

Making Our Voice Count



Feature on Eating Disorders
The Cycle of 'Support'
How you can help
Supporting Eating Disorders Week,
28th February-6th March 2022

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Eating Disorders - The Cycle of 'Support'

How you can help

About this publication

In this publication we feature the voices of people living with eating disorders. We present the double award-winning film 'How do we help everyone to heal? The Cycle of "Support" for Eating Disorders', coproduced by Marie Dawson and Sarah Donnelly together with 34 service users.

Suffolk User Forum is an independent mental health user led, involvement, peer support and advocacy organisation. Listening and giving people a voice by opening conversations about mental health and emotional wellbeing, is at the heart of our organisation. We do this by gathering people's stories and providing a platform so their stories can be heard.

We have worked with Marie and Sarah to present their voices, together with other service user views and experiences in support of this year's Eating Disorders Awareness Week, from 28th February to 6th March 2022. Along with the voices of Marie and Sarah this publication also contains direct quotes and service user views from a recent Mental Health and Wellbeing Focus Group presentation at Healthwatch Suffolk.

We believe that peoples lived individual and shared experiences empower service user leadership which is essential to improve services and to make a difference to the experience of others.

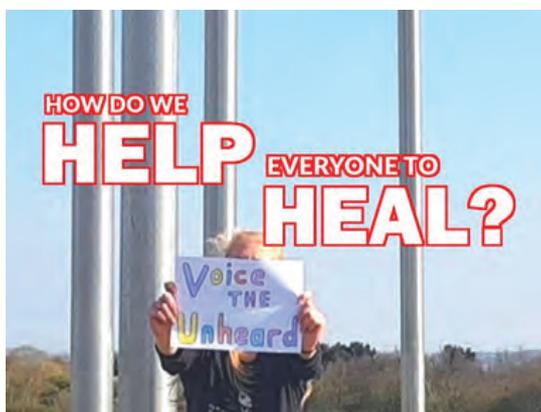
We hope that this publication will lead to new conversations, and enable meaningful involvement and coproduction between service users, family/parent carers, commissioners, and providers. Only together can we make positive change happen.

Jayne Stevens
CEO
Suffolk User Forum

Introduction by Marie and Sarah

We are fortunate that all of us today live in a modern and privileged society. One of the biggest things we should be tackling is that no one should ever feel that it is easier to end their life, than it is to get help for eating disorders and mental ill health. Suicide is not the answer. Early intervention and coproduction for eating disorders is.

Please take time to watch our double award-winning film, called 'How Do We Help Everyone to Heal? The Cycle of "Support" For Eating Disorders'. A collaborative project made by us and 34 people living with eating disorders in April 2021. Our film won two awards in the Suffolk and North East Essex Integrated Care System (ICS) Film Competition - How do we help everyone to heal?



How Do We Help Everyone to Heal?

The Cycle of 'Support' for Eating Disorders:

To watch our film, click on this link:

<https://youtu.be/CfmuqNftcao>

We want to be involved and be part of the change to help improve services, challenge stigma, and to create a better community.

This booklet, published for Eating Disorders Week 28th February-6th March 2022 shares our experiences, views, and solutions for improved eating disorders services, that can make a difference to the lives of people living with these mental health and physical health problems, supporting us all to live Equally Well.

Marie Dawson & Sarah Donnelly

You can contact Marie and Sarah to discuss this publication, to build awareness, increase understanding and to coproduce improved support for eating disorders and mental health services in East and West Suffolk. For contact details please call Suffolk User Forum on 01473 907087, or email us at:

hello@suffolluserforum.co.uk

What is an eating disorder?

Eating disorders are serious mental illnesses affecting people of all ages, genders, ethnicities, and backgrounds. Eating disorders include bulimia, binge eating disorder, avoidant/restrictive food intake disorder (ARFID), other specified feeding or eating disorder (OSFED), and anorexia.

Eating disorders can be fatal and they cause serious harm both physically and emotionally. But even though they are serious illnesses, eating disorders are treatable. Many people make a full recovery.

Like any other illness, the sooner someone with an eating disorder is treated, the more likely recovery is. Individuals should be assessed for the psychosocial impact rather than waiting for a physical problem to present itself.

For us, with lived experience, it is a psychological disorder with complex social, physical, and emotional impacts.

How devastating are eating disorders?

It is estimated that around 1.25 million people in the UK have an eating disorder. Anorexia has the highest mortality rate of any psychiatric disorder both from medical complications and suicide. All eating disorders carry risk of suicide, with one in five people living with binge eating disorder having attempted suicide. The longer a person suffers from an eating disorder, the poorer their prognosis.

Our experience is that when physical risk is prioritised, it disregards the hidden risk of suicide associated with chronic eating distress.

“Bulimia is associated with severe medical complications, and binge eating disorder sufferers often experience the medical complications associated with obesity”

In every case, eating disorders severely affect the quality of life of the sufferer and those that care for them.”

Source:

www.Beateatingdisorders.org.uk/get-information-and-support/about-eating-disorders/how-many-people-eating-disorder-uk/

Our experience

1. Diagnostic criteria for eating disorders

“A person’s BMI should not be a means to deny support. This has been well documented recently, but it is still being used during assessment for access to services to exclude patients, as a gate keeping process, due to lack of funding and resources.” This has led professionals to say unhelpful phrases such as, ‘You’re not thin/or fat enough to get help’”.

“We recognise that services are firefighting demands, and there needs to be an assessment that prioritises those at greater risk, but this should not exclude people solely based on their weight and/or comorbid conditions such as Autism or Personality Disorders”.

“We need to have good nutrition first to have the energy, mental capacity, and cognition to manage other conditions. It is imperative to treat the eating disorders rather than saying ‘When X is under control, then we’ll consider eating disorder support. This impedes cost effective support being offered for both the eating disorder and any coexisting mental and physical health conditions. It also creates a ‘which came first - chicken or egg’ attitude, we feel this contradicts Maslow’s Hierarchy of Needs”.



“Too often services want your weight to reflect medical problems before supporting people because they still consider themselves feeding services as their main approach.”

Mental health clinician with lived experience

“It kind of feels like in Suffolk at least, they’re using every means possible to narrow the criteria to deny help because of tight caseloads. Something needs to be done to help the people that are turned away, because they’ll only come back but in a worse condition and dramatically increase the cost to the NHS”.

“Be proactive - help save lives and money in the longer term by creating and making use of Early Intervention Services”.

Service user feedback



2. GP Surgeries & Practices

“Our GPs want to provide the best quality care for people with eating disorders. But they need proper training to match the seriousness of these conditions. On average UK medical schools provide less than two hours’ teaching about eating disorders, with one in five providing no teaching at all”. Source:

www.theguardian.com/commentisfree/2020/jan/03/anorexia-mental-illness-nhs-hospital-admissions

The National Institute for Health and Clinical Excellence (NICE) states: “If your GP thinks you may have an eating disorder, they should arrange an appointment for you to see a professional who specialises in eating disorders. This will usually be at an eating disorder clinic or centre in your area.”

“However, this is currently an unrealistic expectation for most patients in Suffolk, and GPs are also aware their hands are tied. So, what can be done about this?”

To bridge these kinds of gaps, the Primary Care Network is introducing Mental Health nurses at GP surgeries. These nurses have already been granted funding and provide an ideal opportunity to help support patients with an eating disorder within a primary care setting.

As GP surgeries are independent, when being granted funding, it would be hugely beneficial to ensure that practitioners are given specific eating disorder training. There needs to be effective systems and communication to support people who transition between primary care and secondary care services. This kind of co-operation supports people with the care they need and helps take the pressure off what is already an incredibly strained secondary care service. Much of the medical monitoring required for a patient with an eating disorder can be delivered well in primary care.

This would create better continuity, rapport, and trust, particularly for the future when eating disorder services are no longer involved in someone's care”.

3. Pitfalls of signposting for support

“Professionals often do not know the limitations of support for eating disorders within our voluntary community and social enterprise (VCSE) organisations.

When professionals signpost to VCSE organisations, they need to ensure they have a clear understanding of what support is available within the voluntary and community sector.

When professionals are unsure, then they should research into services themselves or explain that there isn't a service appropriate at this time. This will hopefully avoid further disappointment and distress for the patient".

4. The cycle of 'support' - The experience of service users who reach out and ask for help.

1. I make an appointment and talk to my GP.
2. My GP recognises there is a problem, that I have an eating disorder, so they refer me to secondary care mental health services.
3. Secondary care mental health services tell me that because I do not fit the criteria for eating disorders treatment, I should talk to Beat (the UK's national awareness and campaigning charity for eating disorders) to get assessed for support.
4. Beat – Beat is the UK's leading eating disorder charity. Their mission is to end the pain and suffering caused by eating disorders. They state "It's very important to access treatment as early as possible, as earlier treatment means a greater chance of fully recovering from your eating disorder. Your first point of contact is likely to be your GP". Source: www.beateatingdisorders.org.uk/get-information-and-support/get-help-for-myself

This takes us back to making a referral with our GP, and this is the cycle of 'support' that people are experiencing.



Source: Sarah Donnelly



“Beat advises people to go back to their GP to get support as they need help. This cycle is seemingly never ending, and sadly has ended with patients we know from personal experience taking their lives. This must stop”.

“Beat state that they do not undertake eating disorder assessments. Whilst Beat is a campaigning charity it can be commissioned to deliver eating disorder support services.”

“Currently there is no Beat support service commissioned for Suffolk (there is one in Cambridgeshire)”.

“This cycle shows the pitfalls of signposting. Even if professionals think they know what a service or charity offers, they need to check before signposting people and giving someone false hope”.



5. Binge Eating Disorder (BED)

Service users have raised concerns about gaps in service provision for people with binge eating disorder, stating.

“There is currently no BED service for Adults in Suffolk. People should not be excluded from any help just because they have a different eating disorder, or because there is a lack of funding in our area”.

“Currently there are no NICE guidelines being followed for people with BED, which is a stark inequality. In addition, NICE guidelines state treatment for BED includes actively discouraging weight loss. This conflicts with the massive drive in public health for people with obesity to lose weight and is leading sufferers with BED to not even get the right advice for their condition, let alone any treatment”.



“Suffolk NHS’s approach to overweight people with eating issues is belittling, disrespectful and almost cost me my life”.

“There are plenty of people desperate for help with their disordered eating and being denied it”.

“When doctors state that overweight people cost the NHS so much extra money, it seems counterproductive that they don’t offer them help with losing weight and battling their issues”.

“It genuinely feels like I am being punished for having the wrong type of eating disorder.”

“I’d expect such treatment from the general public judgements based on my weight. However, I do not expect this from the professionals we are told are here to help us.”



6. Inpatient treatment and support for eating disorders

Service users have identified additional gaps in service provision stating.

“We would like to talk about both in-patient and day care. Neither are available in Suffolk, despite pledges to end out of county admissions by 2021.

Money is being poorly spent as out of county admissions are extremely costly.

This target of zero out of county admissions will never happen without sufficient funding for local eating disorder services.

What meaningful changes can we expect from this discussion?

We need to come up with cost effective and sustainable early intervention services for people living with eating disorders, with better cooperation with community services for adults.

Once this is in place, the target of no out of county admissions becomes logically achievable.

Whatever happens, there needs to be greater transparency on what services there are on offer and their limitations. If someone in Suffolk has an eating disorder that falls out of criteria for current provision, there needs to be a clear pathway to get treatment, that is transparent, understandable, and accessible.”

7. Eating Recovery Group (ERG)

Service users have praised the support they have received from the Suffolk Mind Eating Recovery Group. Those receiving this support have commented on the peer support provided, which has enabled them to learn new coping skills and to receive peer mentoring in a nonjudgmental and hugely supportive group.

“The Eating Recovery group is for anybody seeking to improve their relationship with food and anybody managing eating disorders.”

Source: www.suffolkmind.org.uk/services/eating-recovery-group



“It’s a hugely supportive group and is a real lifeline for people with an eating disorder.”

Hearing others’ coping skills and advice is invaluable because they have tried and tested it”.

“It’s helpful to be around other people who understand and who ‘get it’.

“I feel like I can be myself and not be judged”.

“Members and facilitators are fiercely supportive and kind”.

Testimonials from the Eating Recovery Group clients.

“This recovery group needs further resources to further achieve its goals and to be even more effective in its support to people.

“This should include professional cooperation from the NHS and the eating disorders team. The guidance of specialist professionals would increase longevity of the group as a trusted resource”.



Please note:

At the time of publication Suffolk Mind is unable to take new referrals for the Eating Recovery Group.

Eating disorders awareness week

28th February 2022

During this Eating Disorders Awareness Week, Beat are campaigning for all UK medical schools and foundation programmes to introduce proper training on eating disorders.

Beats Campaign for eating disorders awareness week 2022

Eating disorders are devastating mental illnesses that affect 1 in 50 people in the UK.

Recovery is possible. But we rely on our GPs to spot early warning signs that may have nothing to do with a person's weight or appearance.

Their role is crucial. Their responsibility is huge.

But how much training does the average GP receive on eating disorders?
Less than 2 hours!

Less than two hours in their entire medical degree. And a fifth of UK medical schools don't provide any training on eating disorders at all.

This isn't good enough. It's delayed access to treatment and led to misdiagnosis of eating disorders for years. And the consequences for people living with these mental illnesses and their families can be devastating and sometimes deadly.

This has to change. And the time is now.

Our GPs want to provide the best quality care for people with eating disorders. But they need proper training to match the seriousness of these conditions which many of them haven't had through no fault of their own.

This training exists. We have developed clear and comprehensive courses for medical students, which some schools have started to teach.

But 'some' is not enough.

We need all medical schools to offer proper training on eating disorders. And your support can make this happen. It's time to change lives

1 in 5
UK medical schools
don't provide any
training at all.

#TimeToChangeLives
#EDAW2022

Beat
eating disorders

On average, GPs get
less than 2 hours
training on eating disorders
- in their entire medical degree.

#TimeToChangeLives
#EDAW2022

Beat
eating disorders

53%
said they'd have sought help
sooner if they had more
confidence in their GP

#TimeToChangeLives
#EDAW2022

Beat
eating disorders

72%
had to wait over 6 months
to get help from their GP

#TimeToChangeLives
#EDAW2022

Beat
eating disorders

58%
of patients thought their GP
didn't understand eating disorders

#TimeToChangeLives
#EDAW2022

Beat
eating disorders

60%
of patients felt they'd had
poor care from their GP

#TimeToChangeLives
#EDAW2022

Beat
eating disorders

Source Beat:
edaw.beateatingdisorders.org.uk/ways-to-get-involved/social-media-resources

Service User Conclusions and Call to Action



Service users are calling for the following changes and ask commissioners and providers to respond.

This Call to Action sets out the actions that service users believe can break the cycle of 'support'. It sets out a series of targeted actions that can be taken in the short and medium term to make a difference to the lives of people living with eating disorders, by creating informed, skilled support within community and specialist services.

1. Primary Care

Break of cycle of 'support' by developing 'Eating Disorder Champions' through more training for GP surgeries. At least one member of clinical staff/practitioners in GP surgeries should complete extra training in awareness and support of people with eating disorders. These can be supported by the already funded PCN Mental Health Nurses.

2. Early Intervention for Adults

Develop an Adult Early Intervention Service for all eating disorders, including binge eating disorder.

An eating disorder multidisciplinary team should provide an open access group for people at all stages of recovery. Service users propose a two-step process.

Step one.

Trial an online support group facilitated by a rotation of professionals from the eating disorder team. We know this is a cost-effective way to reach as many people as possible and have a working example currently being run by the Addenbrookes Obesity Service. Most patients in this service have Binge Eating Disorder.

Step two.

Add face to face, personalised support planning and practical support sessions for shopping, cooking and communal eating, supporting those further into their recovery. This helps develop the neural rewiring processes for further recovery and relapse prevention, creating a 'new normal'.

3. Binge Eating Disorder Support Group

Using expertise of staff who already provide a service for Binge Eating Disorder in young people, group-based support like that provided at Addenbrookes, Cambridgeshire must be provided for adults living with Binge Eating Disorder in Suffolk.

4. Eating Recovery Group (ERG)

Eating disorders professionals need to work in partnership and coproduction with Suffolk Mind's Eating Recovery Group to support this much valued recovery group.

Free information, support, and services for people with eating disorders in East and West Suffolk

1. Are you feeling suicidal? Get help now.

If you don't feel you can keep yourself safe right now, please seek immediate help.

If your life is at immediate risk call 999 or ask someone else to contact 999 for you or take you to Emergency Department immediately.

If you need help right now contact the First Response Service. This is a 24/7 helpline for people of all ages in Norfolk and Suffolk who need urgent mental health support. This crisis helpline is available all day, every day.

Telephone [0808 196 3494](tel:08081963494). Once you are connected you will be put through to a mental health practitioner who will offer advice and support.

If you are having thoughts of ending your life; or perhaps feeling that you just cannot carry on anymore, then please know that you are not alone. Many of us have had suicidal thoughts at some point in our lives. You can get help in many ways. We provide support resources that can help you through this difficult time.

• **LISTEN for Suicide Prevention**

You can read our support booklet called LISTEN for Suicide Prevention if you are experiencing suicidal thoughts or supporting someone with thoughts of ending of their life. This can be read or downloaded through this link: www.suffolkuserforum.co.uk/wp-content/uploads/2021/08/LISTEN-for-suicide-prevention_Aug2021.pdf

• **Stay Alive App**

The Stay Alive app is a pocket suicide prevention resource for the UK, packed full of useful information to help you stay safe. You can use it if you are having thoughts of suicide or if you are concerned about someone else who may be considering suicide. In addition to the resources, the app includes a safety plan, customisable reasons for living, and a life box where you can store photos that are important to you. You can download the app through this link: www.prevent-suicide.org.uk/find-help-now/stay-alive-app

2. Beat

Beat is the UK's leading eating disorder charity. Their mission is to end the pain and suffering caused by eating disorders.

They provide information, resources, and a national helpline to encourage and empower people to get help quickly. Beat campaigns to increase knowledge among healthcare and other relevant professionals, and for better funding for high-quality treatment, so that when people are brave enough to take vital steps towards recovery, the right help is available to them.

Resources for support

1. Tips poster

Spotting the first signs of symptoms of an eating disorder is extremely important when encouraging individuals to get the help and support they need as quickly as possible. That's why Beat have created their tips campaign – giving you the tips to spot those very first signs of an eating disorder.

If you're worried someone you care about is showing the signs of an eating disorder, the first step is to talk to them and encourage them to seek help from their GP. To download this leaflet visit:

<https://Beat.contentfiles.net/media/documents/tips-2019.pdf>

2. First steps – Talking to your GP.

Beat provide a downloadable booklet on their website which is designed to support you to talk to your GP. It helps people to get a quick referral from their GP to an eating disorders specialist. It has sections giving guidance for the person who has an eating disorder, for people supporting someone with an eating disorder, and for the GP, as well as a space for notes. To download this booklet visit:

<https://Beat.contentfiles.net/media/documents/gp-leaflet-website.pdf>

3. Guide for Family and Friends

This booklet is for anyone supporting someone with an eating disorder. It covers information about eating disorders and treatment and offers guidance on how you might approach the subject if you're worried about someone you know and how to support them after diagnosis, as well as looking after yourself. It also suggests further useful resources. To download this booklet visit:

<https://Beat.contentfiles.net/media/documents/Beat-carers-booklet-1.pdf>

4. Beat helplines.

Helplines are open 365 days a year from 9am–midnight during the week, and 4pm–midnight on weekends and bank holidays.

Beat provides Helplines for people of all ages, offering support and information about eating disorders no matter where you are in your journey. These Helplines are free to call from all phones. Beat is a member of Language Line and can provide access to an interpreter for non-English speaking callers.

England: [0808 801 0677](tel:08088010677)

Scotland: [0808 801 0432](tel:08088010432)

Wales: [0808 801 0433](tel:08088010433)

Northern Ireland: [0808 801 0434](tel:08088010434)

Sometimes the lines are busy. If you can't get through immediately, please do try again or try Beats one-to-one web chat. If you need support outside of these hours, Beat also offer email support.

5. Beat email support

Email support for England: help@Beateatingdisorders.org.uk

Email support for Scotland: Scotlandhelp@Beateatingdisorders.org.uk

Email support for Wales: Waleshelp@Beateatingdisorders.org.uk

Email support for Northern Ireland: NIhelp@Beateatingdisorders.org.uk

Other sources of support such as downloadable resources, finding treatment and recovery stories can be found on the Beat website:

www.Beateatingdisorders.org.uk

3. Community Eating Disorder Service (CEDS) Suffolk

A secondary care community eating disorder service for children, young people and adults with anorexia nervosa, bulimia nervosa, binge eating disorder (children only) and related diagnoses. Co-morbidities will be jointly treated with IDT Pathways. The Eating Disorder service is a county-wide service delivered from two main sites in West Suffolk and East Suffolk.

- Bury North Integrated Delivery Team (IDT): Newmarket Hospital, Exning Road, Newmarket, CB8 7JG. Telephone [01638 558650](tel:01638558650)

- Coastal IDT: Bungalow 6, Walker Close, IP3 8LY. Telephone [01473 279200](tel:01473279200)

The core hours for this community service are 9:00 – 17:00. The service offers extended hours to support mealtime planning.

The service states:

“The aim is for children and young people with an eating disorder to have access to timely and high-quality mental health services. This ensures effective assessment, treatment and support for them and their families.

This will involve holistic service user-centred treatment. This includes psychiatric care, physiotherapy, specialist nursing care, psychological therapies, specialist dietetics and nutrition. The service user’s needs are at the centre of a specialist treatment pathway of care. We support the service user, their families, carers, and supporters towards recovery. We help to improve quality of life and health - physical, psychological, and social”.

How to access this service - People can access this service through a single point of assessment called Access and Assessment (AAT). The service only accepts professional referrals from GPs, school nurses, health visitors and social workers. Professionals can contact AAT on [0300 123 1334](tel:03001231334).

For more information visit the Norfolk and Suffolk NHS Foundation Trust website:

www.nsfh.nhs.uk/community-services/service/community-eating-disorder-service-ceds-suffolk-36

4. Suffolk Mind Eating Recovery Group

For those people currently receiving this service, the Eating Recovery Group is for anybody seeking to improve their relationship with food and anybody managing eating disorders including anorexia, bulimia, and addiction.

Group activities include:

- Planning how to address unmet needs to support recovery
- Sharing healthy coping strategies
- Confidential group discussion
- Handling challenging events and times of year involving eating

The service is also supported by access to one-to-one sessions with a therapist.

Please note: At the time of publication Suffolk Mind is unable to take new referrals for the Eating Recovery Group.



Suffolk user forum

your voice for emotional
and mental health



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