Let's talk about alpha-mannosidosis

for schools and educational settings

A brief overview for schools, educational settings and their teachers on how to support the learning and wellbeing of children or young people with alpha-mannosidosis

This guide is intended 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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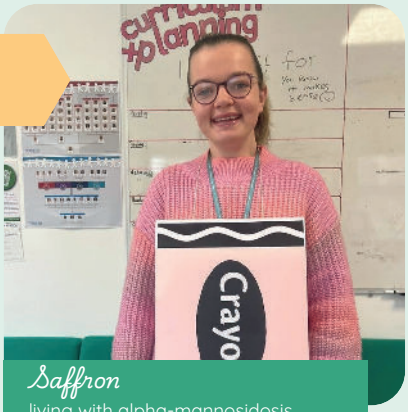
living with alpha-mannosidosis



Saffron
living with alpha-mannosidosis

What is alpha-mannosidosis?[1,2]

Alpha-mannosidosis is a **very rare genetic condition** that affects one in a million babies. It is present from birth and is passed on from their parents. The condition can **affect the brain and many parts of the body**, and symptoms usually become more noticeable as a child grows. Alpha-mannosidosis is a **progressive** condition, meaning that new symptoms may appear over time, and existing symptoms may change or get worse. While there are currently no treatments to cure alpha-mannosidosis, therapies that can help manage symptoms and improve daily life for patients are available.

Each child's experience with alpha-mannosidosis is unique.[1]

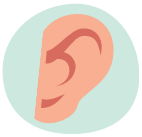
The aim of this resource is to provide information and strategies for supporting children and young people with alpha-mannosidosis, to achieve their full educational potential in a learning environment that is right for them

Signs and symptoms of children and young people with alpha-mannosidosis[1-3]

Every student with alpha-mannosidosis is different. Signs and symptoms vary from one person to another and, because it is a progressive condition, new symptoms may appear in future as they develop.

Body-related symptoms: bones, joints and muscle strength can be affected. These can make walking, movement and coordination more difficult.

Recurrent infections: infections are likely to develop, such as colds, chest infections or ear infections.



Hearing: hearing difficulties are common; these can lead to speech, learning and communication challenges.

Thinking, learning, and communication: cognitive and communication abilities may be affected. Over time, most children will develop some level of learning difficulty, which may affect thinking, processing, understanding, memory or speech. Older children may experience stress and/or anxiety.

Vision: eye symptoms, such as reduced vision, may develop over time.

Teacher Tip

If you notice any changes in the child or young person's behaviour, attention, or learning, always let parents or caregivers know. For example, if they are not paying attention, it may not be misbehaviour but signs of a new symptom (such as hearing loss, vision changes or increased fatigue). Early recognition will help your student get the support they need.

IMPORTANT REMINDERS:

- **Every person with alpha-mannosidosis is different:** a child may not show certain symptoms now, but new challenges can appear as they grow and may be noticed later on during their school years.
- **Be mindful of potential bullying:** teachers have an ethical duty to investigate and address any disability-based bullying/harassment.

What are the desired educational outcomes for children and young people with alpha-mannosidosis?

Before planning classroom strategies, it is important to understand the key educational goals for students with alpha-mannosidosis. These outcomes provide a clear focus for teaching approaches and interventions, ensuring that support is both purposeful and inclusive.

- Access to a curriculum that is right for the student
- Better understanding, retention and recall of key instructions and information
- Increased ability to work independently
- Enhanced listening, attention and focus
- Ability to record and present information in a variety of ways
- Greater confidence and self-esteem, with reduced anxiety
- Stronger social inclusion and participation in school life

Planning for children and young people in your educational setting: what teachers need to know

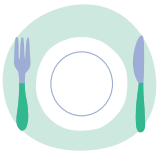
The following tables outline common symptoms and challenges that children and young people with alpha-mannosidosis may experience, along with practical strategies that teachers and school staff can use to support them in the classroom. This guidance is designed to help each student take part fully in school life and achieve their educational potential.

Common physical symptoms of alpha-mannosidosis[1-3]	How it may affect learning or relations with peers	What the teacher should watch out for	How the school and teacher can help
Hearing difficulties *Can impact students at any age, but most commonly starts to impact **young children***	• Hard to hear the teacher's instructions or their friends, especially when noisy • May misunderstand words • Delays in speech/language development • Loss of attention, anxiety	• Asking for instructions to be repeated • Not responding when called • Appearing distracted or tired • Not understanding content covered during lessons	• Reduce background noise • Get their attention first (seat them near the teacher, call their name before speaking, gently tap) • Speak facing them and at their eye-level • Use slow, clear speech and break instructions into small steps • Repeat information and give extra time for responses • Access to teaching assistant and/or assistive technology (e.g. laptops, speech-to-text, AI tools)
Recurrent infections *Can impact students at any age, but most commonly starts to impact **young children***	• May miss school often due to illness	• Frequent absences	• Be flexible with homework deadlines • Provide home learning materials where possible • Coordinate with parents on health needs
Physical difficulties **(bones, joints, muscles)** *Can impact students at any age, but most commonly starts to impact **children and adolescents***	• Difficulty moving around school, using stairs or playground equipment • Difficulty eating or toileting • Difficulty participating in Physical Education (PE)/gym class	• Fatigue • Avoiding physical activity • Trips or falls – clumsiness	• Adapt PE/gym classes and playground activities • Provide physical support, including support during lunch/snack times and toilet breaks, where needed • Allow extra time to move between classrooms and seat them near exits if mobility is limited • Access to teaching assistant to support safe transfer around school
Vision problems *Can impact students at any age*	• Trouble seeing board, printed materials, books or visual aids	• Squinting • Leaning close to materials	• Seat them near the board and teacher • Ensure good lighting • Provide enlarged text or visual aids if needed

Common cognitive impacts of alpha-mannosidosis[1-3]	How it may affect learning or relations with peers	What the teacher should watch out for	How the school and teacher can help
Communication difficulties *Can impact students at any age, but most commonly starts to impact **young children***	• Unclear speech • Difficulty understanding others and/or forming responses • Reduced social inclusion	• Mispronounced words • Difficulty expressing ideas • Withdrawn in group activities	• Model correct speech and repeat phrases • Allow extra time for verbal responses • Use visual supports (e.g. gestures, task boards, pictures) • Encourage participation in a supportive way • Access to speech therapy, if available
Cognitive and learning difficulties *Can impact students at any age, but most commonly starts to impact **children and adolescents***	• Difficulty learning new concepts or following instructions • Difficulty focusing or remembering lessons • Struggling to keep up with peers	• Slow to respond • Difficulty following multi-step instructions • Trouble remembering information	• Seat them close to the teacher, so they can see and hear clearly • Give extra time for processing and completing tasks • Use visual aids, simple instructions, and overlearning opportunities • Break tasks into smaller steps and provide clear deadlines • Adapt curriculum and provide a personalised learning plan • Pair with a work buddy for peer support • Use calendars, schedules and reminders • Access to teaching support worker and technology to support working
Slow processing *Can impact students at any age, but most commonly starts to impact **children and adolescents***	• Difficulty understanding instructions • Taking longer to process information and answer questions • Feeling anxious or overwhelmed • Slower social interactions	• Needing more time to respond • Avoiding participation • Appearing stressed during timed tasks	• Provide structured routines, prewritten class notes/instructions and written homework instructions • Assign quiet spaces for taking exams • Focus on one task at a time and break into small steps • Use clear, simple language, written instructions or visual cues (reminders, lesson plans, guidance sheets, short lists of key learnings, speech to text apps) • Include them in class activities without pressure to respond rapidly (pause and allow time for them to respond, or instead of asking for raised hands, ask them to write down ideas, giving plenty of time) • Provide opportunities for repeat learning and recapping (to help retention) and emailing questions or comments after class
Social, emotional and mental health challenges *Can impact students at any age*	• Feeling frustrated, anxious, or having low self-esteem • Struggling with social interactions	• Withdrawal from peers • Signs of frustration or anxiety	• Provide emotional/mental health support (feelings fans, exit cards, allowing a service animal if appropriate) • Encourage peer support, mentoring and inclusion • Foster confidence through achievable goals • Recognise and celebrate small achievements

Additional support

Nutrition and personal care at school



Some children or young people with alpha-mannosidosis may need support with eating and drinking at school. This could be due to difficulties with chewing or swallowing, fatigue, coordination or a higher risk of choking.

Some children or young people may need help with toileting at school due to mobility challenges, coordination difficulties, fatigue or continence issues. Appropriate support should be put in place as needed, to help ensure their safety, comfort, dignity and full participation in the school day.

If a child or young person is identified as needing additional support with eating, drinking or toileting, the school should carry out a review to assess how best to support them, which may include in-person supervision, adapted food, specialist equipment or extra time to eat/use the toilet.

Educational support plans

Does the child have an Educational Support Plan in place?

YES

- **Involve parents:** meet regularly with their parents or caregivers to discuss observations about the child or young person and evaluate the plan's effectiveness
- **Revise and update:** regularly review and adjust the plan to reflect the current or changing needs of the child or young person, and asses the quality of the support provided

NO

- **Can you provide** for the child or young person's needs to be met with the current resources available at your school or educational setting?
- **Do you need to apply** for an Educational Support Plan?

Supporting the transition from early to higher education

Changing schools can be challenging for children and young people with alpha-mannosidosis. This is often due to significant changes, such as loss of teachers familiar with their needs, assumptions that they will be more independent, less one-to-one supervision, having to deal with multiple teachers and classrooms, a larger school environment, increased academic demands, loss of peer groups and making new friends.

Schools can provide support to help ease this transition. Educational Support Plans should be reviewed yearly to ensure they are up to date. Any educational transition planning should be started two years before transferring to a higher education provision.

People and services who can provide additional information and support

- The child or young person's metabolic or genetic healthcare teams
- Therapists, including physiotherapists, occupational therapists (OT) and speech and language therapists (SALT)
- Educational psychologists and neuropsychologists
- Local support services
- Behaviour support teams: can help the child or young person to learn skills and strategies to help them in class or during playtime
- Patient groups and patient organisations: for advice, resources and peer support

You can provide your student's parents with the booklet **Let's talk about alpha-mannosidosis with schools: guide for parents and caregivers**. 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 8

Teachers notes

You can use this space to note any questions or observations that you would like to discuss with the parents or caregivers of the student with alpha-mannosidosis, as well as any support you think they may need or benefit from.

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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/

1. Ficicioglu C, Stepien KM. Alpha-Mannosidosis. 2001 [Updated 2024]. In: Adam MP, Feldman J, Mirzaa GM, et al. GeneReviews® [Internet]. Seattle (WA): University of Washington, Seattle; 1993-2024. 2. Malm D, Nilssen Ø. Alpha mannosidosis. *Orphanet J Rare Dis.* 2008; 3(1):21. 3. Malm, D, et al. The natural course and complications of alpha-mannosidosis-a retrospective and descriptive study. *J Inherit Metab Dis.* 2014;37(1):79-82.

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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