



# Rethink Carer Support – Cambridgeshire and Peterborough

*Newsletter 322*

*Spring 2024*

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Welcome to the **Spring 2024** edition of our newsletter, where we give a flavour of what we have been doing to support the families and friends of people with mental ill health across this area.

Our aims remain to:

- Support and inform each other – through groups, one to one work, phone and other support
- Work alongside service users and their representatives as well as carers, (including SUN Network, Caring Together, and Making Space) to strengthen the voice of experts by experience so that the limited resources available to mental health and social care are put to the best possible use
- Engage constructively with NHS and local authority commissioners and the NHS Provider Trust Cambridgeshire and Peterborough NHS Foundation Trust (CPFT), to improve services as they are experienced – injecting where necessary a sense of urgency and an element of challenge

As usual, I welcome any feedback on the content of this newsletter, and any contributions.

With best wishes.

Jonathan Wells  
co-ordinator



## **LOCAL NEWS - RETHINK**

- **Vacancies and opportunities.**

The NHS and local authorities now recognize that if they are to make significant improvements to services they need to engage from the start with people with lived experience if they are to get it right. Co-production is very much in the minds of local mental health statutory bodies, and so we are often asked to provide carers to get involved.

I do a lot of this and can say that it can be rewarding and can also be frustrating! If anyone would like to be more involved on behalf of carers in this way, please let me know as I want our voice to be as loud as possible.

- **Our monthly carer support meetings.**

These hybrid meetings continue and are still on the last Wednesday of the month from 7.30 to 9 pm. Zoom invites are sent each month to everyone on our mailing list – about 80 people. The groups are especially valuable in helping carers see that they are not alone whatever is happening in their family. A lot of information is shared about what helps us manage to cope with the role and also about local mental health services, diagnoses and treatments.

- **Other Support.**

Our phone support team deal with contacts by either phone or email from new carers and carers we already know. We respond to messages within 24 hours.

- **Finances.**

We remain in a strong financial position and I just wanted to remind people that we make grants up to £400 to carers if they are in significant financial need. Please contact me by email if you would like to know more.

£12 per hour is payable for attendance at official meetings for anyone from our group representing carers.

- **Our Local Plans.**

Our committee is considering how we might provide more chances for people to learn about mental health conditions and services from guest speakers.

So far we have sometimes organized free workshops and events with speakers primarily from Cambridgeshire and Peterborough NHS Foundation Trust (CPFT). We have also been able to fund carers to attend relevant national events.

We are keen to develop these opportunities further – perhaps through specific courses each year. Please let me know if you have particular thoughts or wishes in this area.

- **Our Priorities for Change.**

We know a lot about the gaps in local mental health services and the struggles CPFT have to deliver the best possible care and treatment to all those who need this. To influence planners and decision-makers, it helps if we are consistent in what we have to say, and that we also propose at least partial solutions whenever we can.

To help us be as effective as we can the committee have agreed a “Top 12” list of issues that we will continue to raise on behalf of carers and their loved ones. Here they are:

**The Top Twelve (in no particular order):**

- Access to a full set of community mental health services via CPFT Locality Teams
- Continuity of care in community mental health services with everyone having a care co-ordinator or key worker
- Ensuring there are enough CPFT inpatient mental health beds so that no-one is sent out of area inappropriately
- Making crisis services simpler and safer
- CPFT staff to be more confident about when to breach patient confidentiality and involve families in high risk situations
- Engagement of carers in their loved one’s care as routine in CPFT (Triangle of Care)
- Implementation of the Carers Strategy – carer identification, information and clarity about carer assessments
- Person centered needs based care from CPFT and others - especially for young people aged 16 to 25
- Re-development of a community mental health rehabilitation service (health and social care)
- Implementation of the All Age Autism Strategy – including Oliver Mc Gowan training for all mental health staff
- CPFT to be willing and able to learn from patients and carers and improve services wherever possible
- CPFT to show greater efficiency and urgency when addressing issues and making improvements to services

- **Other Rethink News.**

Last week I attended a Rethink Regional Event at Chelmsford. It was a good chance to hear about other groups, especially the Rethink Carer Support and Arts groups run by Trina Whittaker based in Braintree.

I had the chance to ask questions of various national Rethink leads and as a result will be meeting the person who leads on developmental work alongside Integrated Care Boards so that I can share how we do this in our area.

My friend Keith Grimwade who runs the excellent local support group for the carers of people with eating disorders recently wrote to the Chief Executive Officer of the Integrated Care Board Jan Thomas to express our concerns that the carer agenda was not receiving much attention in the ICB. One example is the current Carers Strategy which was intended to be joint between the local authorities and the NHS, but never has been.

This led to Keith and I meeting Matthew Smith at the ICB who is in charge of producing an Outcomes Framework for our area of the NHS. He has agreed to add a measure of how well GPs recognize and support carers, which is a start.

**Mental Health First Aid courses** are often free and can be very helpful for carers.

Kathryn attended a recent course and here is her report:

“MHFA Course 7 th and 14 th February.

There were 14 attendees on this 2-day course from a mixture of for either professional or voluntary organisations.

We were given a comprehensive workbook together with even more comprehensive online resources.

The scope of the course was wide and covered a lot of basic information about mental health and well-being. It looked at risk factors associated with poor mental health and identifying possible signs. Also that mental health is a continuum and for all of us this can change over time as does physical health.

We considered how to look after our own mental health and wellbeing with the analogy of the instructions given on aircraft: ‘make sure you have your own oxygen mask on before you try to help anyone else’.

We were given a very helpful acronym to help us remember the main points of action necessary for a first aider.

**ALGEE**

A to approach assess and offer assistance with any crisis.

L to listen and communicate in a genuine, accepting and non-judgemental attitude.

G to give support and information and for this to use the Support App that we have been provided with which uses trusted sources of information.

E to encourage the person to accept appropriate professional help and to explore whether they have already been receiving any such help.

E to also explore and encourage the person to access other appropriate sources of support including that of family and friends where appropriate.

We also considered the boundaries of the MHFA role and to be aware of situations where it would be important to protect oneself and the person being supported. For example to never promise confidentiality where there could be a safeguarding issue which would need to be shared with an appropriate professional.

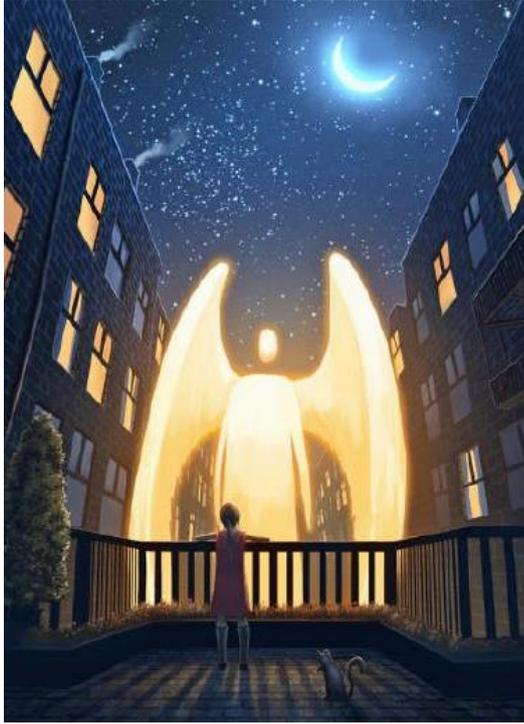
To help us to practice applying and understanding the points of ALGEE we had a mixture of small and large group discussions and in addition took part in some role plays of various situations with one person from each group being an observer.

This was very helpful in enabling us to practice our listening and observation skills.

I enjoyed taking part in the course very much and if there were to be any criticism it would be that there was so much information to take in that it could benefit from being stretched over several more days! Having said that I thought the teaching was excellent.”

### **Poetry Competition 2024**

We had several entries for the national Rethink Poetry competition, where we have a good record over the years. We were asked to respond to the image below. Here are 3 of our poems – one by Ian and 2 by me:



### Questions and Answers.

What should I make of my world?  
Is it a friend or a foe?  
When I lie in my bed snugly curled  
I long for some people to know.

I'm alone, I'm exposed, and I'm small,  
The buildings around me are high.  
They bring me no comfort at all  
And block out the light from the sky.

The windows up there are so bright  
Like searchlights they stare from above.  
They cannot relate to my plight  
Nothing can offer me love.

I don't love myself, I'm depressed  
I alienate people and groan.  
No humour or joy is expressed  
As I hide and make sure I'm alone.

My hopes lie in somewhere out there.  
If I could accept and embrace.  
A benevolent creature so fair

I'd instantly show them my face.

I half-see this angel above me  
I watch as she gently looks down.  
It seems like she never will love me  
I ask should I smile or frown?

Life beckons. I long to be part of it!  
I'll jump and fly into the heart of it!

### Two Reactions

1.

The figure like an angel so scarily looks down.  
Those wings look more like blocks of stone to me.  
A kindly smiling human face is what I long to see  
Not a whiteish image in a gown.

I'm small and faceless too and on my own  
Those blocks of flats seem threatening and cold.  
Horrendously I'm both afraid and bold  
From off this ledge to certain death, I'm thrown.

2.

The figure of an angel so beautifully looks down.  
It bathes the city scene in gorgeous light.  
The air is warm and windows shine although it's night  
At last I feel connected to this town.

### Poem 3

I am on the balcony of life, but I'm not ready to go,  
my mind is playing tricks again, my mood is so low.  
An angel says no, you must fight this,  
but this night my mind is drawn towards the large abyss.  
I just want the pain to end.  
Hundreds of times a day I think self-destructive thoughts.  
Then suddenly they go and all is good.

So I think of life and all that I can do,  
should I really listen to the angel and see this through?  
I step back in fear for that is all I have,  
fear of the future... but the angel of hope looms large.  
For the moment there is peace, calm, recalibration.....  
Thank you dear angel, I can now see the light,  
and I hope for a long time I will not see THAT light.

One of these was counted as among the 3 best entries and so - as previously- the poet got £900 for our group and £100 for himself.

### **Joy's Art**

Many of you will know Joy who is a brilliant published illustrator of children's books. It is great to have the chance to advertise her work here:

#### **“Bold Beasts - brave, boisterous and bad!**

Children's picture books written by Rachel Braddock, illustrated by Joy Rutherford, designed by Mike March, and published independently by Bob Braddock.

Rachel and Joy met at teacher training college - Oastler College, Huddersfield - in the early 1960s. Rachel's main subject was English, Joy's was Art. They grew up together and became close friends. Rachel wrote poems and autobiography; Joy writes songs in the folk and cabaret tradition. They both taught English to a variety of levels, children and adults.

Rachel married Bob, and in time she began to write stories for her grandson Joe. She asked Joy to illustrate them, and her husband Bob became their publisher. Rachel's characters find ways of overcoming their difficulties: eating too many sweets; being annoyed by flies; depending on mother for a carry. She has been compared to Edward Lear. Joy's drawings are influenced by medieval illuminations and cartoons.

Joy is the main carer for her brother Henry, and is keeps drawing and writing for this and other projects. Rachel became ill and was cared for by Bob, who continued to sell the books. Rachel died in 2019, and Bob in 2023. Joy still sells books at fairs and festivals, and directly from home. There is a website, [www.boldbeasts.com](http://www.boldbeasts.com), and you can see pictures on that. But at present the only sales outlet is from: Joy Rutherford, 75a Stanley Road, Cambridge CB5 8LF. 01223 365149 [jrutherford9260@googlemail.com](mailto:jrutherford9260@googlemail.com)

Rachel and Joy didn't put precise age specifications for the books. They were intended to be read aloud, and there have been readings at fairs.

Titles are £6.99 each, except for *Delphine Dolphin*, and *Talleyrand Turtle and his mother Myrtle*, which are £7.99.

If anyone would like to know more, please contact Joy as above. Let a Bold Beast into your house today!”



## **LOCAL NEWS - OTHER**

### **1. Cambridgeshire and Peterborough NHS Foundation Trust (CPFT).**

There are many things that can help our loved ones and ourselves recover from the challenges that mental health conditions bring. The voluntary sector has a big role to play – whether the bigger organizations like CPSL Mind or smaller ones like The SUN Network. Sometimes it is resources, activities or relationships which do not even have a mental health label which have a really positive impact.

But CPFT is the local NHS mental health service provider, and it is no surprise that as a group we are very interested in how it is getting on.

In recent months there have been a few negative stories about CPFT in local media such as BBC Cambridgeshire. I would urge people to be careful how they interpret them, for in my view the reporting has sometimes been exaggerated and irresponsible.

The facts as I understand them are:

- There was a whistle blower a few months ago who highlighted bad practice by staff following an incident; the Trust has responded to this by setting up a Suicide Thematic Review led by an external organisation, of which I am a member. The review was featured in an article in The Times on 26<sup>th</sup> July 2023
- There has been instability at the top of CPFT with Anna Hills Chief Executive Officer resigning and being replaced by Scott Haldane former Director of Finance as Interim CEO
- At the end of last year the Trust reported that it was heading for a deficit at the end of the financial year of around £8 Million. This was largely caused by big overspends on agency staff and on out of area inpatient care which happens when there are no available CPFT beds to admit someone to so they are sent out of county and into a private sector unit. I understand this situation has been brought substantially under control, partly by “freezing” posts when they become vacant
- An internal message about pressures on services was leaked to the media. The main option available to staff internally is Stop The Line when staff can contact Head Office and say a particular service is unsafe. Sometimes, unsurprisingly, the Stop The Line process does not lead to a full solution to the problem. It’s predictable then that there may be further internal communication about pressures on services, which we all know are still considerable.

Sue, Jean and I are involved as carer representatives on interview panels – sometimes advisory stakeholder panels and sometimes the actual interviews. This is another small way in which we aim to influence the quality of care in the Trust. For example, I recently asked candidates for a Consultant Psychiatrist post to describe best practice in working with carers.

The Trust no longer appears wary of having carers in influential roles. For example, Jane Cannon who is passionate about carer issues has recently been appointed as a Non-Executive Director on the Board.

## **2. Cambridgeshire and Peterborough Integrated Care Board**

The major pieces of work led by the Mental Health Learning Disability and Autism Partnership in the ICB continue. These include:

- Implementing the All Age Autism Strategy, which includes all staff in mental health services being trained to adjust their care and treatment when providing care to autistic people with mental health conditions (Oliver McGowan training)
- Implementing the Suicide Prevention Strategy; this work is detailed and well led but the number of Cambridgeshire and Peterborough suicides per year has been fairly static (68 in 2019, 70 in 2020 and 65 in 2021)
- Implementing the national Community Mental Health Transformation Programme; this includes (re) developing a community mental health rehabilitation service, which is very important to us
- Moving Away from CPA (Care Programme Approach)

A lot of time, energy and good intentions goes into these projects, but the pace of change often seems glacial to me. It is so much easier to describe a problem than to tackle it – even partially.

## **3. Local Authorities (Cambridgeshire County Council and Peterborough City Council).**

In Adult Social Care priorities are usually decided by the statutory duties of a local authority – above all, the Care Act.

There are duties under the Care Act to identify informal carers, assess what they need, and provide services so that they are able to carry on in the role. There is now a new Carers' Strategy which I have helped develop.

You may have seen that Adult Social Care at Cambridgeshire County Council are advertising for a carer co-production worker to enable them to work effectively with carers themselves in implementing the strategy. My thanks go to Carol Williams for arranging this. I only hope this will lead to more urgency in making the important changes spelt out by the strategy document!

There is also a tendering exercise now underway to decide which providers are best placed to provide funded carer support in future. The main agencies doing this at present are Caring Together, Making Space and Centre 33. This will be an uncertain time for them and their staff.

#### **4. Voluntary Sector.**

**Family Voice** in Peterborough are the funded carer support service in that area for the parents of children and young people with special educational needs which may include mental health difficulties. They recently produced a very impressive report on what their carers are telling them. Here are the conclusions and recommendations:

“From all the data reviewed most of which has been presented in the full report there are a number of broad themes coming through:

1. Parental blame – for example being seen as a burden, drain on resources, negative and part of the problem, being made to do parenting courses that are not appropriate to Special Educational Needs and Disabilities (SEND), parenting courses make parents feel they are at fault.
2. Lack of support – managing benefit changes, applying for an Education Health and Care Needs Assessment (EHCNA), mental health management to name a few, support after diagnosis
3. Lack of involvement in decision making, support planning and areas of Education Health and Care (EHC) outcome monitoring
4. Difficulty in finding Information – you don’t know, what you don’t know!
5. Lengthy waiting times - Waiting too long for access to assessments and access to therapies and other forms of support once assessed.
6. Preparing for Adulthood – Not knowing what entitlement may be for access to services, having to self-refer to the 0-25 team, lack of access to transitions officers, impact of benefit changes, ‘5’ day offer and other matters.

**The Report suggests ways forward and makes recommendations based on parental requests:**

Family Voice Peterborough (FVP) would ask that the following recommendations be taken under consideration:

- SEND Communication be considered as a priority for strategic leaders, with a refocus on the SEND Strategy and Action Plan.

- key support initiatives be delivered by the Local Authority/ Health

- o Face to Face befriending (Peer to peer support)

- o Benefits Advice and Support (DLA to PIP)

- o Independent Support (EHC process)

- o SEND Navigators (support) to find information to help parent carers

- o Development of a resource for new SEND households (Welcome to Your SEND Journey)

**HAY (How Are You)** is part of CPFT but its main role is about promoting what voluntary sector and community groups offer in terms of helping people with their mental health. Their websites for each District Council are full of useful information and they are keen to do more.

South Cambs HAY now offer an hour each Monday lunchtime when people from the voluntary sector can bring a difficult situation to the group for advice and support. Any patient or family details are anonymized. as you would expect. I have used this twice myself recently in my Rethink role and found it encouraging.

## ***NATIONAL NEWS***

MQ is a national mental health research organization and it recently referred to some stunning data on mental health trends in this country. I read that no less than 1.5 million people in the UK are currently waiting for mental health assessment and treatment.

And secondly that among children and young people the number referred for assessment of their mental health has increased by a staggering 350% since 2016!

These are stunning figures which indicate that some extraordinary things are going on at present in terms of the health of the nation. This picture goes some way towards explaining why our experience tends to be far from ideal when seeking help for our loved ones and ourselves locally. Services are really struggling to cope, but improvements can still be made.

## **AND FINALLY....**

We welcome new people contacting us by phone or email.

We welcome donations from families who may at any time want to show their appreciation of the support we have provided by making a grant, so that we can maintain what we do.

If anyone would like to discuss how this might best be done I would be happy to hear from them.

We aim to keep down costs and make sure we that we do not keep sending this newsletter to people who no longer want it. It is emailed to most people and sent in the post to some.

As you know, Rethink Carer Support – Cambridgeshire and Peterborough is part of the Rethink Mental illness national groups network. Changes to the law mean changes to the way the charity communicates with its supporters. We have adopted an “opt in” policy which means that most kinds of contact now need your permission.

It is easier and less costly to send newsletters by email but we are happy to continue to send by post if that is your preference. We will check with you from time to time (at least every two years) to ensure you still wish to receive the newsletter.

We save your preferences and your contact details securely, and would never sell these details to a third party.

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