ED Transitions Module 1:

Setting the Scene: Definitions and Context

Welcome

Module 1: Setting the Scene: Definitions and Context

Module 2: Supporting Transitions Between Services

Module 3: Digging deeper - Preparing for and talking about transitions

Module 4: University transitions and Emerging into the Wider World

Module 5: Parents and Carers

Note: To avoid lengthy descriptions we will talk about CAEDS (Child and Adolescent ED services) and AEDS (Adult ED services), although we are aware that some such transitions may involve generic CAMHS

Learning Objectives for Module 1

To help you :

- **Consider why service transitions matter**
- **Become familiar with definitions, service context(s) and developmental issues, relevant to age transitions**
- **Reflect on similarities and differences between services and treatments for young people above or below age 18**

Why do Service Transitions Matter?

The five D's of Poor Age-Related Service Transitions

Distress
Delays
Drop-out
Deterioration
Death – see Averil Hart report

A cruel form of snakes and ladders?

Why do Service Transitions Matter?

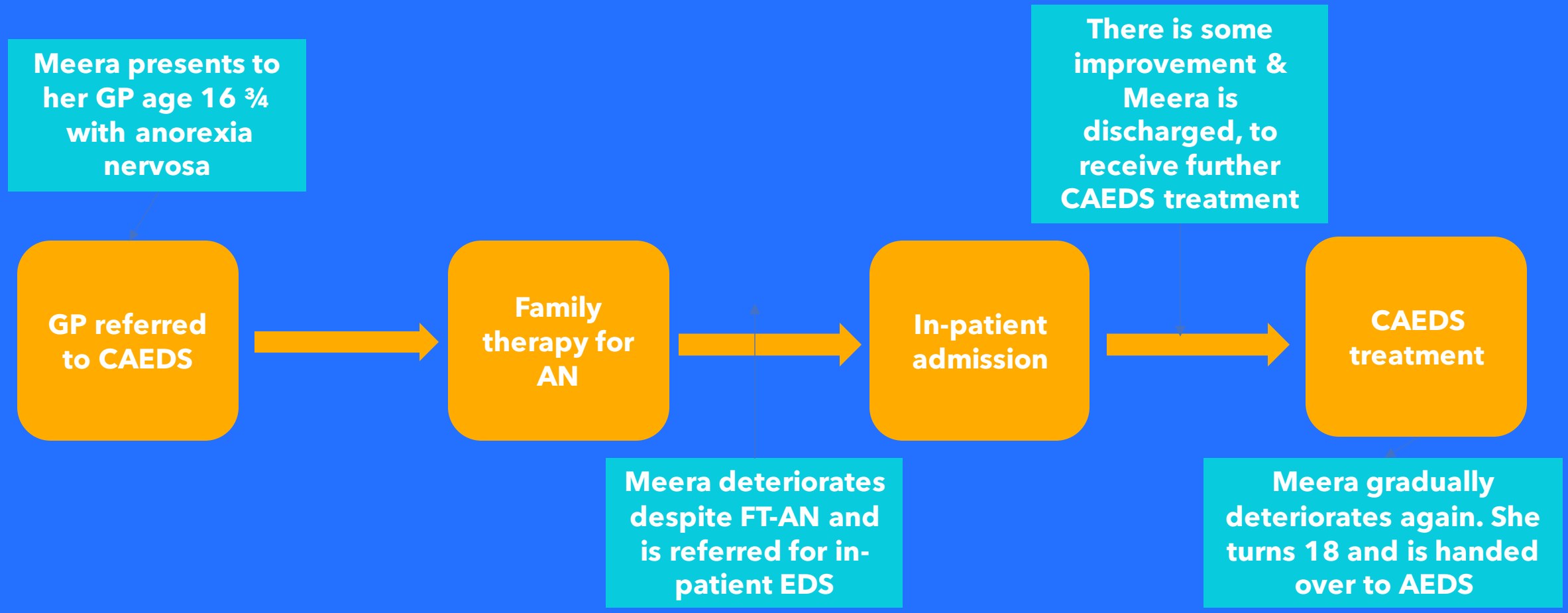
For more information about the potential pitfalls of poorly-managed transitions, you can read **the Averil Hart Report.**

This Parliamentary and Health Service Ombudsman report details the case of a 19-year-old with anorexia nervosa who died after a number of NHS organisations failed to provide adequate care and support as she began her 1st year at university.

Some of the key themes in the report include:

- Failures to properly plan, coordinate and assess Averil's care needs during her transition between services
- Poor communication with Averil's family throughout the final months of her care and after her untimely death
- Failures to support inexperienced clinicians managing Averil's transition
- Failures in joint working arrangements leading to serious signs of deterioration being missed

Meera's Story: A Typical Case



“When I was seen at CAEDS I was really not ready to have help, but I really liked the CAEDS therapist I had after my first admission.

It really sucked having to start with the adult service, but some of the individual work there was useful.“

Meera, service user

Meera's Story: A Typical Case

Referral from CAEDS

AEDS assessment and review

There is a delay in starting treatment. By the time an outpatient therapy is available she has deteriorated so much that she needs another admission.

In-patient admission with AEDS

This admission is more successful, she attains a normal weight post-discharge, but starts to binge eat regularly.
Meera then wants to start University away from home and is referred to services there.

Referred to university service

They have a long waiting list and say they do not accept people with binge eating disorder.

“As a family we have been through hell and back. Our darkest period was when Meera had come out of hospital after her first admission. She was getting worse, yet she was handed over to the adult team regardless and they took their time to spring into action, and by then Meera needed a second admission.

She is a lot better now, but what if she needs help whilst at University? It seems that the system really is not set up for young people moving around.“

Meera

Transitions: The Good, The Not-So-Good and the In-Between

I don't remember there being any mention before the day it happened. I was super disengaged and it felt like it was just decided in that meeting.

If I had known more about what adult services would have been like, that would have really helped. That would have encouraged me to consider it as an option. I don't remember worrying about transition, but that was because I didn't really care about recovery. I think that should have been a warning to services that I wasn't ready to be discharged

It felt like a threat.

Transitions: The Good, The Not-So-Good and the In-Between

Reflecting on the progress that I had made with child services, but also outlining what work still needed to be done and how adult services would help me make those steps kind of gave me a bit of steam.

…having my therapist hand over to my new therapist was really good. I had built such a bond with her and felt like I was really in safe hands once I'd moved over.

I feel like 18 is still quite young and just to have the cut off of "oh it's you birthday now you have to move". 18 year olds are young people still, especially if they're living at home.

I think that having the family involved is really crucial.

Age-Related Service Transitions: Definition

Transition is the **planned movement** of adolescents and emerging adults with **chronic** physical or mental health conditions from child-centred to adult-centred health care systems (Blum et al., 1993)

Issues:

Original model was designed for (and applicable to) young people with conditions that start at birth or in childhood, and potentially require life-long ongoing treatment and support.

E.g. cystic fibrosis, T1 diabetes or neurodevelopmental disorders

This means:

- Preparation can occur over a very long period of time.
- Transition allows young people to make a fresh start with a different team, develop greater autonomy around management of their chronic conditions and their lives in general

Age-Related Service Transitions: Definition

However, the typical transition scenario in relation to eating disorders (EDs) is quite different.

Issues, Opportunities and Challenges

In the UK, most ED services are separated into CAEDS and AEDS, with **service transitions at age 18**, coinciding with the age of majority.

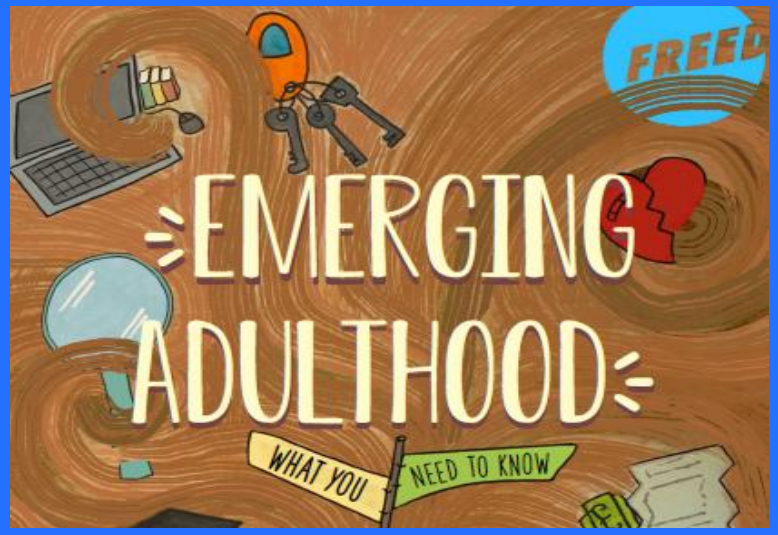
Importantly, the median age of onset of EDs is also at age 18 (Solmi et al., 2022).

This means that, far from having a chronic ED, many young people may be in their **first treatment episode** when they reach CAEDS-AEDS transition age.

A further issue is that a move from home to University often occurs between age 18 and 19, potentially necessitating a **further service transition**.

Implication: There is a lot of potential for the 5 D's to 'kick in' here.

Developmental Considerations in Service Transitions: Emerging Adults



Emerging adulthood, age 18-25, is increasingly recognised as a **unique developmental period** (Potterton et al., 2021a).

The period is characterised by a strong drive for **autonomy** and for the first time combined with the means (legal, financial & practical) for exerting this.

However, 18 year olds will vary enormously in their capacity to steer their own ED care.

Developmental considerations

Thus, we cannot expect them to have the **motivation, knowledge and skills** needed to negotiate the NHS by themselves, especially as AEDS often are not resourced to accept self-referrals.

Research has shown that emerging adults in general & those with EDs specifically find **help-seeking** very hard (Potterton et al., 2021 b)

This has implications for service transitions, as the natural inclination of these young people may be 'not to bother' with another service.

How Common are Transitions between CAEDS and AEDS and What is the Diagnostic Mix?

The answer depends on who you ask:

Of patients seen in CAEDS, 20-30% are transitioned to AEDS (Herpertz-Dahlmann & Schmidt, 2022)

Amongst AEDS referrals, transitions from CAEDS make up only about 5% (e.g. Viljoen et al., 2022)

Why this difference?

Typically in a given area AEDS are larger than CAEDS, therefore transition patients make up a *smaller proportion* of their referrals.

How Common are Transitions between CAEDS and AEDS and what is the Diagnostic Mix?

Other Potential Contributors to the Referral Gap:

- CAEDS patients may decide they don't want to start with a new team, even though they still have problems and therefore are being discharged.
- Some patients, who are referred to CAEDS when close to the transition age-boundary, are not seen there and are re-routed to AEDS. These patients are not counted in transition statistics, and instead will have a delayed start to their care.

How Common are Transitions between CAEDS and AEDS and What is the Diagnostic Mix?

What is the Diagnostic Mix of Transition Patients Referred to an AEDS Team (Belli et al., in prep):

43% are within 3 years of onset, i.e. FREED eligible

Over two thirds (69.5%) have AN, atypical AN or ARFID

Taken together, the presence of a referral gap and the preponderance of AN amongst those referred for transition suggests that patients with bulimic disorders may 'get lost' disproportionately

How Do Different Service Models Fare in Terms of Age-Related Service Transitions?

Conventional CAEDS-AEDS model with transition at age 18:

Pro: Clear rules, equitable.

Cons: Not patient-centred.

Flexible transition age within a conventional CAEDS-AEDS model:

Pro: More patient-centred. Recommended by RCPsych guidance.

Cons: Is vulnerable to 'special pleading' from more resourceful families. Has resource implications.

How Do Different Service Models Fare in Terms of Age-Related Service Transitions?

0-25 services:

Pro: Goes across the peak period of onset of EDs and for many people there won't be a need for a transition.

Con: Does introduce a service transition at a later time point. [To learn more about this model click the link (interview with Sheryllin McNeill)]

Age-integrated or all-age services:

Pro: Bypasses the need for any age-related transitions. Reduces 'transition bureaucracy'.

Con: Need to ensure that staff are dually trained in delivering care for younger and older patients. [To learn more about this model click the link (interview with Ciaran Newell)]

How Do Different Service Models Fare in Terms of Age-Related Service Transitions?

Reflection:

Where does your own service fit in?

How do you think these different service models compare in terms of acceptability and risks for patients and families?

What do Patients, Families and Clinicians Want?

A recent study assessed priorities of clinicians (CAEDS & AEDS), young people and parents with regards to better manage transitions (Wales et al., 2022).

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All Three Groups Highlighted:

- The importance of a gradual transition with continuity of care
- The need to acknowledge that parents/carers want to be involved
- The need for solid handover information plus a fresh assessment by the AED service
- The option of delaying the transition if indicated.

Patients & Carers

Wanted more flexible, patient-centred arrangements where BMI was not a determining factor for whether patients should receive further care.

Clinicians

Valued clear structures, e.g. fixed transition at age 18 years, with body mass index (BMI) as a determining factor, and low-weight patients being prioritised for post-transition AEDS care.

Similarities & Differences between CAEDS/AEDS in Ethos and Treatments

Much has been made of the **different ethos** between CAEDS (more family-focused) and AEDS (more autonomy/responsibility focused).

NICE guidelines recommend family-interventions as the main treatment for young people below age 18 and individual treatments for those age 18 and over.

Similarities & Differences between CAEDS/AEDS in Ethos and Treatments

However, these differences are increasingly becoming blurred.

For example:

NICE emphasise the need for AEDS to involve carers in assessment & treatment, especially where there is high medical risk.

It is increasingly recognised that with adaptations, family interventions are effective in those aged 18+.

Likewise, individual therapies (adapted CBT-ED or MANTRA) are effective in those below age 18.

BN: Schmidt et al., 2007; AN: Eisler et al., 2016; Nyman-Carlsson et al., 2020; Dalle Grave & Calugi, 2020; Le Grange et al., 2020; Wittek et al., 2023

Reaching Across To Each Other

In line with these findings (see previous slide), a recent systematic review on the topic of age-related transitions highlighted that:

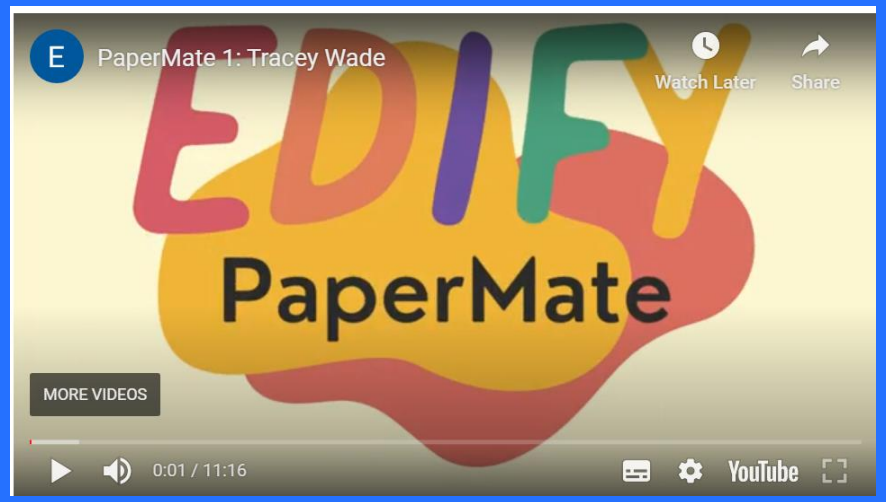
there are **more similarities** than differences between CAEDS and AEDS

there should be **greater integration** between these services

(Wade et al., 2022)

Reaching Across To Each Other

To hear Prof Tracey Wade discuss the findings from her review and its implications, click here



Summary and Conclusion

Some service models minimise the need for age-related transitions. However, if transitions do occur:

Poorly conducted age-related service transitions can be disastrous

Patient and carers want to see flexible, patient-centred, well-planned transition arrangements

The next modules will focus on how this can be achieved