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THE INVISIBLE LOAD

All the extra work disability can add to an ordinary day - and how I can make some of that load visible

NEW DISABILITY WORKBOOK SERIES - BOOK 13

This workbook belongs to:

Two people can complete the same visible task while using very different amounts of energy. This workbook explores the planning, coping, explaining, recovering and adapting that other people may never see.

Welcome

The invisible load is the extra work surrounding ordinary life: preparing, remembering, managing symptoms, navigating barriers, masking, communicating needs, arranging support and recovering afterwards.

Something that looks easy from the outside but costs me a lot:

1. What Is in My Invisible Backpack?

Tick the hidden work you regularly carry.

- ☐ Planning accessibility
- ☐ Managing pain or fatigue
- ☐ Sensory regulation
- ☐ Remembering medication / routines
- ☐ Preparing scripts for conversations
- ☐ Masking
- ☐ Explaining my disability
- ☐ Managing appointments
- ☐ Finding accessible transport
- ☐ Checking toilets / entrances
- ☐ Recovering after activities
- ☐ Organising support
- ☐ Completing forms
- ☐ Advocating for adjustments

My notes / what applies to me:

2. The Task Behind the Task

A visible task may contain many invisible steps.

Visible task	Invisible steps before / during / after

3. Before I Even Leave Home

Going somewhere can start long before the journey.

- ☐ Check energy / symptoms
- ☐ Work out transport
- ☐ Check accessibility
- ☐ Pack medication / aids
- ☐ Prepare communication
- ☐ Choose sensory-safe clothes
- ☐ Plan food / drink
- ☐ Check weather
- ☐ Build in extra time
- ☐ Plan how to get home

My notes / what applies to me:

4. The Cost of Being Prepared

Preparation can reduce risk but still consume energy.

Things I prepare for that other people may not notice:

5. The Mental Load

Keeping track of disability-related information can become a job in itself.

Thing I have to keep track of	How much headspace it uses	What could help
	Low / Med / High	
	Low / Med / High	
	Low / Med / High	
	Low / Med / High	
	Low / Med / High	
	Low / Med / High	
	Low / Med / High	

6. The Sensory Load

Filtering or tolerating sensory input can use capacity even while I appear calm.

Input	Hidden effort	After-effect
Noise		
Light		
Crowds		
Smell		
Touch / clothing		
Temperature		
Movement / travel		

7. The Social Load

Conversation may include hidden processing, interpreting, masking and recovery.

What others see	What I may be doing internally
Having a conversation	
Joining a group	
Making eye contact	
Smiling / reacting	
Answering quickly	
Attending an event	
Meeting someone new	

8. The Communication Load

Being understood may require repeated effort.

- ☐ Finding the right words
- ☐ Using AAC / typing
- ☐ Repeating myself
- ☐ Explaining access needs
- ☐ Waiting for people to listen
- ☐ Processing questions
- ☐ Correcting assumptions
- ☐ Preparing messages beforehand
- ☐ Following up in writing

My notes / what applies to me:

9. The Mobility & Physical Load

Physical access can add time, effort, planning or pain.

Activity	Extra physical / access load
Getting dressed	
Preparing food	
Leaving home	
Travel	
Shopping	
Waiting / standing	
Returning home	

10. The Executive-Function Load

Starting, sequencing, switching and remembering tasks may be significant work.

Task demand	What makes it hard	Support / workaround
Starting		
Sequencing		
Remembering		
Switching tasks		
Deciding		
Estimating time		
Finishing		

11. The Admin Load

Disability can generate paperwork and phone calls that are invisible to everyone else.

- ☐ Forms
- ☐ Benefits / funding paperwork
- ☐ Healthcare letters
- ☐ Appointment booking
- ☐ Prescription / equipment admin
- ☐ Transport arrangements
- ☐ Support rotas
- ☐ Workplace adjustment emails
- ☐ Chasing services

My notes / what applies to me:

12. The Advocacy Load

Repeatedly having to explain or prove needs can be exhausting.

Times I have to advocate or explain myself:

13. The Masking Load

Appearing okay can itself be work.

What I may be doing internally while I look “fine”:

14. The Recovery Load

The visible activity may end before the energy cost ends.

Activity	How long it lasts	Recovery I may need

15. My Hidden Energy Receipt

Add up the hidden costs of one ordinary activity.

Hidden cost	Low / Medium / High
Planning	
Travel	
Sensory	
Physical	
Communication	
Social / masking	
Decision-making	
Recovery	

What would somebody miss if they only saw the main activity?

16. “But You Only...”

Sometimes people notice the visible action but not everything around it.

Complete this sentence: “It may look like I only _____, but actually I also have to...”

17. What Can I Stop Carrying?

Not every load is optional, but some expectations may be.

- ☐ Unnecessary masking
- ☐ Explaining myself to everyone
- ☐ Doing tasks the hardest way
- ☐ Answering immediately
- ☐ Attending every social event
- ☐ Keeping an inaccessible routine
- ☐ Doing everything without support
- ☐ Trying to appear unaffected

My notes / what applies to me:

18. What Can Be Shared?

Sharing a task can reduce load without removing your choice.

Load I carry	Could be shared with	What I still want control over

19. What Can Be Automated or Simplified?

Systems can save energy.

- ☐ Repeat prescriptions / reminders
- ☐ Saved shopping lists
- ☐ Meal shortcuts
- ☐ Calendar reminders
- ☐ Templates for messages
- ☐ Online booking
- ☐ Automatic payments where appropriate
- ☐ Prepared travel routes
- ☐ Duplicate sensory kits
- ☐ Visual routines

My notes / what applies to me:

20. My “Good Enough” Standard

Some days need a different definition of done.

A task I could allow myself to do in an easier or simpler way:

21. Explaining the Invisible Load

Create a short explanation for someone who sees only the visible task.

Template: “The part you see is _____. The extra disability-related work around it includes _____. Afterwards I may need _____. What would help is _____.”

My version:

22. My Load-Reduction Experiment

Remove, share, simplify or adapt one hidden demand.

Hidden load I want to reduce:

Will I remove, share, simplify or adapt it?

What will I change?

What support / tool will I use?

How much energy did it save?

What will I keep doing differently?

23. My Invisible Load Map

See the whole load in one place.

Planning	Body / sensory
Communication / social	Admin / advocacy

24. My Load-Lighter Plan

The biggest invisible load I carry	
Something I can stop doing	
Something I can simplify	
Something I can share	
Something technology can help with	
A boundary that would reduce load	
Recovery I need people to respect	
My first load-lighter change	

What I Wish People Could See

Not all disability-related effort is visible.

If people could see the invisible work behind my ordinary day, they would notice:

The support or understanding I wish they would offer:

Notes

This workbook is a general disability-focused self-understanding and wellbeing resource. The amount of effort required for daily activities varies greatly between people and from day to day. The aim is to identify hidden demands and possible supports, not to compare disability experiences or suggest that every demand can simply be removed.

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