

## CORONA VIRUS / COVID19

## Practical advice for people with Ehlers-Danlos (hereditary connective tissue or collagen disease)

Claude Hamonet MD<sup>1, 2, 3</sup>.

<sup>1</sup>Occupational Therapy Department, University Paris-Est-Creteil, 80 Avenue du General de Gaulle, 94010 Creteil France.

<sup>2</sup>ELLAsante, medical center, 29 bis rue d' Astorg, 75008 Paris.

<sup>3</sup>Integrative Scientific Medicine 60 rue Carnot 92100 Boulogne-Billancourt France

**Corresponding Author:** Claude Hamonet, Occupational Therapy Department, University Paris-Est-Creteil, 80 Avenue du General de Gaulle, 94010 Creteil France.

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### The people concerned

These recommendations relate to patients who, despite their number, are rarely diagnosed or after a painful and dangerous medical wandering of 20 years on average. The diagnosis is however possible without additional examination on the grouping of clinical criteria easy to highlight, validated by international publications: diffuse pain, significant fatigue, movement control difficulties (awkwardness, involuntary movements, pseudo paralysis), joint instabilities (pseudo sprains, dislocations, joint blockages, cracking joints), thinness and fragility of the skin (excessive stretching, venules visible, stretch marks, difficult healing, less protection against static electricity), diffuse joint hyperlaxity, diffuse hemorrhages, hyperacusis (being bothered by noise, sensation of hubbub in the presence of several interlocutors, "musical ear", perception of weak sounds and ultrasounds, better than dogs), gastro esophageal reflux.

FIVE of these signs are sufficient for diagnosis. Hyperlaxity (rather than hypermobility) which is frequent is not necessary for the diagnosis contrary to a very widespread affirmation, it can even be replaced by retractions (shortenings) of muscles and their tendons (knees, ankles, more rarely, elbow, and fingers). The very present pains make its evaluation random.

In total, if we refer to the complaints of the person concerned: "it hurts everywhere", "it bumps everywhere", "it cracks everywhere" and "it bleeds everywhere"

The identification of similar signs in the family provides evidence of hereditary nature with transmission to all children of a person (man or woman) who is affected. Proof that it is very difficult to provide a biological genetic test in the current state of biomedical knowledge.

### People with an Ehlers-Danlos: a fragile population

Ehlers-Danlos patients have a particular sensitivity to infections (ENT, bronchial, bladder, skin ...)

The excessive "flexibility" (hyperlaxity) of their ribs exposes to painful limitations of muscle play by stretching (especially the diaphragm) responsible for very frequent shortness of breath on exertion (climbing stairs),

False routes are frequent by simple flow of saliva or during feeding, with bronchial flooding causing cough and respiratory discomfort and, sometimes, atelectasis.

The presence of emphysema is particularly susceptible to pneumothorax. Pleural effusions can occur.

The hyper reactivity of the bronchial tissue with hypersecretions, sagging of overly flexible bronchi (or, conversely, dilation), explains the possibility of congestion and stasis with secondary infections. Direct damage to the bronchi or lungs by the virus at the very level of the exchange of oxygen between the inhaled air and the blood (the alveolo-capillary barrier) according to Professor Philippe Juvin of the Georges Pompidou University Hospital can only have harmful consequences.

What we know about the COVID19 coronavirus should make us consider that patients with Ehlers-Danlos disease are particularly fragile when faced with this new viral disease. They must therefore be monitored with particular attention and benefit in priority from the therapeutic devices specially developed for viral disease (oxygen therapy in particular).

A complication of viral infection is to be feared: the worsening of the Ehlers-Danlos picture, as has already been observed under similar circumstances after another infection, boreliosis (Lyme).

The remoteness of the workplace seems particularly justified in the case of Ehlers-Danlos to protect these patients.

### Practical advice

The results of the temperature measurement can be distorted in both directions due to its deregulation in Ehlers-Danlos disease by dysautonomia.

ENT or respiratory manifestations can be caused by Ehlers-Danlos and should not be confused with coronavirus.

These people must be particularly vigilant to avoid contamination (confinement), wear a mask in the event of mandatory exit, wash their hands very frequently with a hydro alcoholic solution or soap, avoid direct contact with other people, sneeze or cough in a disposable handkerchief when the mask is not worn, leave the shoes outside the house or apartment, take off your outdoor clothes when you get home.

Drink regularly

Disinfect the upper airways with sprays, aerosols or gargles of antiseptic products is desirable several times a day, especially in the event of inflammation.

Apply all the effective treatments in this disease, in particular compression garments and oxygen therapy (do 30-minute sessions if

Possible)

A minimum physical activity of one hour per day must be maintained for the maintenance of proprioception despite confinement with self-rehabilitation exercises and exercises at home (recommended), walking (this indication must be understood as a derogatory application movements during confinement).



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