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

TREATMENT DISSATISFACTION

100% of patients 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

8% Mild
74% Moderate
18% Severe

IMPACT

90% say living with thyroid eye disease has significantly impacted their lives

WHY 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.”

“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.”
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.

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.
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.

- 98% say stress levels have increased because of concerns about the coronavirus
- 92% say getting treatment during COVID-19 has become more difficult
- 82% say scheduling treatment has become more difficult
- 92% say traveling to get treatment has become more difficult
- 70% 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.

Survey respondents say home infusion:

- **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.

- **100%** would maintain comforts of home.
- **96%** would reduce the burden on caregivers.
- **94%** means fewer disruptions to treatment.
- **100%** would minimize risk of exposure.
- **88%** is a treatment they would utilize for thyroid eye disease if it were available.

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
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**

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<table>
<thead>
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<th>Age</th>
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<td>All participants were age 65+</td>
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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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