

Regular physical activity and exercise play an important part in managing Pompe.

Research has shown that moderate exercise is safe and effective for individuals with Pompe and personalised exercise programmes can be beneficial in maintaining function, improving muscle strength, and walking ability.

General health benefits of keeping active and exercising include:

- Reduces the risk of other conditions (eg. heart disease, type 2 diabetes, osteoporosis)
- Combined with a balanced diet, it is the best way of keeping to a healthy weight
- A great way of tackling fatigue; by exercising regularly you will be able to carry out your day-to-day tasks without feeling so tired
- Can help maintain your strength; muscles are prone to becoming weak without use, making it harder to get around
- Can help with balance and posture to reduce your risk of falls
- Helps to maintain and improve range of movement in your joints
- Can help you feel better, manage stress and give you a good night's sleep .

The type of physical activity and/or exercise most appropriate for you will vary from person to person.



It's important to find something safe to do that you can enjoy, easily achieve, and can fit into your routine. If you haven't done any regular exercise for a while start slowly and gradually and build up.

A physiotherapist who is knowledgeable in Pompe or neuromuscular disease can help guide you with an individualised exercise programme to meet your needs. They can also give advice about how best to prevent falls and help you learn new ways of moving around and managing daily tasks, should your condition change.

A physiotherapist will often work closely with an occupational therapist to provide advice on adaptive equipment, mobility devices or organise your environment to make living with Pompe easier.

Special considerations for exercising with Pompe

- Listen to your body – stop if you feel tired or experience pain (avoid pushing through pain and / or fatigue)
- Get to know your limitations and understand the difference between getting tired from exercise (a good thing) and excessive fatigue (a bad thing).
- Pace your activities, taking into consideration what other things you have planned for the rest of the day/week – little and often is the key.
- Avoid exercise that is aggressive, high

impact or high intensity. Exercise should be performed sub-maximally, at moderate intensity.

- Allow for plenty of rest during and between sessions.
- Researchers have not yet identified the optimum amount and type of physical activity/exercise for people with Pompe. However, it's widely recommended that being active in whatever way you can is good.

Main types of physical activity/exercise

- **Stretching/range of motion**
- **Aerobic/ cardiovascular**
- **Resistive/strengthening**
- **Balance training**

Stretching exercises

It's important to have good muscle length and range of movement for day-to-day activities. Stretches are a vital way of helping to prevent muscles tightening and shortening, which can lead to reduced movement and pain.

Take care not to over-stretch weak muscles. Speak with your physiotherapist who can advise you which muscle groups would be good for you to stretch.

Aerobic exercise

This is a good form of exercise which makes your heart beat faster and/or increases your respiratory rate. Examples include walking, swimming, cycling and doing housework or gardening.

Exercise doesn't mean you have to go to the gym. The key to getting the right amount of daily exercise is to make physical activity part of your everyday routine. You can achieve aerobic benefits from small changes, such as walking a bit further, climbing the stairs instead of the lift or keeping moving in whatever way you can.

How hard should I exercise?

Aim for moderate intensity physical activity. You will feel warmer, will take deeper breaths and should still be able to talk comfortably but be unable to sing.



To benefit from exercise, the general recommendation is that we need at least 30 minutes of moderate intensity physical activity five times a week. But any exercise is better than nothing if you can't achieve the recommended amount. If you are at a lower level, trying to increase your level of activity over time will still be beneficial. Relatively small increases in physical activity can improve your health and quality of life.

You may find it helpful to rate how hard you are working on a scale such as the BORG RPE scale on the next page. Working towards moderate exercise would be between 3-6 on the scale.

RATING OF PERCEIVED EXERTION	10	Maximal Exertion Cannot push any harder
	9	Very Hard Activity
	8	Hard Activity Difficulty breathing, unable to speak
	7	Hard Activity Heavy sweating, difficulty speaking
	6	Moderate Activity Moderate sweating, able to speak
	5	Moderate Activity Speaking is easy, light sweating
	4	Light Activity Breaking a sweat, comfortable speaking
	3	Light Activity Comfortable, slight difficulty breathing
	2	Minimum Activity Barest exertion
	1	Resting No exertion

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TOP TIP: Ideally you should engage in strengthening activities of moderate intensity (8-12 repetitions per major muscle group, two times a week). Avoid strengthening exercises on consecutive days to give muscles a chance to recover. Increase the number of repetitions rather than weight you lift.

You may expect to be a little achy when you start a new strength exercise, but this muscle soreness should resolve after 48hours.

Balance training

Balance training is a combination of exercises that challenge your sensory systems and strengthen muscles that keep you upright, including your core, trunk and leg; for example, yoga, Pilates and tai chi.

Balance training should be specific to your risks and needs. A physiotherapist can assist with developing an individualised balance programme.

How to get started with exercise

The biggest barrier to exercise is often just getting started. Talk to your physiotherapist or medical team if you are new to exercise. Choose an exercise or activity that you enjoy and that is safe and achievable, that you can fit into your day-to-day life. Do short sessions, rest as needed and build up slowly.

Discuss your exercise goals with your physiotherapist or fitness trainer, let them know what you like to do for fun so they can help you be creative about exercise. Find friends to exercise with to keep you motivated.

Strengthening exercise

Resistive exercises are activities that make your muscles contract to increase strength and endurance. This can include working against the force of gravity, using your own body weight, small weights or pulling elastic.

It is important to think about strengthening the muscles of your arms, legs, and core muscles.

Improved core strength can help improve your posture and balance, which can reduce the risk of falling. Talk to your physiotherapist about which muscles you should strengthen and how as this will be different for everyone.

"I am enjoying participating in my weekly physiotherapy exercise classes which I am hoping will continue to aid my mobility, improve my fitness and overall quality of life. As well as the physical benefits I really feel more positive mentally after the classes."

Motivation and FUN are the biggest indicators to exercise adherence.

Maintenance / staying motivated

- Give yourself a break, ANY amount of exercise is better than none.
- If exercise feels too hard at first ease off. Enjoying the activity is vital to sticking with it. You should feel good at the end of your activity session.
- Consistency is key – make exercise a habit. Do short but consistent sessions.
- Incorporate movement throughout your day – a little goes a long way!
- Some people find keeping an activity diary useful; keeping a record of what activity you do and when can help you reflect on gains and improvements.
- Technology is changing the way we exercise, e.g. virtual classes and wearable devices.
- Fitness apps, trackers and websites can be a great way to support and monitor your activity. Track your progress and reward yourself!

TOP TIP: Speak to your physio for the best exercises for you. It does benefit you daily and you will see the changes.

Web resources

[Physical activity for adults and older adults](#)

[Physical activity for disabled adults](#)

(publishing.service.gov.uk)

References available on request

“It is valuable to meet others with Pompe and other GSD’s, albeit virtually, and hear about their experiences whilst exercising with them. It feels good to be doing something constructive to try and help lessen the progression of my illness.”

As I get older and my Pompe progresses I have had to adjust the type of exercise I undertake.

It’s so important to ‘keep moving’ but only if safe and not to the point of exhaustion or pain. I do a lot of stretching and chair exercises.

“It took me a while, but I found an activity I enjoy. So, keep looking for something that makes you smile.”

