came up cautiously in the interviews - as if the spouses were hesitant to attribute this level of stress to their own experience. Helping them own that they do actually have their own trauma will allow them to continue to move forward. Something also striking in my interviews was the spouse’s fear of leaving their partner alone. This will obviously impact service delivery for you, the therapist - as it may be helpful to inquire and plan about this at the onset of therapy. For instance, a spouse may prefer to meet virtually until they gain confidence that their partner will be okay alone.

The overall idea of finding new autonomy for their spouse and being comfortable in those spaces will likely continue as a theme in your sessions throughout treatment. Encouraging them and reminding them they are doing a good job at this will serve everyone well. It will also be helpful to remember that they may have less “alone time;” ensuring self-care needs are met will thus be paramount. Another unique thing described is this new fear of dying and leaving their partner alone. This will likely be new, and very florid to them.

They may have shifted roles in becoming the protector, the financier, the driver, the one with much of the responsibility. While this may not necessarily be a “bad” thing, it will be new in an experience filled with many new experiences. As such, many arguments may arise from this change. Know, as these come up, they are likely symptoms of that bigger theme. With any major life stressors, the success rate of marriages comes down. Keeping an eye on this, and the goals of the spouse you are seeing, will be important to consider as well.

Adult Child of Someone LHON-Affected

Support person Reversed roles

The child of an affected parent may feel the loss of having their parent as their support person; in fact, the roles become reversed. They may be struggling on how to be there for the person who was always there for them, through uncharted waters and without a map.

In this case, child refers to the relationship not the age of the client. In this project, I interviewed adult children. Should you encounter younger children, please adapt the following in a developmentally appropriate manner.

When presenting for therapy, these “children” are likely to have trouble talking about themselves and their needs initially. You may need to allow them extra time and space to get to that point. Once rapport and trust are well established, it will benefit the client to ensure they are the focus of proceeding sessions, and that their own self-care is being prioritized. As sessions continue, you are likely to encounter unique concerns to this role. For instance, they will experience fear of what happens to their parent should they pass unexpectedly.



They may also worry that their parent may “miss out” on important milestones in their life due to sight loss. If they are female, they may worry about family planning and the chances of this passing on to their own children. Lastly, the age of the child when the parent was affected will be important to consider.

Someone with Non-Vision Symptoms

Beyond vision LOSS loss



Some within the LHON community may present with or without vision loss, but have one or more of what are commonly referred to as “Plus Symptoms.” These individuals carry an LHON mutation and their symptoms may consist of any of a wide range of symptoms such as muscle issues (weakness, ataxia, cramping, numbness), heat and exercise intolerance, chronic fatigue, [migraine](#), [cardiac abnormalities](#), tremors, and dystonia. These symptoms can completely debilitate a person, and often do not come on until adulthood when responsibilities are at a peak.

In therapy, assisting someone in functional planning of life (or problem solving) around symptoms may be the needed crux of your work. In my interviews, persons living with Plus symptoms described a new need to coordinate every aspect of life in ways they never had to before.

There can be anger and frustration in this, stemming from a new lack of and need for control. Exploring pre-existing strengths to assist with new challenges may empower your client to understand they may continue their standard of living, just with new tools to do so.

Additionally, and as with many LHON clients, flexibility on your part will be paramount. Some of the symptoms described by those with the disease prevent them from leaving the house or participating in life that day. As such, be willing to waive late cancel fees and change appointment settings (in person to video).

Editor’s Note: *LHON is a very rare disease. LHON Plus is rare within rare. It can be helpful to seek out others dealing with these challenges. For community opportunities and more information regarding LHON Plus, please refer to the [LHON.org](https://www.lhon.org) website.*

Navigating life with LHON is challenging. Individuals with LHON vision loss and their loved ones can benefit from mental health assistance and other support.

Resources

Education

These websites offer educational resources, info about living well with LHON, clinical trials, and potential treatments for LHON.

www.LHON.org
www.globalgenes.org
www.rarediseases.org
www.umdf.org

Connection

Various Facebook LHON support groups and Zoom events connect people in the LHON Community with others who share similar experiences and provide a community of knowledge, resources and encouragement. These are a few examples of support that can be accessed by LHON Community members. Additional resources may be found on the LHON.org website.

[Global LHON Facebook Group](#)
[Moms of LHON-Affected "Kids of All Ages"](#)
[Dads of LHON-Affected "Kids of All Ages"](#)
[Spouses \(or similar\) of LHON-Affected people](#)
[LHON Sisterhood](#)
[Navigating Employment/Careers with LHON](#)
[Navigating Education/School with LHON](#)
[LHON - Assistive Technology](#)



Health Programs

Environmental factors, such as smoke and alcohol, exert excess stress on the mitochondria. Avoiding these factors can prevent or lessen the effects of LHON. If an individual is struggling, many programs can help in the pursuit of a healthier lifestyle. Please note, this is not a comprehensive list and there are other support programs in the U.S. and globally to consider.

[Nicotine Anonymous](#)
[Alcoholics Anonymous](#)
[Al-Anon Family Groups](#)
[Narcotics Anonymous](#)

Crisis Support


Help is available through crisis hotlines to assist with the emotional and health challenges of living with LHON.

For immediate assistance, you can dial 988 to reach the Suicide & Crisis Lifeline in the United States.

[988 Suicide and Crisis Lifeline](#)
[Crisis Text Line](#)



LHON COLLECTIVE

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The 2024 RARE Mental Health Impact grant provides an opportunity for patient advocacy group leaders to improve the health and mental well-being of the rare disease community—including children, siblings, adults, caregivers, care partners, and those who are grieving.

Produced by LHON Collective in partnership with [Christina Baker, PsyD](#)

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This booklet should be considered general guidance only and should not be considered comprehensive or exhaustive. Each client will come to their mental health provider with their own personal stories and their own unique needs. This booklet is meant to give the therapist a starting point to better meet an LHON community member with a greater understanding of the unique impact this diagnosis carries for different parties.