Alpha-mannosidosis Diary

A resource for people with alpha-mannosidosis and their caregivers to keep track of the medical and life journey

This Diary has been funded by Chiesi Global Rare Diseases and developed by Rare Disease Research Partners in collaboration with MPS Society UK, ISMRD, a metabolic nurse, and reviewed by 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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Take a moment to reflect

Keep your diary in hand and fill in each section as soon as you can.

You can print extra copies of specific pages if you need more space.

Keeping everything together makes it easier to stay informed about your care and ensures you have all the information ready whenever you meet your healthcare professional or support team.

How can I use this diary?

This diary is designed to help people living with alpha-mannosidosis and their caregivers keep all important information in one place.

You can use it to:

- ✓ **Plan and stay organised:** record appointments, treatments, therapies and changes to medications.
- ✓ **Keep track of your health and wellbeing:** note symptoms, moods, energy levels, and any changes you notice.
- ✓ **Record questions and support:** write down questions for your healthcare team or other support services and keep contact details for people, companies and organisations who help you.
- ✓ **Prepare for appointments:** bring this diary to your visits so you can share updates and get answers to your questions.
- ✓ **Track your journey over time:** see patterns, progress, and important moments in your care and daily life.

You can print a copy of these pages or download an editable PDF to your phone, tablet or laptop from:

If you live in the UK please use this QR	If you live in the US please use this QR
MPS Society	ISMRD

If you are unable to scan the QR codes, links are provided on page 13

Disclaimer: This diary serves as tool to help people with alpha-mannosidosis and/or their caregivers to record important information in one place. This diary does not provide medical advice; always consult a healthcare professional with any medical concerns.

About me

Me and my healthcare

This is your space to share a little about yourself (Tick ✓or add notes where relevant).

I am completing this diary as:

☐ A person with alpha-mannosidosis

☐ The caregiver of a person with alpha-mannosidosis

Your care team contact details:

Main hospital: ....

Phone: ....

Email: ....

Local/community hospital: ....

Phone: ....

Email: ....

Risks/important alerts:

☐ Back issue, may need caution with anaesthesia, scans, x-rays

☐ Airway issues

☐ Feeding tube

☐ Seizures or episodes of confusion

☐ Heart problems

☐ Immune issues (e.g. infection risk, vaccines may not work well)

☐ General allergies: ....

....

....

☐ Medication allergies: ....

....

....

☐ Other: ....

....

....

....

....

....

....

....

Information about my AM:

Age when signs or symptoms started: ....

Date of diagnosis: ....

Age at diagnosis: ....

Emergency contact details:

Name: ....

Relationship: ....

Phone number: ....

What is important for people who support me to know?

☐ I have hearing difficulties
  ☐ I use a hearing device
  ☐ The person speaking to me may need to face me
  ☐ I need someone with me to support me

☐ I have sight difficulties
  ☐ I may need large print
  ☐ I may need assistance

☐ I have memory difficulties. I may need reminders or help understanding care

☐ I need support communicating

☐ I need help walking or moving around and I use:
  ☐ Wheelchair or mobility scooter
  ☐ Walking aid, such as crutches, cane, walking frame, help from another person
  ☐ Other: ....

☐ I am difficult to cannulate

☐ I have a port/ PICC line/central line

Location: ....

When it was placed: ....

Other important information for the care team to know:

....

....

....

My symptoms or health issues

Use this section to keep a record of any new symptoms, changes in your health, or illnesses you experience.

Writing them down helps you remember what's happened and can be very useful during appointments, **so your healthcare professional can see patterns or new issues over time**. For example, how often you've had infections or what's changed since your last visit.

Description of symptom or health issue (e.g. ear infection, cold, aches, difficulty moving around)	**Date it started**	**How long it lasted for?** (e.g. ongoing, currently 5 weeks)	**My notes** (e.g. possible triggers, did you see the doctor, what checks were performed, what type of medication did you take, how it made you feel, how it impacted your daily life)

My therapies and assistive equipment

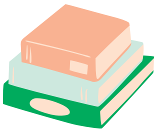
Use this space to record any therapies you usually receive or assistive equipment you use to help manage your symptoms and support your daily life.

Recording your therapies and assistive equipment helps you and your healthcare team **see what support you're using, track what works best, and make sure you get the right help when you need it**.

Therapy (e.g. physiotherapy, diet, speech and language therapy)	**Date first received/ how often**	**Who provides this therapy?**	**My notes**

Assistive equipment (e.g. hearing aid, wheelchair, CPAP or BiPAP machine)	**Date of first use**	**Who supplies me with this equipment?**	**My notes** (e.g. does it need maintenance/change batteries, do I need to be monitored for its use, any issues, etc.)

My special education plan



Use this space to record any special education plans that you have had during your learning journey, such as support received at school, college, or other educational settings.

Keeping track of education plans is especially useful for school-age children when parents, caregivers or students need to gather information for medical appointments, or when reviewing or updating plans with the school. **Having everything in one place makes it easier to share relevant details and advocate for the right support**.

Setting (e.g. nursery, school, college, etc.)	**Plan type**	**Date of last review**	**Support provided** (e.g. extra time on tests, one-to-one support, interventions, note-taking assistance, access to assistive technology, etc.)

My medication tracker

Use this space to keep track of all your usual medications and share important information with your healthcare team. Remember to let them know if there are any side effects, medication allergies, etc.

Keeping track of your medications may help you **stay on schedule, remember what you've taken and what it was for, and keep your healthcare team up to date** with clear information so they can give you the best care.

Medication name and dose (e.g. 50 mg)	**How is it given, how often do I need to take it?**	**Date started** **Date stopped**	**My notes** (e.g. it's helping my leg pain)

My tests tracker

Use this section to keep a record of all your test results in one place.

Keeping track of your tests helps you and your healthcare team **see changes over time and make sure nothing is missed when monitoring your health**.

Test (e.g. hearing test, oligosaccharide levels in urine, neuropsychological, electrocardiogram)	**Date**	**Reason for test**	**Results summary**	**Follow-up actions**

My hospital admissions and surgeries

Use this section to record any time you were admitted to a hospital, whether for an emergency, a planned procedure, or surgery. Note why you went to the hospital and any care you needed afterward.

Keeping a record of your hospital visits and surgeries helps you and your healthcare team **see your medical history, spot patterns, and plan the right care when you need it**.

Type of admission	**Hospital location/ name of healthcare professional**	**Reason for admission** (e.g. what happened, routine test, what was being treated)	**Dates** (admission/ discharge)	**Treatment or surgery performed**	**My notes** (e.g. aftercare and follow-up)
☐ Emergency ☐ Planned ☐ Surgery					
☐ Emergency ☐ Planned ☐ Surgery					
☐ Emergency ☐ Planned ☐ Surgery					
☐ Emergency ☐ Planned ☐ Surgery					
☐ Emergency ☐ Planned ☐ Surgery					
☐ Emergency ☐ Planned ☐ Surgery					
☐ Emergency ☐ Planned ☐ Surgery					

My medical care and support teams

Use this space to record everyone involved in your care and how to contact them, so you can reach the right person when you need help.

Alpha-mannosidosis medical team

Record details of your specialist alpha-mannosidosis medical team (e.g. main consultant, specialist nurse, genetic counsellor, home health team).

Name:
Role:
Hospital:
Email:
Contact number:

Name:
Role:
Hospital:
Email:
Contact number:

Name:
Role:
Hospital:
Email:
Contact number:

Name:
Role:
Hospital:
Email:
Contact number:

Name:
Role:
Hospital:
Email:
Contact number:

Name:
Role:
Hospital:
Email:
Contact number:

Other important sources of support

Keep track of all the helpful people, services, and organisations that help you along the way (e.g. patient organisations, health insurance, psychologist, support services).

Type of support:
Organisation/company name:
Contact name:
Email:
Contact number:

Type of support:
Organisation/company name:
Contact name:
Email:
Contact number:

Type of support:
Organisation/company name:
Contact name:
Email:
Contact number:

Type of support:
Organisation/company name:
Contact name:
Email:
Contact number:

My appointments with healthcare professionals

Use this section to keep track of all your appointments with your alpha-mannosidosis team, specialists, nurse or any other healthcare professional.

Keeping a record of appointments helps you **stay organised, remember your appointments, and share accurate information with your healthcare team** when needed.

Date/time of appointment	**Name/ Profession**	**Phone/email**	**Location/address**	**My notes** (e.g. purpose of the visit, follow-up)

If you are visiting a healthcare professional who is not familiar with alpha-mannosidosis, you may find useful resources to bring to your appointment for both yourself (Let's talk about alpha-mannosidosis with your healthcare team), and to give to your healthcare professional (Let's talk about alpha-mannosidosis for healthcare professionals) by using the links and QR codes provided on page 13.

Questions to ask the medical or support teams

This is a space to write down any questions that come to mind. Keeping track can help you remember everything and makes sure you can ask the right person, whether is a healthcare professional, nurse, physiotherapist, social services, patient organisation, or anyone who is supporting you.

Why keeping track of the question you may have matters: **writing your questions down means nothing gets forgotten and you can get the answers and support you need.**

Who do I want to ask? (e.g. physiotherapist, patient organisation)	**Questions I would like to ask**	**Note here the response to your question**

Take a moment to reflect

My notes diary

This is your space to write down anything that matters to you. You can include notes about your health, energy levels, support you've received, or anything else you notice, like sleep, appetite, or any concerns, but also anything that has helped you or has led to an improvement or positive experience. You may want to share some of the things that matter to you with your medical team, patient organisation or other support teams.

Date:

Date:

Date:

How do I feel today?

Take a moment to check-in with yourself.

Choose the emoji that best matches your mood.

Month:

Why taking a moment to reflect matters?
Keeping track and sharing during appointments how you feel over time means you and your healthcare team can work together to keep you feeling your best.

	Happy ☺☺	OK ☺	In-between 😐	A bit worried ☹	Not so good ☹☹	Notes
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						
11						
12						
13						
14						
15						
16						
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22						
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24						
25						
26						
27						
28						
29						
30						
31						

Where can I get more information and support?

You can find other resources for people living with alpha-mannosidosis and their caregivers here:

If you live in the UK please use this QR code or link:

www.mpssociety.org.uk/conditions/research/alpha-mannosidosis-patient-and-caregiver-resources

MPS Society

If you live in the US please use this QR code or link:

www.ismrd.org/glycoprotein-diseases/alpha-man-test/#patientresources

ISMRD

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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