REST RECLAIMED / FIELD GUIDE 02

Taken Seriously

A field guide for the dismissed patient

Research without drowning. A case file that speaks for you.
Words for the appointment, and for the moment they say no.
Written from inside the experience — not from a clinic.

A Field Guide for the Dismissed Patient

By Josie — Rest Reclaimed

For women whose tests come back "normal" while their bodies keep telling the truth.

I'm not a doctor. Nothing in this guide is medical advice, and none of it is legal advice either. What I am is a patient — still in it, not recovered, not on the other side — who has spent years navigating a broken system with complex, interconnected, frequently dismissed conditions, and who has figured out, through a lot of trial and error, how to advocate effectively for myself within it. For clinical decisions, talk to a medical professional. For legal matters, talk to a qualified solicitor. This guide is written from a UK perspective, primarily about the NHS.

Introduction

I wrote this because nobody handed me anything like it when I needed it.

If you're here, I suspect you know the particular experience this guide is built around: sitting across from a doctor with results that say you're fine, in a body that is very clearly not fine. Being told it's probably stress, probably anxiety, probably nothing. Leaving appointments feeling smaller than when you walked in. Doing it again the next month anyway, because what else is there.

There are two rooms you have to learn to live in. The first is the room where you fight to be taken seriously — the appointments, the referrals, the letters, the complaints process when it comes to that. The second is the room where you live and recover anyway, whether or not the system ever catches up with you. This guide covers both, because you need both, and because the skills for one are not the skills for the other.

Six parts:

1. **Research Like a Pro** — using AI as a research ally without letting it feed your anxiety or replace your judgement

2. **Build Your Case File** — the documentation system that makes your experience harder to dismiss

3. **The Appointment Playbook** — how to walk into any medical appointment prepared, including scripts for the moments you're being dismissed

4. **Working the System** — finding the right people, in the right order, without breaking yourself

5. **When They Say No** — formal processes, complaints, and escalation, clearly explained

6. **The Long Haul** — sustaining yourself as your own advocate over years, not weeks

None of it requires you to be a perfect patient or a tireless warrior. Some of it, some of the time, as you can. That's the whole standard.

One more time, because it matters: I'm not a clinician. This is practical knowledge built from lived experience — the tools and frameworks I wish I'd had earlier. Your doctor is still your doctor. This guide exists to make your conversations with them work better.

Research Like a Pro

Using AI as your medical ally — not your doctor.

The 2am Spiral

I've sat at 2am with a symptom I couldn't explain, typing it into Google, and ended up forty-five minutes later convinced I had something catastrophic. We've all been there. The panic, the open tabs, the wormhole. One article leads to another leads to a forum where someone describes your exact situation and then mentions the terrifying thing they eventually got diagnosed with and now you can't unknow it.

So when people started telling me AI was going to change patient advocacy, my first reaction was scepticism. Another tool to spiral with? No thanks. But I was wrong — or more precisely, I was wrong about how it needs to be used.

AI, used well, is the most useful thing that has happened to patients in years. And I mean that seriously.

It can translate jargon you've never heard into plain English. It can take your scattered notes from three years of appointments and help you find a pattern. It can draft the email to your consultant that you've been staring at blankly for an hour because you're too exhausted to find the words. It can read the research paper you downloaded and tell you what it actually means.

But — and this matters enormously — it can also make everything worse. It can send you deeper into health anxiety. It can tell you things confidently that are simply not true. It can become a substitute for seeing a doctor when seeing a doctor is exactly what you need.

This part is about how to use it well. And more importantly, how to know when not to use it at all.

The Principle That Doesn't Change

Here is the one thing I want you to take from this part, above everything else:

The tools will keep changing. Your critical thinking won't.

New models will launch. Prices will drop. Names will change. Something will come along that makes the current tools look primitive. This has happened every eighteen months for years and there's no sign of it stopping. So I'm deliberately not going to recommend specific tools or versions — anything I named would be out of date before you finished reading.

What you need to know is durable:

- Most of what you'll need is available on free tiers. Don't let cost be a barrier.
- For medical research specifically, prefer tools that show their sources — that cite where information came from, so you can check whether it's true.
- Most major tools can read documents you upload and most offer a voice mode. Both matter for advocacy, and I'll come back to them.

And the approach that works is the same whatever tool you're holding:

- You are the expert on your own body. AI is a research assistant, not a replacement for that expertise.
- AI gets things wrong. Confidently, fluently wrong. Your job is to verify.
- AI doesn't know you're spiralling. You have to know that yourself.
- Your doctor is still the person who examines you, orders tests, and makes clinical judgements. AI cannot do any of those things.
- **Everything AI produces is a draft for your judgement.** Not an answer. A draft.

These aren't limitations that will be solved by a better model. They're fundamental to what AI is.

What AI Can Actually Do for You

Let's be specific, because vague promises aren't useful.

Translation. Medical jargon is a barrier that exists partly for legitimate reasons and partly, honestly, because it creates a power imbalance. AI dissolves it. You can paste a letter from your consultant, a research abstract, your sleep study results — and ask in plain language: what does this actually mean? I've done this with my own test results. I've done it with letters that left me feeling confused and dismissed. Being able to understand what you've been told is the foundation of everything else in this guide.

Finding patterns in your own notes. If you've been tracking symptoms, or keeping notes from appointments, or have a collection of things you've tried and how they affected you — AI can help you see structure in that chaos. You can paste months of notes and ask: what patterns do you notice? What seems to make things worse? What questions does this raise?

Summarising research. There are published studies relevant to your condition. Most patients will never read them because they're written in dense academic language and locked behind paywalls. AI can summarise them. It can tell you what a study actually found, what its limitations were, and whether it applies to your situation.

Drafting correspondence. Writing to a consultant when you're exhausted and in pain is genuinely difficult. AI can draft the email. You edit it, you make it yours, you add the specific details it can't know — but it gives you something to start from rather than a blank page.

Preparing for appointments. You have ten minutes. You need to use them well. AI can help you organise your thoughts, prioritise what matters most, and anticipate what questions to ask. More on this in Part Three.

What AI Cannot Do

It cannot diagnose you. Only doctors can do this — because diagnosis requires examining your body, understanding your full history, ordering and interpreting tests. AI is working from what you type. It doesn't know what it doesn't know about you.

It cannot tell you what treatment to pursue. Treatment decisions are individual. They depend on your specific physiology, your other medications, your history, your preferences. AI can explain options. It cannot tell you which is right for you.

It cannot guarantee accuracy. AI makes things up. This is called hallucination, and it's a real, documented problem with all current AI systems. It makes things up confidently. Fluently. In a tone that sounds certain. The way to manage this is not to trust AI less — it's to verify more.

It cannot see when you're spiralling. This is the one that matters most for people who are already anxious about their health. AI will keep answering your questions. It doesn't know you've been at this for four hours. It doesn't know you're getting worse, not better. It has no mechanism for saying "I think you need to stop and call someone." You have to have that mechanism yourself.

It cannot replace emergency care. If you are in crisis — physically or mentally — you need real human support. Not AI.

The Health Anxiety Trap

I want to spend real time here, because this section might be the most important thing in this whole guide for some of you.

AI and health anxiety are a dangerous combination. Not because AI is uniquely bad — Google was already bad for this — but because AI is more immersive, more responsive, and never runs out of answers.

Here is how the spiral happens:

You notice a symptom. You ask AI about it. AI, being helpful, gives you a thorough list of possible causes — which includes some benign explanations and some serious ones. Your anxious brain locks onto the serious one. You ask a follow-up question. You ask it again, differently. You ask another AI to see if it says the same thing. Two hours later you're researching something that almost certainly isn't what you have, and you feel significantly worse than when you started.

AI didn't cause this. But it enabled it.

Signs that you've crossed into spiral territory:

- You've been researching for more than an hour and feel more anxious, not less
- You're asking the same question in different ways, hoping for a different answer
- You're looking for reassurance, not information
- A specific scary diagnosis has got its hooks into you and you can't think about anything else
- You feel compelled to research rather than choosing to

If you recognise yourself in this list: stop. Close the tab. Drink something cold. Go outside or call someone.

The honest truth: For some people — particularly those with health anxiety, OCD, or who are already in a difficult mental health period — AI is not a safe tool for medical research. There's no shame in that. The goal isn't to use AI. The goal is to take care of yourself.

The VERIFY Method

Every time you get information from AI — every single time — run it through this:

V — Verify the Source. Ask AI where it got this information. "What's the source for that?" If it can't tell you, or the source turns out to say something different when you check, that's a red flag. Tools that show their sources by default make this easier. For anything important, find the original source and read it yourself. Always verify against the actual source, not against the AI's summary of it.

E — Examine Your Bias. Before you ask, ask yourself: what answer am I hoping for? Am I asking this neutrally, or am I already convinced of something and looking for confirmation? Leading questions get misleading answers. "Do I have [condition]?" is a worse question than "What are the most common causes of [symptom]?"

R — Reality Check the Response. Does what AI told you pass a common-sense test? Would a real doctor actually say this? If AI is giving you specific treatment advice without knowing your full medical history, something's wrong. Good AI responses include appropriate uncertainty. Bad ones are too certain.

I — Investigate Multiple Sources. Ask more than one AI. Compare. Where they agree, you have more confidence. Where they diverge significantly, that's a signal to dig deeper — or to bring it to a doctor. And always cross-reference with non-AI sources: medical institutions, published research, patient advocacy organisations.

F — Fact-Check Before Acting. Before you take a supplement AI recommended, change something about your treatment, or make a decision based on AI information — verify it. Especially verify it with a medical professional who knows your history.

Y — Your Doctor is the Final Word. AI informs your conversations with doctors. It doesn't replace those conversations. If AI suggests something your doctor disagrees with, the right response is to bring it to your doctor and have a conversation — not to trust AI over the person who has actually examined you.

The Prompt Library

How you ask matters as much as what you ask. These are templates I use and adapt. Copy them, change the bracketed parts, make them yours.

The universal add-on. Add this to any health-related AI conversation:

> *"Please note my limitations: I'm a patient trying to understand my situation, not a medical professional. Flag anything where you're uncertain or where I should specifically verify with a doctor."*

Safe questions vs. spiral questions. The shape of your question determines whether AI informs you or frightens you.

A safe, bounded prompt for learning about a condition:

> *"I want to learn about [condition name] in a balanced way. Please provide: (1) What is [condition] in 2–3 sentences? (2) Common symptoms — top 5–7. (3) How is it typically diagnosed? (4) What are standard treatments? (5) Three reputable sources where I can read more. Please keep this to 300 words maximum — I tend to overwhelm myself with information. Do NOT list every possible symptom. Focus on typical presentation, not rare cases. Remind me that only a doctor can diagnose this."*

The unsafe version of the same question looks like this — notice the difference:

> *"I have [symptoms]. Do I have [condition]? What are ALL the symptoms? What's the worst case scenario?"*

Bounded, educational, doctor-centred versus open-ended, self-diagnostic, fear-based. After AI responds, check yourself: am I more informed or more anxious? Do I want to see a doctor, or just to research more? Can I summarise what I learned in three sentences? If the answers are anxious, more research, and no — stop.

For translating medical letters, reports, or test results:

> *"I received test results and need help understanding them. I am NOT asking for diagnosis, just explanation of what these terms mean. My results: [paste relevant sections]. Please: (1) Explain each term in plain language. (2) What is the normal range for each? (3) What do deviations typically indicate — in general, not for me specifically? (4) What questions should I ask my doctor about these results? Reminder: I know you cannot diagnose me. I'm seeing my doctor on [date] and want to understand these terms before my appointment."*

For decoding something a doctor said:

> *"My doctor said: '[exact quote or term].' Can you: (1) Translate this into plain language. (2) Explain why a doctor might say this. (3) Suggest what questions I should ask for clarification. Context: [brief context of the appointment]. Do not speculate beyond what the doctor actually said."*

For preparing for an appointment:

> *"I have an appointment with [type of specialist] about [symptoms/concern] and need to prepare a one-page summary. My symptoms: [list with timeline]. Treatments I've tried: [list with dates and outcomes]. My questions: [list]. Please help me: (1) Organise this into a clear, concise one-page summary. (2) Prioritise my questions, most important first. (3) Suggest any questions I might be missing. (4) Keep it under 300 words so the doctor can read it quickly. Do NOT diagnose — just help me organise my information clearly."*

For finding patterns in your symptoms:

> *"I have multiple symptoms and I'm trying to identify patterns to discuss with my doctor. Symptoms and context: [for each — frequency, severity, when it's worse or better]. Please: (1) Group symptoms that might be related. (2) Identify any patterns — time of day, triggers, positions. (3) Suggest what body systems might be involved. (4) Format this as a clear report I can bring to my doctor. Do NOT diagnose what's causing this. Just help me organise the information."*

A caution with this one: AI can see patterns that aren't there, and it can quietly add symptoms you didn't mention. After it responds, verify the patterns against another week or two of your own tracking, delete anything you didn't actually say, and add context it couldn't know — recent stress, medication changes.

For research summaries:

> *"Here is a research abstract/paper. Please summarise the main findings, explain the methodology briefly, note any limitations the authors mention, and tell me how relevant this might be to someone with [condition]."*

For deeper research — the anatomy of a strong prompt. The difference between "tell me about sleep apnoea" and a prompt that actually helps you is structure: give the AI a role, a specific task, a format, and constraints.

> *"Role: You are a medical researcher helping a patient understand current literature. Task: Summarise current research on [condition], specifically: (1) diagnostic criteria — what distinguishes it from [related condition]? (2) treatment efficacy — which treatments have the best outcomes? (3) gaps — what's still unknown? Format: start with a 3-sentence summary, then bullet points per topic; cite published studies; flag any conflicting findings. Constraints: maximum 500 words, plain language with medical terms explained, published research only — no anecdote. Reminder: this is to prepare for a doctor discussion, not for self-diagnosis."*

Asking AI to show its working. For anything factual, asking AI to reason step by step makes errors easier to spot:

> *"I need to understand the difference between [term A] and [term B]. Before answering, please: (1) define each term separately, (2) explain what each one measures, (3) then compare them directly, (4) give an example of when they'd differ. Think through this step by step rather than giving a quick answer."*

You can then check each step against real sources, instead of trying to verify one polished paragraph.

For drafting correspondence:

> *"I need to write a professional email to my doctor requesting [test/referral/appointment]. Context: previous appointment on [date], where we discussed [topic]. Current concern: [brief description]. What I'm requesting: [specific ask]. Why I think it's needed: [reason based on symptoms or previous discussions]. Please draft an email that is respectful, concise (under 200 words), clearly states the request, provides context without over-explaining, and thanks them for their time. Tone: collaborative, not demanding. Patient, not desperate."*

Here's what a good result looks like — this is the shape of email that gets responses:

> *Subject: Follow-up on Sleep Study Discussion — Request for RERA Analysis*
>
> *Dear Dr [Name],*
>
> *I'm following up on our appointment on [date] where we discussed my sleep study results (AHI: 3). While the AHI is within normal range, I continue to experience significant daytime fatigue and unrefreshing sleep.*
>
> *During our conversation, you mentioned that Upper Airway Resistance Syndrome (UARS) might be worth investigating. I've learned that UARS is typically diagnosed through RERA (Respiratory Effort-Related Arousal) scoring, which may not have been included in my standard sleep study.*
>
> *Would it be possible to:*
> *1. Confirm if RERAs were scored in my study?*
> *2. If not, request a re-analysis to include RERA scoring?*
>
> *I understand there may be additional costs, which I'm prepared to cover. I'm also happy to schedule a follow-up appointment if you'd prefer to discuss this in person.*
>
> *Thank you for your time and thorough care.*
>
> *Best regards,*
> *[Your name]*

Why this works: it references a specific previous conversation, states the problem without dramatising, makes a specific and reasonable request, and acknowledges the doctor's time. Before you send anything AI drafts, edit it: add the details it didn't know, adjust the tone if it feels off, and verify every claim — don't let AI put words in your doctor's mouth about conversations that didn't happen.

Uploading Your Own Documents

Most major AI tools let you upload documents. This changes things significantly for advocacy.

You can upload your sleep study and ask for a plain-English interpretation. Your blood results and ask what questions they raise. A medical letter and ask what the doctor is actually saying between the lines. A research paper and ask what it means for someone with your condition. Your own symptom log and ask what patterns it notices.

Two caveats that don't expire:

Privacy. Whatever tool you're using, and whatever its current policies say: **never paste identifying details you don't need to.** Strip your name, date of birth, NHS number, and address from anything you share — the medical content works just as well without them. Check the privacy settings of the tool you're using before sharing medical documents, and assume policies can change.

Accuracy. AI reading your blood results doesn't replace a doctor interpreting them in the context of your full history. But it can help you understand what you're looking at well enough to ask the right questions.

Voice Mode — For When Typing Is Too Much

One thing that has genuinely helped me: voice mode.

When I'm in a bad period — fatigued, foggy, struggling to concentrate — typing coherent sentences is hard. Organising thoughts to write a message is hard. But talking is easier. Most major AI tools now offer a voice mode that lets you speak your questions and hear responses spoken back.

Practical uses: dictating your symptoms when you're too tired to type them. Talking through a situation to help organise your thoughts. Having a document summary read back to you while you rest. Drafting emails by speaking rather than writing.

It's not perfect — transcription isn't always accurate. But as an accessibility tool for people managing chronic fatigue and brain fog, it's worth knowing it exists.

What This All Comes Down To

You are navigating a medical system that was not designed with you in mind. That's not paranoia — it's fact. Diagnostic delays for the conditions we're dealing with are measured in years and decades, not weeks.

AI is a tool that gives you access to information and support that used to require either money (expensive consultants who explain things properly) or luck (finding a doctor who takes the time). That's genuinely significant.

But the tool is only as good as the person using it. And the person using it needs to bring their critical thinking, their self-knowledge, and their judgement — not just their questions.

The mental model: You are the expert on your own body. AI is your research assistant. Your doctor is your clinical partner. These three things are not interchangeable.

The rest of this guide is about the other skills — the ones that don't involve technology at all. How to document your experience properly. How to walk into an appointment prepared. How to handle being dismissed. How to navigate the system when it actively fails you.

AI is a support tool for all of that. But it's not the foundation.

You are.

Build Your Case File

The documentation system that makes your experience harder to dismiss.

The Thing That Finally Made Doctors Listen

For years, I went into appointments and described how I felt. I said I was exhausted. I said I couldn't concentrate. I said my body felt wrong in ways I struggled to articulate. I said this to GP after GP, to rheumatologists, to endocrinologists — and I was, repeatedly, either dismissed or told something vague and then sent away.

It wasn't until I started writing things down — properly, with dates, with specifics, with patterns — that things began to shift.

Not because doctors suddenly became more empathetic. But because I stopped giving them something they could easily dismiss. Feelings are subjective. A documented pattern of symptoms across two years, with dates, severities, correlations, and a timeline of everything that had been tried and failed — that's harder to wave away.

This part is about building your case file. Not because you should have to — you shouldn't. The burden of proof should not fall on the person who is ill. But within the system as it actually exists, documentation is one of the most powerful tools you have.

Think of it as building your evidence base. You are the expert on your own body and your own experience. Your job is to make that expertise legible to the people who have the clinical authority to help you.

What a Case File Actually Is

A case file is different from a symptom diary.

A symptom diary is chronological: what happened, when. Useful. But not enough on its own.

A case file is strategic. It's structured to communicate, to show patterns, to pre-empt dismissal, and to make your experience as a patient legible to someone who has ten minutes and a very limited frame of reference.

Your case file has several components:

1. **Your medical history summary** — one or two pages, covering everything relevant from childhood to now

2. **Your symptom log** — ongoing, structured, searchable

3. **Your treatment history** — what has been tried, when, what happened

4. **Your test results** — kept together, dated, with your own notes

5. **Your correspondence file** — letters, emails, referral documents

6. **Your appointment notes** — what was discussed, what was decided, what follow-up was agreed

You don't need all of these to be perfect before you can use them. Start with what you have. Build it over time. A paper folder, a notes app, a spreadsheet — the structure matters far less than the habit.

The One-Page Medical Summary

This is the single most useful document you can create. It's the document you hand to every new doctor, every new specialist, every locum GP you see when your regular doctor isn't available.

It is not your full story. It is the executive summary of your full story — the version that gives a medical professional enough context to have a useful conversation with you in the time they have.

What it includes:

Your name, age, date of birth — basic, but set the document up professionally.

Primary conditions and diagnoses — in order of significance. Keep this list to what is confirmed or strongly suspected and being investigated.

Key symptoms — not exhaustive, but the ones that are most persistent, most debilitating, or most relevant to the appointment you're attending.

Treatment history — what has been tried, what helped, what didn't, what is current. Include doses if relevant.

Current medications and supplements — everything, including supplements, because interactions matter.

Relevant family history — particularly for conditions with known genetic components.

What you need from this appointment — one clear sentence. "I'm here to discuss [specific thing]." This sounds simple, but having it in writing helps both you and the doctor stay focused.

Format: Print it. Bring two copies — one for the doctor, one for you to refer to. Keep a digital version to update.

The tone: clinical and factual. Not emotional — not because your emotions aren't valid, but because this document is designed to be received by people who are trained to respond to clinical information. Save the honest account of what this has done to your life for the right moment; the summary is not that moment.

Symptom Logging That Actually Works

The most common mistake with symptom logging is writing too much without enough structure, or writing too little to be useful.

A log entry that says "felt terrible today, very fatigued" gives a doctor nothing to work with. A log entry that says "Woke with headache (6/10), fatigue throughout the day despite 9hrs sleep, cognitive fog from approximately 11am, brief relief after 2pm rest, returned by 4pm — worse than yesterday baseline" — that's something.

The information that matters in a symptom log:

- **Date and time**
- **Symptom(s)** — be specific about location, quality, and character where relevant
- **Severity** — a simple 1–10 scale, used consistently, gives you trend data

- **Duration** — when did it start, how long did it last, is it ongoing
- **Relevant context** — sleep the night before, stress level, menstrual cycle day if applicable, weather changes, anything that feels connected
- **What helped or made it worse** — movement, rest, heat, cold, food, medication
- **Functional impact** — could you work, exercise, socialise? This matters clinically because it's how severity gets translated into how much this is affecting your life.

A note on consistency over comprehensiveness: It is far better to log briefly every day than to log exhaustively once a week. A simple daily note — even just two or three lines — builds a picture over time that is genuinely valuable.

Making Your Symptom Data Useful

Once you have a few weeks of consistent logging, you can start to identify patterns. This is where a lot of the advocacy power comes from.

Questions to look for in your own data:

Is there a time of day pattern? Do symptoms peak in the morning, mid-afternoon, evenings?

Is there a cycle pattern? For those with hormonal conditions — do symptoms follow your menstrual cycle? Keeping cycle day alongside daily symptoms can reveal PMDD patterns, for example, that are invisible without that data.

Is there a sleep correlation? How does the quality of the previous night correlate with how you feel the next day?

Are there triggers? Is there anything that reliably precedes a worse period?

Are there things that reliably help, even slightly? This is useful both for your own management and for conversations with doctors.

How to present this:

Not by printing out two months of daily logs and handing them over. By summarising what you've found. "I've been tracking my symptoms for eight weeks and I've noticed that [pattern]. Here's the data if you'd like to see it." The summary first, the evidence available.

AI can help you here — the symptom-pattern prompt in Part One is built for exactly this. Use it as a starting point, not a definitive answer: you know your body better than any algorithm does.

Your Medical Timeline

Many chronic conditions have roots that predate the moment you started looking for answers. A medical timeline traces the arc of your health from as far back as you can go.

This is particularly relevant for conditions like UARS, CPTSD, PMDD, and endometriosis — which research increasingly links to childhood experiences, early hormonal patterns, and cumulative physiological stress.

What to include in your timeline:

- Childhood health: recurrent infections, orthodontic work, early surgeries, any neurological or developmental notes
- Adolescent experiences: when symptoms first appeared, what they were attributed to at the time, any diagnoses received
- Major health events: surgeries, significant illnesses, periods of particularly poor health
- Reproductive history: onset of periods, any notable cyclical symptoms, pregnancies if applicable
- Mental health history: when anxiety, depression, panic, trauma symptoms first emerged
- Key diagnostic moments: first time a condition was named, first time a test came back notable
- Treatment attempts: everything tried, in order

Format: Chronological list with dates (even approximate ones: "age 13 / 2009"). One or two sentences per entry — enough to be informative, not a narrative essay.

This timeline serves two purposes: it gives new doctors context they wouldn't otherwise have, and it often helps you see connections you hadn't articulated before. The relationship between your teenage orthodontic extractions and your current airway symptoms, for example. Or the way your CPTSD symptoms and your physical symptoms share a timeline.

Keeping Your Test Results

In the UK, you have a legal right to your medical records. In practice, this means you can — and should — request copies of test results, scan reports, letters between consultants, and clinical notes. (Part Five covers the formal route — the Subject Access Request — in detail.)

Many GP practices now offer online access to records. Use it.

What to keep:

- Blood test results with reference ranges (and your own notes on what was said about them)
- Sleep study reports in full — not just the summary you were given verbally
- Scan results: MRI, CT, CBCT, ultrasound reports
- Any letters between your consultants
- Referral letters (these often contain clinical opinions that weren't shared with you directly)

Why referral letters matter: The letter your GP writes to a specialist contains their framing of your problem. Sometimes that framing is unhelpful — it might describe your symptoms as anxiety-related, or omit relevant history. If you can read it before the specialist does, you can correct inaccuracies at the start of the appointment rather than fighting a narrative that's already been set.

Practical suggestion: Create a folder (physical or digital) for each condition or each major investigating doctor. Date everything. Note who said what.

Correspondence You Should Keep

Keep everything in writing where you can. This isn't adversarial — it's protective.

Follow up appointments with written confirmation:

> *"Following our appointment today, I understand that we agreed to [X, Y, Z]. Could you confirm by email / could you add this to my notes?"*

This serves two purposes: it ensures clarity about what was actually decided, and it creates a record that can be referred back to if follow-up doesn't happen.

After a phone call, send a brief email summary:

> *"Thank you for the call earlier. Just to confirm, we discussed [X] and the plan is [Y]. Please let me know if I've misunderstood anything."*

When something goes wrong:

Document it at the time. Not a few weeks later when you're calmer and the details have blurred. The date, what was said, who said it, any witnesses.

Why this matters:

Not because you're planning to take anyone to court. But because a documented record of your medical history — including the failures and the dismissals — is something you can point to when you need to escalate, when you need a second opinion, when a new doctor says "why hasn't this been investigated before?"

Writing Your Own Narrative

There is a version of your story that is raw and real and deserves to be told exactly as it is. And there is a version that is strategically structured for medical contexts.

You need both. This guide is primarily about the second.

The structured narrative:

Opening sentence: "I have [conditions/suspected conditions] which have been present since [timeframe]."

Core history: two or three sentences that trace the key arc — when it started, what you were told, what you've tried.

Current status: "Currently, my most significant issues are [X and Y]. I am managing with [current treatment]. What I need help with is [specific ask]."

This is the version you practise. The version you can give in two minutes when you need to. The version that stays factual and specific even when you're anxious or exhausted.

A note on the emotional reality:

The strategic version is not the whole truth. The whole truth is that this has cost you years. That it has damaged relationships, careers, finances, your sense of self. That the dismissal has been its own form of harm, separate from the condition itself.

You are allowed to acknowledge this. There are moments in medical encounters when it's appropriate and even strategic to speak it — particularly with GPs who have long-term responsibility for your care, or with sympathetic consultants who need to understand the full picture of impact.

But you need to be able to switch registers. Lead with the clinical, offer the personal when it's the right moment.

Putting It Together

The case file is not a project you complete. It's a living document.

It grows as you gather more data. It gets refined as you understand your conditions better. It changes as your situation changes.

The minimum viable case file to start with:

1. A one-page medical summary (start rough, refine it)

2. A simple symptom log — even just a notes app entry each day

3. A folder for test results and letters

That's enough to start. You add to it as you go.

The goal is not perfection. A rough case file that you actually use beats a perfect system that you never built.

Your documentation is your memory, your evidence, and your voice in rooms where you're not present — in the letters between consultants, in the records future doctors will read, in the complaints process if you ever need to use it.

Build it. Update it. Bring it with you.

PART 03 / SIX

The Appointment Playbook

How to walk into any medical appointment prepared — including what to say when you're being dismissed.

Ten Minutes to Explain Years of Your Life

I used to leave appointments feeling worse than when I went in.

Not because anything particularly cruel had been said — though sometimes that happened too. But because I'd had ten minutes to explain years of my life, and I'd watched their eyes glaze over about thirty seconds in. I'd forget things I'd meant to say. I'd undersell how bad it was because I didn't want to seem dramatic. I'd leave without asking the questions I'd rehearsed in the car on the way there.

And then I'd sit in the car park and feel the particular despair of having missed another chance.

It took me a long time to understand that I was approaching appointments the wrong way. I was treating them as conversations — as opportunities to be heard. They're not. They're presentations. You have a limited slot, a specific audience, a concrete ask. The more you prepare for them like that, the more useful they become.

This part is everything I've learned about how to do that.

The Reality of Appointments

The ten-minute problem:

GP appointments in the UK are typically ten minutes. Specialist appointments might be longer — twenty minutes, sometimes forty-five with a private consultant — but they still have a time structure, and the doctor has seen multiple patients before you and will see multiple after.

This is not okay. It is also reality.

Knowing this shapes everything about how you prepare. You do not have time to tell your full story. You have time to make one or two points effectively, ask two or three questions, and confirm a specific next step.

The specialist's frame:

Specialists see their discipline's portion of your problem. An ENT sees your upper airway. A rheumatologist sees your connective tissue and pain patterns. A gynaecologist sees your reproductive system. Very few of them are paid or trained to see you whole.

This is not their failing as people — it's how the system trains them and how they're resourced. But it means you may have to do the cross-referencing work yourself, and bring it to them explicitly.

The information asymmetry:

You've been living in your body for years. You've been researching your conditions. You know things that are relevant that the doctor in front of you may never have considered. But you are also not the one with the clinical training, the prescribing power, the authority to order tests.

Your job in an appointment is to bridge those two things: your knowledge of your experience, and their clinical authority. That bridge is built with preparation.

Before the Appointment

Set your single main objective:

Before any appointment, decide what you most need from it. One concrete thing. A specific test. A referral to a specific type of specialist. A review of a current medication. A second opinion.

Having one clear objective does not mean you can't cover other things — but it means that if time runs short, you've protected the most important ask.

Prepare your two-minute summary:

Not your full story. Your summary. The version you can give clearly and calmly in two minutes.

Write it out. Practise it. Include:

- What your main conditions or suspected conditions are
- How long this has been going on
- What has been tried and what the outcome was
- What you need from this specific appointment

Bring your one-page medical summary:

Described in detail in Part Two. Bring two copies. Hand one over at the start.

Prepare your questions in priority order:

Write them down. Then rank them: if you only get to ask two, which two matter most? Mark those clearly.

Know your most recent relevant test results:

Bring them, or have them accessible. Know the key numbers. If you've had a sleep study, know your AHI and RDI. If you've had blood tests, know which markers were flagged.

If it's a new specialist:

Research them briefly beforehand. Do they have a specific interest in your condition? Have they published on it? Have you seen them mentioned in patient forums positively? This helps you calibrate what they're likely to know and what you might need to educate them on.

In the Room

Hand over your summary first:

"I've prepared a brief summary of my history — here's a copy for you." This accomplishes several things: it signals that you are an organised, informed patient; it gives the doctor something concrete to orient around; and it means your history is accurate, rather than filtered through whatever the referral letter said.

State your objective early:

Within the first two minutes, name what you're there for. "The main thing I need to address today is [X]." This prevents the appointment drifting into territory that isn't useful, and it ensures that even if the conversation gets complicated, the doctor knows what you're hoping to leave with.

Pace yourself:

It is better to cover one or two things adequately than five things superficially. If the doctor is going to answer only one question well, make it your most important one.

Use specific, clinical language where you can:

You don't need to perform medical knowledge — and an attempt at clinical jargon that you don't fully command can undermine your credibility. But using accurate terminology where you genuinely know it signals that you are informed. "My RDI, rather than just my AHI" rather than "the more accurate breathing measurement." "Central sensitisation" rather than "my pain has become sort of self-perpetuating."

Observe their reaction:

Not anxiously, but informedly. Are they engaged? Are they writing things down? Are they already reaching for the prescription pad before you've finished your second sentence? Their behaviour tells you things — about what kind of appointment this is going to be, and how to adjust.

Don't minimise:

This is one of the hardest things for people who have been dismissed repeatedly. You start to pre-dismiss yourself. You say "I know this probably sounds strange, but..." or "I don't want to waste your time, but..." Stop. State your symptoms and their impact clearly and directly. "I have had debilitating fatigue for four years. It affects my ability to work and maintain relationships." Not "I've been a bit tired, I don't know if that's significant."

When You're Being Dismissed

Scripts for the most common patterns. Say them in your own words, but keep the shape.

When they say: "Your tests are normal."

> *"I understand the tests don't show [specific concern]. I'd like to understand what we're not testing for. Given that I'm having [specific symptoms] consistently, what else might explain this that we haven't investigated?"*

Or:

> *"I've read that [condition] can present with normal standard tests. Is that something we could consider, and if so, what would appropriate further investigation look like?"*

When they say: "It's probably just anxiety."

> *"I understand anxiety can cause physical symptoms, and I'm not dismissing that as a factor. I'd like to explore both possibilities — rather than either/or. What would you need to see to investigate [condition] alongside the mental health picture?"*

When they say: "Come back if it gets worse."

> *"I want to make sure I understand what 'worse' looks like clinically, so I know what should bring me back. And can we agree a timeframe — so that if I haven't improved in [X weeks], we have a plan for what to try next?"*

When they move toward a prescription too quickly:

> *"Before we go to medication, can I ask — what are we treating this as? I want to make sure I understand the working diagnosis so I can make an informed decision about treatment."*

When they question your research:

> *"I've been trying to understand my situation better so I can have informed conversations with my medical team. I'm not here to override your clinical judgement — I'm here to collaborate with it. Is there something specific that concerns you about what I've found?"*

The principle behind all of these:

You are not being confrontational. You are asking questions. Specific, reasonable, professionally-phrased questions are harder to dismiss than emotional statements, and they demonstrate that you know what you're talking about.

Asking for What You Need

For a referral:

> *"Based on what I've described, I think a referral to [specific type of specialist] would be appropriate. Can we discuss whether that's something you'd support?"*

Name the specialty. If you have a specific consultant in mind — someone you've researched, someone recommended by a patient community — you can name them: "I've read about [Dr X] who specialises in [condition]. Is that someone you could refer me to?"

For a specific test:

> *"I've read that [test] is considered appropriate when [symptom or situation] is present. Given my history, would you consider ordering it?"*

Know why you want the test. Know what it measures. If they say no, ask: "What would I need to present for you to consider it appropriate?"

For a second opinion:

> *"I'd like to explore a second opinion on this. I'm not dismissing your assessment — I just want to make sure I'm covering all the bases given how long this has been going on. Can you support that?"*

You are entitled to a second opinion. In the NHS, you can ask your GP to refer you to a different consultant. Privately, you can simply book elsewhere. Part Four covers when a second opinion is the right move and how to present to the second-opinion consultant.

For more time:

If you're not getting what you need in one appointment, it is completely legitimate to say:

> *"I think this warrants more time than we've had today. Can I book a longer appointment, or come back to continue this conversation?"*

Handling the Aftermath

Sometimes you leave an appointment having got none of what you needed. This is demoralising. It is also recoverable.

Immediately after:

Write down what was said while it's fresh. Not just the decisions — the specific language used. If you were dismissed, what exactly did they say? If a decision was made, what exactly was the plan? Your notes are your record.

Request a copy of the clinical letter:

After specialist appointments, a clinical letter is usually sent to your GP summarising what was discussed. Request a copy for yourself. You can ask the receptionist to add you to the copy list. This letter may contain information — clinical opinions, working diagnoses, next steps — that wasn't clearly communicated to you verbally.

Email a summary to your GP:

If a specialist appointment led to an unclear outcome, or if you were dismissed and disagree with that assessment, follow up with your GP in writing. "I saw [specialist] on [date]. The outcome was [X]. I'm concerned that [Y] wasn't addressed. I'd like to discuss next steps."

Decide what you're doing next:

A bad appointment isn't a dead end. It's information. Options include: requesting a second opinion, seeking a private consultation, escalating through formal channels (see Part Five), or trying a different approach to the same question.

Taking Someone With You

Taking someone to medical appointments can be genuinely helpful. It can also add complications. Here's how to think about it.

When it helps:

- When you have cognitive symptoms (brain fog, dissociation) that make it hard to process information or remember clearly
- When you're at risk of being dismissed and want a witness
- When the appointment is likely to be emotionally difficult
- When you need help staying on track with questions you'd planned to ask

Who to bring:

Someone who can stay calm in clinical settings. Someone who knows your situation well enough to provide accurate context if asked. Someone who will support your account of your experience rather than inadvertently undermining it ("well, she does tend to worry...").

Brief them beforehand:

Tell them: this is what I'm trying to achieve in this appointment. This is what I might struggle with. If I miss [this point], can you raise it? If the doctor starts to dismiss me, can you ask [this question]?

Their role is support, not advocacy:

Ideally they are there to help you function, not to speak for you. Your voice in the appointment matters — it's your body, your experience, your relationship with this clinician. Use them to help you, not to replace you.

A note on going alone:

Many of us do go alone, because we don't have the right person available, or because we prefer it. If you're going alone, consider: using your phone to record the appointment (inform the doctor; most will agree), or asking the receptionist if clinical notes can be sent to you, or asking the doctor to summarise what was agreed at the end.

The Emotional Reality

Advocating for yourself in medical settings is emotionally taxing in a way that people who haven't done it don't fully understand.

Being dismissed — by someone with authority, about something that is causing you real suffering — is a specific kind of wound. It activates something that probably goes back much further than this appointment, for many of us. It says: your experience doesn't count. You don't know your own body. You're probably fine.

It isn't fine. And you are allowed to know that.

But the emotional cost of advocacy is also real, and it needs to be managed deliberately. Going into an appointment already activated — angry, braced, grieving all the previous dismissals — makes it harder to present clearly and professionally. The appointment triggers the accumulated hurt, and the accumulated hurt gets in the way of the appointment.

This is not your fault. It is an understandable response to a genuinely difficult situation.

Practical things that help:

- Give yourself time to recover after difficult appointments. Don't schedule things you need full capacity for immediately after.
- If you have a therapist or a trusted person who understands your situation, debrief with them after hard appointments rather than processing alone.
- Notice if particular types of appointments are more activating than others, and prepare differently for those.
- Separate your assessment of the appointment (was it useful? what's the next step?) from your emotional response to it (that was awful and I'm allowed to feel that).

Both things are true simultaneously. The appointment can have been objectively unhelpful and you can have handled it about as well as was possible. Those two things coexist.

Building Your Appointment Practice

The first well-prepared appointment is hard. It requires conscious effort to prepare, discipline to stay focused in the room, and energy to follow up afterwards.

The tenth prepared appointment is easier. You have a system. You have a template for your summary that you update rather than rebuild. You know your own patterns of what to watch for in yourself. You've got better at reading the signs of how an appointment is going and adjusting accordingly.

This is a practice. Like all practices, it develops.

A simple routine:

Before every appointment:

- Update your one-page summary if anything has changed
- Decide your one main objective
- Write your questions in priority order
- Review the most recent relevant test results

In the appointment:

- Hand over your summary
- State your objective
- Ask your priority questions
- Confirm the agreed next step before you leave

After every appointment:

- Write notes while it's fresh
- Request the clinical letter if applicable
- Follow up in writing on anything agreed
- Decide your next action

That's the whole system. It isn't complicated. The difficulty is in doing it consistently when you're unwell, when you're exhausted, when you've just had a demoralising experience and don't want to engage with the system again.

Do it anyway. The accumulation matters.

PART 04 / SIX

Working the System

Getting the right people, in the right order, without breaking yourself.

Nobody Tells You That Getting the Diagnosis Is Only the Beginning

I remember the relief — complicated and partial as it was — of finally having a name for what was wrong with me. UARS. A real thing with research behind it. A reason for years of dismissal. An actual explanation.

And then: the new problem.

Because knowing the name isn't enough. Now I had to find someone who could actually help. And what I discovered was that the medical system is organised not around your condition but around disciplines — airway over here, hormones over there, nervous system somewhere else entirely — and nobody in any of those rooms would look at the others.

Getting the right diagnosis is the first puzzle. Getting the right people to actually work on it together is the second. Nobody warns you that the second puzzle exists.

This part is about navigating it.

NHS vs Private: The Honest Trade-offs

This is one of the most common questions in patient advocacy communities: should I go private?

There is no universal answer. Here's how to think about it honestly.

What the NHS offers:

A free-at-point-of-use pathway. For some conditions, excellent specialist care. A joined-up records system (in theory). Legal accountability. The right to complain, to escalate, to use PALS.

What the NHS cannot reliably offer for complex, dismissed conditions:

Speed. Specialist knowledge in rarer conditions. Long appointment times. Consultants who will pursue diagnostic uncertainty rather than offering the most available explanation.

What private care offers:

Longer appointments. Specialists you've chosen specifically. Faster access. More willingness, sometimes, to investigate rather than rule things out.

What private care cannot offer:

Continuity across a complex condition (unless you have the money to maintain it long-term). Integration with your NHS records (communication is often poor). Accountability structures (the private complaints process is significantly less powerful than the NHS one). And not all private specialists are better than their NHS counterparts — some are exactly the same people seeing the same patients in a nicer building.

The practical reality:

Most people with complex, dismissed conditions end up navigating both. NHS for the ongoing, the routine, the prescriptions. Private for the specific piece of investigation that the NHS won't pursue or can't do quickly.

The important thing is to approach private care strategically. Not "I'll see anyone who'll see me quickly" — but "I need specifically this type of expertise for this specific question, and I've researched who has it."

Finding the Right Specialist

Being referred to the right specialty is the beginning, not the end. Within that specialty, there are consultants who will be useful to you and consultants who won't — and this rarely has anything to do with their general clinical competence.

What makes a specialist useful for dismissed conditions:

Familiarity with your specific condition. A respiratory physician who has never treated a UARS patient is not the same as one who has a specialist interest in it. Ask before you book.

Willingness to work across specialties. The best consultants for complex conditions are the ones who pick up the phone to their colleagues and say "I've got a patient who might need your input." Ask: "Do you work closely with [other specialty]? Is that part of how you approach complex cases?"

Experience with patients who have been previously dismissed. A consultant who defaults to "tests are normal, therefore nothing is wrong" is not the right consultant for you. Patient community recommendations — forums, advocacy groups — often surface the names of people who have a reputation for being different.

Time and attention. A ten-minute private appointment at significant cost is not necessarily better than a thirty-minute NHS one. Ask, before you book, how long appointments are and whether follow-up is included.

How to find them:

Patient communities are your most reliable source. Reddit communities, Facebook groups, Inspire, condition-specific forums — real accounts from real patients who have actually seen the person. Take individual reviews with appropriate scepticism, but patterns across multiple accounts are meaningful.

Patient advocacy organisations often maintain lists of recommended specialists. Charities and patient groups for your specific condition are worth contacting directly.

GP recommendations can be useful — but your GP's knowledge of the specialist ecosystem for your conditions may be limited. Don't rely on this as your only source.

Red Flags in Specialists

Knowing when a specialist is not going to be useful to you — ideally before you've invested significant time and money — matters.

They dismiss your research without engaging with it. A good clinician, presented with a patient who has done substantial research, either engages with it ("Tell me more about what you've read — what's caught your attention?") or explains specifically why they disagree. Blanket dismissal — "I wouldn't take too much from internet research" — is a warning sign.

They slot your complex presentation into a simple category immediately. If within five minutes of meeting you, a specialist has decided what you have and what you should do about it, without engaging with the complexity of your history, something's wrong.

They tell you symptoms you're describing can't be related. "UARS wouldn't cause that." "PMDD doesn't work that way." Unless they're willing to explain the mechanism — or unless they're genuinely at the frontier of the research — extreme certainty about what a condition cannot do is a red flag.

They respond to your being well-informed with hostility. You knowing a lot about your condition should be an asset in the appointment. If it's being received as a challenge to their authority, that's telling you something.

They recommend interventions without explaining alternatives. Good clinical communication involves explaining options and why this one is being recommended, not simply telling you what will happen.

They make you feel worse about yourself as you leave. Discernment matters here — a specialist who gives you difficult news that's hard to hear isn't making you feel bad; a specialist who makes you feel stupid, dramatic, or like a problem is doing something different.

Green Flags

They ask questions before they answer them.

The consultant who listens for ten minutes before saying anything substantive is often more useful than the one who has a hypothesis within thirty seconds.

They acknowledge what they don't know.

"I'm not as familiar with the interaction between these two conditions as I'd like to be — let me look into that" is a green flag. Medical certainty about complex, poorly-understood conditions is often false certainty.

They ask about your life, not just your symptoms.

How does this affect your work? Your relationships? Your sense of who you are? These aren't therapy questions — they're clinical ones. Functional impact matters for diagnosis and treatment planning, and a consultant who asks about it is thinking about you whole.

They explain their reasoning.

"I'm recommending [X] because [Y]. The alternative approaches are [A and B] and here's why I'm suggesting this one instead." Transparency about clinical reasoning means you can engage with it rather than just accept or reject it.

They communicate with your other clinicians.

The specialists who write to your GP clearly, who reach out to colleagues when appropriate, who flag when something is outside their expertise — these are the people who are thinking about your care as a joined-up thing.

They treat your documented experience as data.

Your symptom log, your medical summary, your account of what has helped and what hasn't — in the hands of a good clinician, this is useful clinical information. If they engage with it seriously, that's a green flag.

Second Opinions

Getting a second opinion is not a confrontation. It is not a lack of trust. It is a standard, respected part of good medical care — particularly for complex or rare conditions, for significant treatment decisions, or when you've been dismissed without adequate explanation.

When a second opinion is appropriate:

When you've received a diagnosis that doesn't fit your experience or that leaves significant symptoms unexplained.

When you've been told there's nothing more to be done, or nothing to investigate — and your symptoms are significantly affecting your life.

When you're facing a major, irreversible treatment decision (surgery, for example) and want to make sure you've considered all options.

When you've been dismissed repeatedly and want confirmation that the dismissal is clinically justified — or evidence that it isn't.

When a diagnosis has significant implications and you want it confirmed.

In the NHS:

You can ask your GP to refer you to a different consultant for a second opinion. Frame it as: "I'd like to explore this further before making a decision — would you be willing to refer me to [specialist/specialty] for another perspective?" (The in-room script for raising this is in Part Three.)

Privately:

Book directly. You don't need a referral for most private consultations, though some prefer a letter from your GP.

How to present to the second-opinion consultant:

Bring your full case file. State that you're seeking a second opinion — most consultants prefer you to be direct about this. Tell them what the first opinion was and why you've sought another. Ask them to make their own independent assessment before you share the first doctor's conclusion, if you can.

Making Specialists Work Together

One of the most frustrating realities of managing complex, multi-system conditions is that your consultants are typically not speaking to each other. Your ENT doesn't know what your rheumatologist said. Your gynaecologist is unaware of your UARS diagnosis. Your GP receives letters they may not read carefully.

This coordination failure has real clinical costs. Treatments that interact. Diagnoses that inform each other. Patterns that are only visible when the whole picture is seen.

Nobody is going to coordinate this for you. You have to do it.

Be explicit about the connection at every appointment. "I also have [condition], which is managed by [specialist]. I want to make sure we're thinking about how these interact." Most doctors are not doing this automatically. Prompting them to do it surfaces connections they might otherwise miss.

Carry connection documents. A brief note — one paragraph — that outlines your interconnected conditions and the key clinical connections between them. Hand it over at relevant appointments. "I've written a brief summary of how my conditions interact, in case it's useful context."

Ask consultants to copy each other. "Would you be willing to copy my [ENT / rheumatologist / GP] on the letter from this appointment? I want to make sure everyone has the same picture."

Use your GP as a coordinator. Your GP is theoretically the person who sees your whole picture. In practice, they often don't — but you can actively engage them in this role. "I've had appointments with [specialist A and B] recently. Can we have an appointment to look at the full picture together and make sure we have a joined-up plan?"

Navigating Referrals

The referral system is one of the most significant practical barriers for patients with complex conditions. Here's how to navigate it.

For GP-to-specialist referrals:

Be specific. "I'd like a referral to a sleep medicine specialist with experience in upper airway resistance syndrome" is more useful than "I'd like to see someone about my sleep." Your GP can decline a referral — but they have to have a clinical reason for doing so, and if they decline, you can ask them to document why in your notes.

Right to choose:

In England, if you're being referred to a specialist for the first time, you have the right to choose which hospital you're referred to. This can include specialist centres, even those at a distance, if they offer better expertise for your condition.

If a referral is declined:

Ask why, in specific clinical terms. Ask what would need to change — what evidence would they need to see — for them to reconsider. Note this conversation in writing afterwards.

If you've been on a waiting list for an unreasonable time:

Contact your GP about the delay. You can also contact the hospital's Patient Advice and Liaison Service (PALS) if the wait is causing you clinical harm. Part Five covers PALS and the other formal processes in full.

Going directly to private:

If an NHS referral is being declined or delayed and the need is genuine, you may choose to see a private consultant directly. A good private consultant will often write back to your GP with their findings, which can then reopen the NHS pathway with stronger clinical backing.

The Specialist Silo Problem

Many of us are navigating conditions that exist at the intersections — between sleep and hormones, between trauma and physical health, between the nervous system and chronic pain. The medical system, organised by organ and discipline, often has no structure for seeing those intersections.

The specialist who helped me most was not the one with the most knowledge of any single condition. It was the one who could hold the complexity — who thought about how things connected, who read the wider picture, who said "I wonder if what's happening here is related to [other thing]."

These people are rare. But they exist. Finding them often requires looking in specific places:

Functional medicine practitioners. I'm cautious about including these, so let me be precise. The field is largely unregulated, and it contains both thoughtful clinicians and people who will sell you thousands of pounds of unvalidated tests and supplements. If you explore this route: prefer practitioners who are also registered doctors, be sceptical of anyone who leads with a test panel or a supplement protocol, set a spending limit before your first appointment, and keep your GP in the loop. What some of these practitioners genuinely offer is time and whole-system thinking — which is valuable precisely because the mainstream system rations it. It is not a substitute for evidence-based care.

Academic or teaching hospitals. Consultants with research interests in complex or rare conditions are more likely to be found at universities and teaching hospitals than at district general hospitals.

Multidisciplinary teams. Some conditions — endometriosis, complex UARS, CPTSD — are beginning to develop MDT (multidisciplinary team) models where multiple specialists contribute to a single patient's care plan. These are emerging. They're worth knowing about and asking about.

Patient advocacy organisations. For many complex conditions, advocacy organisations have identified the practitioners who are both knowledgeable and willing to think outside standard pathways. Contact them.

Protecting Your Energy

Navigating the medical system at this level is work. It is cognitive work, emotional work, administrative work. It requires energy that you may have in limited supply.

This is not a reason to stop. But it is a reason to be strategic about how you deploy yourself.

Triage your efforts. Not every battle is worth fighting. The consultant who dismissed you once and with whom you have no ongoing relationship — is writing a complaint letter to them the best use of your limited energy? Sometimes the answer is yes. Often, the better investment is in finding the right person rather than changing the wrong one's mind.

Batch your advocacy tasks. If you're going to prepare correspondence, do several pieces at once when you have the headspace for it, rather than having a separate cognitive effort for each one. If you're going to research specialists, do a proper session rather than grazing at it repeatedly.

Accept that the system will sometimes fail you, and that this is not your fault. You can do everything right — prepare excellently, advocate clearly, document thoroughly — and still hit a wall. This is a failure of the system, not of your advocacy. Knowing this matters. It means the failure doesn't have to become evidence that nothing you do makes a difference.

Know when to rest from the pursuit. There are phases of this where you can press actively, and phases where the best thing is to hold your current position and rest. Recognising which phase you're in, and giving yourself permission to be in the resting one without guilt, is part of sustainable advocacy. More on this in Part Six.

PART 05 / SIX

When They Say No

Formal processes, complaints, and escalation — using the system as it was designed to be used.

The Word "Complaint"

The word "complaint" made me recoil for years. It felt aggressive, like I was accusing someone of something. Like I was declaring war rather than asking for help. Like I was the difficult patient I'd been trying not to be perceived as for years.

But I've changed my position on this.

Formal processes exist because the informal ones don't always work. Complaints processes, escalation pathways, appeals — these are not adversarial add-ons to the system. They are part of the system. They exist because patients need protection, because standards need accountability, and because no medical organisation should be immune from feedback about failures.

Using these processes is not aggression. It is using the structure that exists precisely for situations like yours.

This part is about when to use them, how, and what to realistically expect.

A note on scope: this is information about formal processes as a patient in the UK — primarily the NHS. Private healthcare processes differ and are covered separately below. This is not legal advice; for legal matters, please consult a qualified solicitor.

Before You Go Formal

Formal complaints take time, energy, and emotional resource. Before going that route, it's worth being clear that informal alternatives have genuinely been exhausted.

Raise it with the practice or department directly:

For GP practices: speak to the practice manager. For hospital departments: ask to speak to the department's patient liaison or the consultant's secretary. State clearly what happened, what you needed that you didn't receive, and what you're asking for. Keep a note of the conversation — date, who you spoke to, what was said.

Ask for a meeting:

Sometimes a face-to-face conversation with a senior figure — a lead GP, a department head — resolves things that correspondence doesn't. Request a meeting to "discuss a concern about my care." Come prepared with your documentation.

Try a different route to the same outcome:

If Consultant A has dismissed you, can you get the same thing from Consultant B without a complaint? Sometimes the most efficient advocacy is redirecting rather than appealing. A formal complaint about Consultant A may take months and exhaust you without guaranteeing a different clinical outcome. Whereas a second opinion with Consultant B might get you where you need to go in weeks.

That said — there are situations where formal processes are the right tool. If a failure in your care has caused you genuine clinical harm. If a pattern of dismissal is so consistent that an informal resolution is clearly not available. If you want something on the record, even if the outcome of the complaint itself isn't the primary goal.

PALS — Your First Formal Port of Call

PALS — the Patient Advice and Liaison Service — is a free service available in every NHS trust in England. Its role is to help patients resolve concerns informally, quickly, and without needing to go through the formal complaints process.

What PALS can do:

- Help you navigate the NHS system and understand your options
- Liaise on your behalf with departments or staff to resolve issues informally
- Provide information about the formal complaints process if informal resolution isn't possible
- Help you get answers to questions that you haven't been able to get answered through normal routes
- Escalate concerns within the trust

What PALS cannot do:

- Force clinical decisions
- Override medical judgements
- Guarantee outcomes
- Replace formal complaints for serious failures

How to use PALS:

Contact them directly — every NHS trust has a PALS office with a phone number and email, findable through the trust's website. Explain your situation clearly. Tell them what you need. They will advise on the best route and, where appropriate, act as intermediary.

PALS is often faster and less draining than a formal complaint. Try it first for anything that feels like a practical or communication failure rather than a serious clinical one.

Making a Formal NHS Complaint

If informal resolution and PALS have not resolved your concern, or if the issue is serious enough to warrant formal process, you can make a formal complaint.

Who to complain to:

If your complaint is about a GP practice: complain directly to the practice first, or to your local Integrated Care Board (ICB) — the ICB took over this role from NHS England in 2023. Your ICB's complaints contact is findable by searching "[your area] ICB complaints".

If your complaint is about a hospital: complain to the hospital trust's complaints department.

If you're unsure: PALS can advise.

Time limit:

Complaints should normally be made within 12 months of the event, or within 12 months of the date you became aware of the problem. Extensions are sometimes possible.

What to include in your complaint:

- Your name and contact details, NHS number
- The name of the practice, hospital, or individual concerned
- A clear, factual description of what happened — with dates
- What impact this had on you
- What you are asking for (an apology, an explanation, a change in care, an investigation)

Format:

Written is best — email or letter. This creates a record. Keep your account factual and specific. Avoid making it primarily about how you feel about what happened; focus on what happened, when, and what the consequences were.

Response timeline:

Under NHS complaints regulations, you should receive an acknowledgement within three working days, and the organisation should tell you how long a full response will take — many trusts aim for around 25 working days, though the regulations set no fixed deadline for the full response. If the acknowledgement doesn't come, or the promised timescale passes, follow up in writing.

What to do if you're not satisfied with the response:

You can take your complaint to the Parliamentary and Health Service Ombudsman (PHSO). This is free. The PHSO investigates complaints about NHS services in England that haven't been resolved at local level. The process is slower — investigations typically take months — but it is an independent body with the power to require changes.

Writing an Effective Complaint Letter

A complaint letter that is effective is one that is read, taken seriously, and addressed substantively. This is different from one that is emotionally satisfying to write.

Structure that works:

Opening paragraph: State clearly that this is a formal complaint. Give your name, date of birth, NHS number, and the dates and locations of the relevant care.

Factual account: In chronological order, what happened. Specific dates. Names of clinicians where known. What was said or done. What was not done that should have been. Keep this section factual — not "I felt dismissed" but "I described the following symptoms [list] and was told [specific response]. No investigation was offered."

Impact: What the failure in care has meant for you. Clinically — has your condition progressed? Have you had to seek private care at cost? Have you experienced harm from delayed diagnosis or treatment? Functionally — has this affected your ability to work, care for yourself, maintain relationships?

What you are asking for: Be specific. Possible asks include:

- A full explanation of the clinical reasoning behind decisions made
- An apology
- A review of your care plan
- A specific investigation or referral that was declined
- Assurance that processes will be reviewed to prevent recurrence
- Compensation (this is possible in some circumstances; if this is relevant, consider getting advice before requesting it)

Closing: Ask them to confirm the timescale for their full response, and note the date you expect the three-working-day acknowledgement by. State that if the complaint is not resolved, you will escalate to the Parliamentary and Health Service Ombudsman.

Tone: Formal, factual, measured. Not cold — you are a human being who has been harmed — but not emotional in a way that allows the complaint to be received as distress rather than substance.

Private Healthcare Complaints

If your complaint is about private healthcare — a private consultant, a private hospital, a private clinic — the process is different, and it's important to understand that it offers less protection than the NHS process.

The Independent Sector Complaints Adjudication Service (ISCAS):

Many private hospitals and clinics are members of ISCAS, an independent body that adjudicates complaints. Check whether your provider is a member (their website will state this). If they are, you can escalate to ISCAS if the provider's own complaints process hasn't resolved things.

The Private Healthcare Information Network (PHIN):

Publishes data on private hospitals and consultants. Not directly a complaints body, but relevant for understanding context.

Regulatory bodies for individual clinicians:

If your complaint is about a specific clinician's conduct rather than organisational failure, the relevant regulatory body is:

- Doctors: General Medical Council (GMC)
- Dentists: General Dental Council (GDC)
- Physiotherapists: Health and Care Professions Council (HCPC)

Regulatory body complaints are appropriate for serious concerns about a clinician's fitness to practise — not for disagreements about clinical judgement. The bar is higher, but the consequences can be more significant.

Insurance:

If you have private health insurance, your insurer may have leverage with the provider that you don't. A claim dispute can sometimes be resolved through the insurer's escalation process.

Insurance Appeals

If private health insurance has denied a claim — refused to fund a treatment, investigation, or referral that your consultant has recommended — you have the right to appeal.

Step 1: Understand why the claim was denied.

Ask for the specific reason in writing. Common reasons include: condition is considered "pre-existing", treatment is considered "not clinically necessary", treatment falls outside covered categories, waiting period not elapsed.

Step 2: Gather supporting evidence.

Your consultant's letter recommending the treatment. Any relevant research supporting the treatment's efficacy for your condition. Your symptom documentation showing the clinical need. A letter from your GP supporting the clinical necessity.

Step 3: Write an appeal letter.

Address it to the insurer's appeals team. Reference your policy number, the specific claim, the date of denial, and the reason given. Provide the evidence gathered above. If the denial rests on a clinical judgement, ask for that decision to be reviewed by an independent medical adviser.

Step 4: Escalate if needed.

The Financial Ombudsman Service (FOS) handles complaints about insurance companies in the UK. If your insurer's appeals process has failed, you can take your case to the FOS. This is free.

A practical note: Insurance companies sometimes deny claims expecting that patients won't appeal. The appeal process, particularly for clinically supported treatments, has a meaningful success rate. Do not accept the first denial as final.

Protecting Your Records

If you think there is any possibility that you will need to use a formal process — now or in the future — the time to protect your records is now, not after.

Request your medical records:

Under the UK GDPR, you have the right to access your medical records. This is called a Subject Access Request (SAR). You can request it from your GP practice, hospital, or any other healthcare provider. It should be provided free of charge and within one month.

Do this. Keep a copy. Your version of your records, dated when you received it, is your evidence.

Note discrepancies:

If you receive your records and find that something has been documented incorrectly — your account of symptoms noted differently than you gave it, a clinical opinion stated as fact rather than assessment, relevant information missing — document this. In some cases, you can request that an amendment be added to the record noting your disagreement.

Keep contemporaneous notes:

Notes made at the time of events are more credible evidence than accounts reconstructed later. For anything that feels significant — a dismissal, a decision you disagree with, a conversation where something important was said — write it down the same day.

Secure your documentation:

Keep copies of everything in a location that won't be lost. A cloud backup of your documents. Printed copies of key letters and test results. Your case file (Part Two) is your evidence, and it needs to be protected.

The Emotional Cost of Formal Processes

Formal complaints and appeals are draining. They require you to revisit painful experiences in clinical, formal detail. They move slowly. The outcome is often disappointing. The person or institution you've complained about may respond in ways that feel like further dismissal.

This is real, and it needs to be factored in.

Before starting a formal process, ask yourself:

What am I hoping to achieve? Is a formal complaint the most direct route to that outcome, or is there a faster or less costly way?

What do I have the capacity for right now? Starting a formal process in a period of poor health, high stress, or emotional instability is harder than starting it from a relatively stable position.

What does success look like, and is it realistic? A formal complaint may result in an apology and an assurance of process change. It is unlikely to directly change a clinical decision already made. Know what you're working towards.

Do I have support for this? Someone to help you draft correspondence, review responses, and hold you when it's hard. Formal advocacy is difficult to do completely alone.

And know this: Taking time — weeks, even months — to decide whether and how to pursue formal action is completely legitimate. The time limits for complaints are generous enough to allow reflection. A decision made from a grounded place, with realistic expectations and sufficient support, is more likely to serve you well than one made in the immediate heat of a bad experience.

Using Your Voice in Bigger Ways

Some of us, having been through the system and navigated it, find that we want to use that experience to contribute to changing it.

This is entirely optional. You are not obligated to become an activist on top of managing a chronic condition. But for those who want to, there are ways.

Sharing your story:

Patient organisations, academic researchers studying diagnostic delay, charities working on specific conditions — all of these benefit from hearing real patient accounts. Your experience is data. Your story is evidence.

Patient participation:

Many NHS trusts and integrated care boards have patient participation groups. These have real, if limited, influence on service design. If this kind of structural input appeals to you, it's accessible.

Research participation:

Participating in research studies on your conditions contributes to the evidence base that will ultimately change clinical practice. Patient advocacy organisations often have registries or lists of ongoing studies looking for participants.

Condition-specific advocacy:

If you feel strongly about a particular aspect of your conditions' treatment — diagnostic delays, specific dismissal patterns, treatments that aren't being offered — the advocacy organisations working on these conditions may welcome your voice.

None of this is obligatory. But sometimes, having been through the worst of the system, the thing that helps is contributing to the possibility that the next person's experience will be less bad.

PART 06 / SIX

The Long Haul

Sustaining yourself as your own advocate — over years, not weeks.

When Advocacy Becomes Another Thing That's Making You Sicker

There came a point where I realised I had made being a patient my full-time job.

I was researching, emailing, preparing, complaining, following up, reading, tracking — all on top of being chronically unwell. And the advocacy, which was supposed to help me, had become another source of depletion. I was so focused on fixing things that I had stopped being able to rest. I'd be at dinner with friends and in my head be composing an email to my consultant. I'd lie awake not from symptoms but from the sheer cognitive load of managing my own care.

This part is about what nobody tells you: that advocacy is a practice with a sustainability problem. How to keep going in a way that doesn't hollow you out. How to pace yourself through what is, for many of us, a years-long process.

Advocacy Fatigue Is Real — and It Has a Nervous System Cost

For those of us with conditions that dysregulate the nervous system — UARS, CPTSD, PMDD, endometriosis — the cumulative stress of medical advocacy is not just emotionally tiring. It is physiologically costly.

Every appointment that requires preparation has a cost. Every dismissal activates your stress response. Every piece of correspondence requires cognitive and emotional resource that, for many of us, is already stretched.

The particular cruelty:

The conditions most likely to require the most sustained advocacy are often the same conditions that make sustained anything most difficult. Chronic fatigue limits how much cognitive effort you have available. Brain fog makes it hard to hold complex information or compose careful communications. Emotional dysregulation from nervous system conditions means that a dismissive appointment doesn't just leave you frustrated — it can send you into a physiological stress response that takes days to recover from.

Knowing this doesn't make it easier. But naming it clearly means you can factor it into how you plan your advocacy — rather than blaming yourself when you can't sustain the pace you think you should be able to.

Pacing Your Advocacy

If you've lived with a chronic condition that affects your energy, you probably know about pacing — calibrating your activity to your actual capacity rather than what you theoretically should be able to do. Most people apply this to physical activity. Few apply it to advocacy. They should.

Not every period of your life is equally suited to intensive advocacy. There are periods when you have more capacity — better health, lower life stress, a moment of stability — and periods when you have less. Calibrate your advocacy work to match.

Intensive phases: When you're more resourced, press forward. Research specialists. Prepare detailed case documentation. Write the formal letter. Make the calls.

Maintenance phases: When you're depleted, hold your current position. Attend scheduled appointments but don't pursue new fronts. Respond to correspondence that requires responses but don't initiate new correspondence. Keep your symptom log running but don't do the analysis. Maintain, don't expand.

Rest phases: There will be periods when even maintenance is too much. During these, give yourself explicit permission to put advocacy down. You are not abandoning your health. You are managing it in a way that takes into account the whole person, not just the medical management of it.

The key principle: Progress is non-linear and that's okay. A period of active advocacy followed by several months of maintenance followed by another push forward is completely sustainable. Trying to sustain intensive advocacy indefinitely is not.

The Emotional Labour

The work of being a patient in the system I'm describing isn't just administrative. It is emotionally skilled labour.

You are managing your own activation — your fear, your frustration, your grief — in order to present as the "good patient" the system responds to. You are absorbing dismissals and processing them without letting them derail you. You are translating your embodied experience into clinical language. And it goes everywhere: into the appointments (presenting as calm and organised when you are frightened and exhausted), into the aftermath (processing disappointments, deciding what to do next), into your relationships (translating what's happening for partners, family, employers — fielding concern and scepticism alike).

None of this is accounted for in any standard advice about patient advocacy. But it's real, it's significant, and it needs resource. What that resource looks like is different for everyone: therapy with someone who understands chronic illness, a peer community where your reality is recognised without explanation, a small number of people who genuinely get it, and honest acknowledgement — to yourself and others — of how much this is actually taking.

Building Your Support Team

Navigating this alone is possible. Many people do it. But it is significantly harder than navigating it with support, and the support that matters is specific.

Someone who understands your conditions. Not medically, necessarily — but experientially. Someone who knows what it is to be dismissed by doctors, to have symptoms that don't show on standard tests. This might be a partner, a friend, or someone from a patient community. The value is that you can talk about a bad appointment and be understood without a lengthy preamble.

Someone practical who can help with systems. The administrative side of advocacy can be shared. A partner who will sit with you while you draft a difficult letter. A friend who will research specialists. Someone who will read what you've written before you send it.

A therapist or counsellor, ideally with chronic illness experience. The emotional processing that comes with chronic illness and medical advocacy is real psychological work. Not all therapists have experience with chronic illness — it's worth asking specifically. CPTSD-informed therapists are particularly useful for those of us where trauma and physical health are intertwined.

Your patient community. Forums, online groups, advocacy organisations. They know things doctors don't. They've found the good specialists (see Part Four). They've made the errors so you don't have to.

Using Patient Communities Wisely

Patient communities can be transformative. They can also become a source of harm. The difference is often about how you use them.

Where they help: finding the names of the specialists who actually help people with your conditions — some of the most valuable practical information available, and it lives almost entirely in these communities. Feeling less alone — the recognition of reading someone describe your exact experience is genuinely therapeutic. Learning from others' journeys. Getting fast, knowledgeable answers to specific practical questions.

Where they can harm: Catastrophisation — people whose treatment went well post less than people whose treatment went badly, so reading primarily the difficult outcomes creates a distorted picture. Misinformation — not everything shared is accurate; apply the same critical thinking you'd apply to AI (Part One). Comparison and despair — everyone's physiology, circumstances, and resources differ. And the spiral — forums at 2am when you can't sleep and are anxious are the same trap as the AI spiral in Part One. Know this about yourself.

A practical rule: Communities for information and solidarity. Not communities as a substitute for professional care, or as a place to make clinical decisions.

When to Rest From the Fight

The idea that resting from advocacy means giving up on your health is one of the most damaging narratives in chronic illness culture.

It is not true.

Resting from active pursuit of answers and treatment is sometimes the most health-preserving thing you can do. The nervous system cost of sustained advocacy in a difficult system is real. There is a point at which the pursuit itself is causing more harm than the not-yet-having-the-answer.

Signs that you need to step back:

- Your advocacy activities are increasing your symptoms — more research, more calls, more letter-writing is making you physically worse
- You've lost the ability to be fully present in your life; everything has become about your health
- You're advocating compulsively rather than strategically — not because each action is the best next step, but because doing something feels better than not doing something

- Your emotional state around your health has shifted from engaged and purposeful to desperate or hopeless
- The rest of your life — your relationships, the things that matter to you outside of being ill — is being consumed by medical management

Resting looks like:

Attending scheduled appointments but not pursuing new avenues. Keeping your symptom log but not analysing it intensively. Staying connected to community but not spending hours in forums. Holding your current medical plan without trying to optimise it.

And trusting that rest is part of looking after yourself — not in a naive "positive thinking" way, but as a break from constant pursuit. I found that periods where I was not researching, tracking or preparing helped me keep going. That is my experience, not a treatment claim.

Holding Onto Yourself

One of the things chronic illness can do — particularly when the illness is poorly understood, diagnosed late, and requires years of active management — is narrow your identity. You can become, over time, primarily a patient. Your energy, your conversations, your community, even your sense of purpose can become entangled with being a patient.

This is understandable. And it's worth watching. Because when your identity is fused with your illness, every setback in your care can become a setback in your sense of self. Every failed treatment is not just a clinical disappointment but an existential one.

What helps:

Protecting the parts of your life that aren't about health. However small. One interest, one relationship, one practice that exists entirely outside of illness. Tend to this deliberately.

Having some conversations, some spaces, some hours where you are fully present as yourself rather than as a patient. This isn't about performing wellness — it's about keeping a self that the illness doesn't own.

Allowing your identity to include your illness without being reducible to it.

Sustaining Hope in a Slow System

I won't tell you to stay positive. That's not the same thing as hope, and you deserve honest conversation, not wellness-influencer platitudes.

What I've found sustains people through years of this — myself included in the better periods — is not optimism, exactly. It's something more grounded.

Evidence of movement, however small. Not cure, not transformation — but any change from what it was. The diagnosis that explains the years of confusion. The appointment that finally took you seriously. The treatment that helped one thing, even if it didn't help everything. Progress in complex conditions is often incremental to the point of being almost invisible. Finding ways to recognise it matters.

People who are further along than you. In every patient community for every complex, dismissed condition, there are people who were where you are and are in a different place now. They don't always have full recovery to report — recovery in chronic conditions often doesn't look like that. But they have more stability, more management, more peace with their situation. Their existence is evidence that things can change.

The quality of your life right now, not only your life when you're better. This is a hard one. But waiting to live until you have answers keeps you from the life that's available to you in the meantime. Meaning, pleasure, connection, engagement — these are not reserved for well people. They are available, however imperfectly, now. Finding and protecting them is not giving up on getting better. It's refusing to let the pursuit of better be the only thing.

The Advocacy That Happens Just by Existing

The chronic illness community has a complicated relationship with the "warrior" narrative. The idea that being ill requires relentless fighting, extraordinary resilience, constant advocacy.

I understand the value of it. It acknowledges the genuine difficulty. It credits people for continuing in the face of it.

But it also sets a standard that can feel crushing on the days — and there are many days — when you are not fighting. When you are just surviving. When you don't have the resources for the good fight.

You don't have to be a warrior to deserve care.

You don't have to advocate eloquently to have your experience be valid.

You don't have to build the case file, prepare the appointment pack, write the letter, escalate the complaint, find the community, pace yourself, build your team, sustain hope — all at once, all the time.

Some of it, some of the time, as you can. That is enough.

And sometimes, just existing as a person with these conditions — living your life, sharing your experience, letting people who know you see what this is like — is its own form of advocacy. The slow change in how these conditions are understood and treated is built on the accumulation of people saying: this is real, this is happening to me, this is what it's like.

Your experience is part of that. Even on the days when you're doing nothing about it.

A Closing Note

This can take a long time. You don't have to run.

And one last time, because it belongs at the end as much as the beginning: I'm not a clinician, and nothing in this guide is medical or legal advice. It's the practical knowledge of a patient who is still in it — built through years of trial, error, and a system that made me work for every inch. If it saves you even some of that work, it has done its job.

Your tests may say you're fine. Your body is telling the truth. You deserve to be taken seriously — and until the room you're in agrees, I hope this guide helps you hold your ground.

— Josie