



National Commissioning Group:
Highly Specialised Services for McArdle Disease & related Disorders

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Highly Specialized Service for McArdle Disease and Related Disorders

We are writing to you from the Highly Specialized Service for McArdle Disease and Related Disorders at the National Hospital for Neurology and Neurosurgery as the team who look after you. A 'related disorder' includes other glycolytic disorders that cause exercise intolerance and myoglobinuria (e.g. GSDVII, GSD0, GSDXIII).

We understand you may be feeling anxious during this unprecedented time. We want you to know that we are available during this difficult time to provide advice and support about your condition. In addition, we have developed the following current advice and guidance related to COVID19 which we would like to share with you.

Clinical guidance for people with McArdle Disease and related disorders

To the best of our knowledge, having McArdle disease and/or a related disorder does NOT increase the risk of contracting COVID-19.

Currently there is no specific information on whether people living with McArdle disease or a related

disorder are at increased risk if they develop infection with COVID-19.

However, we have some specific concerns for people with McArdle disease or a related disorder during the current time:

1. If you develop acute rhabdomyolysis and have to go to hospital, you may be put at risk of catching the virus. Hospital services, especially critical care, will be very stretched during this time.
2. COVID-19 causes a cough, severe coughing may cause abdominal muscle pain and myoglobinuria in a person with your condition. If you can, try every few minutes, to suppress the cough for a break of at least 30 seconds.
3. Rhabdomyolysis and COVID-19 occurring at the same time is likely to be very serious and could result in critical illness.

Preventive measures you can take to avoid becoming unwell

The Government has recommended social distancing and careful hygiene.

We advise all people with McArdle disease or a related disorder and their family to follow this guidance:

- Social-distancing means that you should not go out unless you have to, and keep a distance of at least 2m from other people.
- Wash your hands often (for at least 20 seconds).
- Clean and disinfect frequently touched surfaces.
- Cover coughs and sneezes with a tissue or use inside of elbow. Throw tissues in the bin.
- Self-monitor for symptoms.
- You and all members of your household should self-isolate from other family members if you/they become unwell.
- If you become unwell call 111 for advice, ring 999 if you are seriously unwell

In addition we recommend that you should avoid any activity that could potentially lead to a contracture or acute rhabdomyolysis during the current pandemic.

What is shielding?

Shielding is a practice used to protect the extremely vulnerable from coming into contact with COVID-19 by minimising all interaction with other people, in case they are carrying COVID-19. This means that those who are extremely vulnerable should not leave their homes, and within their homes should minimise all non-essential contact with other members of their household.

Shielding is absolutely essential for people:

- 1) on immune-suppressants (such as methotrexate) or long term steroids. You should not stop treatment
- 2) at respiratory risk: history of COPD, asthma, CPAP, BiPAP
- 3) advised to receive the annual influenza vaccine
- 4) diagnosed with diabetes
- 5) diagnosed with cardiac conditions, for example coronary heart disease and hypertension

- 6) over 70 years of age
- 7) on treatment for cancer that may affect the immune system
- 8) pregnant with significant heart disease (congenital or acquired)

Although there is no information available regarding the risk for COVID-19 in McArdle disease and related disorders, because of our specific concerns, we recommend that all people with these conditions consider themselves as being extremely vulnerable and at high risk of getting seriously ill from coronavirus and thus should consider shielding.

You are strongly advised to stay at home at all times, and to avoid any face to face contact outside your home for a period of at least 12 weeks – this period of time could change. If you live alone and require support, you can register as an extremely vulnerable person on the government website under the category of 'Rare disease'

Public Health England has more information below about who fits into the category of extremely vulnerable and how to get help:

www.gov.uk > coronavirus-extremely-vulnerable

Practical steps to take:

- Check that any medications you take are in date and that you have enough supply
- Keep a copy of your most recent clinic letter to show to other healthcare professionals if needed
- Keep the contact details of our Department and do make sure to carry your alert card available from AGSDUK for McArdle disease (type V) and Tarui disease (Type VII) which can help in times of an emergency

General advice to keep healthy

- Avoid gaining weight during this time, eat well-balanced meals
- Don't drink too much alcohol which has hidden calories and may also disinhibit you, which may increase your risk of muscle injury and rhabdomyolysis
- Stay hydrated when you exercise
- Take time to RELAX in order to avoid muscle tension, avoid stress and anxiety which can lead to muscle tension. Muscle tension can increase your risk of contracture and rhabdomyolysis
- If you feel anxious or depressed during this time and feel that you need support please contact our team

Physical activity

It is important to maintain your fitness during this time, exercise and physical activity are good for your condition and helps to reduce the risk of other conditions such as heart disease and diabetes, improves or maintains your ability to perform everyday tasks, reduces fatigue, can improve bone density, assist in controlling weight, improve mood and mental wellbeing and can improve your sleep.

General exercise advice

Aerobic exercise is gentle physical activity that can be sustained over a period of time, it is the type of exercise we recommend.

If you are shielding, you can still exercise indoors.

Walking is the best exercise, and can be done indoors or outdoors.

Video games to play tennis, badminton or golf are also forms of aerobic exercise for your upper limbs.

There are also virtual exercise classes on line, if you are thinking of joining one of these, please contact our physiotherapy team who can direct you to the most appropriate course.

If you do one of these courses, remember to STOP exercising if you experience pain and wait until the pain subsides.

- Choose an aerobic activity that you enjoy
- Start off slowly to warm up gently, if you have McArdle disease go slowly until you reach second wind
- Listen to your body and SLOW DOWN or STOP if you feel fatigue or pain and rest for 30 seconds or until the pain starts to subside
- When in second wind, continue to exercise at the same intensity.
- You should still be able to talk while exercising.
- Aim to exercise for 30-40 minutes, three to five times per week, but remember to build the time up slowly over several days or weeks if you are unaccustomed to regular exercise.

Things that could help improve your activity levels

- Smart phone apps- Step counter, Fitbit or similar device, pedometers can be used on a daily basis to:
 - Monitor your activity, try to aim to stay active over a 24 hour period.
 - Reduce the amount of time you are sedentary.
- Keep yourself active during the day, if you are sitting for more than 1 hour, stand up, move around, and change your position.

Activities to avoid or limit

Whilst you may find yourselves having more time on your hands to carry out those 'odd jobs' that you have been putting off for a while, it is important to remind that you need to try and limit or avoid activities that might make you sustain positions or are strenuous.

This can help reduce the risk of contracture and rhabdomyolysis.

Examples of activities requiring caution, but not exclusive to:

- Decorating
- Lifting weights such as moving furniture
- Gardening
- Repetitive tasks- DIY- screwing, hammering, brass and silver polishing
- Running

- Squatting or kneeling
- Spring cleaning

If you need to do any of these activities remember the '6 second rule':

Do not sustain a position or strenuous activity for more than 6 seconds and always follow by resting the muscle group for at least 30 seconds before continuing with the activity.

Warning signs to look out for

- Changes in the colour of your urine (dark tea/ coca cola)
- Severe muscle pain or swelling
- You may need to go to A/E, it may be advisable to ring first as they may have a designated area that is COVID-19 free. Be sure to tell them about your condition and that that you may have rhabdomyolysis

We are here to help

Although we are unable to undertake face to face clinics during this time, we will continue to undertake clinics by telephone. If you need further advice and support please do not hesitate to contact the Highly Specialized team for McArdle Disease and Related Disorders. It is easier to contact us via email at present.

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Further information:

- <https://www.nhs.uk/conditions/coronavirus-covid-19>
- <https://111.nhs.uk/covid-19/>
- <https://www.gov.uk/coronavirus>
- <https://agsd.org.uk/>
- <https://www.iamgsd.org/>

Yours sincerely



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