

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



Medical Alert
Information

Scan the QR
Code



Glycogen Storage Disease (2) Pompe Disease

Pompe is a metabolic, degenerative muscle wasting condition that can affect every or any muscle in the body. 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

