

EMILY'S STORY

LIVING THROUGH FRAGMENTED MENTAL HEALTH AND NEURODEVELOPMENTAL CARE

CASE STUDY



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OVERVIEW

Emily is a young adult who has accessed mental health and neurodevelopmental services across Hertfordshire, Norfolk, and Cambridgeshire and Peterborough. Her story highlights the challenges of moving between different NHS systems, delays in diagnosis and treatment, and difficulties accessing consistent support for neurodevelopmental conditions.

Emily's experiences reflect wider trends in our feedback, where overall feedback on mental health and neurodevelopmental services is **68% negative**.

EARLY MENTAL HEALTH SUPPORT AND CHANGING DIAGNOSES

Emily first began accessing mental health services as a teenager while living in Hertfordshire. She initially sought support for anxiety and depression, and over time received multiple diagnoses, including borderline personality disorder (BPD) and later bipolar disorder.

However, in 2021, while living in Norfolk, Emily received an autism diagnosis through an independent autism assessment provider, which she feels is the most accurate explanation of her experiences.

She believes earlier diagnoses were misinterpretations of her underlying neurodevelopmental needs.

Emily reflects that her experience shows how complex mental health presentations can sometimes be misdiagnosed when autism is not initially identified. This is particularly relevant as...

19% of those getting in touch with us about these services are autistic and...

29% of those who are autistic also have mental health needs and learning disabilities.

NAVIGATING MULTIPLE SERVICES ACROSS COUNTIES

Emily has accessed services across three different NHS systems: Hertfordshire, Norfolk, and Cambridgeshire and Peterborough. She describes this as extremely challenging, as each move required her to effectively restart assessments and referrals from the beginning.

When she moved to Cambridgeshire, Emily attempted to transfer ongoing support through her GP practice in Cambridgeshire. However, she experienced inconsistent understanding between different GPs, with some not fully recognising her history or previous diagnoses.

She eventually found a GP who she felt understood her situation and took a more structured approach to referrals and care planning.

ACCESSING LOCAL MENTAL HEALTH SERVICES

In Cambridgeshire, Emily was referred to a specialist community mental health pathway. This service was intended to provide DBT (Dialectical Behaviour Therapy)-informed, skills-based therapy for individuals with complex emotional and neurodevelopmental needs.

Emily's experience also reflects wider feedback we receive about local mental health services, which account for...

25% of all feedback relating to mental health and neurodevelopmental services.

Although Emily was hopeful, she experienced long waiting times of around nine months, during which she received no interim support. She also describes the difficulty of waiting for care while managing work and daily life, particularly as appointment dates were provided at very short notice.

Long waiting times for assessments and delays are a common concern, representing...

26% of feedback received in relation to the demand for mental health and neurodevelopmental services.

On one occasion, Emily missed an appointment due to receiving an email with only a few days' notice. She explained that due to her autism, she does not regularly check emails and relies on support from her partner. Despite this, she was discharged from the service following the missed appointment.

Emily describes this as particularly distressing, especially given the lack of flexibility or alternative communication methods from the service, and the fact that the pathway was designed to support autistic people.

Although she was later re-referred, she reports ongoing delays and uncertainty about whether she will be seen.

BARRIERS WITHIN MENTAL HEALTH PATHWAYS

Emily describes a pattern of repeated difficulties across services, including:

- Being discharged due to missed communications or administrative issues
- Repeated cycles of referral and rejection
- Lack of continuity between services
- Limited understanding of her neurodevelopmental needs in mental health settings

She also reflects on previous experiences where referrals to talking therapies were declined due to her history of self-harm, leaving her feeling **“stuck between services”** with no clear route forward.

Emily feels that services often do not adequately take into account previous assessments or long-term history, meaning she has to repeatedly explain her needs from the beginning. These concerns mirror our wider data, where...

35% of feedback regarding mental health and neurodevelopmental services relates specifically to access to services, help and support, or referral issues.

THE ROLE OF PRIMARY CARE

Emily describes mixed experiences with GP services. Earlier interactions often felt **“dismissive or repetitive”**, with suggestions such as exercise or basic talking therapies, even when she had already engaged with multiple interventions.

However, her experience at her doctor’s surgery improved when she saw a GP who took a more personalised approach. This GP:

- Recognised her neurodevelopmental history
- Avoided inappropriate referrals
- Provided clear next steps and continuity of care
- Encouraged her to return if referrals were not successful

Emily describes this consistency as the first time she felt there was a clear and supported pathway through services.

IMPACT ON DAILY LIFE AND WORK

Emily explains that her mental health and neurodevelopmental needs have a significant impact on her working life. She describes experiencing periods of **“autism burnout”**, where she is able to maintain employment for sustained periods before reaching burnout and requiring extended time away from work to recover.

She says this can be particularly difficult to manage while waiting for services, especially when support is delayed or unavailable during times of increased need.

Despite these challenges, Emily notes that having stable housing and partner support has helped her manage more effectively than others who may not have similar support systems.

Emily’s circumstances also reflect broader engagement patterns, with...

35% of feedback on these services coming from people aged 25–49, the majority of whom are female.

COMMUNICATION AND ACCESSIBILITY BARRIERS

A key theme in Emily’s experience is the lack of flexible communication from services. She highlights that reliance on email-only communication has been a barrier, particularly when appointments are time-sensitive or require quick responses.

She suggests that services supporting autistic people should consider:

- Phone calls or letters as alternatives to email
- More flexible appointment systems
- Longer notice periods for appointments
- Clearer communication about consequences of missed appointments

Emily feels that current systems can **“unintentionally exclude autistic people”** who may process or respond to information differently.

WHERE SERVICES WORKED WELL

Emily identifies some positive aspects of her care:

- Supportive and understanding GP who recognised her needs and provided continuity of care
- Access to an autism diagnosis through an independent assessment provider
- Receipt of a formal autism diagnosis, which she feels accurately reflects her experiences
- Availability of structured therapy pathways, even if access is delayed

WHAT COULD IMPROVE

Emily suggests several improvements to services:

- Better continuity of care when moving between counties
- Reduced reliance on self-navigation of complex systems
- Improved communication methods tailored to individual needs
- Better understanding of autism within mental health services
- Greater flexibility around attendance policies for neurodivergent patients
- Clearer coordination between GP, mental health services, and specialist teams

She also highlights the importance of services providing interim support while patients are on waiting lists, rather than leaving individuals without care during long delays.

EMILY'S REFLECTIONS

Emily feels that one of the biggest challenges is the lack of joined-up support between services. She describes a system where individuals are often required to **“coordinate their own care across multiple providers”**, which can be particularly difficult for autistic people.

She also reflects that without family and partner support, navigating these systems would be significantly more difficult.

ONGOING SUPPORT NEEDS

Emily is still awaiting support from a specialist community mental health pathway. Despite being referred, she continues to experience delays and uncertainty about when she will be seen.

She describes this ongoing wait as **“particularly difficult given her existing mental health and neurodevelopmental needs, and the lack of interim support”** during this period.

ADVICE TO SERVICES

From Emily's perspective, services could improve by:

- Recognising neurodivergent needs earlier in the pathway
- Avoiding automatic discharge without exploration of communication barriers
- Ensuring flexibility in engagement methods
- Providing clearer, more consistent pathways between services

Emily's story highlights wider issues in access to mental health and neurodevelopmental services, particularly for autistic people navigating complex systems across different regions.

GET IN TOUCH

If you or someone you know has experience of accessing mental health or neurodevelopmental services in Cambridgeshire and Peterborough, **we want to hear from you.**


Your feedback helps us understand what is working well, where improvements are needed, and how local services can better support people. Our team can also provide information and signposting support where needed.

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