The Sick List
thesicklist.co.uk

The ADHDer’s guide to surviving hospital

Hospital and ADHD are a spectacularly unhelpful combination

We wish we could tell you hospitals were designed with ADHD brains in mind.

They weren’t.

We also wish we could tell you that reasonable adjustments would always be obvious, ready and waiting when you need them. In reality, support can be patchy, and sometimes you have to know what to ask for.

One of the people behind The Sick List has ADHD and around twenty years of hospital life behind her. So we know the particular joy of long stretches of absolutely nothing, sudden interruptions, important information arriving when your brain has already wandered off, questions disappearing the second the doctor appears, and leaving hospital with three bits of paper, two new instructions and absolutely no idea where you put your charger.

We get it.

This guide is about the stuff that can make hospital a bit easier when your brain is running on ADHD settings.

You can save this PDF and print the pages you need. Read the web version.

In this guide

The 23-hours-and-50-minutes problem

The ward round might take ten minutes.

The trouble is, nobody can necessarily tell you which ten minutes.

You may be told the doctor will come “this morning”, “later”, “after clinic” or some other magnificently useless unit of time.

Meanwhile, you are expected to remain available.

For someone who finds sitting still, waiting without a timetable or doing absolutely nothing difficult, this can be excruciating.

Ask what you actually need to stay for

If you are medically well enough to move around, ask:

- Do I need to stay by my bed right now?
- Is there a time I definitely need to be back?
- Can I go for a walk while I’m waiting?
- Do I need to tell somebody before I leave the ward?
- Is there a way to contact me if somebody arrives while I’m away?

Do not just disappear. There may be a clinical or safety reason staff need to know where you are.

But equally, don’t automatically assume you have to spend eight hours staring at the same curtain if nobody has actually said that you do.

Pack an ADHD survival bag

Your hospital bag contains the things you actually need.

Your ADHD survival bag contains the random assortment of things required to prevent your brain climbing out through the window.

Do not rely on one activity.

At home you might happily knit for three hours. In hospital you may knit for eleven minutes, decide you hate knitting, do half a puzzle, watch seven minutes of something, colour in one leaf, scroll your phone, lose your headphones, find your headphones and suddenly desperately need the knitting again.

This is normal service.

Variety beats ambition

Useful things might include:

- puzzle books
- colouring or drawing things
- knitting or another small craft
- headphones
- downloaded programmes
- podcasts or audiobooks
- an iPad or tablet if you have one
- small games
- a notebook and pens
- something to do with your hands
- very low-concentration activities for when your brain is fried

The Sick List already has ideas for boredom, tech and longer hospital stays, so you do not need to reinvent the entertainment department from scratch.

And no, this is probably not the moment to pack War and Peace because you’re finally going to “get some reading done”.

Contain the chaos

After a few days in hospital, an ADHD bed space can develop its own ecosystem.

Headphones. Pens. Puzzle book. Half-finished craft. Charging cables. Water bottle. Three bits of paperwork. One sock whose partner has entered another dimension.

A separate tote or zip bag for your survival stuff can stop your bedside area becoming an archaeological dig.

Every so often, chuck everything back in it.

Your nurses will thank you.

The plan will change

You may finally get a clear plan on the ward round.

Excellent.

Ten minutes later, somebody else may arrive and tell you something different.

Hospital plans change because test results arrive, another team gets involved, priorities change or somebody reviews your care.

Knowing that does not make it any less bloody confusing.

The problem for an ADHD brain is that you may still be operating from Plan A while the hospital has quietly moved through Plans B, C and D.

Ask for the current version

Try:

- What is the current plan now?
- Has anything changed since the ward round?
- What am I waiting for next?
- Can you write that down for me?

If changing plans scramble your brain, this is worth telling staff directly:

Please tell me clearly when the plan changes. I may still be working from the previous plan unless somebody explicitly tells me it has changed.

Hospital rules can feel completely arbitrary

Hospitals have a lot of rules.

Some make immediate sense.

Some absolutely do not.

You may be told you need to wait for a porter rather than walking somewhere yourself. You may need permission before leaving the ward. There may be routines about meals, medicines, showers, tests or where you are expected to be.

If your brain needs to understand why, “because that’s the rule” can be spectacularly unhelpful.

You are allowed to ask.

Try:

- Can you explain why I need to do that?
- Is that because of my medical care or because of the way the ward works?
- Is there another safe way we could do it?

This does not mean ignoring instructions that are there for safety.

It means understanding what is actually necessary instead of spending the next six hours internally arguing with a rule nobody has explained.

The loss of freedom can be brutal

Hospital means giving up a surprising amount of control over your day.

When you eat.

When somebody wakes you.

When you can shower.

When you can leave the ward.

When you can go for a walk.

When somebody comes to examine you.

When you need to be back at your bed.

For an ADHD brain, this can be really hard.

At home, a lot of us regulate ourselves by moving, switching activities, following interest, taking a shower when our brain suddenly decides NOW IS SHOWER, going outside or doing something because that is the moment our brain is finally willing to do it.

Hospital can strip a lot of that away.

You may feel trapped, restless, irritable or furious even when you understand why some restrictions exist.

Find the freedom you still have

Ask what is fixed and what is flexible.

- Can I shower whenever the bathroom is free?
- Can I leave the ward?
- Where can I go?
- Do I need to tell somebody?
- Is there a time I need to be back?
- Can I eat this later?
- Can I walk around while I wait?

Hospital removes enough freedom without us accidentally giving away the bits we're still allowed to keep.

If this is particularly difficult for you, a useful thing to tell staff is:

I find loss of autonomy very difficult. If something is flexible, please tell me what choices I have.

Things you might not know you can ask for

Hospital can make it feel as though every part of your day has already been decided for you.

Sometimes it hasn't.

There may be options nobody has mentioned because staff are busy, because they assume you know, or because they simply haven't thought to offer them.

It is worth asking.

Can I go home for a few hours?

Sometimes, depending on your treatment and what is medically safe, you may be allowed to leave hospital for a short period and come back.

Can I go home overnight?

In some circumstances, home leave may be possible. That means leaving hospital temporarily and returning to continue the same admission.

You are not automatically entitled to it, and it will depend on your health, treatment and the ward.

But you can ask.

If you want to know what is possible, speak to the nurse in charge, ward sister or ward manager, or your medical team.

Are there other food menus?

If you are thoroughly sick of the standard menu, ask whether there are other options.

Some hospitals have alternative menus such as:

- finger-food menus
- vegetarian or vegan options
- cultural or religious menus
- allergy or specialist-diet menus
- other meals that are not necessarily shown to everybody automatically

Ask the ward host, housekeeper or nurse what is available.

Can I wait somewhere else?

If a busy waiting area or ward environment is becoming too much, ask whether there is somewhere quieter you can wait or sit.

There may not be.

But asking is free.

Can I have this written down?

Yes, ask.

Especially when somebody has just delivered Plan Number Five of the morning and your brain is still processing Plan Number Three.

Can I have some choice about when i do this?

Sometimes the answer will be no.

Sometimes it will be:

“Actually, yes.”

That is why it is worth asking what is genuinely fixed and what is simply the usual routine.

You do not have to assume that every part of hospital life is non-negotiable.

When you need to move

Someone saying “just sit there” may not understand that sitting there is the actual problem.

If movement helps you regulate yourself, ask what you can safely do.

A lap of the corridor may be completely fine.

It may not be fine after a particular procedure, with particular equipment attached, or when staff need you nearby.

So ask.

If it is medically safe, please tell me where I can walk or sit when I need movement.

Three o’clock in the morning lasts approximately seven years

Hospital nights can be especially grim with ADHD.

You are exhausted.

Your brain is not.

The ward gets quieter. Everyone else appears to be asleep. There is nothing happening. You have already watched everything you downloaded and suddenly 3am appears to last until next Thursday.

If lying in bed is making you climb the walls, ask the nurse:

- whether it is safe for you to walk around
- where you are allowed to go
- whether there is somewhere you can sit without disturbing other patients

This is where the ADHD survival bag earns its keep too.

Headphones. A familiar programme. Podcast. Audiobook. Puzzle. Quiet craft. Whatever gives your brain enough stimulation without waking the entire bay.

A head torch can also be ridiculously useful for reading, knitting, finding things or doing something quietly without switching on a big light and illuminating half the ward.

Build yourself a safe 3am plan before you reach the point where you would cheerfully investigate literally anything happening elsewhere in the hospital just for entertainment.

Your questions will disappear when the doctor arrives

You have spent six hours thinking:

When the doctor comes, I absolutely need to ask about that.

The doctor arrives.

Your brain:

Hello. No questions have ever existed.

Write them down.

Not somewhere clever.

Somewhere you will actually find when the ward round arrives unexpectedly.

Use:

- your phone
- a notebook kept on your bedside table
- the ward-round notes printable on The Sick List
- another person who knows what you wanted to ask

And write answers down too.

Important information has an irritating habit of sounding completely obvious while somebody is telling you and vanishing fifteen minutes later.

If spoken information disappears quickly for you, ask:

Can you write that down for me?

You might become the unofficial ward entertainment

Some of us cope with hospital by talking.

A lot.

We chat to the nurses.

We chat to the person in the next bed.

We make jokes.

We discover everybody’s life story.

We become inexplicably invested in whether Jean in bed four has finally got her cup of tea.

Honestly, this can be lovely.

Hospitals can be lonely and miserable places, and the person who gets everybody laughing can make a ward feel much more human.

But there is a catch.

Not everybody wants to talk as much as you do.

Before beginning conversation number eighteen of the morning, have a quick look around.

Are they giving very short answers?

Have they put headphones on?

Are their eyes closed?

Are they trying to read?

Have you been doing virtually all the talking for quite some time?

You do not need to stop being you.

Just remember that the rest of the ward may occasionally need a commercial break.

And the reverse applies too.

You can be wildly sociable for three hours and then suddenly be completely done with humans.

Headphones on. Curtain round. Rest.

You do not have to remain the ward entertainment because you started the day that way.

Other people’s distress can be incredibly hard to tune out

Some people with ADHD find other people’s pain, fear or distress very difficult to block out.

One of the people behind The Sick List certainly does.

Hospital can mean lying a few feet away from someone who is frightened, confused, crying or in pain.

Sometimes for hours.

And when you can hear it, see it and feel it happening around you but cannot actually fix it, it can become overwhelming.

It can feel a bit like sleeping in a room full of wounded puppies you can’t help.

This is not necessarily about your own treatment.

It is about absorbing what is happening around you.

When you’ve had enough

Give your brain less of it to process.

- pull your curtain around if you can
- put your headphones or ear defenders on if it is safe
- watch something familiar
- listen to a podcast or audiobook
- play a game
- do something absorbing with your hands
- give yourself permission to stop listening

Protecting yourself from distress you cannot fix is not the same as not caring.

If what is happening around you has become too much, tell the nurse looking after you.

There may be something practical that helps, including a quieter place if one is available.

Sometimes staff may think you’re being difficult when you’re trying to regulate yourself

You are pacing.

Getting up again.

Talking.

Fidgeting.

Asking why.

Going for another walk.

Struggling to wait in one place.

From your side, you may simply be doing what your brain needs in order to tolerate the situation.

Someone who does not understand ADHD may see something else.

That can be deeply frustrating.

This is why explaining your needs before things become difficult can help.

Not:

“I won’t follow the rules.”

More:

“Long periods of inactivity are extremely difficult for me. If I need to stay here for a medical reason, please tell me. If I don’t, movement will help me cope.”

The distinction matters.

Leaving hospital requires one last functioning brain cell

Then comes discharge.

You have spent days being told when to do everything.

Suddenly somebody gives you:

- medication
- paperwork
- follow-up instructions
- appointments
- things to watch for
- things somebody else may be arranging

…and sends you back into civilisation.

This is not an ideal time to discover that your executive function has left the building.

Before you leave:

- get important instructions written down
- check what medicines or paperwork you have been given
- ask what happens next
- ask who is arranging anything that has not happened yet
- check your bedside area, locker, plugs and bathroom for belongings
- get somebody else to listen if you have someone with you

And perform the sacred ADHD hospital departure ritual:

Phone. Charger. Headphones. Glasses. Medication. Paperwork. Bag.

Then look again.

Because the charger is probably still in the wall.

Ask for adjustments

You do not have to earn help by coping badly first.

Reasonable adjustments are not just for one particular diagnosis. If ADHD substantially and long-term affects everyday activities, it can fall within disability protections, and adjustments may help remove barriers to healthcare.

What helps will be different for different people.

Possible things worth discussing with staff include:

- written information as well as spoken information
- clear warning when plans change
- extra processing time
- knowing what is actually fixed and what is flexible
- somewhere quieter to wait if available
- permission to move around when it is medically safe
- knowing when you genuinely need to remain near your bed
- having another person help you remember information
- a plan for what helps when you become overwhelmed

You can ask.

They may not be able to do everything you request.

But “this is difficult because of my ADHD; is there another way we can do it?” is a perfectly reasonable conversation to have.

We’re making this easier to explain too

Sometimes the hardest part is having to explain all of this when you are already ill, tired, bored, overstimulated and cross.

So alongside this guide we’ve made a short ADHD in hospital — things that might help me sheet you can hand to the nurse looking after you.

It covers things like:

- needing movement
- finding indefinite waiting difficult
- telling you clearly when the plan changes
- telling you which choices you still have
- written information
- needing something to do
- what helps when you are overwhelmed
- finding other patients’ distress difficult to block out
- how staff can contact you if you are allowed to step away from your bed

You will not need every option.

Tick the things that sound like you.

Ignore the rest.

Because the point is not to create a perfect ADHD patient.

The point is to make hospital a little easier for the ADHD patient who actually turned up.