



Rethink Carer Support – Cambridgeshire and Peterborough

Newsletter 323

Summer 2024

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Welcome to the **Summer 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

- **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. We are able to manage more contacts than we currently receive.

- **Finances.**

We remain in a strong financial position and continue to 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.

- **CONFERENCE.**

We are holding a Mental Health and Families conference from 9.30 to 4.30 on Monday 21st October at the Holiday Inn Lakeview Hotel, Bridge Road, Cambridge CB24 9PH.

The aim is to have something for everyone. So far Professor Peter Jones is on board to talk about schizophrenia and Dr Lynne Drummond to talk about OCD – both highly regarded national experts. As well as learning from professionals, those who attend will have a great chance to meet and learn from other carers.

Please HOLD THE DATE. The event will be formally announced within a fortnight.

- **Our Priorities for Change.**

I am repeating the list below as when we have the chance to influence the planning of better mental health services it helps if we are all aware of what we have agreed is most important to us. I won't add to the list but I will say that another thing that comes up time and time again within our group is the need for services to be much more simply

and clearly organized, so that when we or a family member are seeking help it is not so difficult to understand.

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.**

Keith Grimwade and I have continued our efforts to persuade the Integrated Care Board to pay more attention to the needs of carers across our local NHS – as described in the last newsletter.

We have made sure that partner agencies such as Caring Together, Making Space and Centre 33 are involved in what we are doing. We have met the Directors of North and South Care Partnerships and have been invited to do a presentation to the Integrated Care Board which will be a combined effort. We have succeeded in getting some measures of the carer experience included in what they call their Outcomes Framework.

A Rethink member has shared the information below which may be of interest:

[What is the Hub of Hope? | Hub of hope](#)

[Mental Health Support Network provided by Chasing the Stigma | Hub of hope](#)

LOCAL NEWS - OTHER

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

Leadership

The process for finding a new Chief Executive Officer for CPFT is almost finished. I was pleased to be invited to be part of one of the stakeholder panels as the carer rep. The recruitment process was lengthy and I assume we are now at the stage of the Trust agreeing the salary via NHS England.

In the meantime Scott Haldane continues as Interim CEO.

The senior managers I meet are very much aware that the Trust needs more stability and confidence from the top down. They are especially keen to find ways of improving recruitment and retention of staff, part of this being about inspiring and compassionate leadership.

Mental Health Work Programmes

I remain involved in the following major pieces of work:

Development of a Community Mental Health Rehabilitation Service

As mentioned before, Mental Health Trusts are expected to develop this service which used to exist in Cambs and Peterborough before the major cuts to services 10 years ago.

I was part of a very positive event in Huntingdon last month where we heard from national psychiatry leads on what is needed and why. In essence the aim is to have standalone community teams in CPFT for those with the most severe mental illness, providing the best possible care and treatment for as long as it is needed. It is crucial that social care is part of the service – especially a good range of supported mental health housing options – and also the voluntary sector, bearing in mind that organisations such as Lifecraft continue to do great work supporting people who can be very damaged by their mental illnesses, often made worse by substance misuse issues and social problems.

Senior psychiatrists in CPFT – including Catherine Maxey, Caroline Meiser-Stedman and Asha Praseedom – are bringing lots of energy and commitment to this project. An Outline Business Case has been developed. As usual the process for identifying new recurrent funding will not be straightforward.

Catherine and Caroline know that this work is very important to carers, who can still be supporting a loved one with severe mental illness, (usually schizophrenia, often known nowadays as “complex psychosis”), with minimal or zero involvement of CPFT.

Culture of Care

This is a big national project that is about improving people’s experience of mental health inpatient care. I am really pleased that several of us with direct experience of these services are involved.

It has been agreed nationally that people with lived experience – both service users and carers – will be central to the success of the project. Work will be starting soon with a selection of units including one of the Mulberrys, the Darwin Unit for adolescents, and an older people’s unit. As usual we will have no difficulty pointing out the weaknesses of inpatient care, with around 20 people still in inappropriate Out of Area private units. There is no data so far to show whether inpatients actually are discharged feeling better than when they were admitted. The challenge for us all will be to come up with improvements that really make a difference for those desperately in need of hopeful, compassionate, truly person-centered care.

Suicide Prevention

I am still closely involved in the work led by Joe Davies in the Public Health Team at Cambridgeshire County Council to reduce suicides in our area.

On behalf of carers my particular concerns are mostly about reducing suicides by people already known to mental health crisis or other CPFT services. This is where you would reasonably expect expert risk assessment and risk management to be available for all those at high risk for suicide. To be as safe as possible, the whole mental health crisis system needs to work together as closely and efficiently as possible, and I don’t think it does, yet.

This summer I attended on-line an excellent conference hosted by an NHS unit called the National Inquiry Into Suicide and Homicide. It is based in Manchester and led by the excellent Professor Louis Appleby. The first speaker was Philip Pirie who lost his son to suicide. A professional had used a simple rating scale to decide whether this young man was actively suicidal or not. Tragically, it was concluded that Philip’s son was not at immediate risk but he went ahead and took his own life.

You have to be careful in passing judgment about these things. A lot of staff know they are having to work too fast and cannot always do their jobs as well as they would like. But is clearly wrong for such sensitive assessments to be based on a few numbers and a total score. A few years ago the recommended approach was something called “structured clinical judgement”, which basically meant staff needed to organize such interviews around key risk indicators, but in the context of a warm

and curious conversation about how the individual was getting on, including reflection on the person's overall situation based on what I can only call "common sense."

Anyway, I have been trying to find out where CPFT are up to on best practice in this area. I am keen to know whether Trust mental health staff have moved away from too narrow a focus on predicting future behaviour (which is notoriously difficult to do), to more rounded conversations about what patients need to do to stay safe. I want the Trust to be open about its position. So far I have been in touch with about 6 people none of whom could say that they were confident that "stratified" suicide risk assessments were no longer being used. This despite a national message from NICE supported by NCISH that excessive reliance on checklists should cease.

A CPFT Board member has also got involved and I now at least have an appointment booked with 3 senior staff to get an answer to my query before the end of this month.

Moving Away From CPA

I have reported previously about this national project. It now seems to be "on hold" in CPFT which might be a good thing as the idea of a named care co-ordinator is very important to us as carers and it has appeared to be at risk.

Finally in this section I would like to say a big thankyou and goodbye to Maggie Page the manager of the Locality Teams and CAMEO in Cambridge who is retiring after many years service in CPFT. Maggie for several years has included me in her regular governance meetings to provide a carer and service user perspective and I have really appreciated her openness. She didn't waste time pretending things were better than they are. She will be very much missed by colleagues and by me. I intend to maintain this close working relationship with key Cambridge mental health services.

2. Cambridgeshire and Peterborough Integrated Care Board

I continue to be a member of the Mental Health Learning Disability and Autism Partnership's two Strategic Boards – one for Community Mental Health Services and one for Crisis Mental Health Services. I was invited to be part of a new group to develop trauma-informed mental health services but do not consider this a priority.

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

The All Age Autism Strategy was signed off a couple of years ago and I'm sad to say I have not seen much sign of implementation of its stated actions. In particular, I had assumed by now that delivery of Oliver McGowan training would be well underway. This is the training – mandatory for NHS, social care and some voluntary sector practitioners – in memory of an autistic young man who died unnecessarily in a private psychiatric hospital.

I have spent 3 months contacting over half a dozen people and failing to get an answer to my question which is simply “How many staff have had this training so far?” I have learnt that it’s more complicated than that as it usually is – eg. there are different levels of training, and autistic people need to be found trained and supported to deliver their part of the training. But I am still horrified that no one seems to know.

If anyone reading this can help me, please get in touch!

In Adult Social Care I am still trying to find out what supported housing options are available to people with severe mental health problems. I appreciate this will differ between Peterborough and Cambridgeshire. I have learnt these lists are called “frameworks.” But I still don’t have the information which can be really important to families wanting to know what the options are.

The local authorities also have a carers’ strategy to implement. I still want to be part of this.

4. Voluntary Sector.

Fiona Kerr continues to lead the Voluntary Charity and Social Enterprise Project Board of which I am a member. Our aim is to raise the profile of this whole sector which is often better than the statutory sector when it comes to being agile and ready to change. The voluntary sector is also usually closer to its service users. It sometimes has a more immediate sense of where the gaps are and what can be done about them.

As I’ve said before, the HAY websites, hosted by CPFT, provide excellent information about all local initiatives or groups that can benefit someone’s well-being. We need to make the most of them.

NATIONAL NEWS

1. National Rethink.

Winning prizes can do wonders for self-esteem. See below.

Rethink Mental Illness has announced:

“The Pringle Awards are now open!
Celebrating outstanding contributions across the organization.

Join Rethink Mental Illness in celebrating excellence across our charity by nominating a group or your own creative work for one of our membership Pringle awards.

Our annual awards, named after our founder John Pringle, are an opportunity to highlight our registered peer support groups that are making a tangible difference to people's experience of mental illness.

This year we are asking for nominations for the Group of the Year award, as well as art or poetry for the Bill Pringle creative awards. Our teams will identify nominations for the supporter and service nominations.

Group of the Year Pringle Award:

Are you a part of a Rethink Mental Illness group that has made a difference to your life? Has the peer support been invaluable to you or someone you know? Celebrate this by nominating the group for our award.

Celebrating creativity

We're also inviting entries to our two creative awards, the Bill Pringle award for art and Bill Pringle award for poetry.

These two awards are open to those who directly experience mental illness or experience the effects of it.

You may submit your own art or poetry that you have created, or somebody else's if you have their consent. The winner will be the author/ poet, (not the nominator) on the theme of Understanding.

Winners & prizes

Winners will receive a certificate, £100 cash prize, and will be presented their award and trophy at our Members' Day in November.

Get in touch with membership@rethink.org or call the team on 0121 522 7016 to find out more and how."

Entries close 10am on Monday 16 September 2024.

Help and Information

Rethink Mental Illness Advice and Information Service (RAIS): How to contact us:
The Freephone line is 0808 801 0525 and available Mon to Fri 9:30am to 4pm, excluding bank holidays.

You can also email on advice@rethink.org or post to Rethink, PO BOX 18252, Solihull, B91 9BA.

Our website has all you need to know about mental illness, diagnosis, treatment and your rights. With over 120 topics to choose from, our website is the best place to find the information you are looking for.

2. Nottinghamshire NHS Trust Incident.

There has been a lot in the press recently about this tragic event in Nottingham where a young man called Valdo Calocane who had paranoid schizophrenia killed three students late at night on the city streets. Clearly this is a truly awful incident for the students and their families and friends and also for Mr Calocane who can be expected to spend many years now in a high secure psychiatric hospital.

We have been talking about this in our whats app group. Having followed the story closely and having read the latest CQC report on the incident last week, my views for what they worth are:

- Was what happened preventable? Yes. The most obvious decision that went wrong was when Mr C was “discharged back to the care of his GP” simply because his community mental health team including the care co-ordinators had lost contact with him. Given his history it was obvious that his unwillingness to co-operate with services was an indicator that he was at high risk to himself and others. Schizophrenia can be a devastating illness. It is treatable and requires assertive highly skilled and well organised care and treatment. This decision was like an Acute NHS Trust deciding to discharge someone at the late stages of a clearly diagnosed life threatening cancer.
- Is a full external inquiry now needed? Probably not. People rightly talk about the importance of learning from incidents like this, but when they keep happening and the reports make the same recommendations over and over again, where is the learning? Perhaps I am cynical, but for me at this stage the “powers that be” seem too keen simply to be seen to be doing everything they can after the event. In their grief those directly affected will call for justice, but most of all this surely needs to be about taking the necessary actions to reduce the risks of such an incident happening again.
- How surprised should we be that this happened? Not very. At the best of times decisions about risk in mental health services are not straightforward. When the context - as we well know – includes huge demand pressures on both inpatient and community mental health services, and massive problems in recruiting and retaining staff, the honest commentators on this incident have felt sadness about it but not horror or amazement.
- Should the family of Mr C have been more closely involved? Of course they should! There can still be a wariness amongst staff – usually unspoken – about proactively engaging with families. The default position should be that families are regarded as a key resource in working alongside the professionals in the interests of the patient. This is still not happening automatically despite the fact that engaging better with families remains a recommendation of many of the lengthy incident investigation reports that take place in every Trust

I have been so impressed by the family of Mr C who have spoken so calmly and clearly about what happened and what is needed. They were aware, I think, of the massive risk that this event could increase people’s fear and ignorance about severe mental illness. Video clips of a young black man -alone and “at large” on the city streets at night – can cause viewers to jump to the wrong conclusions. Mr C is an intelligent young man whose life was devastated by his schizophrenia. As is common, his first episode of mental illness took place in his early 20s. He was studying

Engineering at Nottingham University. He was never effectively treated. Two years later, when acutely psychotic and presumably very frightened, he did what he did.

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.

Please email groups@rethink.org for our full privacy policy. National Rethink can send you a postal copy if you prefer – please ring 01823 365315