

Julie Garfield - Late Onset Pompe Symptoms (LOPD)



Medical Alert
Information

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Code



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)

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

