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About the NICE guideline on motor neurone disease

Information for people with or affected by motor neurone disease


The National Institute for Health and Care Excellence (NICE) provides national guidance and advice to improve health and social care. Part of this work includes publishing clinical guidelines that make recommendations about treatment and care for specific diseases and conditions.

In 2016, NICE released its clinical guideline (NG42) on the assessment and management of motor neurone disease (MND). This replaces a previous NICE guideline (CG105, published July 2010), which only covered non-invasive ventilation. There is also a NICE quality standard (QS126), which sets out the priority areas for quality improvement in health and social care for MND.

The NICE guideline on MND applies to anyone with MND, aged 18 or over, and their carers. It does not cover other nerve-related conditions or Kennedy's disease.

This information sheet is about the NICE guideline on MND (NG42) and includes the following:

- 1: **What are NICE guidelines?**
- 2: **What is the NICE guideline on MND?**
- 3: **How can the guideline help me?**
- 4: **What does the guideline cover?**
- 5: **How do 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.

"This patient guide accurately reflects recommendations in the NICE guidance on motor neurone disease. It also supports statement 1 in the NICE quality standard for motor neurone disease."

National Institute for Health and Care Excellence, August 2019

1: What are NICE guidelines?

NICE guidelines are produced by a team of experts, known as a guideline development group, using the best possible evidence. Guidelines are used by the NHS and other bodies to develop standards, assess their practice and support education and training.

NICE guidelines give recommendations about treatment, care and support based on the best available research evidence, with the aim of improving the quality of health and social care and promoting best practice among professionals.

Recommendations made by NICE are not a legal requirement, but should be taken into account by health and social care professionals alongside:

- other professional guidelines, standards and law
- your individual needs and preferences
- the need to protect people from abuse.

More information about NICE and their guidelines is available from their website. See *Useful organisations* in section 5: *How do I find out more?* for contact details.

2: What is the NICE guideline on MND?

The guideline covers the assessment and management of MND, and aims to improve care from the time of diagnosis. The NICE guideline on MND covers England. However, the standards and recommendations are also recognised in Wales and Northern Ireland as best practice. Topics include:

- diagnosis
- organising your care
- psychological and social support
- changes to thinking and behaviour
- muscle problems and exercise
- equipment and adaptations
- communication
- nutrition and tube feeding
- saliva

- breathing
- non-invasive ventilation (NIV)
- coughing
- planning for end of life.

The NICE guideline stresses your rights, and those of your carers, to be involved in discussions and make informed decisions about your care.

Always ask if you need any kind of health and social care information at a relevant appointment. If you are disabled, you may require this information in a particular format, such as large print or easy-read. Health and social care services in England must now provide information in a format you can access. For more details, search for *accessible information standard* at:

www.england.nhs.uk

3: How can the guideline help me?

You can check if you are receiving suitable treatment and care by using the NICE guideline on MND. Being familiar with the guideline can help you and your carer to:

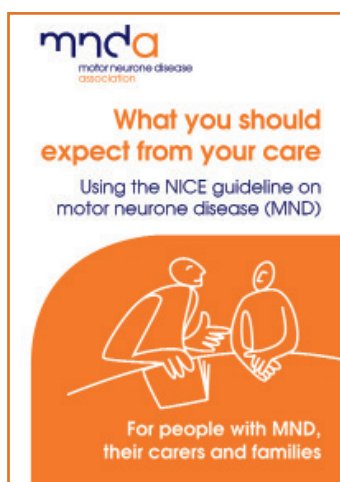
- recognise what good care should look like
- have better discussions with healthcare professionals about your care
- make informed decisions
- challenge decisions with more confidence.



“Now we have the NICE guideline, every person living with MND who points it out to health and social care professionals is making a short-term practical step towards improving standards of care.”

It also gives health and social care professionals evidence-based information to help them provide better care for people with MND.

The MND Association will use the guideline in its campaigning work to ensure it is used to improve standards of care for people with MND.



We have created a pocket-sized booklet to support discussions with your health and social care professionals about your treatment and care. This is based on the main points from the NICE guideline. We include the pocket booklet in the folder of our larger guides on MND.



For more information, see:
What you should expect from your care

What can I do if my needs are not being met?

If you are not receiving the care or treatment you need, discuss this first with the relevant health or social care professional or provider. If this does not improve the situation, make a formal complaint or appeal to the service involved. They should be able to provide information or advise how to do this.

See *Useful organisations* in section 5: *How do I find out more?* for some organisations that may be helpful in this situation.

Or, refer to our webpage at: www.mndassociation.org/mycare

4: What does the guideline cover?

The following information gives an overview of the NICE guideline on MND. For more detailed information, see the guideline or the extended version, with the methods and evidence used. NICE have also produced a version of the guideline specifically for patients.

These are available from the NICE website at: www.nice.org.uk/guidance/ng42
See *Useful organisations* in section 5: *How do I find out more?* for full contact details.

Diagnosis

This topic is covered in section 1.1 and 1.2 of the guideline.

The guideline recommends that healthcare professionals should recognise the symptoms of MND, and that the condition affects people in different ways.

It highlights potential first symptoms of MND, including:

- speech or swallowing problems
- twitching or rippling sensations in the tongue
- muscle problems, such as weakness, wasting, twitching, cramps and stiffness and the impact of muscles problems, such as clumsiness in your hands or trips and falls
- breathing problems, such as shortness of breath or other breathing symptoms, and the impact of breathing difficulties, such as excessive daytime sleepiness, fatigue, early morning headache or shortness of breath when lying down
- changes to thinking, reasoning and behaviour, including frontotemporal dementia (FTD) which affects a small number of people with MND
- laughing or crying at inappropriate times, known as emotional lability.

Healthcare professionals should know who to refer you to if they suspect you have MND and make the referral without delay. You, your family and carers should be offered information and support throughout the diagnosis process.

You should be given your diagnosis by a neurologist with up-to-date knowledge of MND. They should set aside enough time to discuss any concerns or questions you may have and arrange a follow-up appointment with a member of the multidisciplinary team (MDT) within four weeks. See next heading *Organising your care* for more information about MDTs.

If you have any social care needs, they should refer you to adult social care services for an assessment, or your carer for a carer's assessment.

They must ensure people are provided with information about MND and support at diagnosis or when you ask for it. Information should be oral and written, and may include:

- what MND is, likely symptoms and how these can be managed
- how the disease is likely to progress
- where your appointments will be, which professionals will be involved and waiting times
- local services (including social care and specialist palliative care services) and how to get in touch with them
- local support groups, online forums and national charities, and how to get in touch with them
- your legal rights, including social care support, employment rights and benefits
- who you need to inform of your diagnosis, such the Driver and Vehicle Licensing Agency (DVLA)
- who to contact between appointments, during 'out of hours' or in an emergency
- how you can plan for your future care, known as advance care planning.

Organising your care

This topic is covered in section 1.5 of the guideline.

The guideline recommends that you should be given a single point of contact for the specialist MND multidisciplinary team (MDT).

An MDT is where a range of health and social care professionals work together to provide care and support. This allows them to share information more easily and co-ordinate your care more effectively.

The specialist MND team could be based at a clinic, usually in a hospital, or in the community. You may have appointments with them as separate individuals, but they should liaise about your treatment and care.

The team should include staff with expertise in MND, including a:

- neurologist
- specialist nurse
- dietitian
- physiotherapist
- occupational therapist
- breathing physiologist or a healthcare professional who can assess your breathing
- speech and language therapist
- professional with expertise in palliative care (with knowledge and training in helping people with life shortening diseases).

In addition, the specialist MND team should have access to a range of other professionals and teams you may need support from, including:

- clinical psychology and neuropsychology
- social care
- counselling
- ventilation services to help with your breathing
- specialist palliative care
- a gastroenterologist for help with the management of your nutrition and tube feeding
- orthotics who provide braces, splints and other items that support the limbs or spine
- wheelchair services
- assistive technology services, who are experts in aids and equipment that assist with daily living
- alternative and augmentative communication (AAC) services, who are specialists in various methods of communication if you have speech problems
- community neurological care teams.

The specialist MND team should carry out regular, co-ordinated assessments of your symptoms and needs. Your individual needs should be taken into account when they tailor how often they assess and review your particular symptoms. They will continue to be involved in your care and you will not be discharged from their caseloads.


Although it is difficult to predict the progression of MND, healthcare professionals should consider the likely course when planning your care. They should understand that MND can progress quickly. They should think about what equipment and support you might need, before you need it, and regularly review your needs.

Psychological and social support


This topic is covered in section 1.6 of the guideline.

Living with MND can involve a range of emotional challenges and changes that may be difficult to cope with. The guideline recognises the emotional and psychological impact of MND.

At your appointments, healthcare professionals should talk with you about the thoughts and feelings that you and your family have about MND. The guideline gives suggestions of topics to discuss. Healthcare professionals should offer you information about how to access support, and refer you on to counselling or psychology services if needed.

 For more information about managing difficult emotions with MND, see: Information sheet 9C - *Managing emotions*

They should offer your family and carers information about how to access support to take breaks from caring (known as respite care), their right to a carer's assessment and other sources of help.


 For detailed information about support for carers, see our guide: *Caring and MND: support for you*

Changes to your thinking and behaviour

This topic is covered in section 1.3 of the guideline.

Up to half of people with MND experience some changes to how they think and behave. These changes affect people in different ways. For many people, the changes are usually subtle and have little or no effect on daily life. For some, the changes may be more apparent and intensive support may be needed to manage daily routines. A small number of people with MND develop a condition called frontotemporal dementia (FTD).

The guideline states that healthcare professionals should explore any changes to your thinking or behaviour with you, your family and carers. Discussions should be tailored to your needs, taking into account your communication, understanding and ability to make decisions for yourself. You should be referred for a formal assessment if needed.

 For more information about changes to thinking and behaviour with MND, see: Information sheet 9A - *Will the way I think be affected?*

Muscle problems and exercise

This topic is covered in section 1.8 of the guideline.

People with MND can experience muscle problems including cramps and pain. The guideline recommends medications that your healthcare professionals should consider to help relieve these symptoms.

Professionals should review whether the treatment is working and monitor for any side effects you may experience. If these medications do not work for you, you should be referred to a specialist service for further support.

The guideline also recommends that healthcare professionals consider a suitable exercise programme for you. This may help to maximise the use of muscles not yet affected by MND, to reduce stiffness and discomfort and maintain movement in your joints.

Any exercise should be tailored to your needs, abilities and preferences. The professional recommending the programme should check whether your family or carers are able to support you with your exercises, if needed, and offer them advice and equipment to support them to lift and move you safely.



For more information about exercise and MND, see:
Information sheet 6A - *Physiotherapy*

Equipment and adaptations

This topic is covered in section 1.9 of the guideline.

The guideline recommends that your daily living needs, such as personal care, shopping, meals and housework, should be assessed and reviewed. This will help get support and equipment in place for when you need it.

Equipment or building works can make your home more suitable for your needs and help you to continue to live there. These changes are known as adaptations. Healthcare professionals should consider your home environment and mobility, and consider whether you need any adaptations.

Equipment and adaptations should take into account likely changes in the future and be readily adapted to cope with these changes. They should also consider the use of other assistive technology, such as environmental control systems which can help you operate your lighting, door entry, appliances etc.

Equipment, including wheelchairs if needed, should be provided without delay. Any items of equipment should be reviewed regularly to ensure they are still suitable for you. You should be referred to specialist services for equipment if your needs are more complex.



For more information, see:
Information sheet 11C – *Equipment and wheelchairs*

Communication

This topic is covered in section 1.11 of the guideline.

MND can cause weakness in the tongue, lips, vocal cords and chest, causing your speech to become faint, slurred or unclear. The guideline recommends that a speech and language therapist should assess and review your communication ability without delay.

All of your communication needs should be considered, including face-to-face discussions, phone and email. You should be referred for a specialist assessment if your needs are more complex. Communication aids that meet your needs should be provided as quickly as possible. Both low-tech and high-tech options should be considered.

If appropriate, the speech and language therapist should involve other professionals to ensure your communication aid works well alongside any other equipment you may have, such as environmental controls.

There should be ongoing support and review of your communication needs and use of communication aids.



For more information about speech and communication aids, see:
Information sheet 7C – *Speech and communication support*

Nutrition

This topic is covered in section 1.10 of the guideline.

MND can cause difficulties with eating and drinking. Muscles in your throat and mouth may become weak, slow or uncoordinated. This can affect your ability to chew and swallow, leading to weight loss, dehydration and lack of energy.

The guideline recommends that your weight and ability to eat and drink should be assessed and monitored. This should take into account any equipment you use and whether you need someone to help you eat or drink. It should also consider your seating, positioning and posture.

The guideline recommends you are referred for an assessment if swallowing difficulties are suspected. You should be offered support, information, advice and interventions to support you with your nutrition if needed.

Some people with MND choose to have a feeding tube. This is a way of passing fluids, specially prepared liquid feed and medication straight into your stomach through a tube in your abdomen.

The guideline recommends that tube feeding should be discussed early, as there are more risks if you choose to have one fitted later on. Your healthcare professionals should explain this to you. If you choose to have a feeding tube fitted, the guideline recommends that the operation to insert the tube should take place as quickly as possible.



For more information, see:
Information sheet 7A – *Swallowing difficulties*
Information sheet 7B – *Tube feeding*
Our *Eating and drinking with MND* guide

If someone with MND no longer has the ability to make decisions for themselves, the neurologist should discuss with their family and consider whether or not tube feeding is appropriate.

If you wish to ensure you do not have a tube fitted, even in an emergency, you can state this in an Advance Decision to Refuse Treatment (ADRT). This tells people involved in your care which treatments you want to refuse in the future and will only be used if you become unable to make decisions or communicate for any reason.



For more information about making advanced decisions, see:
Information sheet 14A - *Advance Decision to Refuse Treatment (ADRT) and advance care planning*

Saliva

This topic is covered in section 1.8 of the guideline.

Some people with MND find that they have problems with their saliva. If this is the case, you may experience:

- pooling of thin, watery saliva
- discomfort if saliva collects at the back of the throat
- saliva leaking out from the mouth if you are unable to close your lips fully
- dehydration, if the fluids you lose are not replaced
- thick, sticky saliva which is difficult to clear from your mouth and throat.

If you have problems with saliva, healthcare professionals should assess your:

- saliva, for example the amount and thickness
- breathing
- swallowing
- diet
- posture
- mouth care.

The guideline suggests options for managing and treating saliva problems.


Breathing

This topic is covered in section 1.12 of the guideline.

MND can affect the muscles involved in breathing. The guideline recommends that your breathing should be assessed and monitored. If you have breathing difficulties and tests show you may benefit, you should be offered a trial of non-invasive ventilation (NIV).

See next heading *Non-invasive ventilation (NIV)* for more information.

You should receive support and information to recognise and cope if you have times of breathlessness, and how psychological techniques, support and medication may help.


 For more information about breathing, ventilation and MND, see Information sheets 8A-D

Non-invasive ventilation (NIV)

This topic is covered in section 1.14 of the guideline.

Non-invasive ventilation (NIV) uses a portable machine to support your breathing. The machine helps boost the flow of air into your lungs, using a mask that covers your nose, or your nose and mouth.

The guideline recommends that healthcare staff discuss NIV with you soon after your diagnosis and on an ongoing basis, explaining the advantages and disadvantages. They should be clear that, although it can help with breathing difficulties and may prolong your life, it will not stop the progression of MND. They should explain that you may become dependent on NIV.

 For more information about breathing and ventilation, see: Information sheets 8A to 8D

Before you start using NIV, the specialist MND and respiratory teams should prepare a detailed care plan and discuss it with you and your family and carers.


The plan should include information about:

- how you will be supported
- how often your NIV will be reviewed
- how to maintain the equipment
- who to contact for technical or clinical support.

Your family and carers should be asked whether they are willing to assist in providing NIV and what training they might need. They should have the opportunity to discuss any concerns with members of the specialist MND or the respiratory team, or another relevant professional.

Your healthcare team should explain that NIV can be stopped at any time you choose and that help and advice is available. If you wish to stop using NIV, you should be supported by professionals with knowledge and experience of stopping NIV, end of life care and the legal framework. If withdrawing NIV is causing distress, they should offer medication to help.

If you wish to ensure you do not receive ventilation, even in an emergency, you can state this in an Advanced Decision to Refuse Treatment (ADRT). This tells people involved in your care which treatments you want to refuse in the future and will only be used if you become unable to make decisions or communicate for any reason.

 For more information about making advanced decisions, see:
Information sheet 14A - *Advance Decision to Refuse Treatment (ADRT) and advance care planning*

Coughing

This topic is covered in section 1.13 of the guideline.

If you have difficulty clearing mucus from your chest, you should be shown breathing exercises and techniques to help you improve the strength of your cough. If these are not effective for you, you should be offered support through use of a machine to help you cough.

Planning for end of life

This topic is covered in section 1.7 of the guideline.

MND is a progressive life-shortening condition. You should be given opportunities to discuss your concerns and preferences about care at the end of your life, whenever you want to.


Healthcare professionals should take into account how you feel and whether you are ready to have discussions about this.

The guideline suggests times when it might be appropriate to talk about end of life, including at diagnosis, if your symptoms change significantly, or if you need to think about tube feeding or ventilation. You should receive support and advice about how you can plan in advance for your future care, and the guideline gives suggested topics for discussion.

You should be given additional support as end of life approaches. This could include additional care support to help your family spend more quality time with you. Healthcare professionals should ensure you have access to any specialist support, equipment and medications you may need.

 For more information about planning for the end of life, see our guide:
End of life: a guide for people with motor neurone disease

The guideline also recommends that your family should be offered bereavement support after you die.

 For more information about bereavement, see:
Finding your way with bereavement

5: How do I find out more?

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).

Care Quality Commission (CQC)

Independent regulator of health and social care in England. Contact CQC if you are concerned about care from a provider in England. The site can also be used to search for care services, such as nursing homes.

Address: CQC National Customer Service Centre, Citygate, Gallowgate, Newcastle upon Tyne, NE1 4PA

Telephone: 03000 616161

Website: www.cqc.org.uk

Care Inspectorate Wales (CSSIW)

Regulate and inspect to improve care and social services for people in Wales. Contact CIW if you are concerned about care from a provider in Wales. The site can also be used to search for care services, such as nursing homes.

Address: Welsh Government office, Sarn Mynach, Llandudno Junction, LL31 9RZ

Telephone: 0300 7900 126

Email: CIW@gov.wales

Website: www.cssiw.org.uk

Community Health Councils

For confidential advice and making a complaint about healthcare in Wales.

Website: www.wales.nhs.uk/sitesplus/899/home

GOV.UK

Online government advice on a variety of welfare topics for people in England and Wales, including support for disabled people. (See NI Direct for Northern Ireland.)

Website: **www.gov.uk**

Health and Social Care Northern Ireland (NHS Northern Ireland)

Information on health and social care services in Northern Ireland. This is an online service only.

Website: **<http://online.hscni.net/>**

Health in Wales

Information on NHS services in Wales, including a directory of the Welsh health boards.

Website: **www.wales.nhs.uk**

MND Scotland

MND Scotland provides support and information for people affected by MND in Scotland.

Address: 2nd Floor, City View, 6 Eagle Street, Glasgow G4 9XA

Telephone: 0141 332 3903

Email: info@mndscotland.org.uk

Website: **www.mndscotland.org.uk**

NHS 111

The NHS telephone service for urgent, but not life-threatening medical help or advice. Available 24-hours a day, 365 days a year.

Telephone: 111 (England and some areas of Wales)

NHS Direct Wales

Health advice and information service for Wales.

Telephone: 0845 4647 (or 111 if available in your area)

Website: **www.nhsdirect.wales.nhs.uk**

NHS UK

The main online reference for the NHS.

Website: **www.nhs.uk**

NI Direct

Providing government information for people in Northern Ireland on a variety of welfare subjects, including health services and support for disabled people.

Website: **www.nidirect.gov.uk**

National Institute for Health and Care Excellence (NICE)

Provides national guidance and advice to improve health and social care.

Address: 10 Spring Gardens, London SW1A 2BU

Telephone: 0300 323 0140

Email: nice@nice.org.uk

Website: **www.nice.org.uk**

Patient Advice and Liaisons Service (PALS)

Offers confidential advice, support and information on health-related matters in England, including making complaints. They also provide a point of contact for patients, their families and carers.

Website: www.nhs.uk/chq/Pages/1082.aspx

Patient and Client Council

For confidential advice and making a complaint about healthcare in Northern Ireland.

Address: 2nd Floor, Centre House, 79 Chichester Street, Belfast, BT1 4 JE

Telephone: 0800 917 0222

Email: info.pcc@hscni.net

Website: www.patientclientcouncil.hscni.net

Regulation and Quality Improvement Authority (RQIA)

Responsible for monitoring and inspecting the quality of health and social care services in Northern Ireland. Contact RQIA if you are concerned about care from a provider. The site can also be used to search for care services, such as nursing homes.

Address: 9th Floor Riverside Tower, 5 Lanyon Place, Belfast, BT1 3BT

Telephone: 028 9536 1111

Email: info@rqia.org.uk

Website: www.rqia.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 for their kind assistance:

Professor Christopher J McDermott, Consultant Neurologist, University of Sheffield

Rachael Marsden, Care Centre Coordinator, Oxford MND Care Centre

Professor David Oliver, University of Kent

Dr Aleksandar Radunovic, Consultant Neurologist and Honorary Clinical Senior Lecturer and Director, Barts MND Centre

Further information

See the NICE guideline for motor neurone disease at:
www.nice.org.uk/guidance/ng42

See the NICE quality standard for motor neurone disease at:
www.nice.org.uk/guidance/qs126

You may find these information sheets from the MND Association helpful:

7A – *Swallowing difficulties*

7B – *Tube feeding*

7C – *Speech and communication support*

8A – *Support for breathing problems*

8B – *Ventilation for motor neurone disease*

8C – *Withdrawal of ventilation*

9A – *Will the way I think be affected?*

9B – *How do I support someone if the way they think is affected?*

9C – *Managing emotions*

11C – *Equipment and wheelchairs*

14A – *Advance decisions to refuse treatment (ADRT)*

We also provide the following guides:

Living with motor neurone disease – our guide to help you manage the impact of the disease

Caring and MND: support for you – comprehensive information for unpaid or family carers who support someone living with MND

Caring and MND: quick guide – the summary version of our information for carers

End of life: a guide for people with motor neurone disease – includes Information to help people plan ahead for end of life.

Finding your way with bereavement – our booklet on finding emotional support when bereaved. Includes a practical overview of what to do when someone dies and supporting children and young people who may also be grieving.

We also provide the following tools that you may find useful:

What you should expect from your care – our pocket-sized booklet to support discussions with health and social care professionals, containing the main points from the NICE guideline on MND.

Understanding my needs – a tool to help health and social care professionals to understand how MND affects you

MND alert card – a card to carry in your pocket, purse or wallet that states you have MND and provides details of your emergency contacts

MND checklist – a tool to help you manage your condition and think ahead

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 care development adviser.

 **MND Connect**
Telephone: 0808 808 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

We welcome your views

Your feedback is really important, as it helps us to develop new materials and improve our existing information, for the benefit of people living with MND and those who care for them. Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns and applications for funding.

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



Created: 08/19
Next review: 08/22
Version: 1

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