

## Useful sources of information

### Muscular Dystrophy Campaign

**t:** 0800 652 6352

**w:** [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)

### Myotonic Dystrophy Support Group

**t:** 0115 987 5869, **w:** [www.mdsguk.org](http://www.mdsguk.org)

### Benefits enquiry line

**Helpline:** 0345 608 8545

**w:** [www.direct.gov.uk/disability-money](http://www.direct.gov.uk/disability-money)

## Contact us

If you live in the South East Thames Region:

Clinical Genetics Department, 7<sup>th</sup> Floor,  
Borough Wing, Guy's Hospital, Great  
Maze Pond, London, SE1 9RT

**t:** 020 7188 1364, **f:** 020 7188 1369

**w:** [www.guysandstthomas.nhs.uk/genetics](http://www.guysandstthomas.nhs.uk/genetics)

## Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

**t:** 020 7188 8801 (PALS) **e:** [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)

**t:** 020 7188 3514 (complaints)

**e:** [complaints2@gstt.nhs.uk](mailto:complaints2@gstt.nhs.uk)

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A list of sources is available on request

## **Myotonia**

Myotonia is a difficulty in relaxing a muscle after it has been contracted. People with myotonic dystrophy sometimes find it difficult to release their grip on things such as shopping bags or steering wheels. This is a common symptom that usually does not cause much of a problem.

## **Heart problems**

Myotonic dystrophy can affect the heart. Sometimes there are no symptoms at all, or it may cause the heartbeat to be slow or irregular.

Regular ECG tests (heart tracings) are the best way to find out if the heart is affected. We recommend that everyone with myotonic dystrophy should have an ECG every year.

## **Breathing problems and sleepiness**

People who are severely affected may get chest infections. Inadequate breathing during the night can lead to disturbed sleep, snoring, difficulty waking, and morning headaches. Daytime sleepiness is a common problem.

## **Digestive problems**

These are common, as the muscles of the digestive system may be affected. This may lead to:

- swallowing problems (which can be a cause of food entering the lungs).
- pains in the bowels with constipation or diarrhoea.
- gallstones, which can cause painful spasms after eating fatty food.