

CR208

Managing transitions when the patient has an eating disorder

Guidance for good practice

COLLEGE REPORT

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Introduction

The diverse transitions that occur in services for people with eating disorders are a significant cause of relapse and breakdown in treatment (Treasure *et al*, 2005). Lack of communication between services, poor care planning and neglect of carers' needs may result in disengagement from services. This exacerbates patient and carer suffering, increases morbidity and mortality, and wastes precious health service resources; it also reduces the productivity of valued members of society. Differences in services can be impossible for patients to assimilate, leading to drop-out (Muñoz-Solomando *et al*, 2010), unsuccessful treatment (Singh, 2009) and potentially avoidable readmission to hospital (Jencks, 2010).

There are anecdotal reports that some transitions are experienced as positive and helpful. This occurs when 'old' and 'new' services have paid attention to why transition is difficult for both patient and carers and when the 'new' service offers a good fit with the patient's stage of recovery.

The most well-examined transition is that between child and adolescent mental health services (CAMHS) and adult eating disorder services (AEDS). Indeed, there is general recognition of the problems of transitions between CAMHS and adult mental health services (Department of Health, 2008; Lamb *et al*, 2008; Singh, 2009; Singh *et al*, 2010; National Institute for Health and Care Excellence, 2016), but it has been repeatedly argued that transitions for those with eating disorders, services have not yet received sufficient attention (Treasure *et al*, 2005; Arcelus *et al*, 2008; Winston *et al*, 2012). Boundaries between CAMHS and AEDS – as well as between paediatrics and adult medicine – are often poorly defined and differ across the country. Many trusts and health boards lack clear transition procedures (Treasure *et al*, 2005). Although the CAMHS–AEDS transition deserves continued attention, other high-risk transitions will also be considered in this report.

Aims and recommendations

This report will focus on those aspects of transitions that need particular recognition within the operational policies and care pathways of all services caring for patients with eating disorders. It will describe areas of adverse impact, suggest helpful practices, warn against those which are perceived as unhelpful and summarise the main practice learning points in the form of a series of recommendations (Box 1). We acknowledge that resource constraints may limit the extent to which improvements can be implemented. However, we argue that failure to address transition needs is associated with increased costs to the National Health Service (NHS) as well as with poor morale, leading to further impoverishment.

We have not aimed to provide a definitive review of research in this field but have drawn on current literature and on a variety of clinical and lay sources.

Recommendations

The recommendations are based on the discussions outlined in the subsequent chapters and on the following national guidance documents:

- *Working at the CAMHS/Adult Interface: Good Practice Guidance for the Provision of Psychiatric Services to Adolescents/Young Adults*, published by the Royal College of Psychiatrists (Lamb *et al*, 2008).

Box 1 Checklist of key recommendations

- Awareness
- Early identification and notification
- Involve family and carers
- Flexible timing
- Close links between services
- Transition coordinator
- Provide good information
- Clear protocols and pathways
- Patient-centred transition plan
- Multidisciplinary discharge planning meeting
- Overlap period of joint working
- Respect for attachments and therapeutic alliances

- *Guidance for Commissioners of Mental Health Services for Young People Making the Transition from Child and Adolescent to Adult Services*, published by the Joint Commissioning Panel for Mental Health (2012).
- *Guidance for Commissioners of Eating Disorder Services*, published by the Joint Commissioning Panel for Mental Health (2013).
- *Access and Waiting Time Standard for Children and Young People with an Eating Disorder*, published by NHS England (National Collaborating Centre for Mental Health, 2015).
- *Transition from Children's to Adults' Services for Young People using Health or Social Care Services* (NICE guideline NG43) (National Institute for Health and Care Excellence, 2016).

Awareness of the problem

The unique nature of eating disorders means they are often perceived as a coping mechanism, rather than a torment. Thus, people with anorexia nervosa can experience a catastrophic deterioration in their condition when undergoing stressful transitions. Avoidance of treatment is to be expected. We cannot rely on the patient's motivation to seek help. A starved brain finds it hard to see other people as allies unless trust is built carefully. For patients with bulimia nervosa and binge eating disorder, shame and fear of rejection can influence engagement and lead to a retreat from help-seeking.

Early identification and notification of the need for transition

For patients moving from CAMHS to adult services (which may be either specialist AEDS or general adult mental health services), discussion should take place between services at least 6 months before the planned transition. As soon as a need for transition is identified, clinicians should make contact with the appropriate future service and a transition meeting planned that involves the young person and their parents/carers.

Involvement of family and carers

Transition support should sensitively involve the family and carers. Carers have rights to information and support commensurate with the responsibilities placed on them and the burden experienced by them, which could all too easily result in them developing mental illness. Services should provide good information to patients and their carers to minimise the shocks of wholesale, unexpected differences. Addressing expectations around autonomy and confidentiality is important, particularly in CAMHS to adult transitions.

Flexible timing of transition

If at all possible, transitions should be delayed if the patient is in crisis. The timing of transition should take into account the needs of the patient and should not be determined simply by age or by service

convenience. Factors to be taken into account when deciding the time of transition from CAMHS to adult services include: the person's degree of maturity and separation from family, need for ongoing work with the family/carers, education and employment issues, links with other medical and social services, and – above all – the views of the patient and carers.

Close links between services

Good working relationships between services and an understanding of each other's way of working are best developed well before transitions occur. Joint working and training fosters a spirit of mutual respect and reciprocal learning between services. This can also prevent splits developing; these can occur, for example, when clinicians from one team imply that the other provides an inferior service.

Where there has been significant involvement of paediatric or medical services or social care, these services should be involved in transition planning. It is helpful when general practitioners (GPs) can be involved in planning and facilitating the transition; when they cannot be directly involved, minutes of meetings should be copied to them.

The transition coordinator

A transition coordinator or link worker should be appointed for transitions between CAMHS and adult services. These clinicians have also been called transition coaches (Coleman *et al*, 2006). This may involve the identification of a key worker from each service or a permanent joint post shared between services. The role of the transition coordinator is to guide and support patient and carers through the transition process and function as a point of contact. A similar approach may help with transitions between in-patient and out-patient services and between different eating disorder services.

Providing good information

From the earliest stage the provision of good-quality information to the patient and their family/carers will be important. For example, this may include facts about the service they may be joining as well as about the process of transition itself. Aspects of care planning and how that is communicated will of course be part of this. Better information provision will help reduce uncertainty and consequently improve outcomes.

Clear protocols and pathways

Services should have clear protocols and pathways for patients transitioning between them. These can be based on this report, modified for local circumstances. Patients and their carers, as well as clinicians and managers, should be consulted during the development and evolution of such protocols.

The transition care plan

An agreed and well-structured, patient-centred care plan (Box 2), focused on the individual rather than on organisational considerations, can be the most important single element in the whole transition experience. The patient must be consulted and involved in discussions about the care plan, taking into account their stage of recovery, level of maturity, personality, comorbidity and social and personal circumstances.

Multidisciplinary discharge planning meeting

Formal handover of care should be structured by at least one specific multidisciplinary discharge planning meeting. This may be held within the framework of the care programme approach (Winston *et al*, 2012). Since the process of transition is likely to last over several months, more than one meeting may be required to plan and monitor the process.

Joint working

There should be an overlap period of joint working by both services during the transitional phase. This is one of the criteria for 'good transitions' used by Paul *et al* (2013). The purpose of the transitional period of joint working is to:

- explore and explain the differences in the ways of working between the two services
- help the patient to get to know key members of staff from the new service

Box 2 The patient-centred transition plan

The plan should specify the following:

- The time at which the patient is expected to make the transition and the rationale for this.
- Any work which needs to be completed prior to transition and the nature of the work which is likely to be required after transition (this may require a reassessment and re-formulation at that point).
- Plans for a period of joint working, what form this will take, where it will occur, who will be included and how long it will last. In particular, it should be specified which clinicians (with name, role and contact details) and which carers will be involved before, during and after transition.
- The role of any other agencies (e.g. social care, occupational health or education) in the person's care.
- The views, concerns and wishes of the patient and carers regarding the transition.

When the patient is subject to the Mental Health Act 1983 or care programme approach, this should be incorporated into planning and may provide helpful structures.

- put in place arrangements for the necessary therapeutic and other interventions.

Attachment issues

Respect for the importance of attachments and therapeutic alliances is crucial in the work towards recovery from an eating disorder. A sensitive and developmentally informed approach to a transition may transform it from a traumatic and disjointed experience into an opportunity for building resilience and healthy maturation.

Meaning of transitions in eating disorder psychopathology

Eating disorders most often first occur at a time of rapid developmental change for the individual. Anorexia nervosa typically has an onset in early to mid-adolescence (Micali *et al*, 2013) and 50% of patients will remain unwell for 3 years or more (Keski-Rahkonen *et al*, 2007). Many therefore need treatment in both CAMHS and adult services and have to make the transition between them at what is often a crucial time in treatment (Arcelus *et al*, 2008). Adolescents are unavoidably exposed to a bewildering variety of developmental changes and normative life events at a time when both body and brain – the very ‘equipment’ for managing change – are themselves undergoing massive change.

Although bulimia nervosa has traditionally presented later to services, patients with bulimia are increasingly being seen in CAMHS. Approximately 30% of patients with bulimia and related disorders remain ill 10–20 years following presentation (Keel & Brown, 2010).

The classic writings of Bruch (1973) conceptualised anorexia as (in part) a response to overwhelming feelings about change. More recent research has demonstrated traits such as reduced cognitive flexibility and avoidance in the face of high anxiety in people vulnerable to eating disorders; these traits are further amplified in the starved state (Tchanturia *et al*, 2002). Adapting to change will therefore be especially challenging.

The importance of a secure trusting attachment with a team or therapist is particularly important in the slow work towards recovery from all eating disorders, perhaps particularly anorexia. It is also an important part of the professional satisfaction of a clinician, whereas it is countertherapeutic and depressing to have the experience of telling or hearing a life story deadened by the repeated telling or reduced to jargon by the repetition of formulaic explanations.

Increasingly, services are seeing very young or much older people with eating disorders. Young patients may have to face transitions from child to adolescent services and from primary to secondary school, at the same time as puberty. Older patients may have to transition from working-age adult to older adult services, as well as negotiating retirement or the ‘empty nest syndrome’ during the course of treatment.

Transitions are probably inevitable in treatment and certainly in the course of healthy development, but they can also have an avoidable adverse impact on individuals and those around them. Clinical experience suggests that transitional events can sometimes be positive stepping stones in the journey towards recovery. One young adult patient spoke of the benefits of leaving home and using the excitement and support of her new social network as a strong motivation for recovery. Another young woman found that the transition to parenthood enabled her to accept help for her eating disorder when her obstetrician supported her to approach the eating disorder clinic. The available evidence demonstrates, however, that transitions can have significant negative effects on patients and their families, especially when treatment is not designed to deal with the likely challenges and patients are not well informed or supported.

Transitions which occur in the course of treatment

Box 3 lists both the common transitions between different parts of services, and also the concurrent life transitions experienced by patients while they live with their eating disorder. Further chapters of this report go on to examine the CAMHS–adult service transition in more detail and to make recommendations for best practice in the management of all transitions, based on the experience and evidence currently available. We also suggest further exploration and analysis where they are currently lacking.

Box 3 Transitions in the lives of people with eating disorders

Service transitions

- From child and adolescent mental health services (CAMHS) to adult eating disorder services (AEDS) or to general adult mental health services
- Between specialist AEDS and non-specialist services
- Between National Health Services (NHS) and independent sector services
- Between different types of specialist service (e.g. psychotherapy department or substance misuse services and eating disorder services)
- Between primary and secondary care – both into and away from specialist care
- Between in-patient and out-patient care
- Between one eating disorder service and another – usually for geographical reasons – or between private and NHS settings
- Between legally detained and voluntary patient status
- Into and out of physical treatment-oriented services (e.g. admission to a medical ward, perhaps followed by transfer to a specialist in-patient eating disorder unit, or from maternity to perinatal psychiatry or eating disorder service)

Life transitions

- Changes of school – especially from primary to secondary school
- Leaving the family home to more independent living
- Becoming a university student/leaving university
- Starting work, changes of occupation, job loss, retirement
- Family transitions: relationship challenges and break-ups, births, marriages, retirements, bereavements
- Physical transitions: menarche, pregnancy, menopause, physical illness
- Moving to/from another country with different health and medico-legal systems

Transition from CAMHS to AEDS (or to general adult mental health services)

The transition from CAMHS to adult services has been identified as a core area of concern for a considerable time by successive reviews spanning multiple fields of healthcare. Reference to Box 3 will demonstrate that for many individuals this important change is likely to be accompanied by several other important developmental transitions. Young people between 16 and 18 years especially face an almost unprecedented intensity of change, at the same time as the stresses imposed by public examinations, financial pressures and the demands of social media. The recent report and aspirations contained in the *Future in Mind* publication by the Department of Health and NHS England (2015) emphasise principles that include promoting resilience, prevention and early support, and also improving the access to effective support at key times in children's mental health. It also highlights the particular challenges presented by changes of service and transitions in 16- to 18-year-olds.

An ideal solution might be the development of an age-independent service offering seamless treatment regardless of age. However, authorities on the delivery of medical services to children and young people believe that treatment is best delivered in age-appropriate settings wherever possible (Sloper & Statham, 2004). The model of a 0–25 years service is a reasonable compromise that would go some way in addressing many transition issues, and keep age-appropriate services ring-fenced. It could, of course, produce different disadvantages in developmental terms for patients. Moreover, although services might be more flexible, patients could still face moves out of area, particularly when choosing universities away from home. In the short term, therefore, it is probably more appropriate to focus on achieving good transitional arrangements between CAMHS and adult services.

In England and Wales, the 2004 *National Service Framework for Children, Young People and Maternity Services* made it a standard that 'All young people have access to age-appropriate services which are responsive to their specific needs as they grow into adulthood' (Department of Health, 2004: p. 119) (Sloper & Statham, 2004). The

continuing dilemmas raised by situations such as the treatment of children on adult wards complicate the picture and can prevent changes that might otherwise make services' responses to transitions effective.

The 2006 NHS Quality Improvement Guidelines for Scotland also highlighted the importance of these early transition points, advising that 'Services should work together to ensure that transition between services is achieved as smoothly as possible and at the optimum time to best meet the clinical needs of patients' (p. 8). The Fair Deal campaign of the Royal College of Psychiatrists (Fitch *et al*, 2011) included transition-age adolescents as a priority area, and projects through the 3 years of the campaign focused on this patient age group.

In the decade following publication of these documents, such issues remain to be resolved. Winston *et al* (2012) remark that 'given the fact that anorexia nervosa is often considered a developmental disorder, it is perhaps surprising that the issue of transitions between services in adolescence has not received more attention'. Paul *et al* (2013) found that out of 76 cases of transition between CAMHS and general adult services (not confined to eating disorder services), only 4 met all their criteria for optimal transition. Part of the problem has been that simply establishing resources for CAMHS on the one hand and for the specialty of eating disorders on the other, has not so far allowed us to prioritise attention on the finer detail of transitions between such services. There are often no set protocols for this particular change or the individual circumstances are not taken into account (Treasure *et al*, 2005). There is no consistent agreement about service age boundaries across the country (Muñoz-Solomando *et al*, 2010) and this is another problematic factor.

Most CAMHS teams have an upper age limit for treatment, which usually means that young people have to be transferred to adult services at the age of 16, 17 or 18. In some trusts, the referral criteria may differ between CAMHS and AEDS and there may even be a gap between the age at which the CAMHS team discharges patients and the minimum age for referral to AEDS. CAMHS and adult services are often located within different divisions of the organisation, and communication can be hindered by organisational constraints.

Historically, most young people with eating disorders have been treated within generic CAMHS teams (Royal College of Psychiatrists, 2011). Recent new investment in England has led to the establishment of specialist community eating disorder teams within CAMHS teams. However, many of these teams are only just beginning to develop their pathways and look at how they interface with other services. Adults are more likely to receive treatment in a specialist eating disorder service but in some areas treatment is provided by community mental health teams, which may lack skills and experience in dealing with eating disorders. This sometimes results in a reluctance to take on patients from CAMHS as eating disorders may not be classified as severe mental illnesses by adult teams (Treasure *et al*, 2005; Arcelus *et al*, 2008) and they do not generally respond well to the biosocial

approaches which predominate in general adult psychiatry services.

The transition from CAMHS to AEDS is not simply organisational; there are also likely to be significant differences between services in the philosophy and practicalities of treatment. In CAMHS, treatment is often based around family treatment (Dare *et al*, 2001; Treasure & Schmidt, 2003; National Collaborating Centre for Mental Health, 2004; Bulik *et al*, 2007; Lock *et al*, 2010; Eisler, 2011), and sees families as the unit of concern and of communication. In AEDS, individual therapy is usually the standard approach, with a strong respect for individual autonomy and rights to confidentiality. Interestingly, differing approaches to confidentiality are not based on firm legal principles, although it is often implied that this is so.

‘The day I turned 18 everything changed. Not only was it fairly daunting – the prospect of being an adult – but also my treatment was to be changed. The problem lay with the fact that I was not able to make changes on my own without support but was encouraged under an adult service to take responsibility for myself, make the changes independently and not rely on my parents.’ (Patient A)

In-patient treatment for adults with eating disorders is most often provided in specialised eating disorder units (49%) but a significant proportion of patients are admitted to acute psychiatric wards (37%) and a smaller number to general medical wards (9%) (Royal College of Psychiatrists, 2000, 2011). For young people with eating disorders, in-patient care is provided through a combination of specialist in-patient providers (often in the independent sector), generic in-patient adolescent psychiatric units (CAMHS Tier 4 Steering Group, 2014) and paediatric wards when brief medical stabilisation is required.

Some patients who reach the age of 18 while in hospital will therefore need to be transferred from an adolescent unit to an adult eating disorder unit with a very different atmosphere and ethos. This needs to be handled carefully and with adequate preparation of the young person. A further problem arises when young people are admitted to an adolescent unit from a CAMHS team but, because of their age, are discharged to an adult service. These young people have to face two service transitions: from hospital to community and from CAMHS to an unfamiliar adult service. When primary care has to mediate or initiate re-referrals to adult services, further stages are added to the complexity.

The experience of transition

The expectations and experiences of professionals in the two different services involved in each transition may well be mismatched and, at the same time, the ambivalence that characterises eating disorders may well bring a further contrasting agenda into the mix; family members and other lay carers introduce a fourth dimension to this complex situation. The inevitable potential for splitting can lead managers and clinicians who are not familiar with the nature of eating disorders to assume that personality disorder or uncooperative behaviour is present. Trust and mutual respect can all too easily suffer. This section of the report summarises themes emerging from patient and carer accounts of their experiences.

Transition enacted as a re-referral rather than a move within a treatment setting

Case vignette 1

Ms A, a carer, raised specific concerns about the time delay that reassessment in adult services introduced into the treatment, with an initial promised wait of some weeks turning to months. She felt that poor communication between the services confused the messages about the nature and duration of the assessment by the adult service.

This common model of care means that a full re-referral is required for a transition in treatment, whatever the context. For example, patients who would not be discharged from treatment on clinical grounds are offered the option, when they reach the age of 18, of leaving treatment or of being re-referred to a 'new' service. If the transition is treated in this way, it is all too easy for the experiences of patients and families to be similar to Ms A above. If the new service assesses the individual's needs without allowance for the role of intensive support, they may not offer the intensity of support needed to maintain that level – see the account of Carer B on p. 18.

Reduction in service resource for adult patients

'CAMHS [...] offered steady careful support and monitoring, weekly psychologist, dietician, often weekly psychiatrist sessions [...] parental involvement. This has all gone now. The AMHS [adult mental health service] psychiatrist barely sees her, maybe once every 2 months.' (Carer A)

'My daughter feels that she's not being taken seriously. Her anorexic thoughts and body dysmorphia are still strong. She sees an ED [eating disorder] nurse, every 2–3 weeks if she's lucky. That's it.' (Carer B)

Communication barriers justified in terms of 'confidentiality'

'Carers are not looking to know what goes on between therapist and patient. They need support and reassurance for themselves, at all times, particularly transitions, if they are to be effective contributors to their loved one's recovery.' (Carer C)

Transition from home to university

Moving away from home to university brings the additional stress of undertaking studies and deadlines without the supportive structures of school, new social pressures and relationships, and the financial and organisational complexities of modern adult life.

Case vignette 2

Patients describe in qualitative research and contributions multiple challenges. They describe how the demands of study, work and the new social situations encountered taken together can result in a tendency to isolation, that could contribute to the difficulties that are starting to or have already developed. A lack of information-sharing between areas is often seen as contributing to problems, as are the sometimes radically different approaches of services. Finally, a lack of enough links between universities and psychiatric or GP services was quoted as a problem for some. It is important to note that some contributors did make clear that aspects of this transition did contain major steps forward in terms of positive progress in their treatment and recovery.

The Royal College of Psychiatrists has published guidance on the mental health needs of students (Callender *et al*, 2011). This emphasises the need to increase collaboration between the NHS and those internal university resources which offer mental health services to students. It acknowledges that perceptions about the protection of confidentiality can be a barrier to useful collaboration. A particularly useful collaboration would be the establishment in each area of close links between specialist eating disorder services and student health, involving training and joint working. University departments of medical, paramedical and nurse training and of sport might have a dual interest in participation from both the research and training viewpoint and because of the high prevalence of eating disorders in students studying these subjects.

Work on the specific challenges of this transition for people with eating disorders has been undertaken by B-EAT and by Student Minds (the UK's best known student mental health charity) in their report *University Challenge: Integrated Care for Eating Disorders at Home and University* (Hambly & Byrom, 2014). This report highlights the common predicament of a young person having to wait on the waiting list of their local specialist eating disorder service, only to be

obliged to re-register with a new GP in their university town, seek referral and then join the bottom of the waiting list for the new service.

'... my home specialist services did all they could to transfer care smoothly and ahead of time but were constantly told nothing could be set up until I had arrived at university and registered with a new GP, and then despite my history and letter from my specialist consultant urging a rapid referral to specialist services, I still had to go through the referral process from GP to CMHT [community mental health team] to specialist services which takes months and then you are on a waiting list to get treatment too...'
(Hambly & Byrom, 2014: p.5)

Even if the patient is offered treatment, this is usually suspended during the return to the parental home during vacations. The result is repeated mini-transitions, with massive disruption to treatment. Such difficulties may defeat even the most highly motivated student when seeking mental health treatment but, for those with the ambivalent motivation that characterises eating disorders, it is a major obstacle. Attempts to provide treatment in two different locations (and sometimes by two different services) can lead to confusion about the treatment plan and about who is responsible for what. This can result in splitting between professionals and allow important tasks such as monitoring of weight or blood tests to fail to be carried out. Some patients may exploit the situation to avoid follow-up or monitoring.

Student Minds (Hambly & Byrom, 2014) encouraged, among other ideas, the transfer of work between geographical regions that improved electronic access to records and to make use of video-link technology to provide continuity of therapy across geographical divides. Alternatively, there are suggestions that specific professionals should be appointed with the responsibility of providing liaison across transitions, perhaps using the care programme approach as an appropriate structure.

Case vignette 3

Carer D described how her daughter, in the midst of transition to university, used avoiding contact with doctors to evade treatment. Her daughter, through her illness, also realised that different areas did not cooperate well. This meant the transitional issues were used by the eating disorder, so that her daughter – by moving between areas – opposed effective treatment.

Kenyon & Keorner (2009) suggest that the changes of late adolescence, including the move away from home, generate increased conflict between parents and children in terms of differing expectations of personal autonomy. These normal conflicts, the reality of geographical separation and the nature of an eating disorder make carer involvement particularly hard to arrange for students with eating disorders. Nevertheless, healthy young people do characteristically use technology to stay in remarkably close contact with parents, they

are often financially and emotionally dependent on them and they turn to them at times of particular vulnerability or illness.

Existing sources of help include those provided by BEAT. They have been engaged in a series of transition projects and packages, including online training for professionals and online forums for young people undergoing transitions.

Patients and former patients of eating disorder services told us how having family members close by during the move away from home and to university can still be very important to them. Likewise, carers will want to feel they can have good contact with the treatment progress of their children and will be naturally extremely apprehensive about implications of the move.

Finally, many young people plan a 'gap year' before, during or after studying for a degree. The idea of taking a year out can allow people with eating disorders some time to convalesce in a less stressful environment, sampling a variety of voluntary or paid activities, catching up on developmental tasks and sheltering from academic and other stressors without stigma or shame. On the other hand, ambitious long-haul travel projects can threaten the physical as well as psychosocial well-being of vulnerable patients, particularly when foreign health systems are difficult to access or prohibitively expensive. Many clinical anecdotes testify to the morbidity and mortality of independent foreign travel at this stage of an eating disorder. Both eating disorder specialists and GPs need to consider these risks when consulted about such travel.

Transition between general hospitals and eating disorder units

Substantial risks are associated with transitions at the level of in-patient care, including transfer between services. A report by the Scottish Public Services Ombudsman (2006) analysed the fatal outcome of a patient who died tragically after multiple cross-service transitions. Frequent transfers to different services caused confusion and there was disagreement and inconsistency about treatment plans. The growing use of the MARSIPAN (MARSIPAN Working Group, 2014) and Junior MARSIPAN (Junior MARSIPAN Working Group, 2012) guidelines could protect against such tragedies, by encouraging consistency of life-saving medical protocols across different units. Transitions in and out of acute medical care are considered explicitly within the MARSIPAN and Junior MARSIPAN documents, which this report wholeheartedly endorses. Unfortunately, clinicians in some areas have found it difficult to engage general hospital colleagues in setting up the protocols and procedures recommended by the MARSIPAN reports. Risks and challenges arise when patients are discharged from general hospitals. There are further risks when treatment plans are changed because the patient is moved from one medical setting to another. Confusion can be generated, for staff, patients and carers, by differences in the way re-nutrition is delivered, the use of observations and the extent to which the patient's problems are medicalised. Differences in practice can feel to patients and carers like a confused lack of agreement. Work is to be encouraged on agreeing local protocols that link the different units involved in the treatment of patients with eating disorders.

Transition between in-patient and out-patient care

Practicalities for patients and carers

The transition from community-based care to in-patient treatment can be difficult for both patients and family, particularly in the case of younger patients. These difficulties are often exacerbated by unacceptable delays in admission due to a lack of beds, leading to prolonged uncertainty about when and where the patient will be admitted. For the patient, the loss of control of their eating is complicated by the loss of family contact, social relationships and work or study. For parents, who have been used to being heavily involved in their child's care, it can be hard to hand over this responsibility to staff in the in-patient unit. Although some parents may experience this as a relief, others may feel a sense of loss. If time allows, time spent preparing the patient and family for admission can be extremely useful; an opportunity to visit the unit is often helpful. An explanation of rules about visiting and other practicalities before admission helps to avoid misunderstandings and unnecessary conflict and a description of the treatment programme helps to reduce anxiety. A discussion with the in-patient dietitian about how meals and weight gain will be managed is often beneficial. It is very important that the aims of treatment are fully discussed with the patient and family before admission whenever possible. Research by Smith *et al* (2016) into in-patient treatment for eating disorders in Scotland identified concerns about admission including a distressing experience of loss of control and a wish for more collaborative treatment and more information to help deal with the changes.

'Those from the hospital environs graduated to day care before out-patients. Those from other parts of Scotland and Northern Ireland went straight from 24/7 care to one appointment per week or fortnight. We felt this was too big a step. There had been a maintenance period for a few weeks before discharge, but the support was there if required. As carers, we had excellent support by telephone for the first few weeks if necessary. Zero from out-patient service or GP. It was a very scary place to be for parents/partners/carers.' (Carer C)

Discharge

Discharge from hospital is one of the most crucial and one of the most difficult transitions. Smith *et al* (2016) also documented patients' fears about discharge, with concern that there were insufficient out-patient resources available; they and their carers highlighted the extra difficulties when the in-patient location is far from home. This account also demonstrates the particular difficulties of making the transition from a service perceived as having plentiful resources to one where they are more scant – a similar theme to that expressed by some of those leaving CAMHS to attend adult services. Many patients receive in-patient treatment in the independent sector and then return to NHS care on discharge. This introduces an additional layer of complexity to the transition and may further highlight disparities in resources between in-patient and out-patient settings. Even the physical appearance and decor of a clinic can trigger a sense of impoverishment or low investment in patients, or – more positively – can signal that a more sophisticated and attractive environment is now providing their care.

Change in service activity patterns

Patient experiences seen in the development of this guideline described the shock of going 'overnight' from a busy programme of daily therapeutic activities to appointments lasting less than an hour once or twice a week. Intermediate care, such as a day-patient service, can play a helpful role in the adjustment process. Where this is not available, in-patient units can sometimes mimic its effects by providing periods of long home leave (passes), with telephone support or outreach, as described by Carer C (p. 23). During such home leave, attendance at the new out-patient service could usefully begin so that there is a period of overlap, during which the two clinical teams communicate closely. Meanwhile, it is essential that the 'new' service does not fall into the trap of imagining that the good function and improved nutrition of the patient is evidence of their autonomous recovery. A high level of support may be needed for a while after discharge. It is unlikely that an out-patient eating disorder service will be able to replicate the range of multidisciplinary professionals available in in-patient units, and carers should not be expected to mimic the work of the nursing team. In some areas, patients will be discharged to the care of a generic CAMHS team or an adult community mental health team which does not have the skills or resources of a specialist service; lack of input from a dietitian with specialist skills is often a particular concern.

Third-sector and social care

Input from the third sector and social care may be needed alongside that of the mental health team. These organisations should be identified and contacted well in advance of the planned discharge so that their involvement can overlap with the ending of the in-patient team's contact. It is also immensely valuable when the teams concerned provide each other with training, supervision and ongoing consultation, to provide a safety net and a more supportive network around those in transition.

Viggiano *et al* (2012) reviewed some of the initiatives that have been developed to assist with discharge from hospital for mental health patients in general. They highlight the importance of multidisciplinary teamwork at times of transition, family and carer involvement, and improving connections between in-patient and community services. Coleman *et al* (2006) describe the use of psychoeducation and self-management tools in preparation for discharge to a less contained treatment environment. They recommend the use of structured care plans, relapse management plans, advance statements and personalised records of treatment that can follow the patient. This work demonstrated a reduction in readmissions, albeit in an older patient group.

It is invaluable to hold regular liaison meetings between out-patient and in-patient services. When these services are at long distances from each other, telemedicine is useful. Clear transition protocols are specially important between private and NHS providers, to ensure that clinical readiness rather than financial arrangements drive discharge planning. The use of community treatment orders can play a role for some in these instances. The care programme approach offers useful structures for planning and monitoring progress after discharge (Ayton, 2012).

Transition out of eating disorder services: discharge

The prospect of discharge from services can be terrifying for patients, and equally filled with apprehension for carers. Professionals can find themselves divided, with those who work most closely with the patient all too aware of the vulnerabilities that remain to be addressed, whereas colleagues are impatient to free up space to help more seriously ill patients. Respect for the therapeutic value of a strong attachment can inform a timely, well-planned transition back to primary care and the networks of support available in the community. This transition can be usefully informed by psychotherapeutic wisdom about the process of termination. When feelings about discharge are not acknowledged, recovery may be thwarted at this final hurdle and the patient damaged by unaddressed fear and fury at the perceived 'rejection'.

Assertive, early discharge planning can be used to identify (if necessary) and communicate with the patient's named GP. Observing formal ceremonials, such as a discharge planning meeting, with formal documentation and perhaps the construction of a relapse prevention plan or advance statement, can effectively provide 'transitional objects' as patients graduate from specialist treatment. It is also important to acknowledge rather than avoid the notion of possible relapse, and to remind patients and families of the presence of a 'safety net'. Services may be able to offer some form of enhanced access to re-referral to address lapses, rather than oblige patients to wait until their condition meets the criteria required for new referrals. Alternatively, some services have experimented with the offer of very low-frequency contact, in which patients are reviewed once or twice a year rather than completely closed to the service.

Other transitions

Geographical area

Transitions of geographical area may of course occur without the patient attending university. Similar principles apply, but the upheaval is likely to be less, and the frequent alternations of address as a result of vacation times may not apply. It is worth remembering that the very nature of a severe eating disorder may result in some moves – for work purposes for instance – which may not work out, so that the patient is obliged to return to the parental home. Some professions demand frequent geographical transitions – junior doctors may, ironically, be among those most affected. Close links with occupational health and both clinical and educational supervisors are helpful when handled diplomatically and robustly. Some patients report helpful input from pro-recovery online groups and forums, which obviously transcend geographical boundaries. Services have been slow to experiment with provision of moderated groups for ‘discharged’ patients.

Life events

Transitions are life events, which have been shown to be times of both special vulnerability and opportunity. Examples include marriage, pregnancy, changes in employment, bereavement and physical illness. There are important risks around the transition to parenthood, involving fertility issues, the experience of pregnancy, childbirth and the perinatal period and infant feeding. These are clearly beyond the remit of this document, but are flagged up here for further attention. Eating disorder clinicians should involve obstetric and maternity services as well as perinatal psychiatry colleagues. This is a clear example of the importance of an identified ‘case manager’ who can integrate care and ensure that the patient’s needs do not fall into ‘gaps’ where each service imagines that others are providing elements of care.

Transitions and the commissioning of services

The commissioning of services for eating disorders should support greater integration between CAMHS and adult services and between in-patient and out-patient care. In England, however, commissioning arrangements militate against coordinated care and can worsen the experience of transition. Services for patients under the age of 18 are commissioned separately from those for adults and funded out of different budgets. Communication between CAMHS and adult service commissioners may not be optimal and patients approaching the age of 18 can be left in a state of uncertainty about whether in-patient treatment will continue to be funded. In some cases, patients may be discharged from an in-patient unit or transferred elsewhere simply because they have reached the age of 18.

A further problem is that in-patient services are commissioned centrally by NHS England, whereas out-patient/community services are commissioned locally by clinical commissioning groups. This makes it very difficult for these services to be properly integrated and for care pathways to be commissioned as a whole. Given that many patients will move several times between in-patient and out-patient treatment, there is clearly a need for greater collaboration between the two commissioning bodies. New commissioning guidance for in-patient and day-patient care in eating disorder services for young people sets out measures intended to overcome these barriers to joined-up care (National Collaborating Centre for Mental Health, 2015).

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