HOME + FUTURE

SOUTH EAST
CARE COOPERATIVE

A lived experience guide:

Providing meaningful care in a tier 4 setting

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How this book was developed

This handbook was developed as part of a pilot for the South East Regional Care Cooperative (Home and Future). It grew out of a full-day workshop exploring the care resources and challenges faced by children and young people with complex experiences, and how services respond.

We know this group too often face the poorest outcomes and are frequently placed far from home - and across our conversations with Social Care and ICB colleagues locally, they were consistently the children people were most concerned about and most wanted to understand how to better support.

We were fortunate to work with Natalie, Participation Manager for one of the South East Provider Collaboratives, who helped us involve a group of young people directly. They attended the workshop and delivered a powerful presentation - bringing their journeys to life with the support of a graphic recorder who captured their stories in their own words.

At the close of the session, the young people turned to the room - full of integrated commissioners, health colleagues and more - and said: 'We could write you a book, to tell you what good staff look like and what they need to know.' That offer was met with genuine enthusiasm. And so, this book began.

Our stories...

Ella

My story wasn't a linear one, and there were a lot of ups and downs; anorexia took over a decade from me, but I made it out and I want staff reading this to understand that no matter how 'complex' a patient is deemed, there is hope and every young person needs someone that won't give up on them even when others have – be the beacon in a time of darkness.

I was always an overachiever top of my class, I had friends, and by all accounts I was happy. But I was cripplingly perfectionistic - to a fault. And suddenly my body that had slowly been wasting away with excessive exercise and meticulous counting of calories and had started to give up on me. Yet I still craved that semblance of control I felt anorexia could only give me.

I spent a long time in and out of hospitals on bed rest, missing education, events, friends - I was in this complete blur until it hit a breaking point. Eventually I was admitted to an inpatient unit (sectioned) after my mental and physical health declined.

I really struggled in the hospital environment – it was terrifying, (something I contribute to my undiagnosed autism at the time), and I think that resulted in a much longer admission as small changes to accommodate my neurodivergence could have made all the difference, but as a 'high functioning' young woman, autism is often overlooked.

[Continued overleaf]

Our stories...

Ella [continued]

I wish only to ensure other young patients don't experience the preventable trauma that I did due to lack of understanding and awareness.

I remember every single staff member that truly helped me - I remember their names, everything about them, the ones that treated me like a real person - someone separate to my eating disorder. These are the people that gave me hope and a know one day the person reading this could give someone else the hope they need to truly start living again.

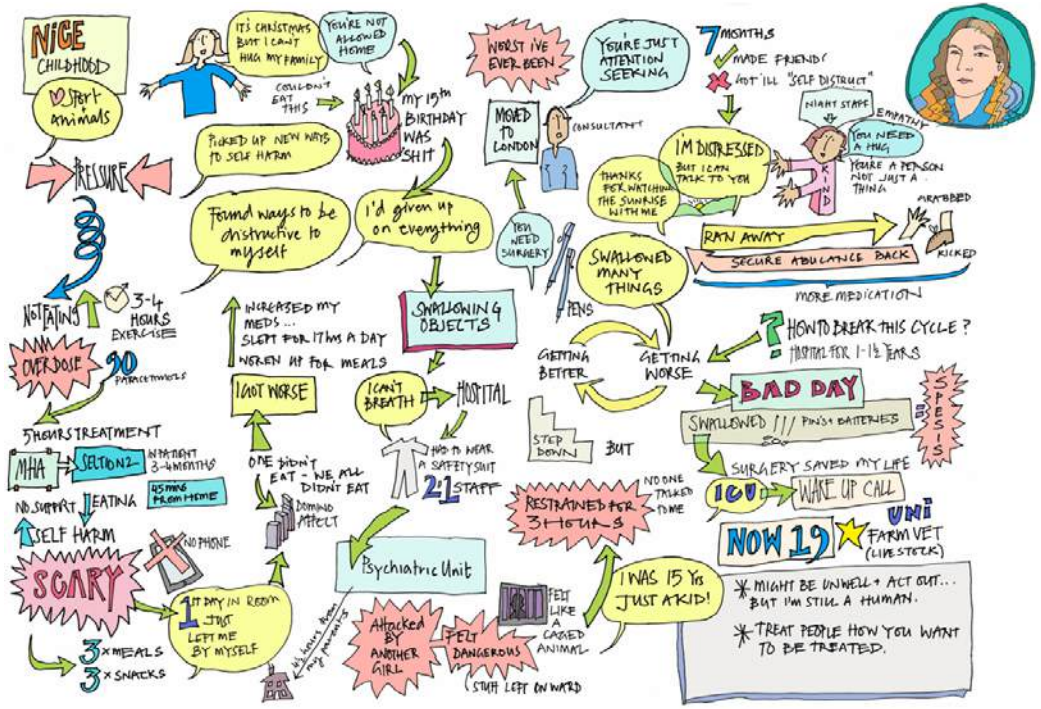
Our stories...

Lydia

Hello, my name is Lydia and I am 20. I started to struggle when I was 13 due to the stress of a high achieving school and unresolved childhood trauma. I had enough of dealing with this alone causing me to have an attempt on my life causing me to be sectioned.

After being sectioned I completely lost myself and quickly deteriorated causing me to be put in a PICU. I felt so scared as I was 200 miles away from my home and I was constantly overwhelmed by the noise of the ward. Everything was so new to me as I had never even heard of psychiatric hospitals and suddenly I was locked in one at 14.

I had to fight to be able to do anything and to be discharged. Eventually after 2 years I was discharged and attempted to get my life back on track. I am now at University studying Agriculture and I have complete freedom to do what I want. It does get better :)



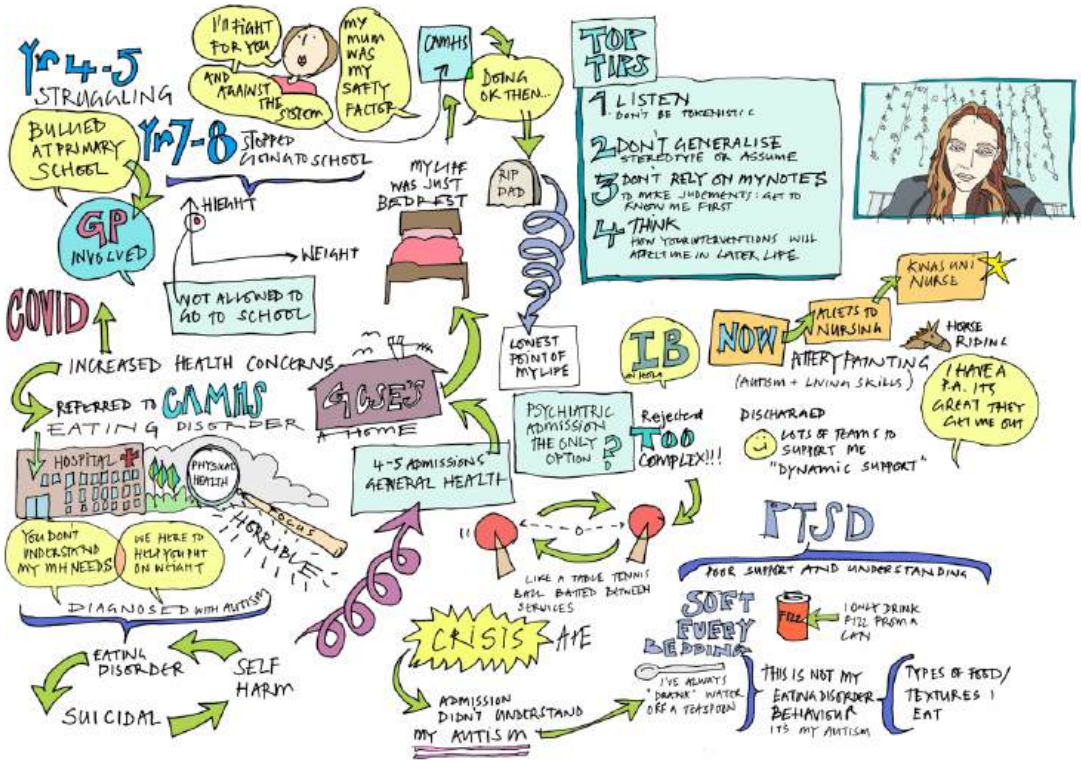
Our stories...

Dulcie

Hey, my name is Dulcie and I am 19. This is my journey, beginning when I was about 9, so essentially it is the past decade of my life depicted in one image; huge credit to Jon because my artistic skills would certainly not be this good haha.

I have struggled with my mental health for as long as I can remember, and appointments and hospital admissions have shaped my everyday life for years. This started with my first referral to services and has spanned my teenage years, with a timeline based on diagnoses and treatments, often being chucked between different services with my needs not being met.

Looking at this drawing makes me feel quite sad thinking about everything that has happened, but it also gives me a lot of motivation to keep progressing in my own recovery and to help improve services for future young people. That is why being part of this booklet feels so important.



Our stories...

Niamh

My name is Niamh and I'm 17 years old, I love to dance, sing, spend time with my friends and family - and I'm also in recovery from mental illness.

My drawn story only reflects a small part of what I went through with being poorly, it could span up to 10 pages and that still wouldn't be enough. I've struggled with my mental health for 6 years and while I classify myself as recovered there are still hard days.

For years my life revolved around starvation, self harm and suicide. I spent my free time dictated by psychiatrists, I never received help that was truly beneficial to me as nobody knew how to help me, and everyone had a different opinion on what was wrong with me and why I was so ill.

Now I get to tell my story the way I know it, this drawing reflects my past, some of my present, but not my future. This drawing will always remind me where I've come from and my 'why' for pursuing a career in mental health.

See us as young people/children first

Before our diagnosis, our notes, and our history - we are children and young people. We have passions and lives beyond what brought us into contact with you. How you see us shapes everything about how you treat us, and ultimately, how we see you and receive your input.

Story/example

The setting of a psychiatric ward can make it easy to forget that the person in front of you is a child, having to experience things most don't over a whole lifetime. Someone expected to navigate an extremely scary and frightening variety of events that will stay with them forever..

"When I arrived on the ward, nobody asked me what I liked to do or what I cared about. They had read my notes and that became who I was to them. But I'm a person who loves crocheting, who had friends, who had a life. It felt like I had been reduced to a list of symptoms.

Another thing that struck me: I had to rely on another young person already on the ward to tell me how things worked. Nobody from staff had shown me round or explained the routines. Don't rely on your patients to do your onboarding for you."

Top tip

Treat us how you would want to be treated. And remember: even a 17-year-old is legally still a child. The ward environment doesn't change that.

Get to know your young person/communication

We are all different. What helps one person may not help another. Communication styles, sensory needs, and ways of relating vary enormously - especially when autism, ADHD, or trauma are part of the picture. Ask rather than assume. This also means understanding what professional relationships look like.

Getting to know us does not mean trying to make us like you, and boundaries matter. Being able to strike the balance to treat us as equal humans whilst still maintaining therapeutic relationships is a huge part of the care. It is so incredibly important to see each person as their own individual, despite what you may have read or been told.

Story/example

"I'm diagnosed with autism. The way they wanted me to eat, communicate, and the bedding I had to sleep on wasn't right for me. The staff kept reading my behaviour through a different lens and didn't understand what I needed to become well."

We also noticed that some staff were popular because they facilitated our illness. We don't need you to be our friend, we just need you to be friendly. You don't get to see the outcome in your role, but in two years, when that young person can eat at a restaurant, that's partly down to you holding the line when it was hard. For example, one staff member would tell us funny stories to make mealtimes lighter, but if we tried to hide food in our sleeves, he'd still challenge us. Warmth and boundaries can co-exist.

Top tip

Before your shift, read the young person's file and ask them one question about themselves that has nothing to do with their mental health. What do they love? What are they good at? How can you show them you are not just repeating the same script to every young person?

Believe me/treat me as an individual

> Being disbelieved when you're already struggling is one of the loneliest things.

Our experiences are real, even when they are hard to understand. When staff dismiss what we say, it compounds the harm we are already carrying. Believe us - we are the experts on ourselves and despite being ill we still have the right to be heard every time.

Story/example

"A consultant told me I was 'just attention seeking' when I was swallowing objects like pens. Being disbelieved when you're already struggling is one of the loneliest things."

Something people forget: being in hospital doesn't mean we lose our sense of self or capacity to make decisions. We might be ill, but we are still in there. We still know ourselves - we know what helps and what doesn't. We have a right to be involved in decisions about our own care, even if we're not always able to portray this perfectly.

Top tip

When a young person tells you something about how they're feeling or what they need - truly believe them, even if it's hard to hear and there is other context to consider.

Empathy/kindness

Empathy is the core of good care. Small moments of genuine human connection can be the difference between us feeling utterly alone and feeling like recovery might be possible. Kindness costs nothing and means everything.

Story/example

"There was one night staff member who changed things for me. On one of my worst nights, she didn't try to fix anything or follow a protocol. She just said, 'You need a hug.' And she sat with me while I watched the sunrise. She told me I was a person, not just a thing. I've remembered that moment for years. When you are surrounded by people who seem to see you as a problem to be managed, one person who sees your humanity can shift the whole experience. That was her."

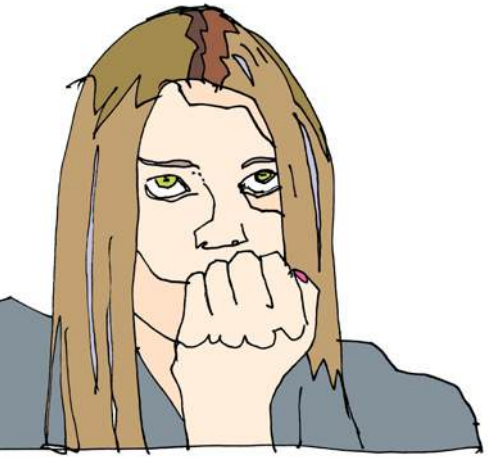
Not everything you do will be quantifiable. You might not get thanked. In the long run, you may have made a huge impact and you'll never know it. That has to be okay , and this needs to be remembered and accepted, as just because it's not immediately visible or obvious, your interaction could transform an experience.

Top tip

Do something simply because it would make a young person feel seen in that moment, while being boundaried and without expecting anything back.

How it feels when you....do or say

> I needed someone to be with me in that moment.



Words and actions carry enormous weight when you're in crisis. Things that might seem routine to staff - how you phrase something, how you respond in a moment of distress can feel defining to us. We notice everything. Please notice what you're communicating, even when you think we aren't listening or reacting.

Story/example

"A trainee staff member said to me, 'Let's talk about perfectionism.' It was so unhelpful at that point. I needed someone to be with me in that moment. The times that helped were when staff said something simple and human: 'I'm here.' 'That sounds really hard.' 'What do you need right now?'"

Also: it's not going to be easy. We're not going to want to engage, especially not the first time you ask. If we decline an activity, that's not the end. We probably won't accept first time. We're angry. We're frightened. Keep gently trying, because the perseverance will make a huge difference and result in us actually getting somewhere, whether that be on the 3rd or 6th time.

Top tip

Before responding to a young person in distress, pause. Ask yourself: am I responding to what they need, or to my own discomfort with the situation?

Your intervention feels like punishment

> “...it felt like I was being punished for being ill. I was frightened.

Restrictions, rules, and clinical protocols are put in place with good intentions. When they are applied without explanation or compassion, they can feel less like care and more like punishment - especially for those of us who are already struggling to trust adults and institutions.

Story/example

“They took my phone away and I couldn’t contact my mum. I was 14 years old, 200 miles from home, locked in a psychiatric unit I’d never heard of before. Nobody explained why. It just happened. Every time something was taken away or restricted without an explanation I could understand, it felt like I was being punished for being ill. I was frightened.”

We don’t owe you our trust. Trust must be earned and it’s hard to do that while you’re watching us go to the toilet or holding us down in a restraint. Don’t make us feel stupid or guilty because we don’t automatically believe you have our best interests at heart.

Receiving treatment is not a privilege. We did not choose to be here. Please don’t make us feel grateful for care we didn’t ask for, or bad for not complying with it , and accept that we are likely not going to have good reactions to such treatment which, although sometimes necessary, is still so rubbish and hard to experience.

Top tip

When you implement a restriction or protocol with a young person, can you explain the reason behind it in a way that shows you understand how it might feel to them?

How to support us generally and at meal times

Support at meal times is one of the most sensitive areas of care for us. The approach of staff in these moments can either support recovery or deepen distress. Consistency, kindness, and a genuine understanding of what eating means to us make a real difference.

Story/example

It's helpful when you give us options rather than asking us broad questions. Options could be: "Should we eat in silence or put something in the background? Should we go over what might be helpful right now from your care plan? Do you want encouragement or should we talk about something random, if anything at all?"

What works is different for everyone. Some people want encouragement; for others it just makes things worse. Some respond to clear consequences being named. Some need silence , in a way that suits them. Not every single time will be the same textbook so you're probably going to need to improvise or read the room sometimes..

And if we're not engaging: don't give up after one try. We're probably not going to say yes the first time.

Top tip

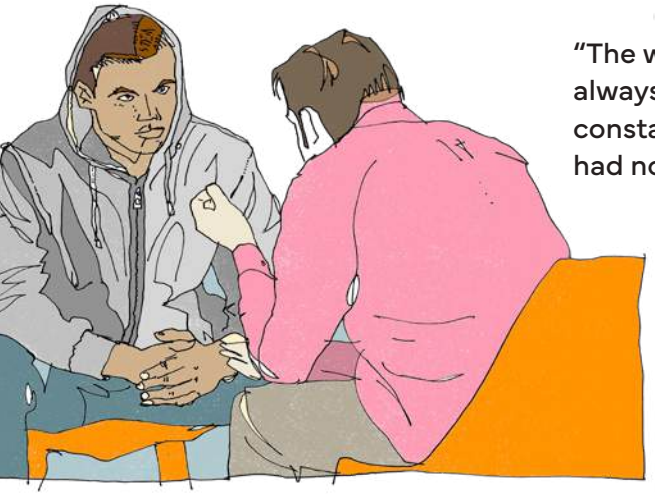
Ask the young person what works for them and give options.

What are good therapeutic spaces?

> “
>
> ...a personal space that is theirs - decorated with their things, reflecting who they are.

The environment we are in affects our ability to recover. Noise, unpredictability, lack of privacy, and clinical spaces can all make it harder to feel safe. We want to be honest: no ward is truly therapeutic. You cannot control other people’s behaviour.

The environment is inherently difficult. But there are things that help.



Story/example

“The ward I was on was constantly noisy. There was always something happening, always someone in crisis. I was attacked by another girl and it felt dangerous. I was constantly overwhelmed. I felt like a caged animal - I was just a 15 year old kid and I had no one to talk to. This wasn’t a therapeutic or safe space.”

What did help: “Having my own room that felt like mine. On some wards, young people aren’t allowed in their bedrooms during the day which removes the one space that belongs to them. There should be a clear difference between the communal ward area (where hard things happen) and a personal space that is theirs - decorated with their things, reflecting who they are. That room becomes a sanctuary and safe space which isn’t intruded and preserving that feeling for young people is vital.”

Top tip

What can you do today to make the environment feel slightly safer or calmer for a young person in your care even if you can’t change the physical space? And does this young person have a space that genuinely feels like theirs?

Questions to ask/answers we want to hear

The questions staff ask and the way they ask them, tells us a lot about whether you're genuinely curious about us or just following a process. We want to be asked questions that treat us as whole people. And we want honest, human answers in return, which don't feel like we're conversing with a robot.

Key questions young people want to be asked:

- What does a good day look like for you?
- What are you finding hardest right now - not medically, but just... in life?
- Is there anything about how we're supporting you that isn't working?
- What helps you feel safe?
- What do you wish staff knew about you that isn't in your notes?

Answers young people want to hear:

- 'I'm here, and I'm listening.'
- 'I don't have all the answers, but I want to understand.'
- 'What you're feeling makes sense given what you've been through.'
- 'You're not a burden. You're a person who needs support, and that's what we're here for.'

What to look for in staff/qualities/values/principles

We notice what kind of person you are. Not just whether you follow protocols, but whether you're genuinely curious about us, consistent in how you treat us, and honest even when it's hard. The qualities that make a good staff member aren't always the ones on a job description.

What young people look for in staff:

- Genuinely listens - not just waits for their turn to speak
- Treats us the same whether or not they think we can see them
- Admits when they don't know something
- Doesn't assume they know our experience from our notes
- Maintains boundaries but stays human
- Follows through on what they say they will do
- Remembers things we've told them

Story/example:

"The staff who helped me most weren't always the most experienced. They were the ones who treated me like a person first. They remembered things I'd mentioned. They knocked before coming into my room. They apologised when they got something wrong. You can tell the difference within minutes of meeting someone and can only be shown by listening to us and what does and does not work. It is not always going to be obvious. That first interaction sets the scene for every future interaction."

Involve lived experience in training

“

I know what a difference one good staff member can make.

When young people with lived experience of tier 4 services are involved in designing and delivering training, the quality and relevance make or breaks the success of engagement.

Story/example

“I’ve been through things that no training manual covers. I know what it’s like to be restrained. I know what it’s like to be dismissed when you’re in real danger. I know what a difference one good staff member can make. All of that knowledge is useful. Involving us in staff training gives the whole picture. We’re co-trainers, rather than case studies, and our perspective is arguably the most important.”

Top tip

Reach out to your participation team, they will be able to put you in touch with young people who can support.

Involving young people in recruitment

The people who work with us should be chosen by us. We can tell things in an interview that a hiring panel might miss. And the process of involving us in recruitment sends a message that our voice matters, and that the service takes that seriously.

Story/example

Often when candidates see a young person on a panel, they change their tone when speaking to them or say specific things to try to impress us, and it can feel like we are still seen as patients rather than as equal members of the panel. This can be disappointing because our opinions and perspectives are just as important as the professionals with qualifications sitting alongside us. The panel should feel like one team, not separate entities.

Staff should be willing to engage with patients and young people in all areas of healthcare. A good indicator as to whether a staff member has the abilities of holistic communication is their engagement with young people on recruitment boards. If a staff member is eager to hear from us and have a professional conversation when faced with EbEs on an interview panel, it often shows that they truly care about the experience of the young people within their care.

Top tip

When involving young people in recruitment, whether before or during the interview process, think beyond qualifications and clinical knowledge. Value our opinions equally so that we can have genuine influence, rather than our involvement feeling tokenistic. It is also helpful when we are kept updated throughout and able to see the process followed through fully.

Expectations/standards

We have the right to expect consistency, honesty, and dignity from every member of staff, every shift, every day. These are not high expectations. They are the minimum. When services fall short of them, someone needs to say so and something needs to change, and then the changes need to be communicated with young people to show their input does directly create meaningful impact. This builds trust.

What we expect:

- To be spoken to with respect, regardless of how we are presenting
- To have our care plan explained to us in language we can understand
- To be informed of decisions that affect us before they happen, not after
- To have our complaints and concerns taken seriously
- To not be left alone for long periods without a check-in
- To be given reasons for rules and restrictions
- To be treated the same by every member of staff, not differently depending on who is on shift

Top tip

When you make changes as a result of young people's feedback, tell them. Show them that what they said made a difference. This is how trust between young people and services is built.

Behaviours you might see

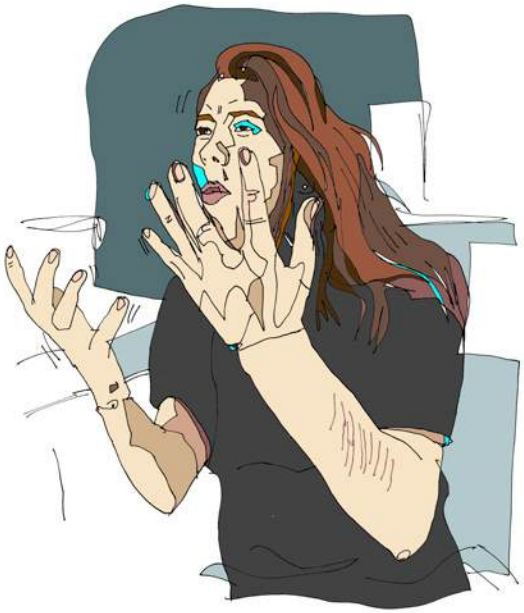
Ward environments can be unfamiliar and confronting, especially for staff who haven't worked in them before. This section is not about shocking you. It's about preparing you, so that when you encounter difficult or unusual behaviours, you can respond calmly and compassionately rather than from a place of surprise or alarm.

Those of us writing this guide have experienced, and in some cases exhibited, the behaviours overleaf on page 23.

We want you to know: these are not performances. They are the expressions of young people in enormous distress, doing the best they can. We are ill and sometimes we can't control how we feel or act, so your reaction and tone is important.

Top tip

If you've never worked in this environment before: be prepared to see and hear things that might be confronting. What matters is that you don't let your reaction show in a way that makes a young person feel more distressed or ashamed.



Behaviours staff might encounter and what they might mean:

- Refusing to engage or declining all activities is often not a definitive 'no', but a first response from someone who is frightened or exhausted. Keep offering gently.
- Verbal aggression, shouting, saying hurtful things is not personal. In a moment of crisis, a young person is trying to cope with something overwhelming. Anything they say in that moment is not a reflection of who they are.
- Hiding food, pouring away drinks, concealing distress are symptoms, not defiance. They require a compassionate, curious response, not a punitive one.
- Distress from other patients affecting the ward - you will be managing one young person's needs while another is in crisis. This is the reality of ward life. Your ability to stay calm is one of the most important things you can bring.
- There is a high likelihood young people are well versed and know how to mask or trick the system. It is important to take this into account and look beyond surface presentation.
- Behaviours which appear difficult or repetitive are forms of communication themselves. In an unpredictable situation where communication is hard, these will often be the way young people tell you they are struggling or want more support.
- Differences in communication like eye contact, tone, and emotional expression are not always someone being rude or disengaging. The issue is usually much deeper and needs further exploration in the right way.

What we want you to know/top tips

If you take nothing else from this book, take these.

Top tip 1: Listen. Really listen.

Don't be tokenistic. Listening means giving us your full attention, not just waiting for a pause to respond. It means asking follow-up questions. It means remembering what we told you last time. Listening is an action, not just an absence of talking.

Top tip 2: Ask, don't assume.

We are not our diagnosis or our history. Each of us is different. Start from curiosity, rather than assumption.

Top tip 3: Don't rely on our notes to make judgements.

Our notes tell one version of the story. Usually the clinical version, written by someone other than us. Get to know us directly. Ask us. The notes are a starting point, not the whole person.

Top tip 4: Think about how your interventions will affect us later

What you do now will stay with us. The words you use in a crisis become memories. They shape how we feel about services, about adults, about whether it's safe to ask for help. Every intervention has a long tail. Please act accordingly.

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September 2026