



# EHLERS-DANLOS SUPPORT GROUP

P.O. Box 337, Aldershot, GU12 6WZ. Registered Charity 1014641  
Telephone 01252 690940 Website: [www.ehlers-danlos.org](http://www.ehlers-danlos.org)

## Publications List & Order Form

### **Ehlers-Danlos Syndrome – 2<sup>nd</sup> Edition**

This basic guide is a 30-page illustrated booklet on Ehlers-Danlos Syndrome (EDS). It has 20 different sections, which cover various aspects of EDS. The sections cover an introduction to EDS, explain what exactly collagen is, the different types of collagen and the abnormality in EDS as well as how EDS is diagnosed. The different Types of EDS are stated and the hereditary patterns for each one. Other sections include: Skin Features; Rheumatological Symptoms; Orthopaedic Complications; Vascular Complications; Gastrointestinal Complications; EDS and the Eye; Hearing Impairment; Pregnancy; The Urinary Tract; Complications of EDS in Childhood; Dental Aspects; Is there a Cure? Treatment; Surgery in EDS; and Anaesthesia.

**ISBN 0 9525986 7 1**

**Price including p&p: - UK £2.00, Europe £2.50, Rest of World £4.00 airmail**

---

### **Diagnosing Ehlers-Danlos Syndrome (Revised Nosology Villefranche 1997)**

This is an illustrated booklet on diagnosing Ehlers-Danlos Syndrome (EDS) for members of the medical profession, revised types and diagnostic tests. Authors: Prof P Beighton, Prof B Steinmann, Prof P Tsipouras, Dr A De Paepe, Dr R J Wenstrup *et al.*

**Free to UK Members. p&p: - Europe £1.00, Rest of World £3.00 airmail**

---

### **The Management of Ehlers-Danlos Syndrome**

This 200-page book is a compilation of 50 chapters written by specialists about their own areas of expertise and has been edited by Professor H A Bird MD FRCP and Valerie Burrows, it consists of a table of revised Ehlers-Danlos Syndrome Types (Villefranche 1997), and four sections: -

#### **SECTION I - Complications of EDS**

A Brief History of EDS; Rheumatological Features of EDS; The Skin in EDS; The Heart in EDS; The Lungs in EDS; Gastroenterological Features of EDS; Neurological Features of EDS; Gynaecological Aspects of EDS; EDS and the Urinary Tract; EDS and Osteoporosis; Spinal Deformity and EDS; Articular Manifestations of EDS; The Eye in EDS; EDS Vascular Type.

#### **SECTION II - Practical Aspects of Management**

Management of the Skin in EDS; Varicose Veins in EDS; Constipation in EDS; Surgery in EDS; Surgical Scars in EDS; Skin Surgery in EDS; Dental Treatment for Patients with EDS; Temporomandibular Joint Management in EDS; Orthodontic Treatment in EDS; Joint Hypermobility; Physiotherapy for EDS; Osteopathy and Pain Control; Relaxation as a Tool for Pain Management; Splinting and Bracing; Ways and Means of Coping with Daily Activities; Self-help for Speech, Language and Swallowing Issues in EDS; Hearing Impairment in EDS; Foot Care in EDS; Orthopaedic Management of Articular Problems; Steps to Chronic Pain Management; Pain Control in EDS; Basic First Aid for EDS; General Health; Daily Dental Care in EDS.

#### **SECTION III - Genetic and Paediatric Aspects**

Genetic Counselling; Visiting a Geneticist for a Diagnosis; Your Child and EDS; Hospital and Your Child; Your Child and Special Education Needs.

#### **SECTION IV - Miscellaneous**

Preparing a Medical History; Consulting Your Doctor; Appraising Treatment for Joint Problems; General Advice Offered to the Support Group by its Members; Coming to Terms With Diagnosis; Coping with Diagnosis - a Parent's View; A Partner and Parent's Perspective.

**ISBN 0 9525986 5 5**

**Price including p&p: - UK £5.00, Europe £6.50, Rest of World £11.50 airmail**

---

### **Pregnancy and Childbirth in Ehlers-Danlos Syndrome – 2<sup>nd</sup> Edition**

This 32-page A5 booklet will be of immense value for medical and caring professionals as well as people with EDS. The main chapters are: - Introduction; Human Aspects of Pregnancy in EDS; Medical Aspects of Pregnancy in EDS; Physiological and Pathophysiological Changes in Pregnancy; Delivery in EDS; Post Partum Period; The Foetus and Newborn Child; and Conclusion. The subheadings cover a wide variety of subjects in an endeavour to answer all the queries likely to arise in a family thinking about pregnancy.

**ISBN 0 9525986 6 3**

**Price including p&p: - UK £2.00, Europe £2.50, Rest of World £4.00 airmail**

## Ehlers-Danlos Syndrome - A Guide for Teachers – 2<sup>nd</sup> Edition

The 'Guide for Teachers' booklet gives a valuable insight into EDS for teachers who have pupils with EDS, as well as giving suggestions for coping with day-to-day management and medical emergencies. It is suitable for use by Youth Leaders and others working with children and gives appropriate advice whether for tots or teens.

**ISBN 0 9525986 8 X**

**Price including p&p: - UK £1.50, Europe £2.00, Rest of World £3.50 airmail**

---

### Difficulties in School/College for Young People with EDS

The results of a survey conducted by a retired Head teacher and the members of the Ehlers-Danlos Support Group with recommendations made by a Physiotherapist, Occupational Therapist and the Head teacher.

**Price including p&p: - UK £1.50, Europe £2.00, Rest of World £3.50 airmail**

---

### Learning to be different

This is a booklet especially written, by one of our members, for young children ages 4-7 years old. It is a combination of a storybook and a colouring book and tells the story of a little girl with EDS who is starting school. In the story, on one visit to the hospital, she meets Michael who also has EDS and enjoys talking to him about their various symptoms.

**ISBN 0 9525986 3 9**

**Price including p&p: - UK £1.50, Europe £2.00, Rest of World £3.50 airmail**

---

### So you have EDS too

An illustrated booklet written specifically for children, aged 8-13 years old, who have Ehlers-Danlos Syndrome. Topics include: So, what is EDS? How did I get EDS? What are the doctors looking for? Will I get better? What happens if I need to go into hospital? What do I tell my friends? Why don't any of my friends have EDS?

**Price including p&p: - UK £1.50, Europe £2.00, Rest of World £3.50 airmail**

---

### Key-facts Medical Card

#### EHLER S-D ANLOS SUPPORT GR OUP UK

The bearer of this card is affected by the hereditary disorder of connective tissue known as Ehlers Danlos Syndrome. The defect gives rise to weakness of the major body structural protein, collagen, resulting in a loss of strength of many structures including the skin, bone, joint and blood vessels which become more fragile and thus more easily damaged or broken thus -

1. The skin is extra stretchy and may break, bruise easily and heal less well with thin and wide scars.
2. Joints are lax (double jointed), dislocate very easily and may develop osteoarthritis in later life.
3. Bones may fracture more easily.
4. Mitral valve prolapse may be present
5. In one form of the disease (EDS M) major arteries may rupture leading to serious haemorrhage.

Warning to health professionals attending the bearer of this card.

1. Handle this patient with great care as bruising and joint dislocation are very easily provoked.
2. Surgical sutures cut through fragile tissues so -
  - (a) Avoid surgery wherever possible.
  - (b) Sutures should be retained for twice the normal period.
  - (c) Use steristrips as an alternative to sutures where possible.
  - (d) For EDS types other than Type IV, providing complete haemostasis is achieved and careful and accurate skin suturing is accomplished no problems arise.
3. In pregnancy there is increased risk of premature rupture of the membranes and of APH and PPH.
4. Anaesthetists should be careful to avoid dislocation of the jaw during intubation.

A small plastic card which gives details of Ehlers-Danlos Syndrome on one side and, on the other, advice to health professionals attending the bearer of the card. One card is suitable for Vascular Type (Type IV) and another for all other types. There is room for an emergency telephone number on both cards. General cards, as above, are available in Italian (I), French (F), Dutch (D), German (G), Swedish (S), Norwegian (N), Russian (R), Turkish (T), Danish (DA), Spanish (SP), Portuguese (P), Greek (GR), Polish (PO), Chinese (C), Finnish (FI). Please state letter code if ordering a foreign card.

(The information on this card is only general and should not in any way replace the individualised medical recommendations of the patient's own specialists. Always use the foreign card in conjunction with the English card, as we cannot guarantee the exact accuracy of the translation.) Price including p&p: - UK £1.50, Europe £2.00, Rest of World £3.50 airmail.

**Suitable For Handling To Medical Professionals**

	<b>Cost Each</b>	<b>Quantity</b>	<b>Total</b>
Autonomic Intelligence	80p		
Chiropody Management – Advice to Professionals treating patients with EDS	80p		
Daily Dental Care in Ehlers-Danlos Syndrome	80p		
Dental Aspects of Ehlers-Danlos Syndrome	95p		
Ehlers-Danlos Syndrome	80p		
Eye in Ehlers-Danlos Syndrome	£1.10		
Fibromyalgia	65p		
Foot Care in Ehlers-Danlos Syndrome	95p		
Gastro-Intestinal Problems in Children with Ehlers-Danlos Syndrome	£1.20		
Geneticist, Visiting a	65p		
Heart in Ehlers-Danlos Syndrome	65p		
Joint Hypermobility	£1.10		
Lungs in Ehlers-Danlos Syndrome	£1.10		
Orthodontic Treatment Considerations with Ehlers-Danlos Syndrome	65p		
Orthopaedic Management of Articular Problems	65p		
Osteopathy and EDS – Advice to Practitioners	80p		
Osteopathy and Pain Control	65p		
Osteoporosis and Ehlers-Danlos Syndrome	80p		
Pain Control in Ehlers-Danlos Syndrome	95p		
Patients Suffering from EDS Type III do not respond to Local Anaesthetics	65p		
Physiotherapy in Ehlers-Danlos Syndrome	£1.50		
Pregnancy – Simple solutions to Ante/Post Natal problems in EDS	£1.20		
Rheumatological features of EDS	65p		
Self-help for Speech, Language & Swallowing issues in Ehlers-Danlos Syndrome	80p		
Skin Management in Ehlers-Danlos Syndrome	80p		
Skin Surgery in Ehlers-Danlos Syndrome	80p		
Speech, Language and Swallowing Issues in Ehlers-Danlos Syndrome	80p		
Spinal Deformity and Ehlers-Danlos Syndrome	95p		
Splinting and Bracing	65p		
Surgery in Ehlers-Danlos Syndrome	95p		
Types of Ehlers-Danlos Syndrome	65p		
Urinary Tract and Ehlers-Danlos Syndrome	80p		
Vascular Type of Ehlers-Danlos Syndrome	80p		
Your Child and Ehlers-Danlos Syndrome	95p		

**Publications**

Ehlers-Danlos Syndrome (EDS)	£3.00		
Diagnosing Ehlers-Danlos Syndrome	£1.50		
The Management of Ehlers-Danlos Syndrome	£8.00		
Pregnancy and Childbirth in Ehlers-Danlos Syndrome	£3.00		
Ehlers-Danlos Syndrome – A Guide for Teachers	£2.50		
Difficulties in School/College for Young People with EDS	£2.50		
Learning to be Different	£2.50		
So, You have EDS too?	£2.50		
Key Facts Medical Card – General	£2.00		
Key Facts Medical Card – Vascular	£2.00		
Language Letter Code	£2.00		

If you wish to make a donation, please add it here:

***Cheques must be in Sterling and payable to 'Ehlers-Danlos Support Group'.  
Wherever possible, overseas orders should be paid by credit card, to reduce  
cheque processing charges. Thank you.***

**GRAND TOTAL:**

**Please see overleaf for payment details**

January 2009

**Order and Delivery Details:**

I wish to order the items detailed overleaf:

**Name:** \_\_\_\_\_  
**Address:** \_\_\_\_\_  
\_\_\_\_\_ **Post Code:** \_\_\_\_\_  
**Tel No:** \_\_\_\_\_

Delivery Address (if different from above):

**Name:** \_\_\_\_\_  
**Address:** \_\_\_\_\_  
\_\_\_\_\_ **Post Code:** \_\_\_\_\_  
**Tel No:** \_\_\_\_\_

*Payment:*

**Grand Total (from overleaf):** \_\_\_\_\_ £  
**If you wish to make a donation, please add it here:** \_\_\_\_\_ £  
**Payment Total:** \_\_\_\_\_ £

*(please tick as appropriate)*

*I enclose a cheque/postal order made payable to: 'Ehlers-Danlos Support Group'*

*Please charge my credit/debit card*

**Credit/debit card authorisation – please complete**

Tick card type: MasterCard  Visa  Maestro  Solo  Issue No:  \_\_\_\_\_  
Maestro & Solo only

Valid From:  /  Expiry Date:  /  Security Code:

Card Number:                      \_\_\_\_\_  
Maestro only

Name (with initials) as printed on card: \_\_\_\_\_

Full address to which statement is sent: \_\_\_\_\_  
\_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_