Other publications available from the Myotonic Dystrophy Support Group:

- Anaesthesia and Sedation for patients with Myotonic Dystrophy
- Basic Information for Midwives
- Bowel Problems in Myotonic Dystrophy
- Congenital Myotonic Dystrophy
- Excessive Daytime Sleepiness and Myotonic Dystrophy
- Facts for patients, family members and professionals
- Just Diagnosed
- Lungs and Breathing
- Myotonic Dystrophy and the Brain
- Myotonic Dystrophy and the Eye
- Myotonic Dystrophy Support Group
- Myotonic Dystrophy Type 2
- Relatives Information
- Swallowing Difficulties in Myotonic Dystrophy
- The Heart and Myotonic Dystrophy
- Why do we get new families with Myotonic Dystrophy?
This question gets asked quite a lot – especially about painkillers after surgical operations, but the principles are the same whatever you take painkillers for. Here is some information on some of the commoner types of painkiller:

**Paracetamol** – Nearly everyone can take the normal dose of paracetamol with the normal spacing between doses – 1g (two 500mg tablets) four times a day. Be careful as paracetamol is often combined with other medication and you should not take more than the recommended maximum – 4g every 24 hours – whether this is in combination or on its own.

**Non-Steroidal Anti-inflammatory Drugs (NSAIDs)** – e.g. Ibuprofen, Naproxen, Diclofenac. People with MyD are not more sensitive to these types of drug, though many people cannot tolerate them for long term use, as they cause stomach irritation, heartburn, and ulcers sometimes. They can also make asthma worse. You should not take them if you are on blood thinners like warfarin or apixaban. Check with your pharmacist to make sure that they will not interfere with any of your other tablets.

**Codeine / Dihydrocodeine – includes co-codamol / co-dydramol / Tylex etc** - this can be bought over the counter in small doses or by prescription only as stronger forms. All codeine-like drugs are converted to morphine in the body and therefore people with MyD may be sensitive to them. This DOES NOT mean you cannot take them. Everyone is different – regardless of whether they have MyD or not – so you have to be careful if you have not had them before. There are also lots of different strengths of codeine, either on its own or in mixtures with paracetamol. Take the smallest dose possible first (break a tablet in half) and give it twice the recommended time in-between doses.

If you don’t get any severe side effects, for example drowsiness or nausea – then you can slowly increase the dose and frequency with which you take them.

**Tramadol** – this is a strong painkiller with some morphine-like properties. Do not take this unless under the supervision of your doctor.

**Oxycodone – Shortec / Longtec.** These are also strong morphine-like drugs, usually given post-operatively. Make sure whoever prescribes them for you knows you could be sensitive to them and use the guidelines as for codeine.

**Oral morphine** – includes oromorph liquid, sevredol, MST, many other brand names. Make sure you know what dose you have been prescribed and again, start with the smallest dose possible and increase slowly.

When people have chronic pain conditions they are often prescribed drugs that are not primarily painkillers – usually for nerve pain. Drugs for epilepsy and antidepressants are often used for this. Make sure that whoever prescribes them for you knows that you could be sensitive to them and start with as small a dose as possible.

While it’s important not to get too many side effects from painkillers, remember that being in pain is bad for you, as it stops you breathing deeply, sleeping, or moving around properly. It is very important to use the painkillers you do have as efficiently as possible. Use the weakest ones – usually just paracetamol – regularly as background pain relief and use the stronger ones in between. Don’t forget other non-medicinal things are also good for pain – heat and cold, TENS, acupuncture and relaxation techniques can all help.

If you are unsure always ask someone first – your GP / Pharmacist / Hospital specialist will all be able to help.