

At work with McArdle's Information for employers

A plain language guide to McArdle Disease and how to assist an employee to carry out their duties safely and efficiently.

- McArdle's is an ultra rare inherited condition which restricts fuelling of skeletal muscles.
- People with McArdle's cannot utilise the energy stored in the muscle.
- They have a serious shortage of energy early in any activity, and throughout all *intense* activity.
- They can develop cramping. If activity continues, muscles become stiff, swollen and very painful.
- They have a 'second wind' somewhat reducing their symptoms after about 10 careful minutes.
- They achieve a lot by utilizing techniques to protect themselves, but for a desk-based role few techniques will be needed.
- They tend to develop determination and "stickability", making them good workers.
- Major adjustments in their role are *not* normally required, but some flexibility is helpful.

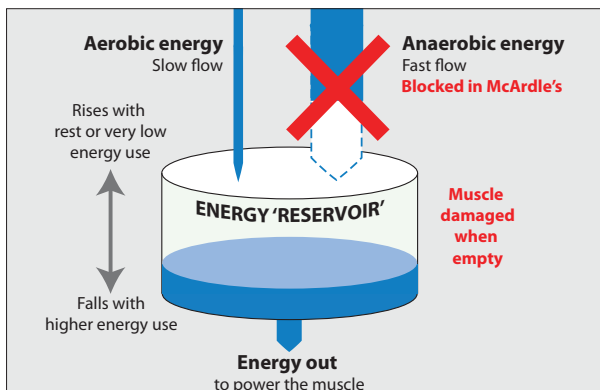


IAMGSD

International Association for
Muscle Glycogen Storage Disease

This is the issue

- The condition is as a result of an inherited gene mutation.
- The 'fast' anaerobic energy pathway is blocked.
- This results in a severe shortage of energy at times.
- Cramping/pain occurs if the energy 'reservoir' is emptied.



Strategies you will notice

A person with McArdle's will use these key strategies to help them handle their physical activity and avoid pain.

Slowing or pausing to balance energy

During activity such as walking, people with McArdle's:

- Slow down to ease the energy demand.
- Pause for 30 seconds rest, then continue more slowly.
- Do these frequently in the first minutes of activity.
- Find symptoms easing after about 10 minutes, when a 'second wind' occurs as other energy pathways open up.
- With each muscle group used this process is repeated.
- 'Second wind' is lost about 30 minutes after activity ends.

Breaking intense tasks into sections

During maximum intensity tasks (such as carrying a heavy object or standing on tip toe) people with McArdle's:

- Interrupt the task after 6 seconds.
- Rest for 30 seconds so the energy 'reservoir' refills, then try again.
- This avoids a painful contracture which may otherwise occur, last for days, and might need medical attention.



Resting before a risk

Before a risk, like climbing a ladder or lifting something heavy, they often first rest for at least 30 seconds to ensure energy is available to get them safely through.

Ideas on adjustments

Line managers or supervisors should liaise with the employee and listen to any concerns. The degree to which individuals are affected by McArdle's can vary greatly. Also, the impact will vary depending on the physical demands of the particular job and task.

■ Recognise a different style of work

People with McArdle's may swap back and forth between physical tasks – a few minutes of one task, swap to another, then return to finish the first. With each swap, the depleted muscles have time to recharge.

■ Avoid time pressures

Rushing is a main enemy of McArdle's. The energy demand can be too great with a risk of muscle cramps. 'Slow and steady' is the motto.



■ Inform others and beware of peer pressure

It is helpful to liaise with the employee to decide what and how to advise work colleagues. There may be a need for support to resist peer pressure to 'keep up', or to do something they should avoid.

■ Offer tools and equipment to suit



Liaise with the employee about equipment – they will know what works for them. A wheelbarrow with two central wheels under the load to avoid lifting weight with the arms. A stool to enable sitting rather than squatting or crouching – both damaging. A step stool? A sack truck? A trolley?

■ Swap some duties with a colleague

Arrange that the colleague does the more anaerobic duties and the person with McArdle's does the more aerobic duties, which can be good for them.

■ Adjust working positions

Holding arms up to work becomes very anaerobic, especially if lifting something – so better to work on a platform. Awkward positions such as working in a confined space or crouching to read a meter also may cause a cramp. If an unstressed position is impossible, people with McArdle's will change position frequently.



■ Consider the working day

If in a physical job, people with McArdle's may prefer a short meal break, to get back to work before 'second wind' is lost. Some may prefer to work part-time or job share.

In the event of overdoing it

Very occasionally, a person with McArdle's may get something wrong and hurt themselves.

- Allow them to rest and have water to drink.
- Ask if you should call a partner or relative.
- In severe cases, ask if they need to go to hospital†.
- They carry a card to remind of the decision points.

† For people with McArdle's who manage well, it is a very rare occurrence to need to be hospitalized.

Further information

The person with McArdle's can share these books with you, or you can request copies from IamGSD.

101 Tips for a good life with McArdle Disease

164 page paperback. Easy to read guide with practical tips for patients.

McArdle Disease: medical overview

20 page booklet. A quick guide primarily for GPs and other medical professionals.

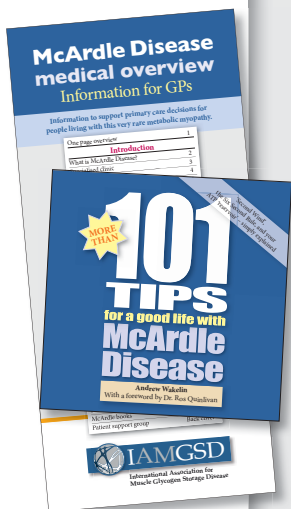
Government information

Employers may wish to search online for information about employing people with health conditions and for disability rights legislation.

More questions?

If you have any further queries, the IamGSD will be happy to assist.

www.iamgsd.org



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