

How to use these pages

Choose only the pages that help you. Print a fresh copy whenever your plan changes.

2. Symptom timeline

Make a short record of episodes, including well days and changes over time.

3. Appointment agenda

Choose your most important questions and gather useful records.

4. Daily impact

Record fatigue, sleep and missed activities separately from symptom scores.

5. School or work conversation

Describe functional needs and agree on practical support.

6. Portable care summary

Keep key facts together when you change clinicians or travel.

7. Monitoring plan

Ask your clinician to complete what is needed, when and who follows up.

8. Treatment conversation

Clarify goals, safety, cost and what to do when problems arise.

9. Travel, refills and transition

Make a plan before a supply runs out or care moves.

10. A plan for illness or a flare

Complete with your care team; this blank worksheet is not a treatment order.

These original worksheets are organizational aids, not diagnostic tests or validated disease-activity measures. They are not the AIDAI. Find the separate AIDAI diary and its instructions on the website.

Do not delay urgent assessment to finish a form. For severe breathing difficulty, fainting, confusion or rapidly worsening illness, seek emergency care.

Keep completed pages private. Share with your care team, not in website comments.

My symptom timeline

A concise history can help when symptoms have passed before the appointment.

When symptoms began; diagnosis or working diagnosis (if any):

Usual duration, frequency and how I feel between episodes:

Dates / duration	Symptoms / measured temperature	Medicine / response

Record the temperature and how it was measured. Note infections, exposures or changes in medicines without assuming they caused the episode. Attach dated photos or reports if helpful.

What has changed recently? What was different from my usual pattern?

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My appointment agenda

Bring this page, a current medication list and the records requested by your clinic.

My three most important questions:

The main effect on daily life that I want help with:

What has changed since the last visit?

Records checklist: symptom timeline; dated photos; blood/urine results; imaging reports; actual genetic report; medicines, supplements and allergies; prior treatment responses.

Before I leave: next step, responsible person and expected timing:

If the diagnosis is uncertain: What are we considering? What would change the plan? When should I return? How do I reach the team during a new episode?

How symptoms affect my day

Optional daily-impact notes. These are separate from AIDAI and have no validated score.

Date	Energy / sleep / pain	Activity affected / support needed

One activity I want to return to, or a change I want help with:

Describe patterns in your own words. Persistent fatigue or pain deserves assessment even when fever is absent. These notes do not identify the cause.

School or work conversation

Share only the information needed to discuss support. Arrangements vary by location.

Tasks or parts of the day that are difficult:

Support to discuss (for example, breaks, flexibility or a missed-work plan):

Who needs to be involved? What information am I comfortable sharing?

Agreed actions, contact person and review date:

For children, include the school nurse and teaching/support team. Ask your clinician about documenting functional needs. This worksheet is not a medical certificate or a guarantee of legal eligibility.

My portable care summary

Update with your care team. Carry only the personal details you need.

Name / preferred contact; diagnosis or working diagnosis:

Clinicians, pharmacy and daytime / after-hours contacts:

Current medicines, doses, purpose; allergies and important reactions:

Important complications; previous treatments and why they stopped:

Key test findings; location of genetic report / records:

Usual symptoms; location of agreed monitoring and illness plans:

Last updated: _____ Reviewed with: _____

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My monitoring plan

To complete with your clinician. The tests and timing depend on your condition and treatment.

Check / purpose	When / where	Who reviews / how I hear back

Which changes or results should prompt contact, and whom do I call?

Ask whether your plan includes inflammation, medicine safety, kidney health, growth or condition-specific hearing/eye checks. Not everyone needs each test. Do not interpret a laboratory flag or change treatment using this sheet alone.

Before starting a treatment

Use these prompts to agree on a plan. This page does not recommend a drug or dose.

Medicine and treatment goal; how and when we assess benefit:

How to use/store it; training or pharmacy contact:

Safety checks; side effects to report; other medicines to review:

Plan for missed doses, infection, vaccines, surgery or pregnancy questions:

Cost / access / refill plan and who can help:

Do not start, stop, combine or change medicines from a general webpage. Ask for written instructions when the plan is complex.

Travel, refills and moving care

Plan ahead with your clinic and pharmacist; storage rules differ between medicines.

Next refill / authorization date, supplies and backup contact:

Travel: storage, transport, documentation and care away from home:

Transition: receiving clinician, first appointment and records transfer:

Who prescribes and monitors during the handoff?

One care skill I will practice; who will support me:

A referral sent is not an appointment completed. Confirm the receiving visit, medication supply and follow-up plan. Family or trusted support can continue when useful.

My illness or flare plan

To complete and agree with your care team. New illness may have a different cause.

My usual pattern and the clinician-agreed plan:

Changes that require an urgent call / same-day assessment:

Daytime and after-hours contact; where to seek care:

Medicine instructions supplied by my clinician; date / clinician:

Emergency: severe breathing difficulty, fainting, confusion or rapidly worsening illness needs urgent medical assessment. Do not wait for an online reply or a completed diary. The examples are not an exhaustive list.

This worksheet becomes an individual plan only when completed with the treating team. It does not establish a clinician-patient relationship with this website.

Keep completed pages private. Share with your care team, not in website comments.