Support for families with children

Information for people with or affected by motor neurone disease or Kennedy’s disease

If you are a parent or guardian of school age children, and are living with or affected by MND or Kennedy’s disease you may be able to get help or financial support.

This information sheet explains the different types of support that may be available, and is split into the following sections:

1. How do we get our family needs assessed?
2. Can I get free meals or milk for my child?
3. Is there help with school uniform costs?
4. Can I get help to transport my child to school and back?
5. What other support is there at school?
6. What other benefits can I claim?
7. How can I find out more?

This symbol is used to highlight our other publications. To find out how to access these, see Further information at the end of this sheet.

This symbol is used to highlight quotes from other people with or affected by MND.

This information has been evidenced, user tested and reviewed by experts.
What do the words mean?

When reading this information, you may come across the following terms:

**Bursary:** a grant awarded to someone to enable them to study, for example at university or college.

**Development milestones:** behaviours or skills that develop at certain ages in infants and children as they grow.

**Discretionary:** the decision maker can choose how to apply rules based on a person's situation or needs.

**Emotional strength or resilience:** a person’s internal coping abilities to adapt to stressful situations and bounce back.

**Grant:** an amount of money given by an organisation to pay for a particular purpose such as studying. Grants do not always need to be paid back.

**Means tested:** this is where your income and savings are taken into account to work out the level of benefit you can claim. This only applies to some claims.

**Scheme:** a plan or arrangement that schools can get involved in. This can be by choice or in some cases schools may be required by Government to take part.

**Working tax credit 4-week run on:** the payment you may receive for a further four weeks after you stop qualifying for working tax credit.

For details about financial support, see: Information sheet 10A – *Benefits and entitlements*
Can I get any advice on benefits?

The MND Association Benefits Advice Service provides free, confidential and impartial advice on welfare benefits by phone and email for people living in England, Wales and Northern Ireland. There is also a webchat function for people in England and Wales.

This service is provided in partnership with Citizen’s Advice Cardiff and the Vale, and Advice NI, by qualified advisers who can help you identify benefits you may be entitled to and advise on how to claim. For more information, see: www.mndassociation.org/benefitsadvice

England and Wales

Telephone: 0808 801 0620
Email: through the benefits advice page on our website, at:
www.mndassociation.org/benefitsadvice

Northern Ireland

Telephone: 0808 802 0020
Email: through the benefits advice page on our website, at:
www.mndassociation.org/benefitsadvice

1:  How do we get our family needs assessed?

If you have MND or Kennedy’s disease and need care or help with daily living, ask for a needs assessment. If you care for someone with MND or Kennedy’s, ask for a carer’s assessment. These assessments can be requested from adult social care services and will determine if you qualify for support.

For details about your rights to support from adult social care services, see: Information sheet 10B – What is social care?

There are two other assessments available that may help families get more support. These are an early help assessment and a young carer’s needs assessment. Adult social care services have a duty to support disabled parents who may need help with parenting responsibilities.

Early help assessment

If you have MND and do not currently need care or support, you can ask for help to plan for the future needs of your family. If your child or another young relative is helping to care for or support you, you can ask for a young carer’s needs assessment.
**What is it?**

It is a way of gathering information to identify current and future needs. It can help families think about the sort of support they may find helpful now and later on as MND progresses. It gives social care services a chance to talk to you about any financial or practical support that may be available for your family. It also helps them to plan for extra support and services later on if you need them.

The assessment is for the needs of the whole family and for each child or young person in the family. It may help you and your family access the right support when you need it. Young people in the family may want to discuss their needs separately with a worker and provide their own information.

This support may help a child develop emotional strength to cope with existing and future challenges. An assessment should consider support to help your child:

- reach their development milestones
- build emotional strength.

It should also identify:

- children and young people who may become carers for an adult or a brother or sister
- disabled parents who may need support to care for their child now or in the future.

**Do I qualify?**

You must have children living at home and be:

- an adult needing care
- a carer for an adult living in your home who needs care
- a parent or guardian with MND or Kennedy’s disease who needs support with parenting responsibilities.

**How do I apply?**

Ask your local authority, or in Northern Ireland your health and social care trust for an assessment.
Young carer’s needs assessment

What is it?

An assessment for children or young people who provide care, or support an adult or another child in their family. It may provide early access to support and services to help your child.

It may include support from:

- a young carers organisation for respite breaks or to attend young carers groups
- a school nurse or pastoral support for health and wellbeing
- pupil premium for support to access help with learning (see section 5: What other support is there in school)
- talking or counselling services.

It may help you plan for emergencies and what to do if:

- your child becomes unwell and you cannot collect them from school
- you become unwell and need support to pick your child up from school.

Does my child qualify?

Your child may qualify if they help you or someone else with:

- practical jobs like cooking, shopping or housework
- personal care like washing or dressing
- physical care like helping a person walk or move around
- emotional support like talking to a person if they are upset
- giving medicine or collecting prescriptions
- communication if a person has no speech or needs help with translation
- caring for brothers and sisters.

“I'd go in and help with his catheter or anything else I could do, like helping him to eat or take medicines.”

How do I apply?

Ask your local authority or in Northern Ireland your health and social care trust for an assessment. You can ask for support to apply for a young carer’s needs assessment or more information from your local young carers group. Find local young carers groups at: www.carers.org.uk or www.carersuk.org
2: Can I get free meals or milk for my child?

If your family is on a low income and you receive certain benefits, you may be able to get school meals or milk for your child. The schemes available include:

- Healthy Start vouchers
- free school meals
- school milk.

**Healthy Start vouchers**

**What is it?**

Healthy Start is a UK-wide government voucher scheme. You can apply if you are pregnant or have children under 4 years old and have a low family income. You can swap your vouchers for fresh or frozen fruit and vegetables, fresh milk or infant formula milk. It is means tested.

Vouchers are sent by post and can be used in certain shops. You will be sent information about which shops accept the vouchers. You may get extra vouchers if you have children aged under one.

You may also receive vitamin coupons that can be swapped for free vitamins if you are pregnant or have children aged six months to four years old.

**Do I qualify?**

You need to be at least ten weeks pregnant or have children under four and receive one of the following benefits:

- Income Support
- income-based Jobseeker’s Allowance
- income-related Employment and Support Allowance
- Child Tax Credit and your income is £16,190 or less
- Universal Credit if your family earns £408 a month or less from employment
- Working Tax Credit, but only if your family is receiving the 4 week ‘run-on’.

You will also be eligible if you are pregnant and under 18, even if you don’t receive any benefits.
How do I apply?

Healthy Start vouchers are a means tested benefit. You can apply online at: [www.healthystart.nhs.uk](http://www.healthystart.nhs.uk) or contact 0345 607 6823 to request an application form. Your midwife, health visitor, doctor or nurse will need to sign your application form before you return it.

**Free school meals**

**What are they?**

If you are on a low family income, your child may be entitled to free meals at school. It is means tested.

**Do I qualify?**

**England**: if your child is in reception, year one or year two, they should automatically get free school meals. This is regardless of your income.

**England and Wales**: your child’s school may provide a free midday meal if you receive certain benefits:

- income-based Job Seekers Allowance
- income-related Employment and Support Allowance
- Income Support or Universal Credit
- Child Tax Credit if you do not get Working Tax Credit, with income of £16,190 or less
- Working Tax Credit 4 week ‘run-on’
- the guarantee part of Pension Credit
- support under part VI of the Immigration and Asylum Act 1999.

**Northern Ireland**: your child’s school may provide a free midday meal if you receive certain benefits:

- income-based Job Seekers Allowance
- income-related Employment and Support Allowance
- Income Support or Universal Credit
- Child Tax Credit if you do not get Working Tax Credit, with income of £16,190 or less
- Working Tax Credit 4 week “run-on”
- the guarantee part of Pension Credit
- your child has a statement of special educational needs and is designated to require a special diet for example blended food or gluten free
- your child is a boarder at a special school
- support under part VI of the Immigration and Asylum Act 1999.

**How do I apply?**

Contact your local authority or child’s school for help applying for free school meals.

Let the school or college know if your child qualifies for free school meals. The school or college may benefit by being able to claim pupil premium to support your child and other children’s learning. See section 5: *What other support is there at school?*

### Free school meals in further education

**What is it?**

Your child may be able to claim free school meals if they are 16 to 18 years old and still at school or college. It is means tested.

**Do I qualify?**

Your child needs to receive certain benefits in their own right:
- Income Support
- income-based Job Seeker’s Allowance
- income-related Employment and Support Allowance
- Universal Credit.

**How do I apply?**

Contact your child’s school or college to find out how to apply for free meals.

The school or college may benefit by being able to claim pupil premium to support your child and other children’s learning. See section 5: *What other support is there at school?*

### School milk

**What is it?**

Your child’s nursery or school may provide 250ml of milk for each child per day if they take part in this scheme.
Do I qualify?

**England:** schools may provide subsidised milk to children. If your child gets means tested free school meals, then milk should also be free. Milk may be available to all children under five at schools taking part in this scheme.

**Wales:** key stage one children should automatically get free school milk. In other schools and colleges, the governing body may decide to provide milk but might charge parents or guardians.

**Northern Ireland:** the education authority has to provide free school milk for children:
- attending special schools
- in schools where school meals are not provided
- with a medical certificate stating that milk is a necessary part of their diet, for example a child who may need extra milk as a substitute due to a restricted diet.

How do I apply?

Ask if your child's school or nursery takes part in the scheme and how to apply. You can apply for school milk up to two months before your child starts school.

**Northern Ireland:** contact the education authority in your region.

“Money can cause arguments for many families, but MND creates such pressure. Our finances were stretched and I know mum felt guilty because she couldn’t always give us what we wanted or needed as kids.”

3: Is there help with school uniform costs?

You may be entitled to support with school uniform costs if you are on a low income.

**School uniform subsidy**

**What is it?**

You may be able to get help to buy part of your child’s school uniform, school shoes or sports kit. Help and arrangements can vary depending on where you live, it is means tested and may include:
- full support with uniform, non-uniform clothes, shoes and sports kit
- school uniform only
- a one-off grant when the child starts school
- regular grants as the child grows
• vouchers to swap for items of uniform
• free second-hand clothing
• a school shop selling second-hand uniform
• discretionary funding from the school’s governing body or parents’ association.

Do I qualify?

**England and Wales:** if you have a low family income you may be able to get help to pay towards school uniform if your child goes to school, a college for further education or sixth form.

**Northern Ireland:** if you are on a low income and your child goes to primary, post primary or a special school, a grant may be available as part of a clothing allowance scheme. One grant is offered for each child per year.

How do I apply?

**England or Wales:** contact your child’s school or your local council for help applying.

**Northern Ireland:** contact the education authority in your region for help applying.

4: Can I get help to transport my child to school and back?

You may be entitled to support with getting your child to and from school.

**Free school transport**

What is it?

Your local authority, or in Northern Ireland the education authority can decide to provide free transport to school if your child qualifies.

If transport is necessary, it should be available:

• free of charge
• for the whole journey
• when there is no safe walking route to school.

The types of transport provided include:

• local authority transport, or education authority transport in Northern Ireland
• hire coaches
• free bus or train passes for use on public transport
• a travelling allowance, for example a cycle allowance
• a car allowance paid to an agreed drop off and pick up point.

**Do I qualify?**

You may get help if your child is aged 4 to 16 years old and:

• is under eight years old (under 11 in Northern Ireland) and you live more than two miles from school
• is eight years old or over (11 or over in Northern Ireland) and you live more than three miles from school
• has any special needs
• receives free school meals, although this may vary
• you are a disabled parent or guardian
• the school route is only safe when accompanied
• your disability prevents you from accompanying your child to school.

Your health and social care team may be asked to provide extra information to help the local authority or in Northern Ireland the education authority make a decision.

If you don’t qualify, your child may be allowed to travel on spare seats on school buses. A charge may be made for this.

**How do I apply?**

**England or Wales:** contact your local authority to apply. You can also ask for information about any other schemes that help with travel costs if your child attends sixth form or college.

**Northern Ireland:** contact your education authority.

**5: What other support is there at school?**

There are different types of support available at school, depending on the age of your child. They include:

• free childcare places
• pupil premium
• school grants
• financial support for young people continuing in education
• emergency and hardship funds.
Free childcare places

What is it?

If your child is aged three or over they may be entitled to free education or childcare as part of an early education government scheme. Places may be in a:

- nursery
- nursery class or reception class in a primary school
- playgroup
- private day nursery
- independent school
- or provided by a childminder in an approved network.

**England**: if your child is three or four you can get up to 570 hours of free education or childcare. This is normally spread out over 38 weeks. This means you can get 15 hours a week in term time.

**Wales**: if your child is three you can get up to 10 hours a week free childcare each term.

**Northern Ireland**: if your child is three or four they can get free early education places. The amount of hours a week during school term may vary.

You will have to pay for extra hours if you want to send your child for longer. If your child is two years old you may also be able to get help with childcare if you claim certain benefits.

Do I qualify?

You may qualify if you receive:

- Income Support
- income-based Job Seeker’s Allowance
- income-related Employment and Support Allowance
- Universal Credit
- Tax Credits if your annual income is under £16,190 before tax
- the guarantee part of state Pension Credit
- support through part VI of the Immigration and Asylum Act
- Working Tax credit 4-week ‘run on’.
Or your child:

- is looked after by social care services
- has a current statement of special educational needs or an education, health and care (EHC) plan
- gets Disability Living Allowance
- has left care under a special guardianship order, child arrangements order or adoption order.

**How do I apply?**

**England or Wales:** contact your local authority and ask for the local family or children information service for details of schools and groups. The schools and groups in the scheme can tell you how to apply for a place and what they offer. If you can’t find a space for your child, contact your local authority for help.

**Northern Ireland:** contact your education authority. Places and hours available can vary depending on where you live.

**Pupil premium**

**What is it?**

Pupil premium is extra money that schools can apply for. This money is paid as a grant to the school. It can be used to support one child or a whole school. It should directly benefit a child by helping them achieve their best in school.

Schools may decide to use the grants to pay for:

- one-to-one or small group support for children
- employing an extra teaching assistant to work in class
- extra homework clubs for key subjects like maths and English
- starting a school breakfast club to improve attendance
- enrichment activities such as music lessons for children whose families cannot afford this
- school trips and visits
- buying equipment to help children’s learning, such as laptops or tablets
- emotional or wellbeing support
- speech and language therapy.
Does my child qualify?

The school will be able to apply for this extra funding to support your child if they:

- receive free school meals
- are in care or have left care
- have a parent in the armed forces
- have a parent who receives an armed forces service pension.

The school may decide to apply for and use pupil premium funds to support your child’s emotional wellbeing. They may also apply if your child is a young carer.

How do I apply?

Ask your child’s school if your child qualifies. They will tell you what to do to register your child for pupil premium. You can apply once a year, but your child needs to qualify each time.

School grants

What is it?

If you have a low family income you may be entitled to a grant to help your child get involved in other activities offered at school. This is means tested. The amount of money available is likely to be limited.

Grants may be given for:

- activities or items which are not part of the school curriculum
- the cost of items for enrichment activities, such as a musical instrument or football boots
- travel costs to attend an interview for continued education or a job interview.

Do I qualify?

Ask your school if your child qualifies and what help is available.

How do I apply?

Ask your child’s school for help applying.
Financial support for young people continuing in education

What is it?

If your child is continuing their education at sixth form, college or university they may be entitled to a range of:

- grants
- bursaries
- discretionary bursaries.

Some of these may be means tested.

Wales and Northern Ireland: education maintenance grants are also available.

Money can be used to help pay for:

- sixth form or college expenses
- tuition
- course fees
- room and board
- travel costs
- books
- anything else students may need money for.

Do I qualify?

Ask your child's sixth form, college or university if they qualify.

How do I apply?

Your child's sixth form, college or university can tell you what type of financial support they offer and how to apply. They can also give you details of how this is paid.

Emergencies and hardship funds

What is it?

Your child's school, college or university may have a separate hardship fund. You may be able to get extra help if circumstances change, or your child has an emergency. This is means tested.
Some charities give grants to parents to help with the costs of education. Grants may be available to help with school items, school uniform or school trips. You may need to meet certain criteria to qualify for a grant. If the grant is discretionary, the amount of money may be limited.

**Do I qualify?**

Ask your local authority, in Northern Ireland your local health and social care trust or your social worker to find out if you qualify. They can tell you about other grants that may be available.

**How do I apply?**

You can apply for any grant if you think you may qualify. Apply early in the academic year if possible. If you have been unsuccessful before you can reapply if your circumstances change.

6: **What other benefits can I claim?**

There are also certain benefits that you may be entitled to if you are responsible for a child or children.

**Child Benefit**

**What is it?**

Child Benefit is a payment to help with the cost of caring for a child. You can claim Child Benefit for every child you are responsible for. You do not have to be the child’s parent to claim.

**Do I qualify?**

You can claim for each child:

- under 16 years old
- under 20 years old if they are in approved full time education or training.

If you or your partner earn more than £50,000 a year you will have to pay tax on these payments. Payments will stop if your child:

- starts paid work of more than 24 hours a week
- leaves approved full time education or training
- starts an apprenticeship.
How do I apply?

To claim Child Benefit, complete form CH2 online or download and print it off to send to the Child Benefit Office. Search for Child benefit at: www.gov.uk or contact HMRC:

Telephone: 0300 200 3100
Textphone: 0300 200 3103

Child Tax Credit

What is it?

Child Tax Credit is a payment to help people on a low income with the cost of bringing up children. This is a means tested benefit, however Child Tax Credit doesn’t affect your Child Benefit.

Do I qualify?

You need to be over 16 years of age to apply and have either:

• a child under 16 years old
• a child under 20 years old and in full time education or training.

The amount you get also depends on:

• your income
• if your child has a disability
• the number of children you have living with you.

When you apply for Child Tax Credit, you will be told if you qualify for Working Tax Credit too. You can’t claim Child Tax Credit if you receive Universal Credit.

How do I apply?

Search for Child Tax Credit at: www.gov.uk or contact the Tax Credit Office for a claim form:

Telephone: 0345 300 3900
Textphone: 0345 300 3909

For details about Universal Credit and Working Tax Credit, see: Information sheet 10A – Benefits and entitlements
Guardian’s Allowance

What is it?

Guardian’s Allowance is paid to a person bringing up a child who is not theirs. This includes children who are related to the person or adopted children. It is tax free and paid for each child on top of child benefit.

Do I qualify?

You can claim Guardian’s Allowance if:

- both of the child’s parents have died (unless one parent has died and the second is missing or in prison)
- you already claim Child Benefit for the child
- one of the child’s parents was born in the UK (or lived in the UK since they were 16 for 52 weeks in a two year period).

How do I apply?

Search for Guardian’s Allowance at: www.gov.uk to download a claim form or contact:

Telephone: 0300 200 3101
0300 200 1900 Welsh language
Textphone: 0300 200 3103

7: How can I find out more?

Organisations that could help

Your local family or children’s information service can give advice about any other local support or services that may help. Contact your local authority or in Northern Ireland your health and social care trust for details. Local services may include:

- childcare providers
- holiday schemes
- local activities or events for children and families
- adult social care services for support for disabled parents.
Useful organisations

We do not necessarily endorse any of the following organisations, but have included them to help you begin your search for further information. The contact details are correct at the time of print, but may change between revisions. If you need help to find an organisation or have any questions, contact our MND Connect helpline (see Further information at the end of this sheet for details).

Advice NI
Provides free advice on welfare changes and benefits for people in Northern Ireland.
Address: 1 Rushfield Avenue, Belfast BT7 3FP
Telephone: 0808 802 0020
Website: www.adviceni.net

Chicks
A charity providing free, week long respite breaks for bereaved children, young carers and children living in low income families in the UK.
Address: CHICKS Head Office, Brentor, Tavistock, Devon PL19 0LX
Telephone: 01822 811020
Email: info@chicks.org.uk
Website: www.chicks.org.uk

Citizens Advice
Free, confidential and independent advice on legal and money problems.
Telephone: 03444 111 444 (for England, or contact your local Citizens Advice Bureau)
03444 772 020 (for Wales)
Text Relay: 03444 111 445
Website: www.citizensadvice.org.uk
www.citizensadvice.org.uk/wales (Wales)
www.citizensadvice.org.uk/nireland (Northern Ireland)

Education Authority
Online help about local education authorities in Northern Ireland.
Website: www.eani.org.uk

Family Action
A charity providing welfare grants, educational grants and information for families.
Address: Family Action Head Office, 24 Angel Gate, City Road, London EC1V 2PT
Telephone: 020 7254 6251
Email: grants.enquiry@family-action.org.uk
Website: www.family-action.org.uk
**Family Holiday Association**
A charity providing British seaside breaks and day trips for families living with challenging circumstances.

Address: Family Holiday Association, 3 Gainsford Street, London SE1 2NE
Telephone: 020 3117 0650
Email: info@FamilyHolidayAssociation.org.uk
Website: [www.familyholidayassociation.org.uk](http://www.familyholidayassociation.org.uk)

**Glasspool**
Professionals supporting families can apply for small hardship grants.

Address: Glasspool, Saxon House (2nd Floor), 182 Hoe Street, Walthamstow, London E17 4QH
Telephone: 020 3141 3161
Email: grants@glasspool.org.uk
Website: [www.glasspool.org.uk](http://www.glasspool.org.uk)

**Healthy Start helpline**
Information about the Healthy Start scheme, and how to apply for vouchers.

Address: Freepost RRTR-SYAE-JKCR, Healthy Start Issuing Unit, PO Box 1067, Warrington WA55 1EG
Telephone: 0345 607 6823
0846 607 6823 (Northern Ireland)
Website: [www.healthystart.nhs.uk](http://www.healthystart.nhs.uk)

**The St Vincent de Paul Society (SVP)**
An organisation that may be able to offer some financial assistance.

Address: The St Vincent de Paul Society, 9 Larcom St, London SE17 1RX
Telephone: 020 7703 3030
Email: info@svp.org.uk
Website: [www.svp.org.uk](http://www.svp.org.uk)

**Turn2us**
A national charity that helps people in financial hardship access welfare benefits, charitable grants and support services.

Address: Turn2us, Hythe House, 200 Shepherds Bush Road, London W6 7NL
Website: [www.turn2us.org.uk](http://www.turn2us.org.uk)

**References**

References used to support this document are available on request from:
Email: infofeedback@mndassociation.org

Or write to: Information feedback, MND Association, PO Box 246, Northampton NN1 2PR
Acknowledgements

We would like to thank the following and their colleagues for their kind support and guidance with this information:

Patrick Buckingham, Education Adviser, Action for Carers, Surrey
Marie Gilmore, Welfare Reform Team Leader, Advice NI, Northern Ireland
Dayne Owens, Adviser and Trainer, Citizens Advice Cardiff and the Vale

Further information

You may find the following information sheets from the MND Association helpful:
4A – Communicating about MND with children and young people
10A – Benefits and entitlements
10B – What is social care?

We also provide the following publications:

So what is MND anyway? – Our guide for young people and young carers. This is also available as a web app at: https://cypapp.mndassociation.org/

Supporting children and young people close to someone with motor neurone disease (MND) – for any professional working with children and young people who have a parent, guardian or relative with MND.

When someone close has MND – Activity workbook to help children understand about the disease and develop ways to cope, with guidance from a trusted adult.

You can download most of our publications from our website at:

www.mndassociation.org/publications or order in print from the MND Connect helpline, who can provide further information and support.

MND Connect can also help locate external services and providers, and introduce you to our services as available, including your local branch, group, Association visitor or regional MND Association staff.

**MND Connect**
Telephone: 0808 802 6262
Email: mndconnect@mndassociation.org
MND Association, PO Box 246, Northampton NN1 2PR

**MND Association website and online forum**
Website: www.mndassociation.org
Online forum: http://forum.mndassociation.org or through the website
Web hub for children and young people
Provides information about MND, support options and news for children and young people  www.mndassociation.org/ypinfo

Young Connect helpline
The Association helpline for children and young people.
Telephone: 0808 802 6262
Email: youngconnect@mndassociation.org

Young person support grants
We offer a grant of up to £250 a year for young people aged 18 or under. Grants can be used towards anything that improves the life of a child or young person, such as a day out or money towards an item like a laptop or mobile phone.
Telephone: 0808 802 6262
Email: support.services@mndassociation.org

We welcome your views
Your feedback is really important to us, as it helps improve our information for the benefit of people living with MND and those who care for them. If you would like to provide feedback on any of our information sheets, you can access an online form at: www.smartsurvey.co.uk/s/infosheets_1-25

You can request a paper version of the form or provide direct feedback by email: infofeedback@mndassociation.org

Or write to: Information feedback, MND Association, PO Box 246 Northampton NN1 2PR