



Lifestyle



Alternative therapies

Acupuncture

Acupuncture is the use of thin needles inserted into selected points on the skin to manipulate energy pathways to produce a therapeutic effect. There is no conclusive scientific evidence to support the concepts surrounding the treatment and claims that it helps to relieve symptoms associated with neuromuscular conditions. Some studies do suggest that acupuncture helps with pain relief even if only temporarily.

It is vital that before embarking on using this type of therapy to ensure that the practitioner is well qualified. Acupuncture needles should not be used between patients to avoid the risk of infection and should be labelled 'single use only'.

A massage form of acupuncture called 'shiatsu' can also be employed to manipulate points on the body without the use of needles. Acupuncture is not likely to be harmful.

Antioxidants

Antioxidants prevent the breakdown of substances by oxygen. They include substances such as vitamins and enzymes. In the body their role is to scavenge free radicals. Free radicals are altered oxygen molecules that are damaging to cell components such as the cell membrane and DNA. They are normal by-products of metabolism and are 'mopped up' by the body's own antioxidants.

An imbalance can occur where the number of free radicals increases. This increase can be due to stress, ageing or environmental factors. Studies show that supplementing the diet with antioxidants may increase the levels of antioxidants in the body and have a protective effect. Antioxidants are present in high levels in fresh fruit and vegetables, so an intake of antioxidants can be achieved by maintaining a healthy, balanced diet.

There is no conclusive evidence that antioxidants help individuals with neuromuscular conditions and excess intake of vitamins can be detrimental to health in some cases. It is advisable to follow the recommended daily dosages of vitamins.

Green Tea

A recent study has shown that a high intake of green tea may have potential for warding off muscle cell death and deterioration in the mdx mouse (animal model for Duchenne muscular dystrophy). The researchers have found that an intake equivalent to seven cups of the tea per day decreased muscle wasting in one type of leg muscle in dystrophic laboratory mice. There is an increase in oxidative damage when dystrophin is abnormal, and it has been suggested that the tea acts as an antioxidant and helps to combat oxidative stress. This result has not been tested in

61 Southwark Street, London SE1 0HL T 020 7803 4800 F 020 7401 3495 Information Line 0800 652 6352 (freephone)
info@muscular-dystrophy.org www.muscular-dystrophy.org

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humans but green tea is generally safe for individuals with neuromuscular conditions to drink.

See the article 'Green tea extract decreases muscle necrosis in mdx mice and protects against reactive oxygen species' The American Journal of Clinical Nutrition, Volume 75, No 4, 749-753 April 2002 and abstract is available at www.ajcn.org

Coenzyme Q10

Coenzyme Q10 (CoQ10, also known as ubiquinone) is a natural substance found within mitochondria (the cell's energy factories) and is one of the components involved in the production of energy. CoQ10 has the ability to remove destructive free radicals. Free radicals are formed when oxygen molecules in the body are altered in a way that causes them to be destructive to the cell membrane and other cell components. They are normal by-products and are 'mopped up' by the body's own antioxidants.

Many claims have been made about the benefits of taking CoQ10 including the prevention of heart disease, increased energy and muscle strength, and a decrease in the production of free radicals. Previous studies have not been well planned or executed, resulting in unclear conclusions, and no signs of any significant improvement.

CoQ10 is found naturally in the body but taking excess of what the body needs will not necessarily have any benefit; it will most likely be excreted in the urine. A balanced, good quality diet will provide all the CoQ10 that the body requires unless the body has a condition whereby the levels are reduced. Those with mitochondrial disorders may be given CoQ10 as part of their 'cocktail' of compounds; however, there is no evidence that CoQ10 is of any benefit when used as a treatment for muscular dystrophy.

There is currently a clinical trial being conducted in the USA where CoQ10 and steroids are being prescribed to individuals with Duchenne muscular dystrophy. They are still in the recruitment phase and hence no results have been published as yet.

Creatine

Creatine is a naturally occurring substance which is found in muscle tissue. It is converted from creatine to phosphocreatine in the muscle which is necessary in the production of the cell's energy. It is widely used by athletes particularly those involved in anaerobic exercise such as weightlifting and sprinting. Creatine is produced naturally by the body, but can also be obtained through the diet. Animal products, high in protein, such as cod, beef, pork and salmon naturally contain creatine.

Many claims are made about the effects of taking creatine, including increases in muscle mass and athletic performance. However, previous studies with healthy individuals are not consistent in their conclusions, and the effects of taking creatine have not been fully substantiated.

There is no substantial, fully supportive evidence that supplementation with creatine is beneficial to individuals with neuromuscular conditions. Clinical trials are currently being conducted in the USA with individuals with Duchenne and Becker muscular dystrophy, myotonic dystrophy and spinal muscular atrophy.

Some side effects such as weight gain and depression have been reported in conjunction with the use of creatine, and people who suffer from kidney disease should not take creatine. However, as creatine is a natural substance it can be bought over the counter and there are no dosing standards currently set.

Homeopathy

Homeopathy is the use of remedies derived from natural materials, such as plants, to stimulate the body's immune system to fight disease. Homeopathic remedies need to be specifically selected to suit both the patient and the symptoms of disease. There are no specific homeopathic remedies for muscular dystrophy or any named disease. A consultation with a qualified homeopath is required to determine which remedy would be the most suitable.

Homeopathic medicine has not been reported to cause any side effects, and there are several NHS centres in the UK. They are usually taken orally in either tablet, powder or liquid form.

L-carnitine

Carnitine is a molecule which transports long-chain fatty acids into the mitochondria (the energy factories in cells). Carnitine is made in part in the liver and the kidneys. The rest of the carnitine that is required by the body is obtained via the diet in red meat, poultry, fish and dairy products.

Fatty acids are one of the main sources of energy for your skeletal muscle and heart. Carnitine also works to transport some of the waste materials left over from metabolism out of cells and into the urine. Without carnitine to 'escort' a lot of the waste products out of the body there tends to be a build up of these waste materials which can cause problems with the cell membrane, where sections are 'dissolved'. This build up of compounds can also cause problems with other aspects of metabolism where they may interfere with other chemical reactions within the cell.

Carnitine can help in some cases where the body has a carnitine deficiency. A lack of carnitine results in the body being unable to effectively utilise its long-chain fatty acids as an energy source. This decrease in energy can cause muscle weakness. There is no scientific evidence that carnitine is beneficial in individuals without carnitine deficiency. Taking in excess of what the body requires results in the free carnitine being excreted in the urine. Carnitine is a natural substance and there are no major side effects that have been reported as a result of taking carnitine.

Massage

Massage has been reported to ease a wide range of symptoms in individuals with neuromuscular conditions. These include pain relief, relaxation of tight or contracted muscles and increased circulation. Studies have not yet been conducted to conclude the benefits of massage, but there is some scientific basis in the claims that massage releases toxins and that it increases circulation.

Overall, massage does not offer an effective treatment or cure for neuromuscular conditions but it may help to relieve tension and provide some therapeutic physical contact.

Generally massage is a safe practice and there is no real reason that people with neuromuscular conditions should avoid it. It is wise to consult your doctor before proceeding to confirm if there are any reasons that massage may not be suitable for you. Massage is not suitable for everyone and people with active infections or inflammation, blood clots, circulatory problems, congestive heart disease, dermatomyositis, malignancies, skin conditions or in early pregnancy should avoid massage.

It is important to ensure that the therapist is qualified and that they are comfortable treating people with disabilities and have the facilities to accommodate disabled individuals. Some therapists may even be able to come to your home. It is worth enquiring about the different types of massage available and whether any of these may be particularly applicable to you.

Royal Jelly

Royal Jelly is a natural substance made by bees for the nourishment of the queen bee and is sold as a nutritional supplement, usually in the form of capsules. It is rich in vitamins, antioxidants, enzymes, hormones and amino acids. In addition it is said to have natural antibiotic and anti-cancer properties.

There are no scientific studies that confirming the use of Royal Jelly as an effective treatment of muscular dystrophy and its associated neuromuscular conditions.

There is a study taking place at the Royal Cells Institute in Greece regarding the use of Royal Jelly. The MDC has not seen conclusive scientific evidence showing a benefit in neuromuscular conditions. The trial includes individuals with a variety of conditions and there is no control which makes scientific interpretation difficult. The study appears to be mainly based on anecdotal evidence.

However, Royal Jelly is a natural substance and there are currently no known side effects. Royal Jelly should be viewed as a health supplement in the same class as vitamin and mineral capsules.

The MDC recommends that if individuals wish to pursue any of these alternative therapies that they first consult their doctor/clinician. There may be interactions or side effects which need to be monitored in a controlled manner.

*Code: MI01
Published: 11/02
Updated: 04/08
Author: Research Department, MDC*

