ED Transitions Module 3:

Digging deeper – Preparing for and talking about transitions

FREED Time to win the race against eating disorders!
NHS South London and Maudsley NHS Foundation Trust
King's College London
hin Health Innovation Network South London

Learning Objectives for Module 3

To understand how to:

- Have conversations about transitions
- Establish a clear transition pathway
- Carry out person-centred planning
- Bring a transition to a conclusion

How to have conversations about transitions

Most people agree on the cornerstones of person-centred transitions.

RCPsych guidance states they should be **gradual**, **flexible, purposeful** and **planned in collaboration** with young people and, with the young person's permission, parents and carers too.

Details on how to go about this in the context of an eating disorder are less readily available.

We asked young people and clinicians working in CAEDS and AEDS to find out their views.

What young people said about how to have conversations

What works well?

We sort of put it on the back burner in our sessions, but still made sure I was preparing for the change. I found that really helpful.

Young person

Starting it sooner than later that would be great. And what does it look like moving forward? So that they have time to ponder it, because again they have so much history built on this and it's so emotional.

So, I think that the sooner they start learning what it's like, it gives them time to mull over it and start thinking about moving on and what growing up looks like with their ED.

Carer

Nadarajah et al. 2021

What young people said about how to have conversations

We started talking about what the differences (between services) might be, what the transition would be like, letting me know who my new person would be.

We had maybe two meetings with both my current child therapist and my new adult therapist and myself, so I could voice my concerns (about my anxiety around my family no longer being involved).

Young person

Nadarajah et al. 2021

The take-home message:

- Introduce conversations gradually
- Keep it on the agenda
- Include AED service in conversations
- Discuss what the transition will look like & what support the young person needs

What professionals said about how to have conversations

Why is it important to start a conversation early?

If [a transition] is known near the beginning of treatment, we will touch on it in an abstract way - acknowledging the process/preparation/planning and impact/opportunity with endings.

This will be discussed throughout the episode of treatment and as the transition approaches, [becoming] more active in planning.

Clinician

We prepare early to keep uncertainty to a minimum.

Clinician

What professionals said about how to have conversations

The take-home message:

Start conversations early, where appropriate, and with sensitivity

But – when would you *not* start a conversation early?

If the client is in acute crisis/deteriorating, we would work on stabilising [them] then move toward transition discussions.

Clinician

If someone is overly anxious during therapy or struggling to engage with therapy. This may seem dismissive and like we are just passing them on.

Clinician

What professionals said about how to have conversations

We sat down with Esther, a Team Manager and CAEDS clinician since 2000, to discuss in more detail how she might talk about transitioning from CAEDS. Press **play** to hear the conversation:

How do you decide **when to have a conversation** about transitions with the young people in your service?

Do you ever use the idea of a transition in a **motivational stance**, particularly with young people being newly referred?

When somebody does have to transition, can you see any **opportunities** for young people?

What professionals said about how to have conversations

How do you **talk about transitions with families**? Is it similar to young people, or might you say something different, that emphasize different aspects of what's going to happen?

Do you ever come across any **instances where young people want to transition**? Where they feel like this is an opportunity for them to access more interventions and support that's relevant to their life stage, and not just a reflection of their recovery?

Resource:
Full audio recording & transcript

Microsoft Word Document

Transition pathways and protocols

RCPsych Guidance states that services should have **clear protocols** and **pathways** for young people transitioning between them.

A joint CAEDS & AEDS **transition policy** may include:

- Clear process for arranging & supporting transitions
- "Issues" log to record e.g. delays to transition, issues contacting the young person
- Transition review panel (e.g., the transition co-ordinator, lead CAEDS & AEDS clinician) to discuss problematic transitions
- Outcome evaluation
  - Number of young people making transition, adherence to policy
  - Feedback from young people (e.g., transition questionnaires)

[Credit to: Worcestershire Health and Care NHS Trust Transitions Group]

Resource:
SLaM Best practice protocol for transitions to adult services

Microsoft Word Document

Monitoring the transition pathway

As the young person moves through the transition pathway, it's important to keep track of their progress. Some suggestions on how to do this are below:

Maintaining a Tracker
Maintain a database of useful patient information, including: Trust ID, date of referral, when they turn 18, current treatment status, status of transition, their last CAEDS session & "issues" log

Weekly Huddles
Your team can meet weekly in 15 minute huddles to discuss patients under the CAEDS pathway. This ensures team members can delegate responsibilities, provide updates & receive support.

CAEDS & AEDS Transition Coordinator
The clinician the young person is working with will help them to prepare for their transition & together they will work on a transition care plan. The co-ordinator will monitor the young person's care until they transition.

The patient-centred transition plan

RCPsych Guidance also recommends having a well-structured, **patient-centred** care plan.

But what does this mean?

Providing care that is tailored to suit the young person's illness, situation and needs

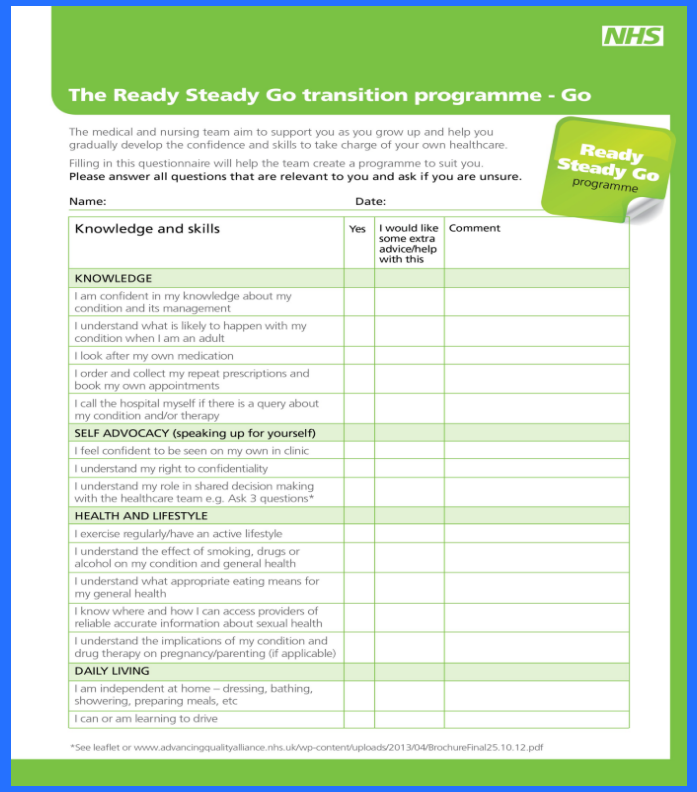
The patient-centred transition plan

The plan should specify the following:

- The (expected) time of the transition & the rationale for it
- Work which needs to be completed prior to & post transition
- Plans for a period of joint working (where, who with, duration etc.)
- The role of other agencies (e.g. social care) in the person's care
- The views, concerns and wishes of the young person & carers

Carrying out person-centred planning

Models assessing **preparedness** and **readiness** to transition have been piloted with young people in physical health settings and, to a far lesser extent, in severe mental illness, but (to our knowledge) not in EDs.



NHS

The Ready Steady Go transition programme - Go

The medical and nursing team aim to support you as you grow up and help you gradually develop the confidence and skills to take charge of your own healthcare.

Filling in this questionnaire will help the team create a programme to suit you.
Please answer all questions that are relevant to you and ask if you are unsure.

Ready Steady Go programme

Name: Date:

Knowledge and skills	Yes	I would like some extra advice/help with this	Comment
KNOWLEDGE			
I am confident in my knowledge about my condition and its management			
I understand what is likely to happen with my condition when I am an adult			
I look after my own medication			
I order and collect my repeat prescriptions and book my own appointments			
I call the hospital myself if there is a query about my condition and/or therapy			
SELF ADVOCACY (speaking up for yourself)			
I feel confident to be seen on my own in clinic			
I understand my right to confidentiality			
I understand my role in shared decision making with the healthcare team e.g. Ask 3 questions*			
HEALTH AND LIFESTYLE			
I exercise regularly/have an active lifestyle			
I understand the effect of smoking, drugs or alcohol on my condition and general health			
I understand what appropriate eating means for my general health			
I know where and how I can access providers of reliable accurate information about sexual health			
I understand the implications of my condition and drug therapy on pregnancy/parenting (if applicable)			
DAILY LIVING			
I am independent at home – dressing, bathing, showering, preparing meals, etc			
I can or am learning to drive			

*See leaflet or www.advancingqualityalliance.nhs.uk/wp-content/uploads/2013/04/BrochureFinal25.10.12.pdf

An example from physical health:
University Hospitals Southampton have a comprehensive **transition programme** ReadySteadyGo.
Link here

They use checklists to guide exploration of young people's ***confidence*** and ***skills*** in taking charge of their health care.

Person-centred planning: preparation

Extrapolating from ReadySteadyGo, you may want to explore:

Practicalities

- Does the young person arrange their own appointments?
- Does the young person contact their care team themselves if there is a query regarding their appointment or ED?
- Does the young person travel to their own appointments?
- If the young person is prescribed medication:
  - do they look after the medication at home?
  - make sure they take it as prescribed?
  - keep track of when to order repeat prescriptions?
  - go to the pharmacy themselves to collect it?

Self-advocacy

- Does the young person feel confident to be seen on their own?
- Does the young person understand their right to confidentiality and when it may be necessary to breach confidentiality?
- Does the young person understand their role in shared decision-making?
- Does the young person feel confident in letting people know about their ED (e.g. tutors, employers, friends)

Person-centred planning: preparation

Transfer to adult care

- Does the young person understand the meaning of transition and transfer of information?
- Does the young person know the plan for their care when they enter adult services?
- Does the young person have all the information they need about the adult service their care is transferring to?
    - who their transition co-ordinator is
    - how to contact their transition co-ordinator
    - when their first appointment will be
    - where the service is located
    - how to get there

Person-centred planning: preparation

Daily Living

- Does the young person have any support practically and emotionally with meal preparation and eating?
- Does the young person shop for and pay for their own food?

Can you think of any other questions that might need asking?

Person-centred planning: confidentiality

RCPsych states that transition support should ***sensitively*** involve the family and carers. While many young people are happy for parents to remain involved in some capacity, others may want more **autonomy** when transitioning into AEDS.

In a **low risk** situation, you can discuss (and establish) with the young person their expectations around confidentiality & autonomy. You may want to ask questions such as:

Can you imagine a scenario where we [AEDS team] are unable to reach you? E.g. your inbox is full, you're overwhelmed with work, you're feeling ambivalent about recovery.

- *What would be the benefits & cons of AEDS being able to contact your parents in this instance, so that they would prompt you or check-in on you?*

Can you imagine a scenario where your parents contact us [AEDS team] directly?

- *What would you be happy for AEDS to share, if anything? E.g., whether you are attending appointments, or anything about symptoms?*

Person-centred planning: confidentiality

Now imagine a **higher risk** situation, where the parents have been involved throughout CAEDS and the young person is ambivalent & only able to maintain therapeutic gains in outpatients because of parents' support.

In this scenario, you would want to be more 'pushy' about having contact with the parents:

We need to have open channels of communication with your parents, otherwise it will be hard to work with you safely and support you in outpatients.

Once consent to contact is established, you can then negotiate what you would or would not tell the parents, and give options.

Case studies: CAEDS to AEDS transition with a low & high risk patient

Click on the icons below to read about the different treatment stages of a CAEDS to AEDS transition for a lower and higher risk patient, along with reflective commentary.

The transition of a lower risk young person: L's story

Microsoft Word Document

The transition of a higher risk young person: E's story

Microsoft Word Document

Bringing a transition to a conclusion

Research suggests that **phasing out** CAEDS services may improve the transition process, by allowing the CAEDS team to **follow-up** with the young person after they have transitioned into AEDS (Nadarajah et al. 2021).

> Think definitely 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....
>
> It wasn't like I was just going off into this completely new thing. It felt like this was very much just within the same realm.

This should:

- alleviate feelings of abrupt withdrawal of CAEDS service
- allow the young person to build relationships with AEDS team
- let the YP discuss these experiences with CAEDS team

Can you think of additional adjustments to improve the post-transition process?

Concluding a transition: service user recommendations

Broad *et al.* 2017: For a positive **post-transition** experience, young people also suggest:

Post-transition flexibility & continuity of care

Adaptations to treatments e.g. *extended* Behavioural Therapy Relapse Prevention

Sharing of clinical information between CAEDS and AEDS

Choice about parental involvement & treatment options

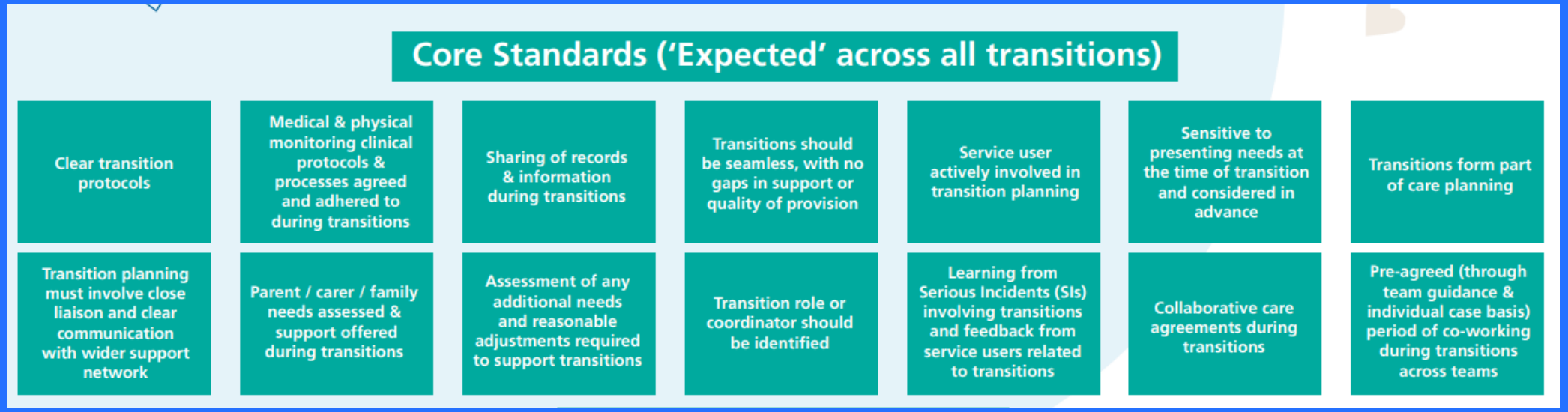
No repeat assessment (unless necessary)

Physical care environments geared toward young adults

AEDS treatments that follow-on from preceding treatment

Resource: A self-assessment checklist for transition pathways

East of England NHS has developed a useful '**Transition Standards**' guide, to help assess your service's transition pathway and consider ways to embed these standards in practice.



Click on the icon to access:

- A list of recommended **transition standards** (pg 9)
- A **self-assessment** checklist (pg 41) to help with benchmarking

PDF

Microsoft Edge
PDF Document