

Let's talk about feelings: counselling

A diagnosis can cause various emotional reactions from different people: "I felt numb", "I could not concentrate", "I cried and cried", "I was confused, I had never heard of muscular dystrophy, neither had my family or my friends". "I wanted to know everything I could about muscle disease", "I was surprised to hear there were so many different neuromuscular conditions".

The aim of this factsheet is to list some of the options available to you should you feel that you need to talk to someone about how you feel. This can be in relation to a new diagnosis, a recent deterioration in your health, feelings of guilt that parents or carers may feel, or any other emotional distress you may feel.

Hearing that your child, a family member or you yourself have been diagnosed with a muscle disease may make you feel overwhelmed and confused. For some people it helps to talk to someone outside their immediate family and friends, such as a Regional Care Advisor, GP, health visitor or social worker. Other people may feel they need or want specialised professional emotional support from a counsellor or child/family psychologist or similar. A referral to professional support can be made by your GP and/or for children, through their school or social worker.

What is counselling and how can it help you?

A professionally trained counsellor or a child psychologist can offer you or your child emotional support. The aim of counselling is to help you find your own solution to personal issues and be helped to come to your own decisions. Counsellors do this by listening and allowing you to talk about your feelings, as speaking out loud about your problems can help you to put your thoughts in order. Counselling can help you make sense of your life, resolve specific problems and help you to make decisions.

You can speak to your GP about your emotional needs and ask that he or she refers you or your child to a counsellor. You can also ask at your child's school for counselling as a part of your child's statement of educational needs. There may be a long waiting list for a NHS or school referral.

What can you expect from counselling?

Counselling sessions are usually once or twice a week, depending on the need. The length of sessions varies but usually they last between 30 minutes to an hour. An initial meeting will be arranged which will allow you to meet the counsellor, speak about the issues that concern you and ask any questions you may have. You will see the same counsellor each week. Usually the counselling will continue for as long as you and the counsellor feel it is helpful – check this at the outset.



Some organisations offer counselling by phone or email with a professional person qualified to help you talk through your concerns, worries and/or anxieties.

Counselling is private and confidential; unless someone's personal safety is at risk.

What will counselling cost me?

Counselling on the NHS is free. If you pay for private counselling the cost usually varies from £20 to £80 per session, or more. Some counsellors have a sliding scale of cost. There are charitable organisations that offer counselling. Some of these organisations will charge, others will not charge a fee but may ask for a donation. If you use a helpline the cost is only the actual cost of the call. However some helplines have numbers that allows you to call them free of charge or for the cost of a local call.

Questions that might help you to decide if you would like to get counselling:

Is it counselling I want or advice and information?

Am I ready to talk about my problems and concerns?

Do I know what I want to get out of counselling?

There are various forms of counselling and it could be useful to find out more about the different types so that you can choose which is most suited to you. You might also need to try different forms before you find something that works for you. This might not be the case with counselling through the NHS, where you might have to take the service you are offered.

Useful contacts:

British Association of Counselling and Psychotherapist (BACP)

The BACP keeps a database of regional counsellors and psychotherapists.

National Information Line: **01455 883300** (Monday to Friday 9-5pm)

Web: www.bacp.co.uk

Email: bacp@bacp.co.uk

Samaritans

A 24-hour free helpline providing confidential and emotional support for people experiencing feelings of distress and despair.

National Helpline: **08457 909090**

Web: www.samaritans.org.uk

Email: jo@samaritans.org

SupportLine

Offers confidential emotional support to children, young adults and adults. They work with callers to develop healthy and positive coping strategies and provide details of counsellors, agencies and support groups across the UK.



Helpline: **01708 765222**

Email: info@supportline.org.uk

Web: www.supportline.org.uk

Universities and colleges have a student counselling service. This information is found in each college's handbook.

UK Council for Psychotherapy (UKCP)

The UKCP keeps a database of regional psychotherapists and provides information on what psychotherapy is.

National Line: **020 7014 9955** (Monday to Friday 9-5pm)

Email: info@psychotherapy.org.uk

Web: www.psychotherapy.org.uk

Youngminds

A national charity committed to improving the mental health of all children and young people.

Parents' Information Service: **0808 802 5544**

Web: www.youngminds.org.uk

Email: ymentquiries@youngminds.org.uk

Marriage Care

A marriage support organisation offering support and counselling to parents of disabled and chronically sick children.

Support line: **0845 660 6000 or 0808 800 2222**

Web: www.marriagecare.org.uk

Email: info@marriagecare.org.uk

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Here for you

The friendly staff in the care and support team at the Muscular Dystrophy UK's London office are available on **0800 652 6352** or info@muscular dystrophyuk.org from 8.30am to 6pm Monday to Friday to offer free information and emotional support.

If they can't help you, they are more than happy to signpost you to specialist services close to you, or to other people who can help.

www.muscular dystrophyuk.org