

Getting mental health support

Mental health refers to our emotional, psychological, and social wellbeing. Our mental health impacts on our thoughts and feelings, and how we act and behave. It also influences how we respond to stress, how we interact with others, and the choices we make.

Being diagnosed with a muscle-wasting condition can often mean adjusting to a new and unexpected reality. Living with a muscle-wasting condition can have an impact on every part of your life, including your mental health and wellbeing. Many people tell us they feel isolated because of their condition. Others tell us that they can feel anxious or depressed as they adjust to their diagnosis.

The impact goes beyond those who are living with a muscle-wasting condition; families and carers can also be affected too. It is important that everyone has access to the right support for their mental health when it is needed.

When might I need support?

Mental health problems can happen for no reason, or they might be triggered by specific life events. If you, or someone you know, is going through a period of poor mental health, it can be hard to know when to reach out for help and who to talk to. You may feel uncertain about seeking help. **It is always okay to ask for help – there is support available.**

You might want to reach out for help:

- If you find that you are regularly feeling worried, upset, anxious or depressed.
- If you are experiencing little enjoyment in your day-to-day life
- If you are regularly having thoughts or overwhelming feelings that are difficult to cope with or affect how you manage each day
- If you have difficulty sleeping or there are changes to your eating pattern.
- If you have low motivation or have lost interest in things which you used to enjoy.
- Following a new diagnosis
- If there has been a recent change in your health or circumstances
- If you are a relative or carer of a person living with a muscle-wasting condition and are experiencing any of the above

Where can I get support?

There are different options available if you need help and support with your mental health.

Mind is a mental health charity. They provide advice and support to anyone experiencing a mental health problem and have produced a guide about seeking help and getting the right support for you - [How to seek help for a mental health problem - Mind](#).



GP Surgery:

You can contact your GP surgery for support. Your doctor is likely to ask you some questions about your life and might ask you to fill out a questionnaire about your mood, thoughts, and behaviour. This can help them decide what kind of support might be most beneficial for you. This may include referring you to local mental health services, discussing self-care techniques, or offering you treatment. They may also check your physical health, and ask you questions about your lifestyle.

Community Mental Health Team (CMHT)

A community mental health team (CMHT) provides support to people, experiencing mental health problems, within the community. CMHTs are made up of different professionals. This may include a social worker, a mental health officer, an occupational therapist, a community psychiatric nurse (CPN) and a psychologist or psychiatrist. You will need to be referred into a community team; your GP will be able to do this. A lead worker from the team will usually be appointed to stay connected with you and to help coordinate your care.

NHS Talking Therapies (England)

If you live in England, you may be able to self-refer to your local NHS Talking Therapies service. This service offers different therapies that can be delivered individually or in group sessions. Your GP surgery can also put you in touch with your local service, or you can find one online using your postcode. NHS Talking Therapies is formerly known as Improving Access to Psychological Therapies, IAPT.

Website: <https://www.nhs.uk/service-search/find-a-psychological-therapies-service/>

Mental health services at NHS 24 (Scotland)

NHS 24 mental health services are available to everyone in Scotland. The services NHS 24 offer include listening, offering advice, and guiding you to further help if required.

When you phone 111 and choose the mental health option, you will be connected to a team of psychological wellbeing practitioners (PWPs). These are specially trained advisors who work in mental health. PWPs can offer advice on coping with mental health symptoms. They can also recommend and connect you with other services if needed. PWPs can access a range of both NHS and charity organisations to find the right support for you.

Living Life is a free service offered by NHS 24. Living Life can provide cognitive behavioural therapy (CBT) by trained therapists over the phone, to people in Scotland, aged sixteen and over. You can self-refer to this service on 0800 328 9655 (Monday-Friday 1pm-9pm).

<https://www.nhs24.scot/our-services/living-life/>.



Lifeline (Northern Ireland)

Lifeline is Northern Ireland's crisis response helpline service for people who are experiencing crisis. No matter what your age or where you live in Northern Ireland, if you or someone you know is in distress or despair, Lifeline is there to help. People living in Northern Ireland can call Lifeline on 0808 808 8000.

SilverCloud (Wales)

SilverCloud is a free online CBT therapy service available to people in Wales, who are aged sixteen and over and registered with a GP in Wales. You can self-refer into this service using the following online system: <https://nhs.wales.silvercloudhealth.com/signup/>.

SilverCloud works with the NHS to help meet mental health and wellbeing needs and is partnered with some NHS Trusts in England. You can find out more about this at the link below:

[Online Behavioural Health Solutions for NHS | SilverCloud® by Amwell®](#)

Community Advice & Listening Line (Wales)

Community Advice & Listening Line provides emotional support and information/literature on Mental Health and related matters to the people of Wales. Anyone concerned about their own mental health or that of a relative or friend can access the service. CALL Helpline offers a confidential listening and support service. You can contact the CALL Helpline on [0800 132 737](tel:0800132737) or text help to [81066](tel:81066)

Specialist Neuromuscular Clinic

If you attend a specialist neuromuscular clinic, you can also ask your consultant to see if you can be referred to mental health support specifically for people with muscle-wasting conditions.

What happens once I am referred?

If you have been referred to a local mental health service such as a community mental health team (CMHT) or NHS Talking Therapies, you may get an initial appointment, or a follow up phone call to ask you some more specific in-depth questions (an assessment). This is to get a better understanding of the difficulties you are experiencing, and what support you may need. Once the team, or service, has this information, they should explain to you what will happen next. They may discuss different treatment options or support available. This could be counselling or cognitive behavioural therapy. You should also get the opportunity to ask questions, share any concerns, or worries you may have.

The waiting list for mental health support will vary depending on where you live. It is beneficial to ask how long you may wait for treatment or support. You may also want to ask if you can access any interim support whilst you are waiting. Some services may offer group therapy sessions or courses to support you in the meantime. They may also give you a number you can call in case of emergency or if you are in urgent need of support.



What support is available for children?

CAMHS (Child and Adolescent Mental Health Services)

CAMHS covers all services that work with children and young people who need support with their emotional or behavioural wellbeing. If you feel your child would benefit from emotional support or one of the therapies mentioned in this factsheet, your GP will be able to refer to your local CAMHS who can provide this support.

Play Therapy

This can be beneficial for younger children who have a health condition or disability, particularly where they may need to undergo medical and surgical procedures as part of their treatment. Play therapy is often offered in hospitals to help children make sense of frightening or unfamiliar experiences. It can help to calm children and help them cope with pain. CAMHS can often refer you to play therapists or specialists, and they can also advise parents and carers about how to implement play therapy as part of your child's emotional care at home.

YoungMinds is a charity providing information and advice on mental health support to children, young people, and parents. They have created a range of helpful guides including how to get help from CAMHS, what to expect, and understanding your rights - [Guide to CAMHS](#). They have also produced a supportive guide for parents and carers about the NHS mental health support available for children and young people – [Parents' Guide to CAMHS](#).

What should I do in an emergency or mental health crisis?

If someone's life may be at risk, or you feel that cannot keep yourself, or someone else safe, call 999 or attend the nearest emergency department (A&E). A mental health emergency or crisis should always be taken seriously.

If you need help urgently because you, or someone you know, is experiencing an emergency or a mental health crisis, support is available.

England - [Where to get urgent help for mental health - NHS \(www.nhs.uk\)](#)

In England, you can contact an NHS urgent mental health helpline (available for people of all ages) who can provide you with 24-hour advice and support for you, or someone else. You will be able to speak with a mental health professional who can help with accessing the right care and support. Find a local NHS urgent mental health helpline in England at the link below:

[Mental Health Helpline for Urgent Help - NHS \(www.nhs.uk\)](#)

Scotland - [Mental health services at NHS 24 | NHS inform](#)

NHS 24 mental health services are available to everyone in Scotland. Phone NHS 24 on 111 if you need emotional support or you are feeling distressed, suicidal or are in a state of despair. When you phone 111 and choose the mental health option, you will be connected to a team of



psychological wellbeing practitioners (PWP). These are specially trained advisors who work in mental health.

Wales – <https://111.wales.nhs.uk>

In Wales, you can call NHS 111 and select Option 2 if you, or someone you know, needs urgent mental health care, but it is not life threatening. Mental Health 111 (Option 2) is available 24 hours a day, 7 days a week, and is free to call from a mobile or from a landline.

Northern Ireland – [If you're in crisis](#)

Lifeline is a free and confidential crisis response helpline available to everyone in Northern Ireland. There is immediate help by telephone at any time every day if you are in distress or despair or someone you know is. Counsellors answer all telephone calls. You can call Lifeline on 0808 808 8000.

[Lifeline freephone helpline | nidirect](#)

Can I get mental health support privately?

Mental health support is available through the NHS for free, but if you wish to get support privately, you can do so by finding a therapist on the British Association for Counselling and Psychotherapy (BACP) website.

Private therapy costs vary, and some local charities offer counselling to people in their area on a sliding scale of cost, depending on your income. They may also offer counselling for free.

If you are looking for a therapist privately, it is important to check that they are registered with a professional body. The following organisations list only registered therapists:

- ▶ [The Counselling Directory](#)
- ▶ [British Association for Counselling and Psychotherapy \(bacp.co.uk\)](#)
- ▶ [British Association for Behavioural & Cognitive Psychotherapies](#)
- ▶ [British Psychological Society](#)
- ▶ [UK Council for Psychotherapy](#)

Helpline and organisations that can support you.

There are several charities who also provide support to people who are experiencing mental health difficulties. We have included information about some of these below:

Mind Infoline

Telephone: 0300 123 3393 (9am-6pm Monday to Friday) or text 86463

Email: info@mind.org.uk

Website: www.mind.org.uk/information-support/helplines

Mind provides confidential mental health information services.

Rethink Mental Illness Advice Line

Telephone: 0300 5000 927 (9.30am - 4pm Monday to Friday)

Email: advice@rethink.org

Website: <http://www.rethink.org/about-us/our-mental-health-advice>

Rethink provides expert advice and information to people with mental health problems and those who care for them, as well as giving help to health professionals, employers, and staff.

Breathing Space (Scotland)

Telephone: 0800 83 85 87 (6pm-6am Friday to Monday & 6pm-2am Monday to Thursday)

Website: <https://breathingspace.scot/>

A confidential listening service for people in Scotland, aged sixteen and over who may be experiencing low mood, depression, or anxiety.

More useful contacts

The following phone lines are available to call if you want to talk to someone anonymously. There is also support available on their websites.

▶ **Samaritans**

Confidential support for people experiencing emotional distress.

Telephone: **116 123 (24 hours)**

Website: <https://www.samaritans.org/>

▶ **Shout 85258**

Shout is a free, confidential, and anonymous 24/7 text messaging support service for anyone who is struggling to cope. You can text from wherever you are in the UK.

Website: <https://giveusashout.org/>

▶ **SANEline**

An out-of-hours mental health helpline offering emotional support and guidance

Telephone: **0300 304 7000 (4pm-10pm)**

Website: <https://www.sane.org.uk/how-we-help/emotional-support/saneline-services>

▶ **YoungMinds**

Information about child and adolescent mental health. YoungMinds can help you if you are a young person, a parent, or work with young people. The YoungMinds helpline is available for parents.

Telephone: **0808 802 5544 (9:30am-4pm)**

Website: <https://www.youngminds.org.uk/>

▶ **Childline**

A helpline for children who need support.

Telephone: **0800 1111 (24 hours)**

Website: <https://www.childline.org.uk/>



▶ **Campaign Against Living Miserably (CALM)**

Support for anyone struggling or in crisis. CALM is leading a movement against suicide and standing up to stereotypes.

Telephone: **0800 585858 (5pm-midnight)**

Website: <https://www.thecalmzone.net/>

▶ **The Line**

A helpline for older people who need emotional support.

Telephone: **0800 470 80 90 (24 hours)**

Website: <https://www.thesilverline.org.uk/>

▶ **Switchboard LGBT+ helpline**

Switchboard is a listening service for LGBT+ people over the phone, via email, and online chat.

Telephone: **0800 0119 100 (10am-10pm)**

Website: <https://switchboard.lgbt/>

Support following a bereavement

We know that no-one can understand exactly what your loss feels like to you. However, we also know that sometimes it can be easier to talk to someone who is not directly connected to you, about the impact of bereavement, grief, and loss on your life. This is why we offer the GriefChat service.

GriefChat is an organisation that supports Muscular Dystrophy UK to provide access to free professional bereavement support. GriefChat helps those dealing with grief by providing them with a safe space to be able to share their story and explore their feelings. GriefChat is open Monday – Friday, 9am – 9pm (except for Bank holidays). During those hours, GriefChat provide a live instant chat service with a qualified bereavement counsellor. Email access is provided at other times and will be responded to by the end of the next working day.

[Bereavement, Grief, and Loss - Muscular Dystrophy UK](#)

Support available for students

Attending university, college, or studying towards something can be an exciting time, but it can also present lots of new challenges. You may be away from home for the first time. You may also have deadlines and exams or find yourself having to balance lots of responsibilities.

There is usually support available within universities and colleges if you feel you need emotional support while studying. You can check your university or college website for more information or speak to your student services team to find out. You can also still access support through your local NHS services.

If you are a student, you can find useful contacts linked below.

▶ [Useful contacts - Student Mental Health \(Mind\)](#)

▶ [Student Minds](#)



- ▶ [Student Space](#)
- ▶ [Nightline](#)

Support in employment

It is very important to look after your mental health and wellbeing at work to avoid experiencing burnout and mental health problems. Factors such as work environment, workload, and capacity, and working conditions can have a significant impact on mental health.

[Mental health at work: statistics | Mental Health Foundation](#)

Mind have resources and advice about looking after your wellbeing when you are at work.

[Mental health at work | Mind - Mind](#)

Support for carers

Caring for someone else can be physically and emotionally exhausting and could impact on your mental health and wellbeing. If you are supporting and caring for someone else, it is important to look after yourself, and your own mental health, and to know where you can get support, if you need it.

Most local areas have carer support groups and advice lines for carers and young carers. Follow the link below to find out what support is available for carers in your area:

www.nhs.uk/Service-Search/Carers-support-services/LocationSearch/374

Carers UK offers support and advice to carers and their families - www.carersuk.org.

Mind has information (linked below) about supporting yourself while caring for someone and where you can find support if you are a carer - [Where to find support for carers - Mind](#)

If you are experiencing distress and need to speak to someone urgently, please call the Samaritans 24/7 helpline on 116 123. If someone's life may be at risk, or you feel that cannot keep yourself, or someone else safe, call 999 or attend the nearest emergency department (A&E). A mental health emergency or crisis should always be taken seriously.

Here for you

If you require further information or support, you can email us at info@muscular dystrophyuk.org or you can call our free helpline on **0800 652 6352**. Our helpline is open from Monday to Thursday, 10am to 2pm. If we are unable to answer your call, you can leave a voicemail and we will get back to you as soon as we can.

If we cannot help you, we can signpost you to specialist services close to you, or to other organisations who can assist.

www.muscular dystrophyuk.org

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