mental welfare
commission for scotland

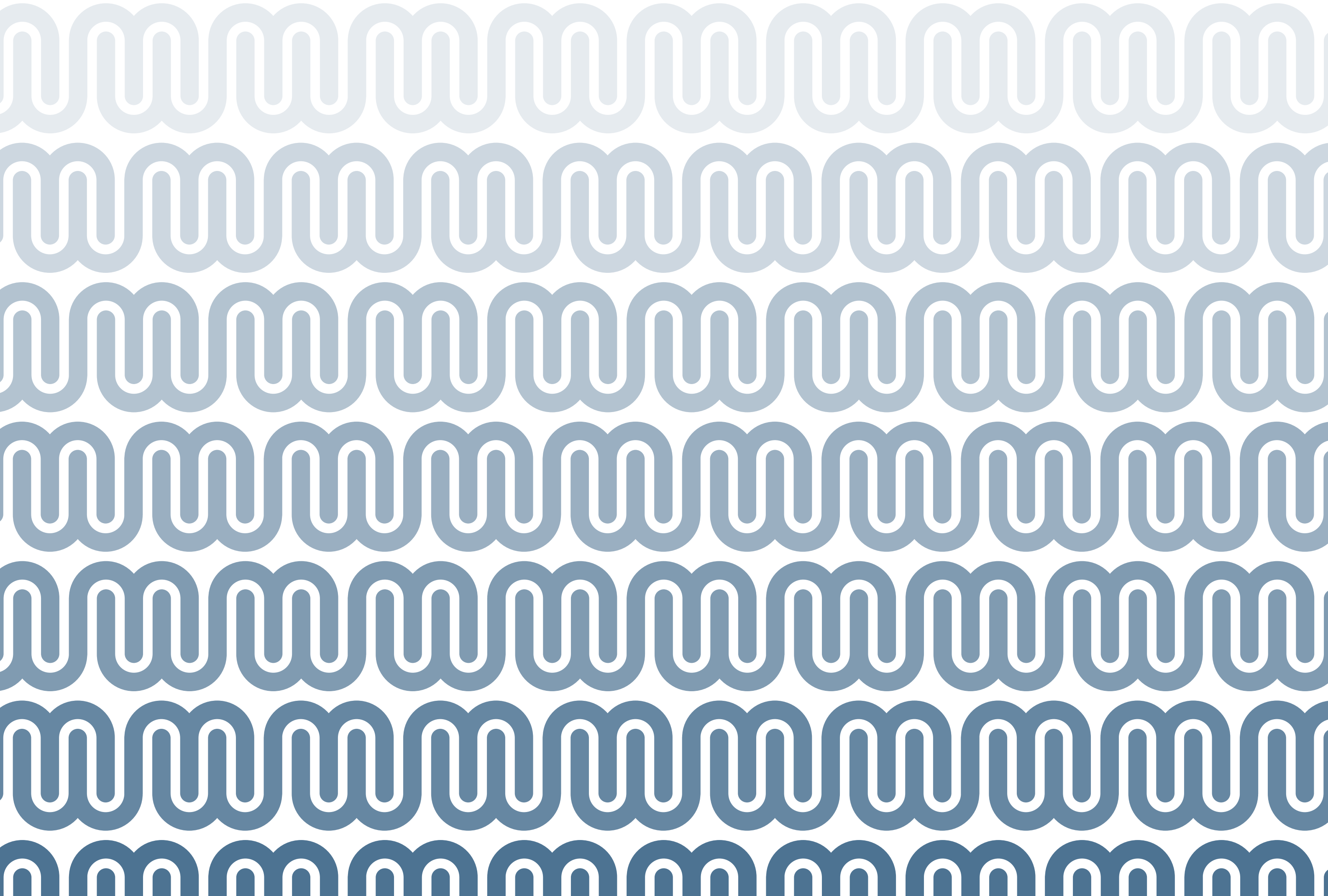
EXECUTIVE SUMMARY

Hope for the future

A report on a series of visits by the Mental Welfare Commission looking at care, treatment and support for people with eating disorders in Scotland

Themed visit report

September 2020



Our mission and purpose

Our Mission

To be a leading and independent voice in promoting a society where people with mental illness, learning disabilities, dementia and related conditions are treated fairly, have their rights respected, and have appropriate support to live the life of their choice.

Our Purpose

We protect and promote the human rights of people with mental illness, learning disabilities, dementia and related conditions.

Our Priorities

To achieve our mission and purpose over the next three years we have identified four strategic priorities.

- To challenge and to promote change
- Focus on the most vulnerable
- Increase our impact (in the work that we do)
- Improve our efficiency and effectiveness

Our Activity

- Influencing and empowering
- Visiting individuals
- Monitoring the law
- Investigations and casework
- Information and advice

Hope for the future - summary

Summary version of report looking at care, treatment and support for people with eating disorders in Scotland

September 2020

"I want to find release from the obsession with food/body as a way of avoiding everyday life. The ability to live life to the full without the mental torture of an eating disorder, the exhaustion, desperation and hopelessness of it all.

I am very hopeful however."

"I want to be able to enjoy myself again, have a milkshake and not feel like I'm a failure. I want to be able to have the memory and focus to work well, and no longer have to use an eating disorder because I can't control how I feel. I want to feel normal."

"I hope for more peer roles within services. Often those with lived experience are dismissed as being able to be on the other side, however, often it can be easier to relate to others with lived experience and can encourage recovery. A huge part of recovery is connection and friendships."

"I hope when I leave that I will be stronger and able to follow up the development gained in the intensive therapies work. I am a mum and a wife and I don't want to miss out on those things."

Executive summary

Eating disorders are serious and potentially life threatening conditions. Anorexia nervosa has the highest mortality rate of any mental illness and can have a devastating lifelong impact.

This is the first time that the Mental Welfare Commission for Scotland (‘the Commission’) has carried out a themed visit in relation to people with eating disorders. We were aware from our contact with people with these diagnoses, their families, the staff who provide treatment and support, and others, that access to general and specialist treatment and support could vary across the country.

The aim of our themed visit was to gain a closer understanding of the current situation in relation to the care and treatment of people with eating disorders in Scotland.

Key findings

We heard that early intervention, support through Community Mental Health Teams (CMHTs), access to psychological therapies, and a positive and engaging relationship with the professionals providing care were critical to people with eating disorders.

However, people with those disorders and their families/carers felt there could often be a lack of support available, and delays in accessing it. Some felt excluded from the diagnostic process and experienced prejudice connected with the stigma attached to eating disorders.

While many family/carers reported positively about excellent care, they also talked about the difficulties they could face. Without exception, they all told us that caring for someone with an eating disorder had devastating and long-lasting effects on the whole family. The impact on families can be traumatic and we heard that many families/carers were sometimes left feeling helpless and unsupported.

A number of concerns were raised about the focus on using BMI (body mass index) alone as a criterion for referral and access to services, and also as an indicator of recovery, with less attention paid to other critical factors including co-existing mental health conditions. For GPs too, this can be felt to act as a barrier to referral to specialist services if symptoms are present but BMI is still within acceptable limits.

We noted inequalities in the provision of services, including the availability of psychological therapies, with some people accessing support privately. We also found confusion and conflict over the responsibility for physical health monitoring between GPs and psychiatrists.

Compliance with, and awareness of, guidelines on waiting times for assessment and referral varied. We heard about gaps in care provision between services following transitions from one service to another, and also from inpatient to community care.

Our mapping exercise provided an overview of the wide variation in the organisation of services caring for people with eating disorders in Scotland. This is the first time such an overview has been achieved, and the process of gathering this information highlighted differences in health boards' approaches when providing details of their services.

Feedback on dietary management from inpatients raised questions about the quality, choice and presentation of meals, as well as the structure and management of mealtimes.

Finally, we noted the need for more specialist training, knowledge acquisition and skills development for some professionals involved in the diagnosis, care and treatment of people with eating disorders. Where this is not present, it can create a lack of confidence and trust.

We will be sending this report to those noted in the recommendations and will follow up formally on their responses, and report publically on those responses.

Recommendations

Recommendations for integration authorities

Because services are delivered differently across the country – and not simply through health boards – we have made recommendations to integration authorities. An integration authority can be a local authority, a health board or an integration joint board, according to the model of integration adopted locally. All medical, psychological and GP services remain the responsibility of health boards.

We recommend that integration authorities:

- have clear and detailed operational guidance and policies relating to services that look after people with eating disorders and ensure care transitions are coordinated;
- have a comprehensive range of services available across all ages and gaps in provision are identified and addressed; have clearly defined access to inpatient mental health beds for people with eating disorders, across the age range;
- ensure support is maintained following discharge from hospital and specialist community services including support for families/carers;
- develop protocols about physical health monitoring, including the assessments and investigations that should be undertaken by primary and secondary care providers and clear guidance on how different services are expected to work together;
- put in place protocols outlining how the provision of medical care for 16-17 year olds, who require medical inpatient treatment, will be supported by mental health and eating disorder services;
- ensure that there is access to the appropriate level of training in ED for their staff;
- have in place a range of supports, in relation to all aspects of health, for people with an eating disorder;
- family/carers should be involved, where appropriate, in the planning of treatment, and have access to a range of information and support that can provide help when caring for a person with an eating disorder, or when in a crisis situation.

Recommendations for Scottish Government

While undertaking this themed visit, we were told that eating disorder services will be subject to a national review by the Scottish Government, designed to assess and improve support for people with eating disorders. We recommend that Scottish Government:

- use this report to help inform the work of their national review;
- look to establish a managed network in relation to eating disorders; this would help to address issues of inequality in access to services, public education, staff education and the sharing of best practice.

Recommendations for Healthcare Improvement Scotland (HIS)

We recommend that HIS progress with a review of the Scottish Intercollegiate Guidelines Network (SIGN), which requires review, revision and update of the efficacy of treatments and therapies to support people with eating disorders in Scotland.

How we carried out this visit

Initially, we met people with eating disorders, their families/carers and with support organisations - through group meetings and individual interviews - and asked what they felt our priorities should be, and what we should focus on in our questionnaires.

We asked health boards about services and practices in their areas. We sought opinions from a broad range of professionals involved in the care and treatment of people with eating disorders including GPs, psychiatrists, psychologists and therapists, and dieticians.

The two most common topics identified were services using BMI (body mass index) as a criteria for admission, and the lack of support in the community for people with eating disorders and their families/carers. Difficulties in achieving access to early intervention, specialist service input where there is a dual diagnosis, and challenges around transitions from CAMHS (children and adolescent mental health services) to adult services, were also highlighted.

We then created questionnaires aimed at people with eating disorders, families/carers, and professionals.

We visited 10 eating disorder services across Scotland, conducting staff questionnaires, reviewing case notes and meeting patients and families/carers. Those not able to meet us could take part via questionnaires. We also asked for information from health boards about the provision of services for people with eating disorders in their area.

We later consulted more widely using online surveys aimed at people with eating disorders, their families/carers, GPs, psychiatrists, dietitians and therapists.

Overall, 74 people with a diagnosis of eating disorder gave us their views – of these 68 were female and six were male. Twenty one GPs, 27 dieticians, 24 psychiatrists and 31 clinicians delivering psychological therapies and 20 relatives/carers responded to these surveys.

Due to the pandemic, we were unable to include all of the information we collected in our report as some data on paper files remains in our (closed) office. It will be reviewed later.

Accessing support

The vast majority of people with eating disorders are treated in the community by their local CAMHS, primary care team or community mental health team, sometimes with links to other support services. The local GP is often a first step. Some people will go on to support themselves at home with the help of family/carers, others will need specialist support in the community or in hospital.

People told us about the difficulties they can experience when trying to get support in the community. They said some treatments were only available in specialist hospital wards, not in the community. And they told us that not getting support at a time when it's needed can lead to a deterioration in physical, mental and emotional wellbeing, sometimes resulting in hospital admission. They talked about stigma and said that due to a lack of knowledge and understanding of eating disorders, they were subject to prejudice from friends, family and members of the public.

Geographical differences

People with eating disorders and their families/carers, told us that services are limited regionally, even more so in rural areas. Some people told us that they had to seek private therapy in the absence of NHS Scotland provision locally.

Understanding where support comes from

We asked 48 people who were receiving support from an inpatient or specialist community service about that service. Of those who responded, around a quarter told us they were receiving all the support they needed, a quarter were only receiving some of the support they needed, and a few said they were receiving very little support. People said more support was needed, specifically in local communities.

From our surveys, we asked people to tell us who was providing their current care. Of the 26 respondents there was a fairly even spilt between those receiving care from their GP and those receiving care from a specialist team.

We asked families/carers if their relative had support to help them manage their eating disorder. A third of the 30 family/carers told us that there was no access to support.

Delays in receiving specialist support

Delays in accessing help and support may involve either delays due to individuals having symptoms but not yet realising they have a problem or not yet ready to seek help, or delays when the person has sought help but is waiting for treatment.

Some people told us they had experienced lengthy delays for treatment, admission and access to specialist services, even to get into a support group. People said that not being able to access support quickly was traumatic and made it difficult to form therapeutic relationships when help was finally obtained.

Crisis support

Crisis situations can happen at any time, and the way people with eating disorders cope varies from individual to individual and is influenced by the length of time they spend in the crisis situation, the coping strategies available, and the level of support they need to manage the situation. Knowing where to access help or support in a crisis is vital for people with eating disorders and their families.

Around a third of families/carers told us they had a crisis plan in place, but many said they didn't have access to any specific advice on how to handle a crisis. Of the 30 relatives/carers who responded to this question, a third said they did not have access to help in a crisis. Some had good access to crisis support, but others told us of calls not being answered and of having to go back to their GP for a further referral.

Families/carers suggested that access to crisis support was often dependent on whether the person with the eating disorder was being supported by a specialist community eating disorder team as opposed to generic services.

Geographical differences

Again, accessing support at a time of crisis varies across the country. While some areas had crisis intervention teams, a number told us that they would contact NHS24 or go to A&E.

Understanding the impact of the illness on families/carers

The majority of those with eating disorders were adults living independently or semi-independently. The vast majority were cared for in the community, often by families who have children to support, jobs to go to and no medical knowledge or experience.

To successfully support people with eating disorders, these families/carers need help to manage what is a very steep learning curve, and this support should be both psychological and practical. Around half the people we spoke to said there was no community support for this.

The impact of eating disorders on families/carers is significant. Comments were overwhelmingly negative – and upsetting – with the situation most commonly described as 'devastating' as well as 'exhausting' and 'relentless'. Families/carers described feeling 'helpless' and talked of the enormous strain on all interpersonal relationships, as well as the negative impact on other children. Loss of meaningful relationships with extended family and friends was also mentioned, along with concerns over being judged on parenting skills. Some of the people we spoke to told us it was impossible to continue with employment and this resulted in financial pressures. Very few relatives/carers had been directed to any support for themselves.

From referral to diagnosis

The most common reasons people were referred were physical deterioration and weight loss. The reasons for people developing eating disorders are complex, and we wanted to find out if aspects other than weight restoration and BMI were being properly addressed.

Individuals’ and families’ experience

People with eating disorders and families/carers frequently voiced concerns about services appearing to concentrate on weight alone as a threshold for accessing treatment. They said it meant that people who needed support did not get it, and it made them concentrate on the very thing that they should not concentrate on – in other words, low weight became a target to achieve, either in order to access services or to leave services behind.

Several mentioned that services, including GPs in primary care, put excessive focus on weight restoration and nutrition, while not addressing associated mental health issues which would still be present even if weight and BMI were within acceptable ranges.

We wanted to explore the concerns that people with eating disorders might have had at the point of being referred. We were told of negative or unhelpful experiences while in contact with the service and the staff, lengthy waiting times to access a service, variations in service provision and weight as the main focus.

Several families mentioned other complicating diagnoses such as autism, mood and personality disorders, which they felt were impacting on the eating disorder but were being ignored by services.

Referral and admission criteria for specialist services

For most of the specialist services, the main admission and referral criteria were low BMI, significant risk factors and/or physical healthcare monitoring. For half of the services, identified needs for either psychological or psychosocial intervention also formed part of their referral criteria.

We asked consultant psychiatrists who provide inpatient care if there were any exclusion criteria for admission. Of the nine inpatient psychiatrists who responded, three reported there were. It was noted that if people required acute medical care due to physical health risks, they would be admitted to a general hospital medical ward instead. The majority of psychiatrists also told us that there were gaps to service provision.

Difficulties for GPs

Over half of the GPs surveyed experienced barriers when making referrals for people with eating disorders. These included lack of services, long waiting lists, lack of psychiatrists, lack of support for patients to use online tools, lack of resources for under 18s, rejection of referrals, little or no support for bulimia nervosa and restrictive disorders, BMI cut off points and rapid weight loss not being seen as an appropriate measure for some patients.

The assessment and diagnosis processes

The early phase of an eating disorder is potentially critical for preventing or modifying the onset of illness, as well as its course and duration. We asked each service how long they took to establish an eating disorder diagnosis. This varied across the eight units who replied, from one session to two or more, depending on prior history and complexity.

On receiving a referral, all services reported using a screening process which mainly included an initial review by the team leader and/or consultant. Nearly all the services requested an indication of urgency.

Diagnostic assessment

Specialist services told us that when carrying out an assessment for eating disorder they all used diagnostic criteria set out in ICD-10 (the International Classification of Diseases, World Health Organisation) or DSM-V (the Diagnostic and Statistical Manual, American Psychiatric Association) with the majority using ICD-10. When assessing weight, child and adolescent specialists noted that weight for height was a more appropriate measure for some young people than body mass index.

Advising a person of their diagnosis

When we asked who was involved in advising the person with an eating disorder (and their family/carer if appropriate) of a formal diagnosis, all the services told us that this was given by the consultant psychiatrist involved in the team. For some of the community-based eating disorder services, the focus on providing a formal diagnosis depended on whether the person with the eating disorder wished to know this; whether there was a clinical indication that giving the diagnosis was required; and whether it would help the individual access mainstream psychiatric services.

The majority of people with eating disorders who responded said they felt that they been fully or partially involved in their own diagnostic process, although a significant number told us they were not involved.

The involvement of family/carers in the assessment process can be helpful and all services told us that where possible, and with the person’s consent, families were encouraged to be involved.

Co-existence of eating disorders with other mental health issues

We know that people with eating disorders often have additional mental health issues. This can complicate both diagnosis and treatment options, often resulting in the person either falling between services or feeling that one part of their health is being addressed and the other is not.

We asked family/carers if they had experienced any difficulties in getting appropriate ‘joined up’ treatment for their relative, and if recognition had been given to other conditions present. A third said no recognition was given, while less than a third said recognition had been given. Some felt that the separation of physical and mental health support was detrimental, and some mentioned having to travel long distances for specialist help and support.

Waiting times and waiting lists

Given the severity of symptoms and the physical and mental health risks association with eating disorders, we looked at waiting times from referral to admission and/or treatment.

All of the services who provided data at the initial stage said that from the time they received a referral, the person with the eating disorder would wait no longer than eight weeks until they were admitted or assessed.

In the second stage of our work we asked psychiatrists about waiting times for assessment for both young people and adults in their area. Two of three CAMHS psychiatrists said the four-week time frame for young people was met locally, with another saying young people with suspected anorexia were usually seen within a week. When we asked about adults with an eating disorder, half the psychiatrists surveyed answered (12 out of 24). Seven said there was a locally agreed timeframe for adults, three said there was not and two didn't know. Timescales quoted were two to 18 weeks. Where a locally agreed referral time was in place, six of the seven psychiatrists said adults were seen within it, some noting that, in practice, they would be seen more quickly.

Thirteen psychologists/therapists told us there was a waiting list for therapies, and 11 of those said this ranged from one to 40 weeks (with a median of 25).

Waiting times for young people

The NICE quality standard states that young people should begin assessment within four weeks of referral, and although NICE standards do not have formal status in Scotland, they have influence, as clinicians should have regard for evidence based recommendations and quality standards, particularly in areas where SIGN guidance is not currently available.

When we spoke to inpatient and specialist commuity services, about half reported that this usually happens in their area. Individual comments suggested that those presenting with rapid weight loss were usually seen withing the standard waiting time.

However, over half of the GPs surveyed said children and young people being referred to an eating disorder service don't start the assessment within the four weeks of referral outlined by NICE.

Information at point of assessment

Some people with eating disorders said they received no information when assessed, but most said they were given leaflets, information from websites or signposted to peer group organisations. A few were given advice about books to read, and some said they gained an understanding of their diagnosis through hospital admission or attending a support group.

All of those using specialist services were given a verbal explanation. Most also received leaflets, websites links and books. A few were signposted to peer group organisations.

Services explained their different approaches to providing information at time of assessment. Psychiatrists said they didn't have dedicated staff to offer support for relatives/carers of people with eating disorders, but provided information packs and signposted relatives/carers to local support groups.

Information at point of diagnosis

We also wanted to find out what information was provided at the point of formal diagnosis.

About a third of the families/carers who had been involved in the diagnosis process felt they had been given enough information and advice, while a few felt overwhelmed. Of those who were unhappy, a lack of practical advice when back at home was cited, along with a lack of support when other issues such as autism are present. Some families/carers had educated themselves from websites and books; several felt that far too much was left for them to pick up themselves via peers and online forums rather than through specialist service provision.

Information on admission to hospital

We asked whether a welcome or introduction pack was given at the point of coming into hospital. Around half of the people with eating disorders responded, with most saying they did receive information, however some told us they did not and a few were not sure. We also asked if the information had been helpful and the majority said it had been either very, or fairly, helpful with only a few saying it was not.

We asked psychiatrists what information hospital patients were given about their diagnosis. The most commonly response was a verbal explanation, followed by signposting to online information and to other support services.

Care and Treatment

NHS Quality Improvement Scotland (QIS, 2007) and the Royal College of Psychiatrists in Scotland (RCPS, 2014) have both set out in detail what people with eating disorders can expect from the NHS specialist eating disorder services, and what support and treatment they should be offered. The RCPS report noted that a number of services had been developed to provide alternatives to hospital admission, or shorter admissions where possible. A full description of these services can be found on the Commission's website here.

What makes a good specialist service?

During our visits to 10 specialist adult and CAMHS inpatient and community services, we asked the senior charge nurse or clinical lead to describe in advance what was available for people with eating disorders and their families, and what worked well. Out of the seven responses we received, a number of common themes emerged:

- well motivated, structured and supported staff
- one-to-one time with patients
- patient-centred treatment – flexible and evidence-based
- standardised evaluation of outcomes
- multi-disciplinary team (MDT) working
- good links to other services and clear, seamless pathways of care and
- use of feedback to provide insight.

What would make it better?

We also asked the specialist services to tell us about any improvements that would make a positive difference to care and treatment. This is what they told us.

- Address gaps in service.
- Create clearer, agreed pathways across health board areas.
- Establish eating disorder day and inpatient services locally which are appropriately resourced to offer a high standard of clinical care with an established MARSIPAN pathway.
- Become a FREED (first episode early intervention for eating disorders) service to further enhance and develop work on early intervention.
- Increase staffing resource to meet clinical demand.
- Increase resources to support expansion of the SEED (severe and enduring eating disorders) pathway and develop pathways from hospital to community.
- Implement feedback mechanisms for people with eating disorders, their families/carers.
- Increase access to CBT ED (cognitive behavioural therapy for eating disorders) and FBT (family based therapy) plus CRT (cognitive remediation therapy) and DBT (dialectical behavioural therapy) for those with poor prognostic features.
- Have time to target early stages and improve entry into specialist service care with more capacity to develop.
- Provide staff with the facilities they need so that they feel confident in their skills to help people with eating disorders.
- Create a model of care that is consistent over all ages.
- Provide more psychologically-led training for staff.

Helpful points of contact and support

We asked people with eating disorders which services they came into contact with, what treatments they found most helpful, and what types of support they were receiving. Friends and family were most helpful to many, but not all. Contact opportunities through work, education and volunteering were helpful to many. People said they'd like more access to a psychologist, a dietician and community mental health support.

We also asked what one thing people with eating disorders would change about their care, treatment and support to make it better. We received 52 comments with some clear themes emerging. They include increased and earlier support from staff in eating disorder services, more group and activity therapies, more gradual implementation of eating plans, more opportunities to be at home, more support for those who have had an eating disorder for many years and more community support.

Family/carer perspectives on care and treatment

Just under half of the families/carers we spoke to made positive observations about care and treatment. Around a third had mixed views and a few made negative comments.

Families/carers supporting people with eating disorders in hospital were overwhelmingly positive about their relationship with staff and said they were happy that their concerns were being listened to and that their views were respected.

However, in community settings, a third said that they were not completely happy with care. A few said that, on occasion, they felt dismissed, patronised and had concerns about staff's attitude to the person with the eating disorder. Several families cited a lack of resources and felt progress was limited due to staff shortages, especially in community support.

Highlights of care

We asked families/carers what they felt were the most helpful aspects of care, and the most common answer was the benefit of psychology input, and FBT (family based therapy) in particular. However, lack of psychology input and long waiting lists for CBT (cognitive behavioural therapy) were an issue. Dietetic advice was also appreciated as was ongoing support for other conditions like anxiety. Continued support after discharge and specific input into the home was also said to be useful, with a dedicated consistent team with different skillsets cited and several families mentioned very useful peer support from BEAT.

Opportunities for improvement

We asked families/carers if they had any suggestions on how services could be improved. There were many responses, including improved access to services in the early stages, improved training for GPs or new and improved protocols that can be followed and monitored, a means of communication with the team while on the waiting list, reduced waiting times, FBT to be more widely available, a move away from focus on BMI, earlier focus on other mental health issues as the driving force behind eating disorders.

Medication, psychological therapies and other treatments

We sent out questionnaires to the 10 specialist adult and CAMHS inpatient and community services we visited, asking about treatment and psychological therapies provided for people with eating disorders. From a list of 12 therapies and treatments, medication was stated by professionals as the best perceived treatment, followed by individual therapy, then group therapy and CBT.

In general, we found that access to psychological therapies is still limited.

Physical healthcare interventions and medication

We asked the eating disorder services we visited about physical health monitoring. All said they carried out regular monitoring of patients' blood pressure, heart rate, weight and BMI, as well as regular blood tests and ECGs. When we reviewed the case files of people we visited in hospital, almost all had received physical health screening within 24 hours of admission.

Practices around prescribing medication

Of the 48 people with eating disorders we consulted in the first stage, we were able to review the case files of 37. We found that over two thirds (27 of 37) were prescribed medication. All but one of this group had a diagnosis of anorexia nervosa. Antidepressants were the most commonly prescribed medication, followed by antipsychotics. Thirteen people were prescribed a combination of both antidepressant and antipsychotic medication.

When we looked at additional mental health conditions, 16 of the 27 people prescribed medication had an additional diagnosis. Nine had an anxiety or mood disorder, six had personality disorder and one had autistic spectrum disorder (ASD).

Care plans

Most inpatient services reported that they provided a copy of the care plan to the individual and also discussed and agreed whether this should be shared with family/carers. When we asked about the frequency of care plan reviews, some said care plans were reviewed weekly, some at the multi-disciplinary team meeting and others between four to six weeks.

When visiting the specialist adult and CAMHS inpatient services it was possible to review care plans and, of those we reviewed, we considered half to be fully satisfactory, in line with our good practice guidance on person-centred care plans[1]; 12 were satisfactory with some issues; one was unsatisfactory.

Engaging in activities

For most people, how they spend their day is important to socialisation and self-esteem, and is therefore a core focus of mental health care planning. Meaningful activity can involve hobbies, socialising with family and friends, exercising, sport and other leisure activities, as well as more structured educational and vocational courses. While some of these activities can be provided, mental health services are increasingly making links with mainstream community resources to develop collaborative approaches.

We explored this. Only a few of those with eating disorders who responded told us they had access to all the activities they wanted. We asked about the activities they found most helpful - nearly a third said arts, crafts, colouring in and puzzle books. People told us they would like regular groups – painting, music, lunch for example – to share experiences and learn more about their eating disorders.

During our visits to specialist adult and CAMHS inpatient and community services, we noticed positive examples of a range of activities such as music and art groups, daily journals, cooking, shopping and visits with families. However, we also noted the challenges to participation for people on bed rest and also those not willing to engage in scheduled activities.

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[1] Person centred care plans good practice guide, 2019

When we asked about gaps in activity provision, the key themes emerging from staff included more focus on group work and peer support worker involvement.

Dietary requirements, inpatient meals and artificial nutrition

We asked respondents across both phases to tell us about their specific dietary requirements.

When we asked about changes that could be made to meal times in inpatient settings, the most common theme to emerge was around routines, but this included conflicting feedback on whether separating people at different stages of treatment, or with different eating disorders, was a good or a bad thing. Respondents also commented on the need for more staff (and more support from staff) at supervised meals and on the poor quality, choice and presentation of food.

Nutrition by artificial means (naso-gastric (NG) feeding)

When people with anorexia nervosa are not able to eat due to their eating disorder their body can become so malnourished that their health and life is at significant risk. In these cases nutrition by artificial means, which commonly takes the form of NG feeding, can prevent further deterioration and provide the person with essential nutrition as a step towards them being able to eat more normally.

When a person is being treated under the Mental Health Act, nutrition by artificial means can only be given if one of the following criteria applies -the person has capacity to consent and gives consent in writing, a designated medical practitioner (DMP) authorises the treatment or urgent medical treatment provisions apply.

We reviewed the use of NG feeding in specialist adult eating disorder and CAMHS inpatient units and nine people told us they had been fed in this way. Eight of them commented on the experience and all described it as negative using words such as ‘distressing’, ‘painful’, ‘uncomfortable’, ‘inhumane’ and ‘traumatic’.

Observing rights and restrictions during treatment

In line with the principles of the Mental Health Act, any restrictions on an individual’s freedom should be proportionate and the least necessary. We have produced guidance and information for clinical staff to follow when restrictions are being considered[2] as well as advice about people’s rights.

Of the 74 people with eating disorders who took part, 25 people were detained under the Act. We asked if they had been told about their rights, been made aware of advocacy and had prepared an advance statement. An advance statement is written by someone who has been mentally unwell and sets out the care and treatment they would like, or would not like, if they become ill again in future.

The majority who had been detained under the Act said they had been told about their rights but of those, nine said they didn’t understand them. Most said they had been made aware of advocacy with around half of those opting to use this service. Five who had been detained said they had an advance statement in place. Of both those detained and non-detained, half told us that they hadn’t heard of advance statements and five said they would like one.

We asked for people’s experience of restrictions that might have been put in place when they came into contact with specialist services, particularly in hospital. Of the 48 we met initially,

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[2] https://www.mwcscot.org.uk/sites/default/files/2019-06/rights_risks_2013_edition_web_version.pdf

seven said restrictions had been placed on access to their mobile phone and the internet, four of whom did not agree with this. Eleven people advised that they'd been placed on an increased level of observation during an episode of care, seven recently and four some time ago. Six people told us they'd been physically restrained during an episode of care.

We asked families/carers about any concerns. Most said they were satisfied and recognised that restrictions were imposed in the best interests of the person with an eating disorder.

Step down and going home

Some of the relatives/carers we spoke to commented that they felt that professional support can be withdrawn too soon. Having no 'step down' between hospital and home was cited as a real difficulty in maintaining positive progress on discharge.

It was also felt that once weight was restored, then discharge followed even if other issues remained unresolved. One parent commented that despite raising mental health concerns, their child was discharged with no follow up once they'd reached an appropriate BMI. Others commented that they felt they'd been prematurely discharged from CAMHS without being referred onto adult services, leaving them to cope along with ongoing problems.

Most psychiatrists who worked in community services reported that there was, or mostly was, pre-discharge planning for people with eating disorders moving from inpatient to community care; that there was/mostly was good communication; that information was shared in a timely manner; that responsibilities for monitoring were made clear; and that family/carers were kept informed about decisions.

Moving between services, monitoring and protocols

The very nature of an eating disorder requires assessment, treatment and monitoring in relation to both mental and physical health. This can present challenges for services because it often requires a number of them to work together to provide good patient care. Critical elements of care require focus being kept on complex details while ensuring that the wider perspectives of an individual's needs are not lost. Additionally, many eating disorders develop during adolescence, which is a time of great change.

It was particularly striking to see how health boards differed in their readiness to describe services for people with eating disorders in their areas. Some were able to provide very detailed descriptions of services while others were much less equipped to respond.

The coordination of care for people with eating disorders has been included as a standard by NICE, especially the transitions associated with young people moving from child to adult services, transitions where more than one service is involved, and transitions for people who need care from different areas at different times – for example, university or college students living away from home.

When we asked GPs and psychiatrists, many commented on the need to improve joint working and improve transitions. We heard about staffing shortages, especially among psychiatrists, and were told that informal rather than formal relationships are often what enables things to work in practice between services. This can lead to problems when one clinician leaves or retires and the replacement does not share the same role.

Common themes emerging were the need to clarify roles within primary care, the need to develop pathways with transition and supervision (particularly for the transition from CAMHS to adult services), more shared care and support and specific eating disorder resources for physical healthcare monitoring.

The transition from inpatient care to community services

Few GPs reported good communication between services – this included lack of timeline information sharing, lack of clarity around responsibility for ongoing monitoring and lack of information for family/carers on decision making. A relatively large proportion of psychiatrists said they didn't know about the various aspects of transition from inpatient to community.

The transition from CAMHS to adult services

The transition between children's and adult mental health services has been recognised for some time as one that commonly causes difficulties. We found mixed views from professionals on this. While GPs reported difficulties with transition, all four CAMHS psychiatrists believed there was good planning around transitions, and three reported that the transition period was flexible and could last for up to six months. Three believed that good communication was in place and all felt that transitions centred on young people's needs and that family/carers were involved.

Only two of the nine general adult psychiatrists thought that good planning was in place in their area, with three stating it was not, and only four agreeing that the transition was led by young people's needs. Three of the six specialist adult eating disorder psychiatrists thought that transitions from CAMHS involved good planning and the same three thought communication was good.

From families/carers, although transition from CAMHS was only relevant to six of the thirty respondents, it was universally felt to be unsatisfactory with comments including ‘very, very challenging’ and ‘shockingly bad and almost negligent’.

Transition issues for students living away from home

This provides challenges in coordinating care since a person’s GP may change several times over the course of a year and services may vary greatly between health board areas.

Thirteen GPs responded to our question around the care and monitoring of students with eating disorders who are registered with a different GP during term time. Of those, only three had come across the issue and all three told us there was poor communication in place, particularly as registration with a GP during the holidays may be temporary.

Sixteen psychiatrists responded to the question of coordination and management of care for students. Four had not come across this, and the remainder gave varied responses including that it was challenging, depended on GP registration and how often the person was back at home, but comments included that it was done to the best of the service’s ability with attempts made to liaise with the other location.

Who’s responsible for physical health monitoring?

Responsibility for the physical health monitoring of patients with anorexia nervosa seemed largely uncertain. Monitoring of patients being looked after by mental health services was found to be an area of significant difficulty for all respondents to our survey, despite physical health monitoring being a fundamental and core element of eating disorder care.

Only a very small number of mental health services said they were able to undertake their own physical health monitoring, with most health boards relying on this taking place between mental health and primary care GP services working together. We were told that few boards had formalised this joint working protocol – not just in terms of who decides what investigations should take place and how frequently – but, critically, around who is responsible for acting on the results and ensuring that information is available to inform ongoing and holistic assessment of the health of people with eating disorders.

Many GPs reported that they didn’t know whose responsibility it was, while the majority said it was the responsibility of the mental health or eating disorder service. Several GPs expressed concern that if physical health monitoring is left to primary healthcare services, then a lack of planning for monitoring, combined with increasingly nurse-led services, means that there is a lack of staff to interpret results and no good shared care.

Six of the 13 psychiatrists who responded to our survey reported that their area had locally agreed protocols for physical health monitoring while five didn’t have such protocols and two didn’t know.

Protocol for admission to medical or mental health wards

It may often not be clear whether admission to hospital for people with eating disorders should be to a medical ward or a mental health ward.

Due to the regional nature of child and adolescent inpatient provision in Scotland, care closer to home versus care in a specialist unit often influences decisions. However, only two of the four CAMHS psychiatrists who responded to our survey told us that a local protocol existed around who should be looked after in a mental health ward and who in a medical ward. Three of the six specialist adult eating disorder psychiatrists told us that their health board had a protocol to guide this decision but only one of the nine general psychiatrists described this.

Specific protocols for 16-17 year olds requiring admission to a medical ward

We found mixed responses to the question of whether such protocols were in place, notably few that related to young people over the age of 16 being admitted to medical wards.

It is vital that the needs of young people, who might be looked after by both adult medical services and children's mental health services are not overlooked, and that work to develop protocols and joint working arrangements are not restricted to paediatric services only.

Staff education and training

A research study, undertaken in 2017 with all UK medical schools revealed that medical students receive less than two hours training on eating disorders over their four to six years of undergraduate study. We were interested in finding out what training was available for staff across various professional disciplines.

Half of the health boards areas involved in our survey had undertaken further accredited training. Two health boards supported staff to undertake further training to enable them to be accredited supervisors in their service.

Specialist perspectives on confidence and training needs

During our consultation with people with eating disorders and their families/carers, we were told that they did not always feel that the professionals they were working with had sufficient knowledge and expertise.

GPs are likely to be the first port of call for people with eating disorders and we wanted to find out more about their training experiences; 21 GPs completed our phase 2 online survey and their involvement in providing eating disorder consultations varied from daily to six monthly. Overall, GPs did not express high confidence in managing patients with eating disorders. Only five GPs felt they had an opportunity to attend education or training, and 11 agreed that they would welcome more training.

Twenty-seven dieticians responded to our survey and some worked across multiple settings. The majority reported feeling confident about managing patients with severe anorexia and while most either strongly agreed or agreed that they had received a good level of training, even more said they would welcome more training.

Twenty-four psychiatrists from various clinical specialties responded to our phase 2 survey. While most either agreed or strongly agreed that that they were confident in managing people with eating disorders and had received a good level of training, nearly half said they would welcome further training.

Specialist inpatient and community services training

When we met with senior charge nurses and clinical leads across the specialist services we asked about opportunities to develop their skills and knowledge. We were told that there was a range of training options available across heath boards. Staff told us they had undertaken training in a range of specialist areas.

Training in psychological interventions varied across health boards but therapies included CBT (cognitive behavioural therapy), DBT (dialectical behaviour therapy), FBT (family based therapy), and SSCM (specialist supportive clinical management). While we heard about good examples of training, challenges included limited resources to support staff going off the ward for training, limited budgets and the lack of a psychologist to support nursing staff.

Confidence and trust: the family/carer perspective

It’s important that families/carers have confidence in the therapeutic team, trust professionals to know what they are doing, and believe them to be fully informed on the latest treatments. During our first meetings, the majority of family/carers engaging with specialist services told us that they felt staff had enough knowledge and training. Just over half in the survey stage said they felt staff had enough knowledge and training.

The use of ‘bank’ nursing staff without specialist knowledge in hospitals was mentioned.

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