



Vision and ME/CFS

Visual disturbances and underlying conditions



Including:

How can ME/CFS affect your vision?

Maintaining good eye health

Visiting the optician

Visual symptoms often related to ME/CFS

Research findings on

visual problems in ME/CFS

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Medical information checked by the ME Association's Honorary Medical Adviser, Dr Charles Shepherd.



VISION AND ME/CFS

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DISCLAIMER

We recommend that the medical information in this leaflet is discussed with your doctor. It is not intended to be a substitute for personalised medical advice or treatment. You should consult your doctor whenever a new symptom arises, or an existing symptom worsens. It is important to obtain medical advice that considers other causes and possible treatments. Do not assume that new or worsened symptoms are solely because of ME/CFS or Long Covid.



Experimental studies have demonstrated that ME/CFS patients exhibit altered visual perception.

INTRODUCTION

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a complex, multi-system illness that can affect various bodily functions, which can include vision. While some visual disturbances are commonly reported by individuals with ME/CFS, others may indicate underlying conditions requiring separate medical attention.

Problems relating to vision are quite commonly reported in a range of neurological conditions such as Alzheimer's and Parkinson's disease. Some of these symptoms may be related to what is termed cortical hyperexcitability – in other words, parts of the brain involved with visual messages become over-sensitive. There is currently very little information in the medical literature about visual symptoms in ME/CFS but these problems are frequently discussed and may have a significant impact on the quality of everyday life.

This booklet aims to provide an overview of how ME/CFS can impact vision, provide information on potential ME/CFS-related and unrelated visual problems, and explore management strategies for specific visual symptoms.

HOW CAN ME/CFS AFFECT YOUR VISION?

Individuals with ME/CFS often experience a range of visual symptoms. Research indicates that these symptoms are measurable and consistent across different studies. For instance, a study using the DePaul Symptom Questionnaire found that 92% of participants reported sensitivity to bright lights, 88% had difficulty focusing vision and/or attention, and 86% experienced eye pain.

Additionally, experimental studies have demonstrated that ME/CFS patients exhibit altered visual perception. For example, a study assessing pattern-related visual stress found that ME/CFS patients had significantly higher pattern glare scores compared to controls, indicating increased sensitivity to certain visual patterns.

To explain, visual perception means that it is your brain's way of making sense of what your eyes are seeing. This is not just seeing clearly (i.e. visual acuity), as it also concerns the brain actively interpreting and organising visual information to understand shapes, colours, distances, patterns, and movement.



HOW CAN ME/CFS AFFECT YOUR VISION?



Conditions such as glaucoma, retinal disorders, or neurological issues can present with similar symptoms and require appropriate medical evaluation.

Visual symptoms are a significant aspect of ME/CFS that can impact daily functioning and quality of life. Understanding the nature of these symptoms and distinguishing them from unrelated visual problems is crucial for effective management. By implementing appropriate strategies and seeking professional guidance, individuals with ME/CFS can better cope with visual challenges and this should be part of overall symptom management.

However, it is very important to note that not all visual problems are related to ME/CFS. Conditions such as glaucoma, retinal disorders, or neurological issues can present with similar symptoms and require appropriate medical evaluation. Therefore, persistent, deteriorating or unusual visual disturbances should be assessed by a healthcare professional to rule out other causes.

The visual disturbances that people with ME/CFS often report include:

- increased awareness or sensitivity to bright light (photophobia),
- visual or reading fatigue,
- difficulty with focussing on images and following moving images,
- visual disturbances related to headaches/migraine after reading and screen use,
- pain in or around the eye,
- dry and/or itchy eyes (dry-eye syndrome).

As with many of the symptoms of ME/CFS these symptoms may occur due to various underlying causes - some may be in part to ME/CFS and others may be treatable. At your optician appointment, the optometrist will be able to identify if spectacles may help reduce symptoms.

Your dispensing optician will then be able to discuss the best lenses to fit your lifestyle. They may ask questions about how you spend your time, where you sit at home, if you drive and if you use mobility aids in the home. This is to assess your posture, lighting, any risk of falls etc, and



If you are experiencing changes to your vision, your first appointment should be with your optometrist.

HOW CAN ME/CFS AFFECT YOUR VISION?

enable them to advise you of the best solutions for your visual problems. The optometrist may also be able to conduct investigations that assist your G.P. in investigating headaches.

If you are experiencing changes to your vision, your first appointment should be with your optometrist. For new or worsening pain, headache or migraine you should first consult with your GP who may advise a sight test as part of investigating the underlying condition.

The MEA has produced a leaflet, Headaches and Migraine, in which we discuss what we know about headaches and migraines and the way they affect some people with ME/CFS:

<https://meassociation.org.uk/qhed>

MAINTAINING GOOD EYE HEALTH



Individuals with ME/CFS may experience various visual disturbances, some related to the condition and others requiring further evaluation. Maintaining eye health is essential, and opticians provide valuable services to help address visual disturbances. Regular eye examinations can often detect early signs of eye conditions, thus ensuring timely intervention.

Effective management often involves addressing underlying causes, utilising any appropriate treatments, and seeking help from medical professionals when necessary.

Opticians can offer services such as:

- Eye examinations: Assessing vision and eye health.
- Prescription glasses and contact lenses: Providing corrective lenses tailored to individual needs.
- Detection of eye conditions: Identifying signs of conditions like glaucoma, cataracts, and any signs of macular degeneration.



VISITING THE OPTICIAN

Until we have a problem, many of us take our vision for granted. So although sight tests are recommended for everyone from childhood, many people first present for an eye exam as an adult experiencing problems and are rather apprehensive.



In most high street opticians' practices, you will meet several people. The first person you are likely to meet is an optical assistant; they will assist the optometrist by taking some preliminary details and measurements and scans.

The optometrist is the health professional who tests your eyes. They will ask you questions about your health, medications and eye history as well as questions about your current problems. They will measure what you can see, and will measure the strength of lenses needed to improve your vision.

Some of the examination equipment requires you to lean forward and rest your chin on a small platform.

Optometrists are highly trained to detect eye diseases, so they will use the scans and measurements taken by the optical assistant as well as examining your eyes in the consulting room with a microscope or a hand-held ophthalmoscope. Optometrists can detect eye diseases and sometimes may detect something in your eye examination that could suggest a general health problem.

If the optometrist finds anything of concern they will discuss next steps with you. They might recommend spectacles, monitoring or very occasionally referring you to your GP or an ophthalmologist for further investigation and formal diagnosis.

If you need spectacles, you will discuss this with a dispensing optician or an optical assistant (who will be working under the supervision of a dispensing optician). They will be able to discuss in detail the frame and lenses that are most suitable for your visual needs as well as any practical or any aesthetic needs.

All of the staff you meet will be used to helping patients with various disabilities and will be able to adapt to your needs. It is worth letting the practice know when you book the appointment that you have additional needs so that they can be prepared. For example, many consulting rooms have examination chairs that can be removed if you need to remain in your wheelchair.

Some of the examination equipment requires you to lean forward and rest your chin on a small platform.



A fee may be charged, however depending on the optician, some conduct eye tests at your home free of charge.



HOME VISITS

For those unable to visit opticians due to mobility issues or other health concerns, home eye-care services are available. With ME/CFS, a trip to a high street practice may not be possible or may be detrimental and cause post-exertional malaise. In this case, there are opticians who can visit you at home.

Usually, this service is provided by a specialist company as they use specialised portable equipment and can set up a consulting room in your home very quickly. Often this is done in your living space, however, if you are bedbound, the in-depth assessment can be done in your bedroom.

NHS-funded Home Eye Tests: In the UK, individuals who are housebound can access free NHS-funded eye tests at home. Some opticians offer a service for disabled housebound clients, bringing the optician to your doorstep and delivering new glasses directly to your home.

Private Home Visit Services: Some opticians offer private home visit services for a fee, providing comprehensive eye care in the comfort of your home.

VISUAL SYMPTOMS OFTEN RELATED TO ME/CFS

ME/CFS can lead to a range of visual disturbances, which may be directly related to the condition or due to associated factors like medication side-effects.

Blepharospasm

Blepharospasm is a condition characterised by involuntary eyelid twitching or spasms, that can often occur in ME/CFS. Management may include the use of medications, or lifestyle modifications and stress-reduction techniques.

Botulinum toxin (Botox) injections:

Botox injections into the orbicularis oculi muscle temporarily paralyze the muscle, reducing spasms for 3–4 months. Repeat injections are typically needed.

Note: The orbicularis oculi is a sphincter muscle surrounding the eye, responsible for closing the eyelids, blinking, winking, and assisting in tear drainage.



VISUAL SYMPTOMS OFTEN RELATED TO ME/CFS

Oral medications:

Used less frequently and may be considered when Botox is contra-indicated or ineffective:

- Anticholinergic agents (e.g. trihexyphenidyl)
- Benzodiazepines (e.g. clonazepam) for muscle relaxation
- Muscle relaxants (e.g. baclofen)



Lifestyle modifications:

- Stress management and relaxation techniques can help reduce frequency/intensity of spasms.
- The same techniques can also be used to help avoid eye strain or fatigue.

Blurred vision

Blurred vision in ME/CFS may result from visual processing difficulties or ocular surface issues. Management strategies may include the following:

Corrective Lenses:

Prescription glasses or contact lenses tailored for refractive errors.

Visual Ergonomics:

- Ensure adequate and even lighting when reading or working.
- Use anti-glare filters on screens.
- Implement regular breaks (e.g. 20-20-20 rule: every 20 minutes, look at something 20 feet away for 20 seconds) to reduce eye strain.

Medications:

There are no medications for blurred vision, however if the underlying condition is related to dry eyes or migraine, treating those may improve vision clarity.

Lifestyle modifications such as avoidance of eye strain and fatigue can help with visual difficulties.





Eye pain may be associated with increased sensitivity or strain. Use prescription glasses if needed.

VISUAL SYMPTOMS OFTEN RELATED TO ME/CFS

Dry eyes

IMPORTANT: While dry eyes may be common in ME/CFS, in some cases it could be a symptom of other conditions, e.g. Sjogren's Syndrome. It is therefore important to discuss your new or worsening symptoms with the GP, as this may need further investigation.

Dry eyes are a common complaint among individuals with ME/CFS. Treatment options may include the following:

Artificial tears:

- Preservative-free lubricating eye drops are preferred for frequent use.
- Gel or ointments for overnight use if symptoms persist.
- Warm Compresses

Medications:

- Topical cyclosporine (Restasis) or Lifitegrast can be prescribed for chronic inflammatory dry-eye.
- Oral omega-3 fatty acid supplements may help improve tear quality.

Lifestyle adjustments:

- Avoid dry, windy environments or use protective eyewear.
- Limit screen time or take frequent breaks.

Eye pain

Eye pain may be associated with increased sensitivity or strain. Management may involve the following;

Identifying and mitigating triggers, such as:

- Screen glare, poor lighting, and prolonged visual tasks.

Modifying eye wear:

- Use prescription glasses if needed.
- Blue Light Glasses: Although blue-light-filtering coatings may enhance visual comfort for some individuals - by reducing eye strain or lessening potential sleep disruption - current research does not support claims that they prevent eye disease.





*Wear sunglasses
with UV protection
outdoors.*

VISUAL SYMPTOMS OFTEN RELATED TO ME/CFS

Cochrane Review on blue-light filtering spectacles:

<https://tinyurl.com/2wfpcczw>

Association of British Dispensing Opticians (booklet):

<https://tinyurl.com/2j6zdrsz>

This is an evidence base for the efficacy of blue-blocking spectacle lenses for visual comfort and as protection against macular disease. This was written by John Lawrenson and Professor Chris Hill and comes as a downloadable pdf.

<https://tinyurl.com/mr3wzed5>

Whilst there is no scientific evidence to support the use of blue light or coloured overlays, we understand that some members of the ME/CFS and Long Covid community use them as they feel they benefit from them personally.

A qualified optometrist might recommend anti-reflective lenses for computers, night driving and reading. Polarising lenses might be suggested for outdoor activities in the daytime or daytime driving.

Rest periods:

- Take frequent breaks to reduce eye fatigue.

Medications:

- Discuss with your GP the use of over-the-counter painkillers (like Paracetamol or NSAIDs) for mild pain.
- If inflammation is suspected, your specialist might want you to consider using ophthalmic steroids.

Referral:

- For persistent or severe pain, an ophthalmology review is essential to exclude serious pathology (e.g., uveitis, glaucoma).





The MEA has a free leaflet, Sensitivities, Intolerances, and Hypersensitivities. In this leaflet, we review common sensitivities, intolerances, and hypersensitivities that can occur in ME/CFS and offer management options and tips.

<https://meassociation.org.uk/zbvf>

VISUAL SYMPTOMS OFTEN RELATED TO ME/CFS

Migraine-associated visual disturbances

Individuals with ME/CFS may experience visual disturbances associated with migraines, such as aura or visual snow. Management may include the following:

Medications:

- Triptans (e.g. sumatriptan) or non-steroidal, anti-inflammatory drugs (NSAIDs) at onset of migraine.

Preventive therapies :

- Beta-blockers (e.g. propranolol), anti-epileptics (e.g. topiramate), or anti-depressants (e.g. amitriptyline) may reduce frequency/severity of migraines.

Lifestyle modifications:

- Identifying and avoiding migraine triggers (e.g. stress, certain foods, sleep disturbances).
- Maintaining regular sleep, hydration, and diet.

Photophobia

IMPORTANT: Please seek medical intervention if you experience a sudden and acute episode of photophobia or worsening symptoms, as this may need urgent medical attention.

Sensitivity to light, or photophobia, is prevalent in ME/CFS. Strategies to manage this may include:

Environmental adjustments:

- Wearing sunglasses with UV protection outdoors.
- Using tinted lenses or FL-41 tinted glasses that reduce blue-green light.
- Adjusting indoor lighting to minimise glare (e.g. use lampshades, soft white bulbs).

Screen filters:

- Blue light filters or screen-dimming apps can reduce eye strain from digital devices. See page 9 regarding Blue Light information.





A study assessing visual attention found that ME/CFS patients exhibited significant impairments in selective-attention tasks, indicating difficulties in processing visual information.



RESEARCH FINDINGS ON VISUAL PROBLEMS IN ME/CFS

Medications:

- There are no medications for photophobia, however treating underlying conditions (e.g. dry eyes, migraines) may alleviate symptoms.

Additional measures:

- Take regular breaks from screen use.
- Use hats or visors when outside in bright sunlight.

IMPORTANT INFORMATION

Please seek medical intervention if you experience any of the following visual symptoms that may not be directly related to ME/CFS and therefore warrant further investigation:

- Sudden Vision Loss: A sudden loss of vision in one or both eyes requires immediate medical attention.
- Double Vision: Persistent double vision should be evaluated by an ophthalmologist.
- Visual Hallucinations: Seeing things that aren't present may indicate neurological or psychiatric conditions and should be assessed promptly.

Recent studies have provided valuable insights into the visual challenges faced by individuals with ME/CFS. For example, a study assessing visual attention found that ME/CFS patients exhibited significant impairments in selective-attention tasks, indicating difficulties in processing visual information.

Furthermore, research on reading performance revealed that individuals with ME/CFS had slower reading speeds and poorer visual acuity in crowded conditions, suggesting that visual-processing issues may impact daily activities.

These findings underscore the importance of recognising and addressing visual symptoms in ME/CFS management. While current research has primarily focused on visual perception and attention, further studies are needed to explore the underlying mechanisms and develop targeted interventions.

RESEARCH STUDIES

1. Pattern-related visual stress

Study: Wilson RL, Paterson KB, Hutchinson CV. "Increased vulnerability to pattern-related visual stress in myalgic encephalomyelitis." *Perception*. 2015 Dec;44(12):1422-6. doi: 10.1177/0301006615614467. Epub 2015 Nov 3. PMID: 26562880.

<https://pubmed.ncbi.nlm.nih.gov/26562880/>

Summary: This study found that individuals with ME/CFS are more susceptible to visual discomfort and perceptual distortions when exposed to certain striped patterns, indicating heightened sensitivity to visual stimuli.

2. Reading performance

Study: Wilson RL, Paterson KB, Hutchinson CV. "Visual aspects of reading performance in myalgic encephalomyelitis (ME)." *Perception*. 2018 Aug;47(8):877-888. doi: 10.1177/0305735618781530. Epub 2018 Jun 11. PMID: 30174633.

<https://pubmed.ncbi.nlm.nih.gov/30174633/>

Summary: This research assessed reading speed and acuity in ME/CFS patients, revealing slower reading speeds and poorer visual acuity, particularly in crowded visual environments.

3. Visual attention

Study: Wilson RL, Paterson KB, Hutchinson CV. "Patterns of abnormal visual attention in myalgic encephalomyelitis." *Perception*. 2013;42(11):1187-1198. doi: 10.1068/p7412. PMID: 23689679.

<https://pubmed.ncbi.nlm.nih.gov/23689679/>

Summary: This study found that ME/CFS patients exhibited significant impairments in selective attention tasks, indicating difficulties in processing visual information.



RESEARCH STUDIES

4. Deficits in basic visual spatial processing

Ahmed, N. S., Gottlob, I., Proudlock, F. A., & Hutchinson, C. V. (2018). Restricted Spatial Windows of Visibility in Myalgic Encephalomyelitis (ME). *Vision*, 2(1), 2

<https://pmc.ncbi.nlm.nih.gov/articles/PMC6835387/>

Summary: This study found that people with Myalgic Encephalomyelitis (ME) have reduced contrast sensitivity, particularly at low spatial frequencies, resulting in a narrower range of visible detail compared to healthy individuals. These visual processing deficits may serve as objective markers for ME and suggest abnormalities in both retinal and cortical visual pathways.





“Thank you for producing such a helpful magazine. The standard is consistently high and each edition is interesting and varied. I need all the help I can get and this magazine is consistently encouraging, realistic, and helpful.”



HOW WE CAN HELP

■ **COMMUNITY:** We provide a safe and welcoming community for people affected by ME/CFS and Long Covid who come together and benefit from sharing their experiences. We provide membership, an essential support service, excellent website resources and we host engaging discussions on the most popular social media channels. Knowing that you are not alone can be a great comfort and we are happy to answer your questions and share helpful tips.

■ **MEMBERSHIP:** We put the interests of members at the heart of everything we do. Your subscription means that we can support more people, campaign more effectively and fund more medical research. Members receive the exclusive ME Essential magazine which carries the latest news, medical information, personal stories, and feature articles. **Join us today.**

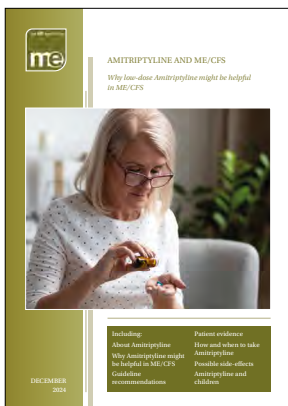
■ **SUPPORT:** ME Connect is the charity’s support and information service. We listen and we understand. We provide a personalised service and we’re here when you need us most. We have knowledge and understanding of these medical conditions. To view the ME Connect telephone helpline opening hours, please visit: <https://meassociation.org.uk/me-connect/>

■ **INFORMATION:** We produce reliable and timely information written by topic experts and have the **largest range of free literature covering all aspects of life with ME/CFS and Long Covid**. We can show you how to recognise and manage symptoms, get an accurate diagnosis, a referral to specialists, and to obtain the healthcare that you deserve. We also provide an **e-newsletter** and free access on the website to **Medical Matters** and other relevant information.

■ **RESEARCH:** We fund medical research via the **Ramsay Research Fund** and are especially interested in research that can find diagnostic markers, causes, and treatments. We support the UK ME/CFS Biobank and the Manchester Brain Bank, and we have invested £2.6m in medical research over the last 35 years. This works out at an average £108,000 in each year.

■ **MEDICAL EDUCATION:** We arrange training for healthcare professionals, offer a medical magazine, ME Medical, and are working with the Government, NHS, Royal Colleges of Medicine, and Local Authorities to implement the recommendations of the 2021 NICE Clinical Guideline on ME/CFS – the successful result of 14 years lobbying and hard work.

“The MEA is doing exactly what it said it would by providing support, actively lobbying for recognition, improvements to health and social care, and funding biomedical research.”



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Number 801279



HOW WE CAN HELP

■ **LOBBYING:** We campaign to raise awareness and bring about positive change. We believe in collaboration and work with the NHS and social care services, the Department of Health and Social Care, the British Association of Clinicians in ME/CFS (BACME), Forward-ME, the ME Research Collaborative (MERC), DecodeME, the All-Party Parliamentary Group (APPG) on ME, Physios4ME, the Chronic Illness Inclusion project (CII), Hidden Disabilities Sunflower, and Long Covid initiatives.

■ **HEALTH & SOCIAL CARE:** The charity works with healthcare providers to successfully implement the NICE Guideline recommendations on ME/CFS and Long Covid to ensure that everyone receives the very best healthcare, wherever they live in the UK. We want well-trained healthcare professionals providing excellent services because timely intervention can lead to better health outcomes and improved quality of life.

■ **DONATIONS:** In order to help more people and invest in medical research, we depend on your generosity. If you feel able to make a donation or want to raise funds in other ways, please get in touch with the fundraising team: fundraising@meassociation.org.uk or you can **make a direct donation via the website.**

WHAT ARE ME/CFS AND LONG COVID?

We answer key questions about these medical conditions and compare similarities and differences. You'll also find the NICE Guideline reproduced in full in an **easy-to-use database.**

MEDICAL MATTERS

Medical Matters is an easy to use online supplement to the more detailed literature. The same topic experts provide answers to commonly asked questions.

<https://meassociation.org.uk/medm>



NHS REFERRAL SERVICES

If you need to locate an ME/CFS specialist service or Long Covid Clinic then we can help. We have listed all secondary care referral services in an **easy-to-use database.**

THE ME ASSOCIATION

me



Freephone

0808 801 0484

For opening hours visit:

meassociation.org.uk/me-connect

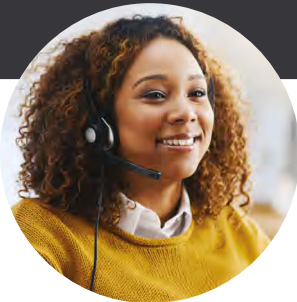
ME CONNECT

The Support and Information Service
for people affected by ME/CFS/PVFS
and Long Covid

Contact ME Connect

3 WAYS TO GET IN TOUCH:

by phone, email or
social media private message



HERE TO LISTEN

We are here to listen,
validate and empathise
with any issues you might
be facing.



VITAL SUPPORT

We are here to help
you reach an informed
decision.



SAFE ENVIRONMENT

We provide a safe,
confidential and
understanding
environment where
you can be heard
and understood.

We're here for you!



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