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WELCOME

Welcome to the Summer Edition of the Quality Network for Eating Disorders (QED) Newsletter. This newsletter has been designed for those who work in the field, or who have had lived experience of an Eating Disorder. It's also for anyone who might have an interest in learning more about Eating Disorders. Therefore we encourage our readers to share this article with anyone you feel may be interested in reading it!

In this edition we look over the last several months of work within the Quality Networks both QED and the Quality Network for Eating Disorders CAMHS (QNCC-ED) , and what you can expect to see In the future.

We'd like to say a HUGE Thank You to all those who have made contributions to this edition, and we hope it's a positive and enjoyable read for all of you across the networks.

If you'd like to be included in the next edition please submit your entries to QED@rcpsych.ac.uk.



Project Update

Take a look at what's been happening across the Network:

The QED Annual Forum was held on 12th July 2017, and it was a great success!

Thank you to those of you who came along on the day—we had a whopping 90 attendees which is a huge improvement from last years forum. We'd like to extend a special Thank You to Dr. Frances Conan, Aki Fukutomi, Dr. Tony Winston, Dr. Janet Treasure, Vicky Mountford, Amy Brown, Dr. Melanie Bash, Sonia Parsons, Veronica Kamerling, Helen Cain, Hannah Stevenson, and Jessica Griffiths for speaking on the day. You all did fabulously and we've received

some really positive feedback about the different presentations, so Thank You all!!

If you'd like to have a look at the presentations that were delivered on the day please visit our website [here](#).

The QED Service Users and Carers Day was held on 24th March 2017, and this too was another successful event. We hope to make this an annual event going forward, so please do let us know if you have any ideas/suggestions for the next event to be held in 2018.

We held our first [Community Standards Development](#) workshop in May for the adult Network. There will be future sessions with the current steering group, and we hope to set-up a pilot scheme for the Adult Community ED services next year. If you know of a service that might be interested in taking part in the pilot, please contact us at QED@rcpsych.ac.uk

Other News:

QNCC-ED

QNCC-ED was launched in March 2016, and has a total of 20 services. The network has positively engaged with services, working collaboratively with them to help improve care within community based eating disorder services. As it moves into its' second year the network has welcomed a further three services and we hope to expand over the course of the coming year.

Personnel

Harriet Clarke (Programme Manager) who worked across both QED and QNCC-ED sadly left the college in July. She will be greatly missed by all, but we look forward to welcoming the new Programme Manager, Emily Cannon, In October.

Herbie Taylor joined us as Senior Programme Manager in January of this year.

Collaborating as a Family in pursuit of Recovery

**Veronica Kamerling; Carer
Representative (QED)**

My story begins in 1994 when my youngest daughter developed anorexia. This was an illness that I had never heard of and knew nothing about, but instinctively I felt that there was something not quite right.

What followed were a few months of trying to get her to eat while watching her lose more and more

My daughter was discharged from her clinic after four months and went on to have intensive outpatient therapy for three years, and from there she was able to pick up the threads of her life again.

In 1996 my eldest daughter developed bulimia/ binge eating. Unlike my youngest daughter she suffered from huge bouts of depression and would hole up in her room for days with the curtains closed, constantly telling me she would commit suicide.

I had very different relationships with my two daughters. My youngest was very independent and was determined to stand on her own two feet, and my eldest daughter was the complete opposite and very needy.

This characteristic of my eldest daughter resulted in her always wanting me to be available to listen for hours to her problems, whether it was on the telephone or around our kitchen table. She always wanted me to come up with the answers for making her better and in her own words "fix her". Just as I would think I had solved everything for her and taken away the tangible pain, she

weight until eventually her ability to function was impaired. By that I mean she lacked any energy and her capacity to think coherently was affected. Eventually a decision was made to admit her to an inpatient clinic.

I can still remember to this day the chilling sensation I felt as the door of the clinic closed behind me and I was told that I could not see her for several weeks and we could only communicate by telephone once a week. I thought that this was what seeing someone in prison must feel like.

would come back for more lengthy conversations or with requests for money as she had literally eaten through all that she had.

My eldest daughter struggled terribly with her bulimia and her continuing thoughts of suicide, created by her deep feelings of depression, was very sad and worrying to watch. One day instead of talking about suicide she decided to try and act on her feelings. Luckily she survived the experience! As a parent I was devastated, with endless questions going around in my head as to how and why it had come to this when I had



spent so much time trying to help her. After this episode and seeing it as a cry for help, she was admitted to an inpatient clinic.

It was at this clinic where the story of recovery for both of us begins. You may think 'why for both of us?' What I had to learn was that my eldest daughter and I had become co-dependent and by constantly meeting her demands and trying to 'help her' through the endless conversations we had, I was actually not helping and she was in fact becoming more ill. My behaviour was taking all responsibility for her own recovery away from her and not letting her see the consequences of her actions. I was sheltering her from making the mistakes that teach us how to cope with life.

While she was undergoing her programme of recovery for her eating disorder I was doing mine for co-dependency at the same clinic as her. I will always be so grateful for being offered this chance to understand the hallmarks of healthy and unhealthy caring for someone who is very distressed. My eldest daughter and I had to set boundaries around our relationship so that I didn't go into over-helping mode. By doing this, slowly but surely we both got into our own recovery.

The outcome of both our programmes has brought recovery for us and our family unit. We are so much stronger for the experience, principally because we have healthier relationships based around healthy caring. For all of us this has been a painful and challenging journey but our lives have been changed for the better. It sometimes seemed like a bereavement-like I have lost the children I knew. I didn't get back the two daughters I had but I wouldn't

have wanted that as our family is much happier now. Yes we have all had to make changes but I had to realise that what I was doing wasn't working, and as they say, 'If nothing changes then nothing changes"! One of the other things that helped our recovery was when we all started to work as a team. In my youngest daughters case that was with her, me and her psychotherapist and in my eldest daughters case it was with her, me and the clinic. My view is that the more collaborative you can be the better the chances are for good recovery outcomes.

Nothing prepares you for a loved one developing an eating disorder and certainly nothing prepared me for two out of my three children developing one. I was exhausted, I blamed myself, I was consumed by guilt and thought that it must be something I had done as a parent that had brought all this on. It also impacts on the whole family.

My two daughters are both in good recovery now. They have friends, good jobs, homes of their own and my eldest daughter is now married. All these things a few years ago looked like an impossibility but it is always good to remember that recovery is an option.

[Ted Talks Video](#) This is a very empowering and positive recovery story, which has been inspirational for other patients and motivational for staff. This has had over a quarter of a million hits on YouTube and has been very positively received. I hope by sharing it, others may benefit from her experience.

Debbie Whight, Team Manager, Leicester Adult Eating Disorders Service

The Letter Your Teenager Can't Write You; A creative piece developed for parents of young people with eating disorders

**Zoë Hepburn and Emily Rothwell—
Gloucestershire Eating Disorders Service—2Gether NHS FT**

Young people might be thinking and feeling when they are in the depths of an eating disorder and unable to verbalise this for themselves. Zoë came up with the idea of a letter and Emily wrote it as it appears below;

Two Eating Disorders professionals have joined forces to create a unique resource for parents of young people suffering

from an eating disorder. **Zoë Hepburn** and **Emily Rothwell** wanted to find a way of helping parents to understand what >

To my family and friends,

I know you are hurting. I know you lie awake at night worrying about me. I know you sit there now wishing more than anything for me to be better – for me to be well and happy and getting on with my life. Deep down I wish for those things too, but right now the Eating Disorder is all encompassing. It has me trapped believing the lies it feeds me.

It may seem like I should just be able to snap out of it and pull myself together; that I should just eat normally again. But Eating Disorders are an illness, not a choice. They are neither of our faults. I know there are times when I blame you but these are because I'm scared. I'm terrified that this is how my life will always be, but I am also petrified of losing the Eating Disorder. I feel like whichever way I turn is wrong.

The Eating Disorder offers me a sense of control; it helps me block out everything else around me and minimises the world into food and calories, weight and shape. It prevents me from thinking about school, exams, relationships, growing -up and aspects of the world I feel scared to face. It can feel like my best friend and my sole supporter. It provides me with an identity and lowers people's expectations of me. It offers me a language outside of words – a way in which I can express that I'm not coping, without me having to state this. The Eating Disorder is something I'm good at and something I feel like I need to protect at all costs, because I can't feel good enough about myself just for being the person I am.

I know that these things are difficult to understand. They are for me too. There are times when I too hate the Eating Disorder – I can see all that it is taking from me and I wish we were having arguments over

The QED Network: Through the eyes of a Service User Representative.

Stacey's Account

I decided to volunteer with the QED as a service user after the inpatient unit I was in underwent an inspection. I remember meeting with the service user representative who was part of the peer-review team and thinking how vibrant and engaging she was. I'd spent a good few years of my life in and out of inpatient, daypatient and outpatient care and in those settings all you tend to see are your fellow sufferers. You often see patients follow a familiar cycle of recovery and relapse, recovery and relapse, and when you're stuck in that cycle yourself it's very easy to lose perspective, and most importantly, hope.

What that service user representative did just by being there as part of the peer-review team was give me hope that eating disorders don't have to be chronic, that they don't have to be a life sentence, that my world could be more than fear and rules and restriction. Not only that, but her presence showed me that my experiences of illness treatment could actually be put to a positive use. All those years of misery and self-destruction, once over, didn't have to just be put in a box never to be spoken of again. Maybe one day, if I focused hard enough on my recovery, I could be that person giving hope.

Fast forward 18 months or so and I was gearing up for my first peer review. I'd attended the training day, read all the guidance and been through all the pre-review documentation with a fine-tooth comb. But I was anxious. I was in recovery, but not recovered. I was back at work full time and had started to claw my life back together again, but it was very much a work in progress. I still relied on outpatient support and was very rigid in my food rules and routines. Although I very much wanted recovery, my grip on it was precarious and I was wary of anything that might cause me to lose purchase on it. I was worried that being back in a unit would trigger the urges to fall

back into bad habits. Or that I would compare myself negatively against the patients that I met. Or that my familiarity with that kind of environment would tempt me in a weird way, with its safety and sense of disconnect from the 'real' outside world.

So before that first visit I thought long and hard and made sure that I felt 'ready' to face an inpatient unit again and the memories that would inevitably surface. I'm glad that I was initially anxious and that I spent time considering how I would be affected, because it brought it home to me just how much I valued my health. For the first time in a long time, I was prioritising my recovery, and that's how I knew that I was ready to take the role of an objective service user.

I'm so happy that I was ready to take part in that review. Chairing my first patient meeting, I felt so privileged to have the opportunity to chat to patients and actually be able to fully empathise with their concerns. I'd been that patient in tears with anxiety because a staff member wasn't sure how to portion out the meal. I'd lain awake on a Friday night dreading the weekend to come because there would be no groups running and I couldn't leave the ward. I'd felt the negative impact of poor staffing levels. All those bad experiences were now being used in a positive way, as I'd originally hoped way back when I was a patient listening to a service user representative.

I don't know that I've ever given anyone hope, as the first service user rep that I met did for me. But I'd like to think that at least I've helped in some small way. I've listened, I've shared my own experiences, and I've tried to offer empathy and understanding. If any of that has helped only one person in some way, I'll be happy. There is one thing that I'm sure I can be happy about though - the fact that I'm part of something incredibly positive that's working to address issues and ensure high-quality care.

We are Proud to Announce:

The team at Kimmeridge court have been selected for two awards in the top 3 for the Annual Hero's Awards in September 2017. The first award was nominated by a patient for compassion and kindness. The team feel extremely humbled to have received a nomination and even if we are not successful in winning the award we have been successful in supporting a patient through their journey of recovery by showing compassion and kindness through a difficult time in their life.

The second nomination was by the practice educator from the Trust for being a good learning organisation. We regularly have nursing students on placement within the eating disorder service and we enjoy having the opportunity to support and develop the student's skills.

We look forward to attending the Annual Hero's awards in September which will be held at Weymouth and Portland Sailing Club.

***Angela Ballard, Clinical Team Leader, Kimmeridge Court ,
Dorset Healthcare University Foundation Trust***



One year on; Reviewing a newly established CEDS-CYP service

Eloise Perry, Assistant Psychologist, Vincent Square

Collecting feedback from families is an important process in improving services, allowing us as staff members to understand how the service is actually experienced, whilst empowering families to shape their service. As part of our annual review by commissioners, the Community Eating Disorder Service for Children and Young People (CEDS-CYP) completed an evaluation exploring views of our service by asking young people and parents about their experiences. The questions asked were taken with permission from Rethink who conducted an evaluation of the service with families from inner London boroughs. This was replicated to obtain feedback from those who are based in the other boroughs we are commissioned to work in.



Overall view of service

When asked about their overall views of the service, parents expressed positive comments about the service: its accessibility, helpfulness and professionalism. Comments from young people indicated that staff come across as being supportive and non-judgemental. One family discussed that the intervention was not what they were expecting in terms of involvement of family, as they were not expecting to be so involved in the intervention. One parent mentioned that they would value having the opportunity to speak to professionals without their child being present to discuss any issues.

Views and worries being taken seriously

Young people reported that they felt their views were listened to and taken seriously. However, a couple of young people did not feel listened to. One young person felt that this was not intentional, but the result of there being lots to cover in sessions. Parents cited that staff at CEDS-CYP are professional and compassionate. In addition, they felt that staff listen to and take any worries raised seriously, even though putting advice into practice can be difficult. One parent felt as if they would value more instruction from staff, due to the self-doubt they felt about whether they are doing the right thing in terms of supporting their child.

Location and environment

There seemed to be mixed opinions about the environment, although many felt the location was good for them. Some felt the environment was cheerful and bright, whilst others felt it was too clinical. One parent raised concerns about the service being based at a mental health hospital and did not feel that was a positive environment for a young person.

Overall experience of service

Generally the feedback from young people and their parents was extremely positive, feeling as if the service was professional, compassionate, and delivered high quality care. A number of parents cited how thankful they were for the service in terms of helping their family through a tricky time. One parent shared that although the service was excellent, they had not seen results yet but were pleased to be part of this process. Young people shared that they felt the format of sessions was good. One young person mentioned that her and her therapist had adapted the format to utilise writing as opposed to talking which she was finding helpful. Another young person discussed that at times a session might go in a different direction from the initial focus of the session.

Suggestions to improve the service

Most young people when asked did not feel that the service needed changing, or they could not generate any suggestions. One young person felt it would be useful if there was a website that they could go to if they were worried and get some advice anonymously. They felt it would be reassuring if it was monitored by professionals working at CEDS-CYP. One young person shared that they would like more information given about the plan of care and the goals that the team would like young people to reach. This person would also have liked information about self-discharging. Many parents praised the service and had no suggestions to improve the service, but would value improvement in GP detection to speed up referral, and for more professionals, services and families to be more aware of CEDS-CYP. Two parents shared that they would value a group where parents could speak to other parents in the service to discuss and exchange ideas, ideally facilitated by staff at CEDS-CYP.

Involvement in decisions about care (asked only to young people)

The majority of the comments suggested that most of the time young people felt listened to and their views taken into account. One person felt some of the short term decisions had not been helpful.

Recommending the service to other families (asked only to parents)

Most parents were extremely complimentary of the service, and felt they would recommend CEDS-CYP, or already had recommended it.

Information about their child's care (asked only to parents)

Many parents expressed that they would appreciate more information about their child's care, yet were able to acknowledge and appreciate the confidentiality between the young person and the professional. One felt that they would have appreciated this being outlined explicitly to them at the beginning. A couple of parents felt that they would have benefitted from more structured information about refeeding following the assessment but prior to treatment starting.

Helpfulness of family therapy (asked only to parents)

Many parents in their comments cited the usefulness of family therapy, allowing them to support their child and improving communication within the family. Aforementioned, one parent discussed that they would find it useful to have a parent only space at times to discuss the plan and express their worries. One parent felt that their child may value having individual work. One parent expressed that their presence in sessions did not necessarily feel helpful, due to the relationship she has with her child.



Looking forward – utilising the feedback.

Based upon the feedback received, we are currently working on: further promotion of our service to our GPs and other key referrers, being more explicit in our assessments about what treatment entails and the confidentiality agreement between a young person and their practitioner in addition to setting up a parents group facilitated by a member of staff. We value the contributions that families can make to service improvement, and hope to collect feedback and suggestions on a regular basis so we can continue to provide a service that is sought after by families.

Inpatient Experience

Róisín's Story

Despite being in the course of my third inpatient admission for the treatment of anorexia nervosa, I must admit I am somewhat unsure where to start when writing an article on the topic. Where do you start? I could tell you numerous anecdotes of my time in hospital, or even give you a full account of what so many people would love me to call my 'journey', but if I'm honest I'm not sure that is all that helpful. After all, I am just one patient and my 'story' would solely be one example. I therefore want cover one statement which I feel is universally experienced by those of us receiving inpatient treatment for anorexia: being an inpatient is hard. This may sound obvious- of course being made to challenge the destructive behaviours which have kept you going for so long, and changing long term habits is going to be difficult, what else could be expected? And, as a general rule, staff and other health care professionals tend to recognise this, however, when I say 'it's hard' I don't just mean in regard to the challenges to my eating disorder. Take away the food and therapy, spending all your time in the same place and having very limited freedom is a huge task in itself.

If you work in a unit, think of all the little things that niggle you- that colleague who you don't quite get on with, that difficult patient, the light that flickers, and the radiator that's on too hot. They're annoying, right? But at the end of the shift, you get to go home and leave those behind; you can drive home, pour a cup of tea (made just how you like it as opposed to by someone else), and have a good moan at your parents, partner or housemates about those qualms and then simply move on- forget them, no big deal. But when you're a patient you don't quite get that respite; it's constant. So those little things all of a sudden become very big things- after all, when your world is the size of a pinhead, everything is important as everything becomes magnified. Therefore when staff simply laugh off your concerns, it's frustrating and upsetting; it feels like nobody wants to give you the time of day that the things which upset you don't matter and, in turn, that makes you question your own value and worth. Another thing I found particularly difficult on coming into an inpatient eating disorders unit

was the contrast it held to the life I had been living prior to admission. I came into the unit I am on straight from Oxford University. I had been living independently and working at a high academic standard. I had been taking part in large events with people of high profiles and holding positions of responsibility- alright, my existence and experiences had been limited by my illness, but, all in all, I had been an independent and high functioning woman. Going from that to having all control taken away from you, that's truly hard. It is made all the more difficult if you do not feel that staff are aware of the life that you have come from and treat you as if you are completely incapable or a child. The staff who have made the biggest difference to me over the course of my treatment are those who have spoken to me as an adult, respected me, and always remembered that just because I have mental health problems does not mean I am stupid, and this applies to all patients. I have been in units with doctors, teachers, academics, business people and an array of other professionals, all of whom had lives outside of their eating disorders, even if they had lost them due to the illness, and thus coming into hospital can feel like a regression back to childhood. And yes, that is unpleasant, and weirdly can even start making you act like a child. All of a sudden the rational side of your mind can fly out of the window and you'll start having a tantrum and crying over the smallest thing and I can guarantee you, the one thing that is going to make this worse is responding as if we are toddlers. This is not a 'them and us' situation between staff and patients; patients are not inferior to health professionals, we are just poorly people who need supporting to get through a tricky time anybody could find themselves in, and being made to feel less because of this is one of the most horrible things I have encountered over my time in treatment.

So to conclude, yes being an inpatient is hard, but not only for the reasons which might spring to mind. It's the little things, and remembering this as a healthcare professional and still treating patients as grown adults can make more difference than you would imagine.

Education on Oaktrees Ward

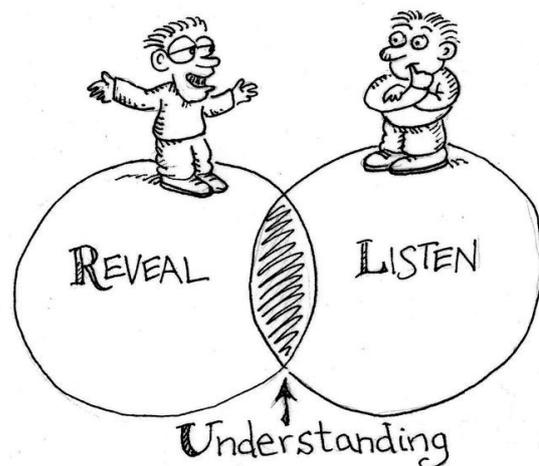
Nichola Spinney, Ward Manager

We are proud of the training that we offer to our nursing students on the Oaktrees Eating Disorder Ward on the Wirral, Merseyside. We have achieved 97.2% positive feedback from our student evaluation (on line PARE) which reflects the ongoing work and effort we are putting into our training program. We have developed the educational role of the ward by supporting students to develop their knowledge, competence and confidence in looking after people with severe and complex eating disorders.

We decided to revise the overall supervision and management of mentors and students. This was because we had identified risks, such as mentor's updates being out of date as there were no formal reminders for when updates were due. Also, allocation of students was not balanced, and mentors felt unsupported when managing difficult decisions regarding student's progress.

Our Clinical Lead Nurse further developed the mentor lead role and now manages the mentor and student experience. She manages the mentors' passports, keeping a record of which students they have mentored, and when their multi professional updates are due. This ensures that the mentors fulfil the criteria for their triennial review and that NMC standards are met. By documenting the allocation of students to mentors, staff who need developing in this role can be more easily identified and fair allocation of students is ensured. Staff requiring development towards mentorship role is identified.

The mentor monthly peer reflection group has been introduced. The aim of the peer reflection group is to reflect upon the student's progress, any problems which arise, and to provide an opportunity for shared learning. This ensures the mentor feels supported especially when there is a need to involve the PEF (Practice education facilitator) and the University.



Following discussions with fellow mentors, it was felt both students and mentors would benefit from a clear list of expectations of students and what students can expect from mentors.

She has subsequently revised the induction process for students, making it more specialised to the placement area, as it was felt this would enhance the students learning experience and aid learning. In addition to identifying mental health and learning needs, dietary needs now form part of the induction, which also includes an overview of eating disorders, diabetes, food intolerances and allergies, along with discussions around how to support patients during meal times, and explaining the importance of role modelling and appropriate eating behaviours.

We have devised a graded approach to students supporting patients at mealtimes, so that both patients and the students do not feel overwhelmed. All students receive training from our dietitian early in their placement covering risks of re-feeding syndrome, and how this is managed through the dietary stages. Additionally students receive an overview from our psychologist about her role, and the different therapies offered to patients and family.

Dates for your Diary

Please take note of these important dates for your diary for the upcoming months! Further advertisements and booking forms will be sent out via the QED Email Discussion Group. Sign-up if you haven't already! Full contact details are on the back page.



When	What	Where
September	QED To Go Live on College Accreditation and Review System (CARS)	Online - CARS Handbook
Wednesday 8th November	Community CAMHS Annual Forum (INC. QNCC-ED)	Royal College of Psychiatrists, 21 Prescott Street, London E1 8BB
Monday 11th December	QED Peer-Reviewer Training	Royal College of Psychiatrists, 21 Prescott Street, London E1 8BB <i>Need to RSVP - Bookings Available soon</i>



Useful Links & Contacts

College Centre for Quality Improvement

<http://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement.aspx>

QED

<http://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/ccqiprojects/eatingdisorderservices.aspx>

Contact The Team

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QED Discussion

The purpose of this group is to provide a platform to gain advice from contributors and share best practice between adult Eating Disorder Services across the UK.

We as a team also use this group to advertise, and share information about what is going on across the network.

If you aren't a member yet, and would like to join the group please email "join" to QED@rcpsych.ac.uk

QNCC-ED

<http://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/ccqiprojects/childandadolescent/communitycamhsqncq/qncc-ed.aspx>

MARSIPAN: Management of Really Sick Patients with Anorexia Nervosa (2nd Ed.)

<http://www.rcpsych.ac.uk/files/pdfversion/CR189.pdf>