# Elastic Head Support for Persons with Dropped Head Syndrome – Case Series in Veterans with ALS

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## INTRODUCTION

Neurologic diseases such as amyotrophic lateral sclerosis (ALS) can lead to weakness of neck extensor muscles and a chin-on-chest posture known as Dropped Head Syndrome (DHS; Sharan et al, 2012). Cervical orthoses can be used for persons with DHS; however, some provide excessive support, some provide support only when seated in a wheelchair, and most hold the chin, which restricts eating, talking or turning the head. Chin support systems can be uncomfortable after prolonged use.

## METHOD

We developed an elastic head support system consisting of an elastic strap between the back of a baseball cap and the back of the pants (Figure 1). Seven men with ALS consented to participate in the study and answered questions related to breathlessness, communication efficacy, eating and swallowing, neck discomfort, hours of sitting and standing prior to discomfort, and comfort in social settings. Questions were answered before and after a 2 week trial of the elastic head support system.

**Figure 1 –** Elastic Head Support

## RESULTS

One of the seven subjects (S4) did not return for follow-up, but provided comments by phone that the device did not work for him due to the lateral deformity of his neck. Of the remaining six subjects, four commented that they would recommend the device for others (S2, S3, S5, and S7). The elastic head support system provided substantial benefits for some subjects (e.g. S2), but not for others (Table 1). Some subjects experienced forehead discomfort and headaches after prolonged use of the elastic head support system. Some subjects felt more comfortable in social settings, related to their ability to avoid the chin-on-chest posture and maintain eye contact with their friends and family, while others were less comfortable due to the social stigma of wearing a hat indoors. Subjects with limited caregiver support had difficulties toileting while using the device. One subject commented that the device made his pants ride up on him, causing discomfort.

**Table 1** – Questionnaire results (Dark gray indicate improvements; light gray indicate negative changes).

| | Subject | S1 | S2 | S3 | S5 | S6 | S7 |
|---|---|---|---|---|---|---|---|
| **Modified Borg Scale – Rating of Perceived Dyspnea[a]** | Pre | 0 | 2 | 3 | 3 | 0 | 0 |
| | Post | 2 | 3 | 0 | 0 | 0 | 0 |
| **Communication Effectiveness Scale for Individuals with ALS[b]** | Pre | 4.8 | 1.4 | 4.7 | 2.6 | 1.0 | 1.2 |
| | Post | 4.8 | 2.2 | 5.0 | 2.6 | 1.0 | 1.2 |
| **Eating Assessment Tool[c]** | Pre | 0 | 35 | 1 | 35 | 40 | 33 |
| | Post | 0 | 14 | 0 | 35 | 40 | 33 |
| **Level of neck discomfort (0 to 10)** | Pre | 0 | 5 | 0-1 | 0 | 5 | 5 |
| | Post | 0 | 2 | 0 | 1 | 7 | 5 |
| **Hours of sitting prior to discomfort** | Pre | >6 | 0-1 | 1-3 | 0-1 | 1-3 | 1-3 |
| | Post | 3-5 | >6 | >6 | 5-6 | 3-5 | 1-3 |
| **Hours of standing prior to discomfort** | Pre | 0-1 | 0-1 | 0-1 | 0-1 | 0-1 | 0-1 |
| | Post | 0-1 | 0-1 | 1-3 | 0-1 | 0-1 | 0-1 |
| **Comfort in social settings (0 to 10)** | Pre | 10 | 5 | 10 | 7 | 8 | 2 |
| | Post | 10 | 10 | 8 | 8 | 7 | 1 |

[a] Modified Borg Scale: 0=no breathlessness; 10=maximum breathlessness
[b] Communication Effectiveness: 1=not understood; 5=effectively understood
[c] Eating Assessment Tool: 0=no problem; 40=severe problem

## DISCUSSION

The elastic head support system is similar to the baseball cap orthosis described by Fast and Thomas (2008) except the strap connects to the pants and not to a strap around the rib cage. Connecting to the pants is preferred when patients have difficulty breathing or when they have feeding tubes. Connection to a strap around the rib cage may be preferred when caregiver support is limited (toileting).

## CONCLUSION

The elastic head support can be effective for persons with DHS who have good caregiver support, well-fitting pants, and a comfortable hat.

## CLINICAL APPLICATIONS

The elastic head support should be considered as a primary or supplemental head support system for persons with DHS, given its low cost and simplicity.

## REFERENCES

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