



Behçet's Syndrome Society

Behçet's Syndrome Society
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SOME EFFECTS OF HAVING BEHÇET'S DISEASE

Unpredictability: impossible to predict onset or clearing-up of symptoms, onset of symptoms sudden, difficulties in keeping to arrangements, appointments, working, affairs, managing household, family, social activities, hobbies

Arthritis: reduced mobility or complete immobility, pain.

Oral ulcers: pain, diet restricted to soft or liquid food, inability to eat at all, inability to talk, dribbling, dehydration, malnutrition.

Genital ulcers: immobility, sex-life affected, embarrassment, suspicion, urinary retention, pain.

Visual level: fear of onset of blindness, handicapping according to level of impairment and ability to adapt, pain.

Skin: disfiguring and embarrassing skin lesions, easy bruising, poor slow healing, pain.

Gastro-intestinal: wind, diarrhoea (with blood and mucus) or constipation, severe abdominal pain. Mimics inflammatory bowel diseases, irritable bowel syndrome. Stomach ulcers, ulcers in gullet. Risk of perforated ulcer. Dehydration, malnutrition

Thrombophlebitis: immobility, pain.

Thrombosis: immobility, pain. Risk of embolism.

Ears: hearing loss, tinnitus, vertigo

Chest: wheezing, breathlessness, haemorrhages, haemoptysis, pleurisy, pain.

Cardio-vascular: breathlessness, haemorrhages, dysrhythmias, pericarditis, valve problems, pain. Risk of ruptured aneurysms.

Neurological: paralysis, strokes (CVAs), transient ischemic attacks (TIAs), memory & concentration impairment, seizures, migraine-type or meningitis-type headaches, double

vision, incontinence, impotence, strange sensations, motor impairment ranging from mild clumsiness to vegetative states, personality changes, psychoses.

Fatigue: profound persistent exhaustion affecting all activity.

Feverishness: effects like having 'flu, night sweats, bizarre sense of feeling cold or warm.

Medication: most used for treatment of Behçet's have problematic side-effects, many needed simultaneously, expense.

Doctors & hospitals: frequent appointments, visits to different clinics at different times in different hospitals because Behçet's is multi-system. Rarely one overall specialist. Doctors with interest in Behçet's few and scattered.

Travel and referral problems getting to centres of expertise out of home area.

Ignorance amongst the profession because of its rarity. Being patronising, contempt, marginalisation, lack of belief, ignoring, dismissiveness all occur.

Welfare benefits: difficulties with obtaining benefit because of rarity of disease and ignorance of its effects, fluctuating nature makes assessment problematical.

Public image: lack of sympathy because sufferers look all right, poor understanding of chronic, incurable, fluctuating disease, healthy people defensive or dismissive because they don't know anything about it.

Personal life: partner's life can be seriously affected by having to take time off work or giving up employment to help out, having to be a carer beyond normal expectations, loss of income, sex-life poor, sleep disturbed, patience stretched to limits, children become carers and miss out on normal family activities, child sufferers may have trouble with schooling.

Psychological: depression, loss or limiting of expectations, ambitions, employment, effects of chronic pain and exhaustion, effects of handicap or impairment, pressure on relationships, behaviour of health professionals, civil servants, isolation, fear, self-blame, guilt, denial, anger, despair, personality changes, inability to accept or understand ("Why me?").