

## 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) Late Onset 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

