Assessment wheel - hEDS & HSD

The following extract is taken from: Understanding hypermobile Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorder

Chapter 3
Diagnosis and Management

© Claire Smith
Redcliff-House Publications
Why patients must be assessed on an individual basis

Taking a ‘seen one person with hEDS, seen them all’ attitude to hEDS patients is not acceptable. The signs, symptoms and associated disorders which affect an individual with hEDS most profoundly can vary not only between different individuals, but also (during any given period) in each individual themselves.

‘The severity of the wide ranging symptoms, the joints that are affected and the level of pain / fatigue experienced by those with HSD or hEDS, can vary greatly from day to day, or even hour to hour’ (3/HMSA 2014).

Trying to categorise one individual as being more or less severely affected than another, in anything other than the extremes of severity, can also be futile. For example, how can someone affected by debilitating levels of gastrointestinal dysfunction, chronic fatigue, moderate levels of pain, but minor levels of joint instability (see B) be graded as more or less severely affected than someone who suffers with disabling levels of dislocations and soft tissue injuries and high levels of widespread pain and depression (see C)? In each case, the patient’s most severe presenting symptoms are different, but can significantly interfere with their daily activities of living, including schooling or work.

When deciding on an appropriate treatment pathway for patients, such variations must be taken into account. Patients should be assessed on an individual basis and a tailored plan for referrals, treatments and management put in place and regularly reviewed.

Diagram A represents the range of symptoms and levels of severity frequently seen in hEDS

Asterisks mark levels of symptom severity described by patient No 1 and patient No 2. Least severe symptoms (inner ring marked ‘0’) to most severe symptoms (outer ring marked ‘5’).
© Claire Smith
Author; Editor for the Hypermobility Syndromes Association; International Consortium for EDS and Associated Disorders Expert Patient (UK)
Assessment Wheel Diagram - extract taken from:
Understanding Hypermobile Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorder.
Date of Review: April 2020.

For more information on this publication, please visit: redcliffhousepublications.co.uk

References:
HMSA 2014 - An educator’s guide to the hypermobile child - V3.9
- Copy written by Claire Smith, Donna Wicks and Alan Hakim
Permission has been granted for the following extracts from this publication to be reproduced by the Royal College of General Practitioners (RCGP):

- Assessment wheel diagram; Craniocervical instability and hEDS/HSD; Fibromyalgia and hEDS/HSD; Initial diagnosis by clinical assessment; Mast cell activation syndrome and hEDS/HSD; Pregnancy and childbirth; Surgery.

This permission has been granted on the understanding that the extracts will form part of the reference resources available on the RCGP online toolkit for Ehlers-Danlos syndrome and Hypermobility Spectrum Disorder, helping to improve awareness and understanding of these conditions and their comorbidities.

This book and the individual contributions contained in it are protected under copyright by the author and publisher (other than as may be noted herein). The front cover, including image are designed and owned by the author and subject to copyright, all rights reserved.

Except as expressly stated above, no part of this publication may be reproduced or transmitted in any form or by any means, electronic or mechanical, including photocopying, recording, or any information storage and retrieval system, without the permission in writing from the source /publisher - Redcliff-house Publications (redcliffhouse@hotmail.com)

International Standard Book Number: 978-1-9997300-0-0

Printed in the UK

First printing 5 June 2017

Use of a term in this book should not be regarded as affecting the validity of any trademark or service mark.

Notices:
Every effort has been made to make this book as complete and accurate as possible, but no warranty or fitness is implied. To the fullest extent of the law, neither the Publisher nor the author, contributors, or editors, assume liability or responsibility for errors or omissions, nor any liability or responsibility for any injury and/or loss or damages to persons, entity, or property as a matter of negligence, products liability or otherwise, or from any use or misuse/misapplication or operation of any methods, products, instructions, or ideas contained in the material herein.

Knowledge and best practice in this field are constantly changing. As new research and experience broaden our understanding, changes in research methods, professional practices, or medical treatment may become necessary.

Readers are urged to take appropriately qualified medical advice in all cases. The information in this book is intended to be useful to the general reader, but should not be used as a means of self-diagnosis, or for the prescription of medication. It is the responsibility of practitioners, relying on their own experience and knowledge of their patients, to make diagnoses, to determine dosages and the best treatment for each individual patient, and to take all appropriate safety precautions.

Practitioners and researchers must check clinical procedures and always rely on their own experience and knowledge in evaluating and using any information, methods, compounds, or experiments described herein. In using such information or methods they should be mindful of their own safety and the safety of others, including parties for whom they have a professional responsibility.

With respect to any drug or pharmaceutical products identified, the publisher and the author make no representation, express or implied, that any drug dosages in the book are correct. Lay readers are advised to check product information and to always seek advice from their general practitioner or healthcare provider. Practitioners are advised to check the most current information provided (i) on procedures featured or (ii) by the manufacturer of each product to be administered, to verify the recommended dose or formula, the methods and duration of administration and contraindications.

The book from where the following extracts have been taken was produced in association with the Hypermobility Syndromes Association (HMSA) registered charity number: England and Wales (1011063) and in Scotland (SC037916), holding NHS England Information Standard accreditation. Having been through the HMSAs information standards process, there is an excellent level of medical accuracy and sound management advice to be found in this easily accessible book.