Let's talk about alpha-mannosidosis with schools:

Guide for parents and caregivers

Preparing for school meetings and ensuring support for children and young people with alpha-mannosidosis

This guide is intended for **parents and caregivers,** to support children and young people up to age 25 from early education to higher education.

This booklet has been funded by Chiesi Global Rare Diseases and developed by Rare Disease Research Partners in collaboration with MPS Society UK, ISMRD, and reviewed by educational specialists and people with alpha-mannosidosis (AM) and their caregivers. Everyone involved received a fee for their consultancy advice, except for people with AM and their caregivers, who kindly shared their invaluable time and expertise voluntarily.

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PLACEHOLDER
FOR PATIENT PHOTO

Children and young people with alpha-mannosidosis often face challenges in communication, learning, social interaction, and physical participation at school. These challenges can affect their confidence, progress, and wellbeing.

As a parent or caregiver, you know your child the best and play a vital role in ensuring they receive the right support. Schools have a legal duty to provide reasonable adjustments and inclusive education under various legislations. You can therefore request assessments, support plans, and adaptations to help your child thrive.

What is this guide for?

This guide can help you to:

- Prepare for meetings with teachers and school staff
- Share important information about your child
- Understand what support is available
- Work together with school staff
- Identify gaps and request additional support

The aim of this resource is to provide information and strategies for supporting children and young people with alpha-mannosidosis, to achieve their full educational potential in a learning environment that is right for them

Making the learning environment work for your child

Type of educational setting: all students respond uniquely to different learning environments – understanding which ones work best for your child may help with identifying an appropriate mainstream or specialist school. There is no "right" or "wrong" with choosing a school, so long as your child is feeling happy, supported and able to reach their full educational potential.

Support at school: schools should make reasonable adjustments to ensure that children and young people with additional needs are not disadvantaged.

Educational/Individual Support Plan (ESP/ISP): if your child needs additional support, you can request an ESP/ISP. The plan outlines their needs, the adjustments or support they require and the resources the school can provide to meet these needs.

Being involved: as a parent or a caregiver you have a right to be involved in decisions about your child's education. The school should meet with you regularly to talk about your child's progress and any adjustment to the support they need.

Hints and Tips for parents: Preparing for a meeting with school

Write down your child's needs and strengths: Think about what your child finds easy, what is challenging, and what support helps them most. The information below may help guide you with this.

Gather reports or medical letters: Bring any documents that explain your child's needs, such as medical letters, assessments, or previous school reports.

Make a list of questions: Write down any questions you want to ask the school, so you don't forget anything during the meeting.

Information about the child or young person that you may want to share with school

How my child communicates

It can help the teacher to understand how your child or young person communicates at home. You may wish to share:

- Their preferred communication style (e.g. verbal, gestures, devices, visual supports)
- Hearing or speech challenges
- Sensory needs
- Strategies that support their understanding (e.g. step-by-step instructions)
- How they indicate when they need clarification or a short break to refocus

You can use this space to note any observations you would like to share with school.

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How my child learns best

Everyone learns differently. This section helps you share practical information with school about how your child or young person learns, processes information, and stays organised, so they can be better supported in the classroom.

What is their learning style?
You may wish to share with school if the child or young person could benefit from:

☐ Visual support (pictures, charts, diagrams)

☐ Hands-on learning or movement-based activities

☐ Extra time

☐ Step-by-step instructions

☐ Written instructions for homework/assignments

☐ Other ....

Do they need support staying organised?
Consider whether they need help staying organised (e.g. tracking homework, afterschool activities, sports uniform or equipment). This might include:

☐ Using calendars, planners or digital reminders

☐ Colour-coded systems (e.g. folders of the same colour for one subject) to support independence and help them stay organised

☐ Prompts to remember homework, equipment or schedules

What is their processing speed?
You can also describe their processing speed, as classroom explanations may feel too fast to keep track of. To process information efficiently, they may need:

☐ Slowly paced and/or written explanations

☐ Repetition

☐ Time to review material with support

☐ Additional time to respond to questions

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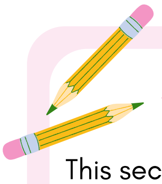

What support they may need in the classroom

This section is to help teachers understand how to best support your child or young person in the classroom. You might consider sharing information about:

Is there a hearing, visual or sensory issue?

☐ Do they need an amplification system?

☐ Would sitting closer to the front help?

☐ Are they sensitive to noise?

How do they cope with changes in their schedule?

They may be particular about their expected schedule and feel safer when every day is very similar.

☐ Do they follow a reliable routine?

☐ Do they need warnings before changing environment (e.g. moving from the classroom to the playground or assembly hall)?

☐ What helps them feel safe when things change unexpectedly?

Do they need emotional support?

- How do they make friends and take part in group activities?
- What helps them stay calm and confident?
- How can adults recognise signs of worry, frustration, or overstimulation?
- What strategies work for managing emotions or mental health challenges (e.g. low self-esteem)?

Do they get distracted or hyper-focused?

If there are distractions around them, staying on task can be challenging. Equally, they may hyper-focus on one task.

☐ What triggers distraction (e.g. movement, noise, peers)

☐ Do they sometimes focus so much on one task that starting a new one is difficult?

☐ Would timers or visual countdowns help?

How do they interact with others?

Some children find socialising at school easy, while others may need support. For example, some enjoy noisy playgrounds, while others can become overstimulated. Think about:

- What helps them feel comfortable with peers in class or on the playground?
- Do they get overstimulated or need quiet breaks?
- What signs show they may need help from the teacher?

Notes:

What are their strengths and interests?

Sharing this with the teacher can help support your child or young person:

- Favourite activities, topics or books
- Hobbies and things that motivate them
- Activities that help them calm down when anxious
- Skills they are proud of

What medical or physical support they need

This section helps the school understand any medical or physical support your child may require during school hours. You can check off or make notes about the points listed below.

Symptoms and medication

You may want to note:

- Important symptoms for staff to watch for
- Fatigue or tiredness, which is common in alpha-mannosidosis
- Medication schedules
- Any changes noticed by the teacher should be reported to the parent or caregiver without delay

How easily can the child or young person move around and participate in physical activities?

☐ Can the child or young person access and move independently around classrooms, corridors and playgrounds?

☐ Do they need assistance? (e.g. support from a peer to carry their books, help with their wheelchair, can they access a lift)

☐ Can physical education or sports activities be adapted to their needs?

☐ Can group activities be modified to allow full participation?

How are absences and missed assignments handled?

Sickness or regular appointments with health services, to be monitored or to receive treatment, can be frequent. You may want to note:

- How can they catch up on missed lessons?
- Will extra time be given for class work and homework, if absent?
- Preferred communication and process for managing absences due to illness or appointments

Notes:

Questions parents and caregivers may want to ask the school

These questions may help you understand your child or young person's support options and ensure your voice is included in decisions. You can select the ones most relevant for your next meeting:

Understanding school support

- ☐ What support does my child need to reach their goals?
- ☐ What support is available at school or locally?
- ☐ How will you meet my child's needs?
- ☐ How do you monitor and review progress?
- ☐ How will you keep me updated?
- ☐ What can I do to support them at home?

Learning and classroom support

- ☐ How is the child or young person's learning style considered in lessons?
- ☐ Are lessons or activities adapted for their needs?
- ☐ How do you support them when tasks are difficult or frustrating?
- ☐ How do you help them stay focused or manage distractions?
- ☐ Are there organisational systems already set up in school?

Educational/Individual Support Plans (ESP/ISP)

- ☐ How will I know if my child needs an ESP/ISP?
- ☐ How will I be involved in the process?
- ☐ What can I do if I feel my concerns are not being heard?
- ☐ What if my child is told they do not need an ESP/ISP?
- ☐ Will an existing ESP/ISP continue into higher education?
- ☐ How often is the ESP/ISP reviewed?
- ☐ Can I request a review? How?

Health and physical needs

- ☐ How do you manage the child or young person's daily medical or physical needs?
- ☐ Who is responsible in emergencies or medical situations?
- ☐ How are absences due to illness or appointments handled?

Mobility and physical activity

- ☐ Can they move independently around school?
- ☐ Can sports and group activities be adapted for their physical needs?

Social and emotional support

- ☐ How do you support the child or young person in making friends?
- ☐ How do you handle situations when they feel anxious, upset, or overwhelmed?
- ☐ Are quiet spaces or strategies for breaks available if needed?

Communication and involvement

- ☐ How often can we meet to discuss updates about my child's needs?
- ☐ Who can I contact if I have questions or concerns between meetings?
- ☐ How are decisions about support communicated to me and my child?

Notes:

Notes about the child or young person that I would like to share with the teacher or school

Use this space to write down anything you would like the teacher or school to know about your child or young person, or any questions you may have. You might include how alpha-mannosidosis affects them day-to-day, any recent experiences or changes at home or in their health, positive milestones or achievements, challenges they are facing, or any other information that helps the teacher understand your child or young person's daily life and needs.

You can provide your teacher or school with the booklet **Let's talk about alpha-mannosidosis for schools and educational settings**. You can download this booklet here:

If you live in the UK: MPS Society

If you live in the US: ISMRD

! If you are unable to scan the QR codes, links are provided on page 10

Contact and Communication Plan

Who at school do I talk to about my child's needs?

Name: ....
Role: ....
Phone Number: ....
Email: ....

Name: ....
Role: ....
Phone Number: ....
Email: ....

Useful contacts for the school

Here you can add the contact details of healthcare teams such as occupational health, speech and language and your specialist medical team, which the school may need to engage with

Name: ....
Role: ....
Phone Number: ....
Email: ....

Name: ....
Role: ....
Phone Number: ....
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Notes:

Meeting schedule

Meeting date	With whom?	Topics for discussion (e.g. child’s hearing, review of Educational/Individual Support Plan)

You can print or download this leaflet here:

If you live in the
UK: MPS Society

If you live in the
US: ISMRD

If you are unable to scan the QR codes, please use these links:
If you live in the UK: http://www.mpssociety.org.uk/conditions/research/alpha-mannosidosis-patient-and-caregiver-resources
If you live in the US: www.ismrd.org/glycoprotein-diseases/alpha-mannosidosis/#patientresources

Where can I get more information about alpha-mannosidosis?

MPS Society UK: http://www.mpssociety.org.uk/conditions/related-conditions/alpha-mannosidosis
ISMRD: http://www.ismrd.org/glycoprotein-diseases/alpha-mannosidosis/

The MPS Society (**www.mpssociety.org.uk**), the Society for Mucopolysaccharide Diseases, is the only registered charity providing professional support to individuals and families affected by MPS, Fabry and related lysosomal conditions in the UK. We are committed to transforming lives through specialist knowledge, support and research, making sure anyone affected by these conditions gets to live the life they want.

ISMRD (**www.ismrd.org**), the International Society for Mannosidosis and Related Diseases, is an internationally focused not-for-profit organization whose mission is to advocate for families and patients. We are The International Advocate for Glycoprotein Storage Diseases. Our mission, through partnerships built with medicine, science and industry, is to seek, detect and cure these diseases while providing a global network of support and information.

Rare Disease Research Partners (**www.rd-rp.com**) is a wholly owned, not for profit subsidiary of the MPS Society. Its social objectives are to reinvest any surplus to support the mission of the MPS Society to transform the lives of patients through specialist knowledge, support, advocacy and research.

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