



TREATING THYROID EYE DISEASE FROM HOME

A National Survey of Medicare Beneficiaries

The COVID-19 pandemic has led policymakers to explore how Americans can receive treatment for medical conditions while minimizing potential exposure to the coronavirus. While many patients benefit from novel approaches to treatment and policy flexibility during the pandemic, one population merits particular consideration: older Americans with thyroid eye disease.

A national survey of Medicare-age people with the debilitating autoimmune disease revealed that disease symptoms, combined with the heightened risk of COVID-19, made traditional treatment difficult. Survey respondents relayed that alternatives, such as receiving infused treatment for thyroid eye disease at home, could allow them to treat their disease without risking unnecessary exposure to the coronavirus.



FINDINGS SUMMARY

SIGNIFICANT DISEASE IMPACT



90%

patients say thyroid eye disease has “significantly” impacted their lives



TREATMENT DISSATISFACTION

100%

are undergoing treatment, with 64% taking steroids

More than half (54%)

are not satisfied with their current treatment

56%

say impaired vision due to thyroid eye disease makes it difficult to receive treatment on a regular basis



TREATMENT COMPLICATIONS DURING COVID-19

70%

have skipped or missed appointments because of the coronavirus

92%

report that getting treatment during COVID-19 has become more difficult

92%

say traveling to get treatment has become more difficult



POTENTIAL BENEFITS OF HOME INFUSION

100%

say home infusion of thyroid eye disease medication would be more convenient and less risky

96%

say it would reduce the burden on their caregivers

94%

say it would reduce disruptions to care for thyroid eye disease

ABOUT THE STUDY

Through a partnership with nationally recognized polling company Public Opinion Strategies, the Vision Health Advocacy Coalition combined individual patient interviews with a national online survey to capture the experience of living with thyroid eye disease during COVID-19.

Phase I: Telephone interviews with five people living with thyroid eye disease. Several interviews also included the patient’s spouse, providing additional insight.

Phase II: National online survey of 50 people age 65 or older and living with thyroid eye disease.

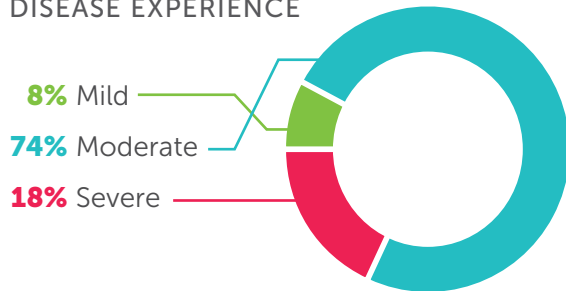
Demographics: Respondents were 44% male, 56% female. All were age 65 or older. Respondents were 60% white, 20% Black, 14% Hispanic and 6% Asian.

Timeline: Beginning with Phase I, the study ran March–July 2020.

LIVING WITH THYROID EYE DISEASE

From pain to vision impairment, loss of independence to social stigma, **thyroid eye disease clearly has a powerful impact on those who live with it.**

DISEASE EXPERIENCE



IMPACT



90%

say living with thyroid eye disease has **significantly** impacted their lives



WHAT IS THYROID EYE DISEASE?

A rare autoimmune disease. Increasing inflammation in tissue around the eyes causes:

- Pain
- Bulging eyes
- Double vision
- Vision loss in severe cases

"I am **embarrassed** to go in public."

"My eyes **hurt** from bulging."

"I have **difficulty** walking."

"I get **dizzy**."

"It makes it hard for me to **drive**."

"I don't like having to **depend** on my kids, grandkids or friends."

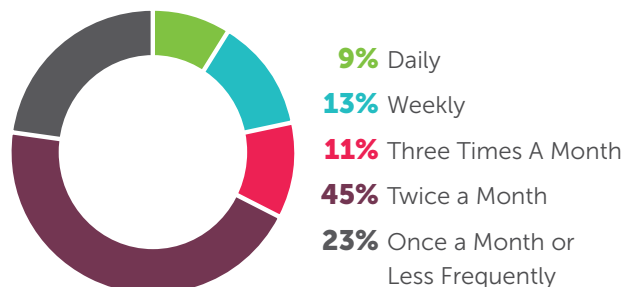
"The disease has caused my **eyesight** to worsen."



TREATMENT OPTIONS

People living with thyroid eye disease have traditionally had few viable treatment options. Steroids are often prescribed to reduce inflammation, but they don't change the course of the disease. Orbital radiation can offer some relief but is not a cure. Some patients turn to surgery.

TREATMENT FREQUENCY



100%

are undergoing some form of **treatment**



64%

are taking steroids



More than half

(54%) are **not satisfied** with their current treatment

56%

say impaired vision due to thyroid eye disease makes it **difficult to receive treatment on a regular basis**



In 2019, the Food and Drug Administration approved the first medication designed specifically to treat thyroid eye disease.

Called teprotumumab, the drug is an infused therapy administered via IV every three weeks for about five months.



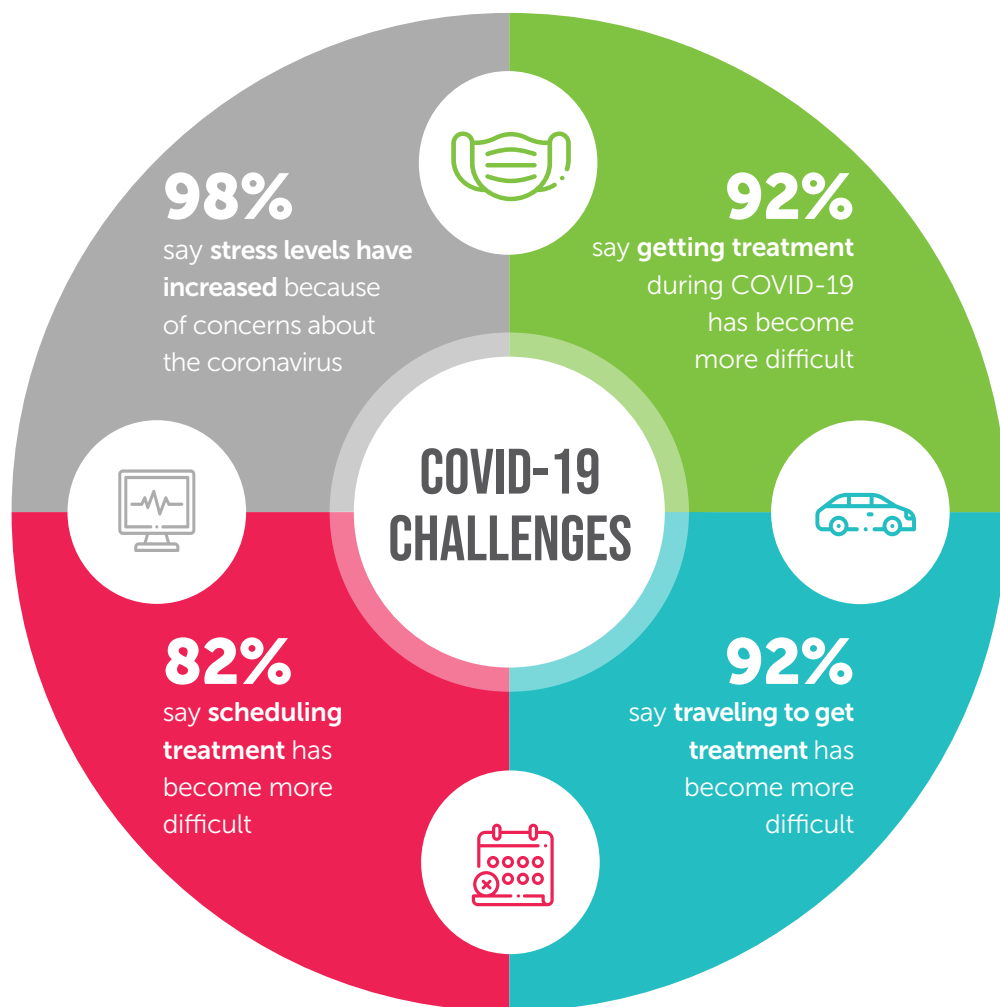
98%

say FDA-approved **infused treatment** specifically for thyroid eye disease is "worthwhile"

COVID-19 & TREATMENT DISRUPTIONS

Since the onset of the COVID-19 pandemic, older people living with thyroid eye disease have encountered new barriers to treatment.

The Centers for Disease Control and Prevention identified people age 65 and older as having a higher risk of contracting the novel coronavirus. As concerns about potential virus exposure rose, so too did challenges with accessing treatment.



have skipped or missed appointments because of the coronavirus

POLICY FLEXIBILITY & HOME INFUSION

To protect access to care during the pandemic, Medicare has allowed more treatments to be administered in the safety of patients' homes. Survey input suggests that expanding Medicare's approach to also include **home infusion of thyroid eye disease medication could make continued treatment more feasible for people age 65 and older.**



100%

say **home infusion is a sensible solution** for thyroid eye disease patients with impaired vision who have difficulty visiting an infusion center

100%

say home infusion would be **more convenient** and expose them to less risk than travelling to a medical center for treatment



Survey respondents say home infusion:

✓ **100%**

would **maintain comforts** of home

✓ **94%**

means **fewer disruptions** to treatment

✓ **88%**

is a **treatment they would utilize** for thyroid eye disease if it were available

✓ **96%**

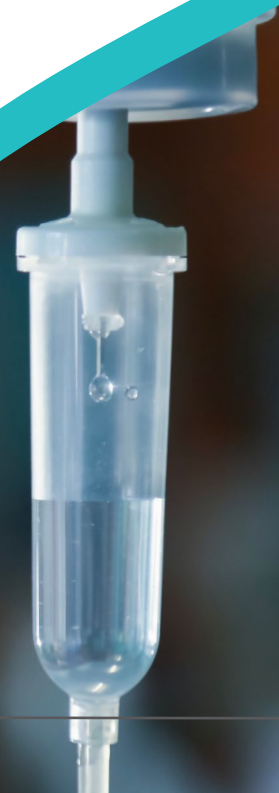
would **reduce the burden** on caregivers

✓ **100%**

would **minimize risk** of exposure

HOW DO PATIENTS ENVISION HOME INFUSION?

- **Qualified medical professional** administering the infusion
- **Contingency plan** for reactions or complications
- **Precautions** to minimize COVID-19 risk
- **Coverage** and affordable cost sharing





CONCLUSIONS

Survey findings confirm that the challenges of living with and treating thyroid eye disease are compounded by the COVID-19 pandemic.

To encourage continued treatment for Medicare beneficiaries who struggle with vision, transportation and worries about virus exposure, policymakers could consider allowing home infusion of FDA-approved thyroid eye disease medication.

DEMOGRAPHICS

Ethnicity	Gender	Age
60% Caucasian Or White	44% Male	All participants were age 65+
20% African American or Black	56% Female	
14% Hispanic or Latino		
6% Asian		



VISION HEALTH ADVOCACY COALITION

The Vision Health Advocacy Coalition promotes patient-centered policies that make services, devices and life-changing treatment accessible for people with vision conditions.

To learn more visit VisionHealthAdvocacy.org



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