EDSH TREATMENT

There is no curative treatment. It is possible that in the future, with Genetic Therapy, this might be possible. These patients need to be treated by a Rheumatologist, since it is necessary to recognize other HCTD and to rule out other forms of arthritis. He also needs to diagnose early Osteoarthritis and early Osteoporosis.

Sympomatic treatment :

a.- Prevent complications.

b.- Treat patients early. “We need to treat the treatable”.

EDSH treatment

A.- Prevention.

- **Avoid hyperextention of joints.**
- **Avoid sports or hobbies that produce recurrent lesions, specially contact sports.**
- **Do stretching and use joint protectors.**
- **Strengthen muscles and tendons with proper exercises. Swimming, bicycling, Yoga, Pilates and Tai Chi, are recommended.**
- **Avoid inactivity and do not stay long hours in the same position without moving.**
- **Children should not carry heavy backpacks.**
- **It is necessary for children to have school accident insurance, since they are prone to musculoskeletal lesions.**
- **Avoid overweight and sedentarism.**

B.- SYMPTOMATIC TREATMENT

- **Reassurance. Patients need to know that they have an organic disease, that causes acute and chronic pain, that can be at times disabling (they need to be believed).**

- **Psychological considerations. It is necessary to remember that these patients have fear, anxiety and anger, that needs to be relieved.**

- **Musculo-skeletal pain is treated with analgesics, anti-inflammatories, codeine, tramadol, muscle relaxants and aplications of cold or heat. We recommend Yoga, Pilates, Tai Chi, swimming and bycicling.**

- **The treatment of acute episodes, such as tendinitis, bursitis, lumbago, etc. are done in the usual way, including steroid infiltrations.**

- **Capillary fragility is treated with Vitamin C and trying to avoid trauma.**

SYMPTOMATIC TREATMENT (cont.)

- **PHYSIOTHERAPY: Needs to be done by a person trained in working with hypermobile patients. Caution is needed in handling these patients, because of fragile tissues. Includes physiatrists, kinesiologists and occupational therapists.**

- **Aims of rehabilitation:**
  Reassurance, education and advise.
  Develop core stability.
  Enhance joint stability.
  Improve joint propioception.
  Avoid resting in end of range postures (ie. Genu recurvatum).
  Restore normal (hyper) mobility.
  Pacing, coping, behavioral strategies.
  Reversing deconditioning.
  Fitness and stamina by aerobic exercise.
  Self management.

After Anna Edwards-Fowler and Rosemary Kerr. London. UK.

SYMPTOMATIC TREATMENT (cont.)

- **Acrocianosis is prevented with activity and reducing cold exposure. To improve the peripheral circulation it is important to move hands, knees and ankles.**

- **It is necessary to prevent poor cicatrization, by avoiding unecessary surgery and being careful with the treatment of wounds.**

- **The patient reduces his depression and anxiety when he gets a definitive diagnosis and a physician that knows his problem. Ansiolitics and anti-depressants can be of help.**

- **The treatment of Dysautonomia improves the quality of life of the patients. The general meassures should be done rigorously (walk fast, do not stand in line, drink 2-3 liters of fluids a day and increase salt intake, elastic stockings, rest after lunch, avoid carbohydrates, sweet drinks and alcohol). Medicines such as Midodrine, Phenilefrine and Fluodrocortisone are very effective. Occasionally antidepressants or ansiolitics are recommended.**

SYMPTOMATIC TREATMENT (cont.)

- **It is necessary to diagnose Osteoporosis early, so we need to do densitometries in all HDCT patients, even to adolescents. Treatment including Calcium, Vitamin D and an alendronate, needs to be started early. We recommend walking half an hour 3 times per week and to avoid falls.**

- **Prevention of Osteoarthritis (OA) includes loss of weight and correction of mal aligment of the joint, if present. If OA is already present, we need to improve muscle fitness, diminich excess joint work, use anti-inflammatories and Glucosamine with Condroitin Sulphate (even though its effectiveness is not proven).**

- **For muscle cramps and for MVP we use magnesium oxide.**

SYMPTOMATIC TREATMENT (cont.)

- I treat all my patients with **Folic Acid** (FA), since it has been demonstrated that it is useful to strenghten bone collagen, prevention of congenital malformations in new borns and because I have the theory that in some cases the lack of FA could be instrumental in causing genetic mutations responsable of EDSH. If has many benefits and nearly no contra indications (Pernicious anemia).

- **Support Groups** are essential so patients can learn more about their condition and alternate with other patients with similar problems. They are very useful also for the patient´s relatives.

SYMPTOMATIC TREATMENT (cont.)

- **Team approach.** A multidiciplinary group of specialists is essential for good results. It should include rheumatologists, orthopedists, physiatrists, physiotherapists, occupational therapists, neurologists, cardiologists, gynecologists, psycologists, psychiatrists, orthodontists and social workers.

- Ocassionally we need to use Bio-feed back, TENS Units or Acupunture. In exceptional cases it is necessary to do **Surgery** or to send the patient to a **Pain Clinic**.