

Accepting the diagnosis

It can be difficult, but we can do well

Whilst coping with McArdle's can be extremely challenging, there is much that we can do to help ourselves and improve our condition. Luckily, with commitment and being open with friends, for most of us McArdle's is generally neither progressive nor life-threatening, and we can thrive with the disorder.

What everyone should do

To look after ourselves we should take plenty of aerobic exercise, have a healthy diet and keep our weight under control – all of which everyone should do anyway for general good health.

Guidance on exercise

- Your first action is to get guidance on exercise.
- Refer to the Training Support page on the Medical menu of the IamGSD website.
- With that help you can achieve and maintain the best level of fitness possible for you.
- Activity will lift your mood through production of endorphins, give you a sense of achievement and improve your self-image.



Learning the benefits of walking poles.

Amazing what you can do

- You will be amazed at just how much you can do, considering that 80% of your body's store of carbohydrate energy is not available to you.
- Once in "second-wind" (see "Living with McArdle's" booklet) you should be able to do most aerobic activity, although perhaps at a slower pace than other people.
- Rest before intense anaerobic activity and you can do bursts of up to 6 seconds. You need to break down tasks like those into small sections.

Now checkout all the ideas on the center pages.

Further information

A range of leaflets, and other publications, is available on our website. Browse on-line or download free PDFs.

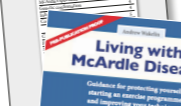
Information/Emergency Card. Folding card, to be carried at all times. Brief explanation of the condition, reminder of when to seek medical assistance.

McArdle Disease: medical overview. 20 pages. A quick guide, primarily for your GP.

Living with McArdle Disease. 52 pages. In-depth advice and guidance on a range of subjects.

101 Tips for a good life. 164 pages. Easy to read guide with practical tips.

Check the IamGSD website "Resources" menu for more publications and links to our videos.



Do you need more help?

- If you find that issues such as anxiety or depression persist, maybe seek support from a professional such as a psychologist.
- Consult with your McArdle's specialist or GP for a referral to a suitable professional.

DISCLAIMER: IamGSD uses its best endeavors to provide accurate, factual and up-to-date information on this ultra rare condition. However, each person must take into account their own circumstances, diagnosis, and any additional genetic and medical factors and is advised to consult with their doctor before making use of our generic guidance. Please refer to the disclaimer on the Medical menu of our website.



www.iamgsd.org

Explore our website for a wide range of information, publications and videos.

At peace with McArdle's

Ideas to help with mental well-being

After a confirmed diagnosis it is highly beneficial to come to acceptance and focus on how good life can be despite this condition.



A typical delay in diagnosis of about 20 years can sometimes result in psychological issues such as poor self image, isolation, embarrassment, anxiety and depression.

With the McArdle's diagnosis comes the opportunity to develop a positive attitude towards living with this muscle disorder.

BACKGROUND

The effect of a long delay in diagnosis

Impact on mental health

The average delay from first awareness of symptoms to a confirmed diagnosis of McArdle's is about 20 years.

Dismissal as being lazy or unfit, and multiple misdiagnoses, can lead to frustration, embarrassment, isolation, anxiety, feeling as though others don't understand, etc.

People with McArdle's can also develop bad habits through not having been advised on how to manage their condition. This is likely to exacerbate the psychological position.

START HERE

Addressing the issues

Starting the journey

With diagnosis at last comes the opportunity to address all the physical and psychological issues which are likely to have developed.

An invisible condition

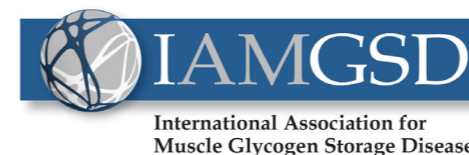
It can be tough when, due to McArdle's being invisible, friends, work colleagues, neighbors or acquaintances do not accept our difficulties. We don't have a limp, a bandaged limb, etc. They may need help to understand and accept our issues.

Ideas to help

Inside we offer a range of ideas which have helped others with mental well-being. Everyone should find at least a few ideas which work for them. It may at first seem overwhelming but in due course most of these things become automatic and you will do them without even thinking about them.

A positive outlook

Most people with McArdle's will learn to manage the physical symptoms well, overcome the psychological challenges and develop a positive outlook.



International Association for Muscle Glycogen Storage Disease

Creating a support system

You can find people who understand

- You can get a great deal of information from IamGSD and national GSD groups (see websites).
- Benefit from the years of experience of the many who have been diagnosed before you.
- Link up with others with McArdle's - people who know what you deal with every day, who understand.
- You will find your stories are remarkably similar.
- You could book on a walking course, where you will be surrounded by McArdle peers, 24/7.



Making friends for life on a McArdle's walking course.

Your friends will support you

- Use the IamGSD "At Home" leaflet† to tell your friends about your McArdle's.
- There is almost always a positive response.
- Browse our videos, see website: Resources, Videos.
- Friends usually want to be supportive, are happy to go slow or take a break without even mentioning it.
- They will even watch out for us making mistakes and step in – such as stopping us lifting or carrying something that is really too challenging for us.

You get on better with teachers/employers

- Use IamGSD's "At School" leaflet† to help teachers and school staff to better understand your needs.
- It is helpful to share accounts of how others have succeeded in the school or work environment, e.g. personal stories from the IamGSD website.
- Use the "At Work" leaflet† to explain to employers and work colleagues.
- Gain better understanding, be supported and have adjustments made to help play your part in the team.



IamGSD leaflets help to explain your condition to teachers or employers.

†See Publications, on Resources menu of our website.

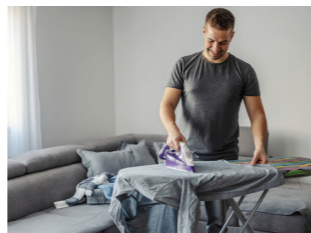
Learning about McArdle's

Getting into second-wind becomes easier

- As you improve your fitness, getting into "second-wind" (see "Living with McArdle's" booklet) gradually becomes easier.
- It's a very positive and encouraging feeling.
- You recall that when less aerobically fit it was a bit of a struggle, maybe taking as long as 10 or 12 minutes.
- Once very aerobically fit you may get into "second-wind" much more quickly and with less difficulty.
- You find activity and exercise so much more achievable and enjoyable.

You find most activities can be adjusted

- You can adapt and adjust almost any activity to make it McArdle-safe.
- You break down tasks into sections, or alternate between different activities using different muscles.
- You do things in a different way to others, or simply allow more time.
- With help of the "101 Tips" book†, a bit of creativity and adjustment, you can do almost anything!



Adapting household tasks.

You can adapt rather than avoid

When life is already so busy, change can feel like a burden. But as we start to manage better, the benefits multiply and in due course the burden is lifted.

- Before diagnosis you probably avoided activities which you feared would cause pain and cramping.
- Now you have an understanding of what the problem is, you learn ways to adapt activities.
- You can now do much more than you did before.

Part of who we are

- McArdle people tend to like a challenge.
- Without your McArdle's you might be different in character and personality.
- It makes you good at planning ahead, you are more adaptable and you have "stickability".
- McArdle's is part of who you are as an individual.

Putting things in perspective

You get the big view

- Seeing a big landscape, by say hill walking, or at sea, can help to put your troubles into perspective.
- You realize that your muscle issues are just a small part of who you are.
- And you are a very small part of a very big world.
- You realize that there are many people facing much larger problems.



Getting things in perspective in the Italian Dolomites.

You focus on the positives

- You start to focus on the positive aspects.
- You find that you can turn negatives into positives.
- You share positives with others who are affected.
- You learn what amazing positives others have achieved.

You are less stressed

- You reduce stress by concentrating on calm and controlled deep breathing when you pause for a rest.
- You become less concerned and stressed about such things as forthcoming activities with friends.
- Less stress, muscles are less tense and work better.

You become more determined

- You become very determined and a good employee.
- Whilst you can achieve equally with others, you may have to take longer or keep coming back to the task.
- e.g. walking uphill you take 2 to 3 times as long as others.
- You become more determined, maybe even stubborn, not wanting to give in.

You find you can avoid pain

- With good information you can learn to generally avoid anything worse than a mild cramping sensation that lasts for no more than a minute.
- Gone are the times when you easily hurt yourself due to not understanding what was going on.
- Pain is almost eliminated from your day-to-day life.
- Significant pain becomes very much the exception.
- Painful contracture only occurs if you make a mistake or get caught out by external factors.

Feeling better

You have more energy so want to do more

- The more you do the more energy you have.
- Undertaking even more activity is a pleasure.
- In broad terms, the more you do, the better you feel and the more you want to do.

You gain from your diagnosis

- Understanding of how to manage your activity.
- A global network of friends who understand you. (See the Social Media page on our website.)
- An imperative for exercise, which will benefit your general health as well as your McArdle's.
- The opportunity to support others.

Looking ahead

A sense of achievement!

- You will be encouraged as your aerobic fitness improves.
- Keeping an exercise log will focus you on your achievement.
- Do the 12-minute walk test each week to see your distance improve and give that tangible sense of achievement. Watch video on our YouTube channel – IamGSD videos.
- You may even want to challenge yourself in more ways.



12-minute walk test at home.

Get a buzz from helping others

- It feels great when you can pass on the benefit of your experience to other patients and doctors.
- As an ultra-rare disorder, very few doctors understand McArdle's, and even fewer have first hand experience of helping people affected by it.

Still struggling?

- You keep as active as possible within your limits.
- You note any worries and share them with your family and friends, or on the McArdle's social media.
- You consider seeking on-line guidance on self-help mental health techniques.
- See the "more help" panel on the back cover.