

Best practice in managing service transitions for patients affected by eating disorders



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Summary

There are a number of reasons why people with a diagnosis of an eating disorder may transition between services, for example, moving between child and adolescent services (CAMHS) to adult services due to age, a change in location due to reasons such as moving house or going to/leaving university, moving between inpatient and outpatient services, and moving between different types of specialist services. These transitions are often a vulnerable time for people affected by eating disorders, and can result in the person experiencing a lapse or relapse, and difficulties in accessing treatment (1–4). The devastating consequences of this were evident in the Ombudsman report into the death of Averil Hart, who tragically died from a heart attack triggered by starvation from anorexia nervosa, at the age of 19 years old. The Ombudsman report stated that “inadequate coordination and planning... when (Averil) was leaving home to go to university” was one avoidable failing that contributed to her death (3). This devastating loss highlights the importance of managing transitions; best practice guidance around this process have been widely reported in relation to both eating disorders specifically (5–9), and mental health services more generally (10–12).

This paper proposes a series of best practice standards for adoption by all healthcare providers offering eating disorder services. These build upon the Royal College of Psychiatrists’ (RCPsych) guidance for managing transitions (5). The paper will also share the experiences of both those affected by eating disorders and those supporting someone who have undergone a transition between services in the last five years, and will review these transitions against RCPsych’s recommendations.

Results demonstrate that best practice is often not followed. When asked to describe positive experiences about the transition, the most cited theme from both those affected by an eating disorder and those supporting someone was “nothing”, with people commonly being left with no information or support at a very difficult time. Although some people were able to describe positive experiences, findings emphasise that more needs to be done to ensure people are supported throughout this vulnerable period to avoid potentially devastating consequences (3).

Best practice standards in managing transitions for patients affected by eating disorders

RCPsych’s guidance around good practice can be read in more detail in their report (5). The guidance includes recommending that transitions are identified as early as possible (with the patient being informed at least six months prior to any planned transition) and that the timing around the transition is flexible to take into account the patient’s needs; that both the patient and their family/carers are involved in the process; and that there are close links between both services, for example through joint meetings and a nominated transition coordinator.

Taking into account RCPsych’s guidance (5) and responding to the findings reported below, Beat recommends that all providers of eating disorder services should:

1. Have a policy that ensures transitions are managed in accordance with RCPsych’s guidance and these standards.
2. Train all service staff in the application of the policy, with particular focus on ensuring that the needs of the patient and their family/carers are central to this process.
3. Inform and engage patients and family/carers when a loved one faces a transition between services as soon as this need is identified.

4. Provide all patients and their family/carers with useful and comprehensive information about the transition process, including information about what to expect from the process and any key differences between services/treatment approaches.
5. Ensure that the transition process is managed flexibly, prioritising the needs of the patient rather than being unduly dictated by the service's protocols. This includes working flexibility to reduce unnecessary transitions, such as those driven by age restrictions.
6. Ensure effective coordination with the service to which the patient is to be transferred, including joint meetings with and full participation by the patient and their family/carers.
7. Ensure that at all times, the patient stays under the active care of a specialist eating disorder service throughout the transition process.
8. In the case of university students, ensure that the patient has access to the appropriate support whether they are at home or at university, exploring the possibility of temporary GP registration, and that the patient's medical records are appropriately shared between the involved healthcare services to support this.

We recognise that some patients will not want their family/carers to be involved in their recovery. However, it is important that these family members/carers are still respected by the service and offered support and information within the constraints of confidentiality.

Investigation

In order to investigate people's experiences of transitions and the degree to which these met the recommendations outlined in RCPsych's report (5), Beat conducted an online survey in June 2020. This was promoted through Beat's website and social media account. The survey was designed to be completed by individuals with an experience of an eating disorder who had undergone a transition between services, or individuals who had supported someone with a transition of this nature, in the last five years.

Participants

408 individuals completed the survey. Results were filtered to only include those who:

1. Had experience of an eating disorder, experience of supporting someone with an eating disorder or both

2. Had experience of a transition between services in the last five years, and
3. Experienced this transition in the UK

This left responses from 340 individuals (83.3%).

271 people (79.7%) identified as having experience of an eating disorder, 50 people (14.7%) identified as having supported someone with an eating disorder, and 19 people (5.6%) identified as having had both experience of an eating disorder and of supporting someone with an eating disorder. For those who had had both experiences, 16 individuals (84.2%) noted that when responding to the survey they were reflecting on experiences they had as someone with an eating disorder and two individuals (15.8%) were reflecting on experiences they had when supporting someone.

Respondents were asked to select the age range of the person affected by the eating disorder at the time of the transition. Of those who responded, the most selected age range was 19–25 years (N=112, 40.3%), closely followed by 16–18 years (N=103, 37.1%). Respondents were also asked about the eating disorder diagnosis at the time of the transition. The most frequently reported diagnosis was anorexia nervosa (75.9%), as shown in Table 1.

Table 1. Diagnosis at the time of the transition

Diagnosis	Lived Experience	Carer	Overall Response
ARFID	5	0	5 (1.6%)
Anorexia Nervosa	198	38	236 (75.9%)
Binge Eating Disorder	4	3	7 (2.3%)
Bulimia Nervosa	29	2	31 (10.0%)
OSFED	17	4	21 (6.8%)
Don't know	10	1	11 (3.5%)

173 people (50.9%) reported that either they or the person they had supported had experienced more than one transition in the last five years. Respondents were asked to select the nature of the transition(s) – 364 transitions were described (Table 2). The highest number of responses (N=82, 22.5%) related to a transition between inpatient to outpatient treatment.

Table 2. The types of transitions that respondents had been through/supported their loved one through

Nature of this transition (tick all that apply)			
Type of transition	Lived Experience	Carer	Overall Response
Inpatient to outpatient treatment	67	15	82 (22.5%)
CAMHS to adult eating disorder services	49	13	62 (17.0%)
Change in geographical location specifically to do with going to or leaving university	50	7	57 (15.7%)
Other change in geographical location	52	3	55 (15.1%)
Outpatient to inpatient treatment	33	7	40 (11.0%)
CAMHS to general adult mental health services	21	7	28 (7.7%)
Other... ("Other" included a variety of transitions, with the most common being "within team transitions", N=7)	35	5	40 (11.0%)

Results

278 people responded when asked to score various aspects of the transition process. A breakdown of their scores can be found in Tables 3–9.

Table 3. Overall management of the transition

On a scale of one to five (one being extremely poor and five being very good), how would you rate the way the transition was managed overall?			
Score	Lived Experience	Carer	Overall Response
1	57	16	73 (26.3%)
2	50	16	66 (23.7%)
3	63	6	69 (24.8%)
4	42	4	46 (16.5%)
5	21	3	24 (8.6%)

Table 4. Communication throughout the process

On a scale of one to five (one being extremely poor and five being very good), how would you rate the communication you received about the transition process?			
Score	Lived Experience	Carer	Overall Response
1	57	17	74 (26.7%)
2	60	12	72 (25.9%)
3	59	7	66 (23.7%)
4	34	4	38 (13.7%)
5	23	5	28 (10.1%)

Table 5. Involvement throughout process

On a scale of one to five (one being not involved at all and five being very involved), how involved did you feel in the transition process?			
Score	Lived Experience	Carer	Overall Response
1	67	17	84 (30.2%)
2	56	12	68 (24.5%)
3	54	4	58 (20.9%)
4	33	9	42 (15.1%)
5	23	3	26 (9.4%)

Table 6. Transition plan

Were you aware of yourself/the person you supported having a transition plan?			
(241 responses were included – those who ticked 'can't remember' were excluded)			
Response	Lived Experience	Carer	Overall Response
Yes	66	14	80 (33.2%)
No	132	29	161 (66.8%)

Table 7. Involvement in transition plan

If yes to a transition plan, on a scale of one to five (one being not involved at all and five being very involved), how involved were you in producing this?			
(76 responses were included – those who ticked 'can't remember' were excluded)			
Score	Lived Experience	Carer	Overall Response
1	9	3	12 (15.8%)
2	14	2	16 (21.1%)
3	12	2	14 (18.4%)
4	12	5	17 (22.4%)
5	15	2	17 (22.4%)

Table 8. Number of joint meetings

How many joint meetings did you have with both services before the transition?			
Number	Lived Experience	Carer	Overall Response
0	125	23	148 (62.4%)
1	48	10	58 (24.5%)
2	18	2	20 (8.4%)
More than 2	8	3	11 (4.6%)

Table 9. Timing of the transition

How long before the transition occurred were you made aware of the transition occurring?			
(117 responses were included – those who ticked 'can't remember' or that their transition had been in or out of inpatient treatment were excluded, since often decisions around this transition need to be made in a more time sensitive way.)			
Number	Lived Experience	Carer	Overall Response
Less than 1 week	11	4	15 (12.8%)
Between 1 week and 1 month	24	5	29 (24.8%)
Between 1 month and 3 months	29	2	31 (26.5%)
Between 3 months and 6 months	18	4	22 (18.8%)
More than 6 months	15	5	20 (17.1%)

Respondents were also given an opportunity to provide more information about the experiences of their/their loved one's transition through completing open-ended text responses. Individuals were asked to describe what they thought was positive about the transition process, and what they thought could have been improved. Responses were grouped into themes which have been reported below.

Positive experiences from the perspective of those affected by an eating disorder

Of those who had experienced an eating disorder themselves, 162 people responded to the question "Please describe what you think was positive about the transition process you experienced".

Responses were grouped into themes. The most cited theme (N=44, 27.2%) was that "nothing" had been positive about the transition experience.

"Can't think of anything really, it was awful."

"It was an extremely hard time for me and there wasn't anything positive about the experience for me."

The second most cited theme (N=27, 16.7%) was that communication between services was positive and that this was valued by the individual.

“Good communication from CAMHS and explanation of the process”

“Communicated well with me made me feel comfortable although I was nervous”

The third most cited theme (N=25, 15.4%) was that joint meetings were a helpful part of the transition process.

“Well managed in that we had a few joint sessions and I felt involved in making a care plan for after transition.”

“Attended joint meetings and did not feel separate.”

Other themes included the services and staff generally being supportive (N=23, 14.2%), that the new service was felt to be better for the individual (N=14, 8.6%), and that the process took into account the individual's needs and personal circumstances (N=8, 4.9%).

Suggested improvements from the perspective of those affected by an eating disorder

Of those with experience of an eating disorder, 168 people responded to the question “Please describe what you think could have been improved about the transition process you experienced”.

Responses were grouped into themes. The most cited theme (N=48, 28.6%) was that better communication would have improved this transition. This was communication both between the different services, and communication between the individual and the services.

“Definitely more communication between services, less assessments as information could be passed on, paperwork was lost leading to the wait becoming longer for me.”

“It could be improved by having certain aspects of information put into writing. For me I struggled to remember things so having it there to read could have been really beneficial to me.”

The second most cited theme (N=39, 23.2%) was that the process would have been improved through ensuring the new support was offered without a delay, since too often people were left time without any information and with little or no support for an extended period of time. Seven of these people (17.9%) also specifically reported that a new referral had been made, rather than a transition between services, meaning that they had to go through the assessment process again and were put on a waiting list.

“I wasn't transferred to the mental health team I had to start a new referral after getting a new doctor in the new location.”

“I had to be re-assessed for the service which took time, so I didn't see anyone for quite a while and so I didn't feel I had much support at a time where I felt particularly vulnerable.”

The third most cited theme (N=23, 13.7%) was that increased patient involvement would have improved this transition, and commonly this was cited in relation to the process feeling too sudden (N=7, 30.4%).

“Could have been eased out of the service, or gradually leave. I lost everyone all at once who I'd been working with.”

“I wish people had talked with me about it. Nobody asked me what I wanted - they (services) just did everything without me... I relapsed badly during that transition time.”

Other themes included the general need for more support (N=16, 6.0%), the need for “everything” to be improved (N= 9, 5.4%), and the need for “nothing” to be improved (N=6, 3.6%).

Positive experiences from the perspective of those supporting someone affected by an eating disorder

Of those supporting someone, 32 people responded to the question “Please describe what you think was positive about the transition process you experienced?”.

Responses were grouped into themes. The most cited theme (N=16, 50%) referred to “nothing” being positive about the transition experience.

“For me as a carer not positive at all. No involvement, no communication, we had to almost beg for information and explanations let alone try to understand process and what onward treatment was to be. No offer of any support to us or siblings... no onward contact...”

“Nothing. The ED unit decided unilaterally that they'd finished treating my daughter and within a month they'd step out entirely. It was very sudden and caused immense trauma to my daughter as she felt as if she was being abandoned.”

The second most cited theme (N=5, 15.6%) was that the transition process was supportive, for example through taking the individual's needs into account and staff being reassuring.

“CAMHS tried hard to try and encourage my daughter to continue onto adult services. They

were kind and tried to balance the message that it was important for her to follow onto adult services but at the same time respect her decision to decline."

"Once my daughter was admitted to an eating disorder unit she was supported well and as a family we had family therapy which help understand what she was going through."

The third most cited theme (N=3, 9.4%) was that the new service was viewed as an improvement from the previous service, so the transition process had led to better treatment.

"Finally, I was involved as a parent in my daughter's eating disorder. Got a diagnosis and a plan that we felt we could support as a family."

Suggested improvements from the perspective of those supporting someone affected by an eating disorder

Of those supporting someone, 35 people responded to the question "Please describe what you think could have been improved about the transition process you experienced?"

Responses were grouped into themes. The most cited theme (N=13, 37.1%) was that the individual was left with little or no support following the transition, therefore more support was needed following the transition.

"There was no transition process. CAMHS simply signed her off as she turned 18 and let her go to university unsupported. A plan, any plan would have been an improvement."

"I felt as soon as she hit a 'target' she was quickly removed from dietician"

The second most cited theme (N=8, 22.9%) was improved carer involvement. Several carers described experiences of being excluded from treatment, particularly once their loved one turned 18 years.

"Full engagement with the parents. Don't exclude us... Anorexia kills - engage with the parents!"

"As a mother I did feel excluded once adult services took over. I was still living with and caring for my daughter but felt excluded from the process. Now I recognise that my daughter needed to take ownership of her own decisions and goals. It just felt scared that the treatment was dramatically excluding me at the time."

The third most cited theme (N=6, 20%) was better communication, with respondents describing situations where they were not made aware of what was going on and next steps in the process.

"More communication- both regularity and content with emphasis on next steps long before they're due to be implemented."

"I only need one word COMMUNICATION!"

Other themes included "everything" needing to be better (N=3, 8.6%) and that no improvements were needed (N=2, 5.7%).

Conclusion

Findings suggest that both people affected by eating disorders and those supporting them commonly have an adverse experience of the transition process, with 50% of respondents stating that the way the overall transition process was managed was either "extremely poor" or "poor". In particular, both communication between services and communication between the individual and the service is often lacking, with 52.6% of respondents stating that communication was "extremely poor" or "poor". This was also found in the qualitative responses, where better communication was suggested as something that would have improved the transition process, by both those with lived experience of an eating disorder and those supporting them.

Over 50% of respondents (54.7%) reported that they did not feel involved in the transition process, despite the recommendations highlighting the importance of prioritising the patient's needs and involving the family. This also contravenes Beat's best practice standards in the engagement and empowerment of families and carers (13) which state that eating disorder services should inform and engage services when a loved one faces a transition. Additionally, despite the RCPsych's guidance (5) stating that, where possible, the individual should be made aware of the transition at least six months before the planned transition, only 17.1% of people who responded (excluding those who experienced transitions related to inpatient units) received more than six months' notice of the transition. We appreciate that due to the nature of transitions this will not always be possible. Nevertheless, it is evident from respondents' comments that in many cases, more notice could have been provided and would have been appreciated by those affected.

We recognise that there will have been self-selection bias, however this does not detract from the reality of the experiences that are described. Most concerningly, when asked to describe any positive aspects around the transition process, the most frequently cited response from both those affected by an eating disorder and those supporting someone was "nothing".

Many individuals described a lack of information or support from services during the transition period, and how this exacerbated their or their loved one's eating disorder thoughts and behaviours. In some cases when the individual was changing geographical location for reasons such as moving to or from university, a new referral was made rather than a transition, meaning the individual was left on a waiting list with no support.

Results also highlight how valuable factors such as good communication and joint meetings can be, since when these were implemented by services, both those affected by an eating disorder and those supporting someone commented on how helpful they were. This also demonstrates that it is possible for individuals to have positive experiences of transitions.

Beat therefore calls upon all healthcare providers offering eating disorder services to implement the above standards, and for NHS commissioners to ensure that services are appropriately resourced to do so, in order to prevent avoidable distressing and potentially devastating consequences.

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