

# McArdle Disease

## Glycogen Storage Disease Type V

### Newly diagnosed?

A diagnosis of McArdle's usually provides a sense of relief. At last comes recognition of the problems you have had since childhood. Proof of not just being unfit or lazy. With a diagnosis you can learn to manage well. McArdle's is a very rare metabolic disorder of the muscles, with only about 300 people diagnosed in the UK and we believe maybe another 300 undiagnosed.

### The future

McArdle's is one of the best muscle conditions to have. It is not progressive or life threatening. You can learn to adapt day-to-day activities. For the vast majority of affected people it is not seriously disabling.

### Information cards

Keep these cards handy to explain the condition or to show if you need some help. It includes a reminder of when to go to hospital, if ever it is necessary. 4 pages, credit card size.

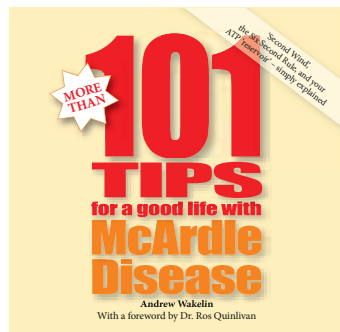


### Looking after yourself

There is no cure for McArdle's but there is much that you can do to ensure a good quality of life. Most importantly avoid 'bad' activity (static or intense activity such as heavy lifting or sprinting). Take plenty of 'good' exercise (gentler exercise such as walking) to improve your aerobic fitness and thus extend what you can do without pain or muscle

cramps. You will learn to refine these points.

*This book provides a simple introduction, with lots of ideas to avoid injury, reduce pain and manage your condition. 105x105mm, paperback, 164 pages.*

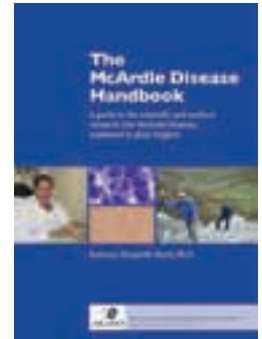


### UK McArdle Clinic

You can be referred to this national service. It is a centre of excellence. The multi-disciplinary team will assess your fitness, address any issues, help you improve your fitness and advise you of developments.

### Support

Our McArdle's Co-ordinator can assist you with information and guidance. People with the condition support each other through shared understanding and experiences. There are internet groups enabling you to share with McArdle's people around the world. Meeting others with the same condition is very helpful, whether on-line, face-to-face, or on a course.



### More information

AGSD-UK has a wealth of information about McArdle's. You can learn more through our website, newsletter, annual conference, workshops and other events.

In addition to the cards and 101 Tips, we publish:



*The McArdle Disease Handbook*  
A guide to the scientific and medical research into McArdle's, explained in plain English. 230x150mm paperback, 208 pages.

*One Step at a Time*  
One woman's account of coming to terms with her condition as she walked 210 miles across Wales. Full colour, 230x150mm, paperback, 96 pages.



[www.agsd.org.uk](http://www.agsd.org.uk)

Please make contact with our McArdle's Co-ordinator.  
Email: [type5@agsd.org.uk](mailto:type5@agsd.org.uk). Telephone: 0300 123 2795.