

PRELIMINARY REPORT FROM A SURVEY ON EHLERS-DANLOS SYNDROME IN CANADA “EDS: YOUR NEEDS AND PRIORITIES”

This survey was conducted by the Quebec Coalition of Orphan Diseases/Regroupement québécois des maladies orphelines and the ILC/Canadian Ehlers-Danlos Foundation.

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Following are the combined results of the French and English surveys
(153 participants: individuals affected by EDS)

Characteristics of the respondents:

	Responses	Percentage
Female	144	94.11%
Male	9	5.89%

[Note: In principle, the genetics of Ehlers-Danlos syndrome dictates that boys/men and girls/women should be equally affected, but it is now well known that women are more severely affected. In the genetics field, this phenomenon is called “a disease influenced by the sex”.]

Age	Reponses	Percentage
14 to 19 years	9	5.89%
20 to 29 years	18	11.77%
30 to 39 years	38	24.83%
40 to 49 years	42	27.45%
50 to 59 years	37	24.19%
60 to 69 years	7	4.57%
70 and over	2	1.30%

Province	Reponses	Percentage
Ontario	50	32.68%
Quebec	78	50.98%
Manitoba	0	0%
Alberta	3	1.96%
Saskatchewan	0	0%
British Colombia	2	1.31%
Nova Scotia	12	7.84%
New Brunswick	7	4.57%
Prince Edward Island	0	0%
Newfoundland and Labrador	1	0.66%
Yukon	0	0%
Northwest Territories	0	0%
Nunavut	0	0%

Q4 What are the five (5) most challenging aspects of living with EDS?

(Note: we list only the 10 most frequent responses for each question)

Problem	Frequency
Pain	67
Lack of awareness from medical community	49
Fatigue/exhaustion	39
Lack of medical resources/proper care from physicians	31
Dislocation	16
Lack of understanding from social community	15
Not being able to work / financial uncertainty	13
GI problems/IBS	10
Medical expenses	10
Comorbidity/Many symptoms to cope with	8

Q5 If you could present to a room filled with experts who are willing to work on the problem that most limits your quality of life, what would you ask them to focus on?

Problem	Responses
Pain	34
Lack of awareness from medical community to get effective treatment	11
Fatigue	11
Determining effective treatment options	6
Digestion	4
Joint hypermobility	4
Sleep	3
Methods of ensuring reasonable wait times to see specialists	3
Multiple symptoms at once	3
Lower risk of injury	3

Q7 Name the top five (5) EDS symptoms you experience that limit you. List them in order from most bothersome to least bothersome.

Problem	Responses
Pain	117
Fatigue/exhaustion	61
Dislocation/subluxations	43
GI issues/IBS(2)/Bowel rupture/constipation	33
Headaches, blurred vision, migraines, dizziness	23
Sleep	17
Brain fog	15
Joint issues/instability	12
Physical limitations	11
Weakness	11

Q8 What is the most frustrating thing you have to deal with each day (or routinely) related to EDS?

Problem	Responses
Pain	26
Fatigue/exhaustion	20
Limited physical ability	14
Unpredictability for injury	7
Loss of autonomy/humiliation	4
Lack of understanding from everyone including doctors	16
Sleep	3
Judgment	2
Difficulty with braces	2
Overtaking life in every aspect, overall management	2

Q10 The symptom or aspect of life with EDS that is most under-appreciated by my doctor is...

Problem	Responses
Extreme pain despite looking "fine"	28
Fatigue/exhaustion	16
Lack of medical knowledge	9
GI issues	7
Not taken seriously	4
Dislocations	4
Many symptoms at once	3
Impact on all aspects of life	3
Mental state	3
Physical limitations/ limited energy	3

The following questions were answered by affected mothers who have children affected by EDS

Q13 Do you have children affected by EDS

	Responses	Percentage
No	54	52.9%
Yes	48	47.1%

Q14 What are the five (5) most challenging aspects for your child/children living with EDS?

Problem	Responses
Lack of help/knowledge from doctors	12
Pain/ pain control	11
Being different/ left out (social isolation)	6
GI issues	6
School	5
Limitations/not being able to do activities	5
Fatigue	4
Dislocations/subluxations	2
Sleep	2
No treatment /information	2

Q17 Name the top five (5) EDS symptoms your child/children experience that limit them. List them in order from most bothersome to least bothersome.

Problem	Responses
Pain	12
GI issues	10
Fatigue	9
Dislocations, subluxations	7
Lack of endurance, physical ability, energy	4
POTs/Orthostatic intolerance	4
Hypotonia, hyperlaxity	4
Anxiety, depression (1)	3
Lightheadedness, headaches, migraines	3
Falling	2

Q20 The symptom or aspect of your child/children's life with EDS that is most under-appreciated by their doctor is ...

Pain (X 4)
Fatigue (X 3)
Gastro intestinal symptoms and poor growth (X 2)
The doctors we dealt with, for the most part, did not believe the pain and fatigue were real ... or their severity and therefor did not understand or appreciate the multifaceted impact this had on the everyday life of my children (X 2)
They blame it all on her mental health. My daughter has literally had 2 doctors let her go because they could not help her. We have gone see so many therapist and psychiatrics and no one could help. She does not do well with any antidepressants therefore we have given up.
The mental health issues that follow or are exacerbated by chronic pain.
Impact on most aspects of daily living
The impact of EDS on his ability to be physically active.
Perineal pain and incontinence
POTs
Lack of understanding from family
Comorbidities
Lack of energy

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