Late Onset Pompe Symptoms (LOPD)

Head and shoulders

Muscle weakness in eyes

Dropped eye lids

Morning headaches

Sleep apnoea

Difficulty swallowing

Difficulty clearing airway after eating

Weak cough

Difficulty clearing throat

Speaking voice changed, volume, texture

Impaired alertness

Arms and hands

Arms feeling very heavy

Difficulty lifting arms above shoulder height

Difficulty lifting objects

Weak grip

Body

Protruding stomach

Muscle weakness in mid section

Continence issues

Bowel issues

Bladder frequency/leakage

Difficulty bending and straightening

Respiratory Insufficiency/failure

Difficulty breathing when led down/reclining

Hips and legs

Difficulty getting up from a seated position

Muscle cramps

Difficulty bending and straightening

Difficulty climbing stairs

Weaker front thigh muscles

Unsteady when standing for longer periods

Waddling gait

Struggling to walk

Thicker calf muscles

Tightness in calf muscles

Pain when standing for short/long periods

Unsteadiness when turning round

Difficulty lifting foot

Dropped foot, sometimes feels heavy/sags

General well being

Feeling tired/total exhaustion

Temperature regulation - Feeling hot/cold

Tremors - feeling shaky

Limbs feeling heavy

Limited mobility when bending/stretching

Mental health - depression/anxiety

Test results

Low oxygen levels

Raised CO2 levels

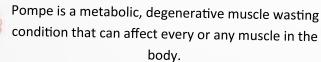
Raised Creatine Kinase (CK) levels







Glycogen Storage Disease (2) Pompe Disease (LOPD)





It is an inherited genetic condition caused by the lack of the GAA enzyme which inhibits the breakdown of Glycogen causing muscles to fail.



Everyone with Late Onset Pompe has a range of symptoms that may manifest at any time in their life. We are born with Pompe it is not caught and is not a lifestyle choice

The list of Pompe symptoms is only a guide and has been collated from the world wide Pompe family.

Treatment and Support

Enzyme Replacement Therapy

Dietitian - High protein, low carb, low sugar diet

Metabolic Consultant

Respiratory Consultant

Physiotherapist - Exercise to 70% sub maximal

Counselling - Mental Health

