



9: Support for children and young people

This section provides guidance to help you support children or young people who are close to the person with MND or become involved in care tasks.

The following information is a section from our full guide *Caring and MND: support for you*.

Other sections, and the full guide, can be found online at: www.mndassociation.org/carerguide

The full guide can be ordered in hardcopy from our helpline, MND Connect:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org



**Caring and MND:
support for you**

9: Support for children and young people



This section provides guidance to help you support children or young people who are close to the person with MND or become involved in care tasks.

How do I explain MND to children and young people?

When someone is told they have MND, it can be confusing and shocking for the whole family. If children and young people are involved, it can feel particularly difficult.

“We’re trying to hide it from the kids, as we’re unsure what to say or do.”

Our natural instinct is to protect younger members of the family from distress or worry, but MND is not something that can be hidden or disguised. Children and young people will see the disease progress and symptoms will get worse.

“I can’t remember being told that mum had MND, just feeling confused and that everything was changing.”

They may try to find out information on their own, often through the internet, which can be unreliable or cause alarm.

If children and young people are left to their own imaginations, they may blame themselves or feel isolated.

“I blamed myself for dad dying for a very long time. I saw it as my fault he’d got ill.”

How you explain MND to a young person will depend on their age and ability to take in new information. Try to use words that will be clear to them. It can help to talk about the physical effects of the disease so they know what to expect.

For example, if the person with MND has problems with facial expressions, this may not be obvious to the young person. They may even think they have done something wrong. To help them, you could say, ‘The muscles in Grandad’s face aren’t working properly. He’s not cross with anyone – he just finds it difficult to smile.’

Key facts to help a young person are:

- it’s no-one’s fault if someone gets MND – nobody is to blame
- it’s not caused by something that someone does
- you cannot ‘catch’ MND by touching someone who has the disease

- young children do not get MND and although younger adults have been diagnosed, most are 50 years or more when this happens
- there is a type of MND where more than one person in a family has had it, but this is extremely rare.

As the disease progresses, keep communication open with children and young people. If they know what is likely to happen next, they will be more prepared and less likely to feel shock as a symptom gets worse.

Is there anything that can help me with this?

The following table explains how we provide information and support to help children and young people.

See *Further information at the end of this section for details about how to access our publications and services.*

What we provide:	What this can do:
Telling people about MND	A booklet to help people with and affected by MND explain the diagnosis to family, children, friends and professionals.
Why is everything changing?	Our storybook for young children, with three gentle family stories about MND. These can help begin conversations about a diagnosis. You can also listen to them read aloud on our MND Buddies hub (see next row).
MND Buddies activity hub:	Animal characters in this online hub act as guides, taking children through facts, games, stories and other activities about MND in a kind and interactive way. See www.mndbuddies.org
When someone close has MND	An activity workbook for children aged 4 to 10. The content can be introduced gradually, to help a trusted adult communicate with the child. The activities help the child develop ways to cope with the changes that MND brings.
So what is MND anyway?	A guide to help young people up to 18 understand what a diagnosis of MND means and what to expect if a member of their family has been diagnosed. The aim is to help them feel more prepared and aware of available support.

What we provide:	What this can do:
<p>Web pages for children, young people, parents and guardians</p>	<p>Find family resources at: www.mndassociation.org/cyp</p>
<p>Young Connect</p>	<p>Young people can contact our helpline for support and information:</p> <p>Telephone: 0808 802 6262 Email: youngconnect@mndassociation.org</p> <p>Or email our contact for children and young people's services: cyp@mndassociation.org</p>
<p>Link with ChildLine</p>	<p>If a child or young person affected by MND contacts ChildLine for information about the disease, they will be referred to our Young Connect helpline.</p> <p>If a child or young person contacts our helpline because they need counselling or emotional support, we refer them to Childline.</p> <p>ChildLine telephone: 0800 1111</p>
<p>Young Person's Grant</p>	<p>We offer grants to young people aged 18 or under, and to young carers aged 16 or over. A family member, health and social care professional or the young person can submit the application. These one-off grants can be used for a range of support, such as:</p> <ul style="list-style-type: none"> • days out • additional tutoring • out of school activities • driving lessons • a laptop • decorating their room at home. <p>For details, contact our MND Connect helpline: Telephone: 0808 802 6262 Email: mndconnect@mndassociation.org</p>
<p>Useful organisations for children and young people</p>	<p><i>See Section 12: Useful organisations, which includes a separate list of providers for children and young people.</i></p>

Who are young carers?

A young carer may be the child, grandchild, brother, sister, other relative or friend of the person with MND.

They may live with the person who has MND or live nearby and visit. Finding a balance between life and care can be difficult when young people are involved.

“It’s hard to know when to ask the girls for help and when not. They have seen things they shouldn’t at their age, but what is the alternative? I think the strain on them is the greatest, but they are a credit to themselves. I wish I had more time for them.”

Once children and young people know what is happening, they often get involved in care tasks in some way. This can happen because:

- they want to feel involved and offer their help
- they want to spend time with the person who needs care and begin to do things for them
- there are helpful things they can do around the house while you are caring for the person with MND
- you need help as the main carer
- they live with the person who has MND (and you may not)
- the person’s care needs become complex and need additional support
- they live with a single parent who has MND and they become the main carer.

“I didn’t think of myself as a young carer – I just did what had to be done. I didn’t really have a choice.”

What do young carers do?

Young carers may do all of the tasks that an adult carer would do, but this is not always appropriate. This is where assessment of their needs becomes very important to ensure the right support is in place.

Depending on the type of care needed, young carers may get involved in:

- helping younger brothers and sisters
- housework or laundry
- shopping for food and supplies
- making meals
- helping the person with MND to eat and drink
- giving medication
- helping the person with MND to get washed and dressed
- providing emotional support and company.

“At first nothing much changed, but gradually I had to help out more and more.”

A young person’s needs assessment is usually arranged through your local authority in England or Wales, or your local health and social care trust in Northern Ireland. Contact them to find out what you need to do and book an appointment.

The assessment will consider the impact on their wellbeing, school work or employment, social life and interests. A care support plan will be developed in agreement with the young person and their parents or guardian.

See later heading, *Rights for young carers* for more information about assessing the needs of children or young people who get involved in caring.

How will being a young carer affect their life?

Young carers can be affected in some or all of the following ways:

- the feeling that caring has taken over their life
- that the expectation on them is overwhelming
- attending school or work feels difficult
- friendships may be tricky to manage if there is less time to socialise
- they may feel embarrassed to bring friends home if they worry about equipment installations, changes to their environment or the person's disabilities
- they may feel jealous of friends whose lives seem 'normal'
- family relationships are often challenged by the effects and demands of the disease
- they become very tired and irritable (especially if dealing with puberty at the same time)
- they feel their needs always come second
- they may worry about money if the family are under financial pressure – particularly if one or both parents have to leave work because of MND.

“It’s very difficult trying to study for A-levels, keep up with friends, look after my dad and help mum look after him too. I feel a lot of responsibility and think about things that wouldn’t even cross my friends’ minds.”

As with adult carers, young carers can feel many different emotions, and their emotions can change rapidly. They may feel down one minute and up the next.

When 'up', they may feel:

- happy they can help make a difference
- proud of an achievement
- a sense of control through being involved
- positive about themselves and what they can do
- closer to the person with MND
- that today is a good day or even just a 'normal' day
- a growing sense of independence
- they are building memories with the person who has MND.

When 'down', young carers may experience feelings of:

- sadness
- anger
- worry
- fear
- stress
- guilt
- embarrassment
- neglect
- indifference or apathy.

Your own emotions are also likely to be affected by trying to support more than one person at a time, while dealing with the demands of MND.

“As a parent, I worry all the time that if anything happens to me, she’ll have no-one. I feel anxious, inadequate and constantly torn between our daughter and caring for my husband. Her life is a reduced version of what it could have been.”

Children and young people can be resilient and discover their own strengths when someone close is diagnosed with MND. If they find it particularly difficult, these feelings may become intense or overwhelming. In some cases, this can lead to extreme reactions, which may include:

- becoming withdrawn or depressed
- poor attendance or falling grades at school
- eating disorders
- self-harming
- drug or alcohol abuse
- being bullied or bullying
- disruptive or aggressive behaviour
- running away.

If you need advice about support for children or young people in your family, talk to someone as soon as you can. You may wish to contact our MND Connect helpline who can direct you to our own and external services:

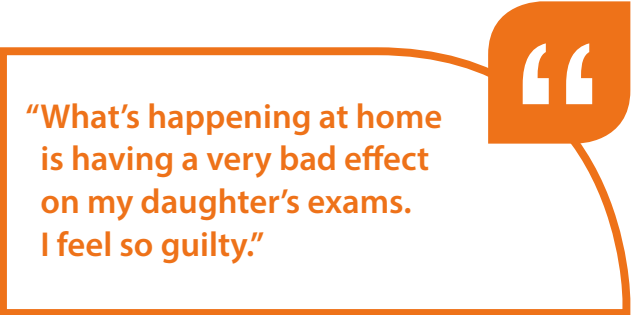
Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

There are many other organisations that can also help, that offer services designed for children and young people. They can also advise you on how to find support for younger members of the family if you have concerns.

See the end of this section for organisations that support children and young people.

There may be waiting lists, even with services for children and young people. If a service is stretched, you may have to wait for support, which can be difficult if you are worried.



“What’s happening at home is having a very bad effect on my daughter’s exams. I feel so guilty.”

If the child or young person needs immediate support, they may find it helpful to contact:

- ChildLine: **0800 1111**
- Samaritans: **116 123**
- Our contact for children’s services at the MND Association, **cyp@mndassociation.org** which includes a way of gaining fast referral to counselling through Barnardo’s
- Our YoungConnect helpline, part of our main MND Connect helpline service. They can offer support and information:
Telephone: **0808 802 6262**
Email: **youngconnect@mndassociation.org**
- Their teacher or head teacher, who may be able to arrange support services through the school.

See later heading in the section, *School, study and work.*

Rights for young carers

The United Nations Convention on the Rights of the Child (UNCRC) is an international human rights treaty that grants all children and young people (aged 17 and under) a comprehensive set of rights. All UK government policies and practices must comply with these rights.

The rights included in the UNCRC are wide ranging, but some are important in terms of UK laws that support young carers. Children have the right to:

- a childhood
- an education
- health and health services
- be heard, listened to and believed
- be protected from physical and psychological harm
- privacy and respect
- have their views taken into account when decisions are made that affect their lives.

Further detail can be found at: **www.unicef.org.uk/UNICEFs-Work/UN-Convention**

This means young carers have the right to information, choice and wellbeing. In order to protect these rights in the UK, young carers can have their needs assessed, similar to your own carer's assessment.

Assessment of a young person's needs leads to a care and support plan, which may include a range of support.

For example:

- practical assistance in the home
- support to enable recreational activities for the young person
- support to enable holidays
- equipment to help communication and contact, such as a mobile telephone.

Some services and assistance may be free of charge for children and young people. Where service or equipment charges do apply, the parents or guardians are financially assessed to see how much they may need to pay. However, this may depend on the age of the young person (under 16), whether they are employed and how they have been assessed.

The following information looks at rights to assessment for young carers in England, Wales and Northern Ireland.

Young carers' rights in England

Under the new Care Act 2014, all young carers under the age of 18 have a right to assessment regardless of who they care for, what type of care they provide or how often they provide it. You can find the full Act online. Search for *Care Act 2014* at:

www.legislation.gov.uk

An assessment can be requested through your local authority, but should be offered if there is an 'appearance of need'. This appearance of need may be identified as a result of a care assessment for the person with MND or a carer's assessment for yourself.

The assessment looks at why the child or young person is involved in care tasks, what may need to change and ways to help the family prevent the need for the child to take on inappropriate responsibility.

Young carers' rights in Wales

In Wales, local authorities have a duty to assess any 'child in need' under the age of 18, for any services they or their family may need. A young carer with significant caring responsibilities would be recognised as a child in need.

This would be done through a Children Act Assessment, but young carers who are 16 or older can request a full carer's assessment if they wish. The aim of any service provision to young carers is to ensure they can achieve or maintain a reasonable standard of health and development.

See Section 4: Carer's assessment and Section 3: Your rights as a carer for more on carer rights in Wales.

Young carers' rights in Northern Ireland

In Northern Ireland, young carers up to 18 are assessed under the Children (NI) Order 1995, using a process called *Understanding the Needs of Children in NI* (sometimes known as UNOCINI).

If aged 16 to 18, a young carer can ask for a full carer's assessment under the Carer and Direct Payments Act 2002, but it may be in their best interests to use the process mentioned above.

You can request an assessment for a young carer through your local health and social care trust. When assessing a young carer's needs in Northern Ireland, the aim is to help them avoid levels of responsibility for caring that could impact on their health and wellbeing.


For more information about the laws governing assessment in Northern Ireland, see: **www.nidirect.gov.uk/an-overview-of-carers-rights**

School, study and work

Some young people prefer to keep their home life private, but it can help to let their school or employer know what is happening.

What can their school do?

If a young carer is struggling to keep up with schoolwork or has missed any school as a result of caring, it is best to keep the school informed.



“Watching her granddad get worse week by week really affected her, but her school has been arranging counselling.”

Pastoral services in schools provide support for a range of practical, emotional and behavioural needs. This type of support is often provided by teachers, a school nurse or even other pupils who act as mentors.

Ask the school what they offer and how this might help. Once aware of challenges the young person may face, they may provide a pastoral care plan (following discussion with the young person’s parents or guardian - which may include you). This can help the young person feel more secure at school and gives them a point of contact if they feel worried or upset about anything.

The school nurse is a useful contact, who can:

- support and provide advocacy for the young person
- look at what support can be given if there is an emergency at home
- refer the young person to wider support services if needed.

Supported by the Department of Health, the Carers Trust and other partners, a programme has been established to train school nurses to become ‘Young Carer Champions’. This aims to improve support for young carers in schools and ensure they and their families are linked into and receive support from services they may need.

There is usually a lead teacher at each school who is nominated as main contact for students who are young carers. It is worth finding out who this is.

Teachers can help by:

- allowing extra time for homework
- arranging support services through the school, such as counselling sessions
- providing information about external support services in the local area
- introducing a young carer to other young carers in the school for peer support
- advising about school commitments and homework, especially if an emergency happens at home.

Young Carers in Schools programme

This is an initiative across England to make it easier for schools to support young carers. Run jointly by Carers Trust and The Children’s Society ‘Young Carers in Focus’ partners, it provides:

- guidance for school staff and teachers to help them identify and support young carers
- opportunities for teachers, young carer services and health and social care professionals to share knowledge
- the Young Carers in Schools Award, enabling schools to gain recognition for good practice.

Ask the relevant school to find out if they are involved or search for young carers in schools at: <https://carers.org>

What can employers do?

If a young carer is employed, in either part-time or full-time work, they may worry about their job being affected by the demands of caring. In most cases, employers are willing and able to help. They may be able to:

- adjust working hours to suit the caring role
- allow flexible working, so hours can change when appropriate
- provide some form of carer’s leave (this may be unpaid, but could be useful in urgent situations).

Which professionals support young carers?

Young carers are likely to meet a wide range of professional people or groups during their caring role, in a variety of locations. This may include home visits where appropriate and with your permission.

These professionals can be involved with:

- the direct health or social care of the person with MND
- support for young carers
- school or college life, if the young person is still a student.

The following list provides a brief explanation for each of these contacts:

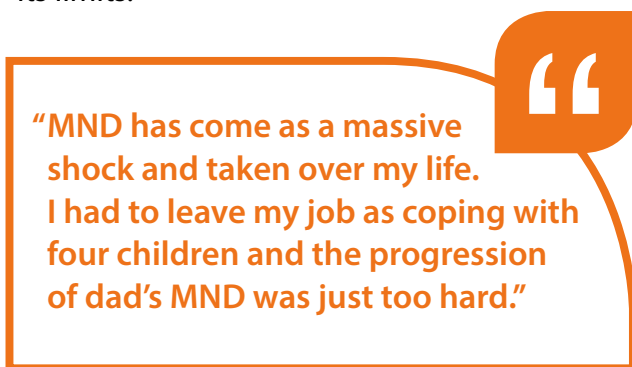
Person or group:	What they do:
Lead teacher	These teachers are appointed by a school to lead in a particular area. Often, a lead teacher becomes the main contact for students who are young carers.
School nurse	Often involved in pastoral care within a school, the school nurse can provide support or refer children and young people to wider health and social care assistance where appropriate.
Education Welfare Officer (EWO)	An EWO identifies problems with school attendance, but also looks at possible solutions. They can help families get benefits for school meals, transport or clothing. They also have knowledge of other local services and professionals.
Social worker	A member of staff from adult social care services, who helps people with their social care needs. They can assess the needs of young carers, offer support and help arrange services, as appropriate.
Children and Adolescent Mental Health Services (CAMHS)	<p>Children and young people and their families can be referred to CAMHS if children need professional help to cope emotionally with daily life. CAMHS can help with the effects of traumatic events or diagnose and treat serious mental health problems.</p> <p>To find your local CAMHS service:</p> <ul style="list-style-type: none"> • speak to your GP who can refer you (there may be a waiting list if the service is stretched) • search online for <i>Child and Adolescent Mental Health Services</i> in your area.

Person or group:	What they do:
Carer's centre	<p>A local carer's centre can provide information about services for carers and young carers, in your area. Contact your local authority or in Northern Ireland, your local health and social care trust, to find your nearest centre.</p>
Health and social care professionals	<p>Many health and social care professionals will be involved in the care and treatment of someone with MND and young carers may meet a wide range, especially if care becomes complex and professionals make home visits.</p> <p><i>See Section 5: What kind of support is available? for a list of these professionals with an explanation of each role.</i></p>
Multidisciplinary team (MDT)	<p>An MDT is a team of health and social care professionals from different disciplines, who work together in a co-ordinated way to provide care and treatment.</p>
MND care centre or network	<p>The MND Association has established and part-funds MND care centres and networks across the UK. The centres are usually based in hospitals and the networks operate as outreach teams. They provide co-ordinated care through a team of health and social care professionals (see multidisciplinary team below).</p> <p><i>See Section 5: What kind of support is available?</i></p>
Hospice staff	<p>Hospices are not just about end of life care in the final stages. With a life-shortening illness like MND, hospice and specialist palliative care teams provide a wide range of services to maintain quality of life, from the point of diagnosis onwards. This type of care includes support for families and young carers. This can help young people cope with difficult situations and learn how to deal with grief in the future.</p>
Youth workers and youth advice services	<p>These provide advice and support on a wide range of issues for young people. Contact your local authority or in Northern Ireland, your local health and social care trust, to find out contacts in your area.</p>

Person or group:	What they do:
Young carer projects	A huge number of special projects exist for young carers across the UK. These may provide activities, support or information. Contact your local authority or in Northern Ireland, your local health and social care trust, to find out what may be happening in your area.
Young carer festival	This is an annual weekend festival held in Hampshire and attended by young carers from all over the UK. It provides an opportunity for young carers to have fun and take a break, in the company of others who have a similar experience of life. Find out more through the Children's Society at: www.youngcarer.com

Support for you

Supporting someone with MND is challenging, but adding dependent children into the mix can stretch the caring role to its limits.



“MND has come as a massive shock and taken over my life. I had to leave my job as coping with four children and the progression of dad’s MND was just too hard.”

If you feel you need help to manage all the demands, ask for a carer’s assessment from your local authority or in Northern Ireland from your local health and social care trust.

See Section 4: Carer’s assessment and Section 8: Looking after yourself.

Key points

- Discussing MND with children and young people may feel difficult, but there is less chance they will feel isolated or blame themselves if they are kept informed.
- Try to ensure children and young people accept that no-one is to blame for MND.
- If an assessment of need has not been offered to the young carer, you can request one from your local authority or, in Northern Ireland, your local health and social care trust.
- Children and young people can learn life skills from care tasks and may find it positive to be involved.
- A lead teacher who supports young carers, or a teacher that the child trusts, can offer practical and emotional support at school.
- If a young person is employed, they may find it useful to let their employer know what is happening and find out about flexible working.
- If you are worried about how a child or young person is coping, ask your GP for advice. There may be a specialist organisation that can provide appropriate support. You can also contact our MND Connect helpline for guidance towards relevant help.

Further information

We produce a wide range of publications about MND and the support that may be needed. This includes resources for children, young people, parents and guardians. See **page 87** for details about these resources.

How to access publications and further information:

Most of our publications can be downloaded at: **www.mndassociation.org/publications** or you can order them from our MND Connect helpline:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

MND Connect can also help direct you to external services and providers, and introduce you to our services as available in your area, including branches and groups, Association visitors and regional staff.

See Section 11: *How the MND Association can help you for details about our services.*

Young Connect

Young people can also contact our helpline for support and information:

Telephone: **0808 802 6262**

Email: **youngconnect@mndassociation.org**

Or our services for children at the MND Association at: **cyp@mndassociation.org** which includes fast referral to counselling through a collaboration with Barnardos, where this would be appropriate.

MND Association - Young Person's Grant

We offer grants to help young people and young carers affected by MND. Contact our MND Connect helpline as listed on this page.

Online forum:

The forum provides an opportunity to share information and experiences with other people affected by MND. Hosted by the MND Association at:

<https://forum.mndassociation.org>

Please note, this forum is designed for adults to share information and you need to be 18 years or older to register.

Information for professionals

We provide information to help professionals support people with MND, their families and carers. This can be accessed at:

www.mndassociation.org/professionals

Useful organisations for children and young people

We provide a list of suggested organisations who offer services for children and young people in this guide.

See Section 12: *Useful organisations, which includes a separate list of providers for children and young people.*

Document dates:

Last revised: December 2021

Next revision: December 2024

Version: 1

Motor Neurone Disease Association
Francis Crick House, 6 Summerhouse Road,
Moulton Park, Northampton NN3 6BJ

Tel: 01604 250505

Website: www.mndassociation.org

Registered Charity No. 294354

Company Limited by Guarantee No. 2007023

© MND Association 2016

All rights reserved. No reproduction, copy
or transmission of this publication without
written permission.

For references and acknowledgements
please refer to the full guide, *Caring and
MND: support for you*.

The full guide can be ordered in hardcopy
from our helpline, MND Connect:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

**This resource has been evidenced,
user tested and reviewed by experts.**



Patient Information Forum