



Rethink Carer Support – Cambridgeshire and Peterborough

Newsletter 324

Winter 2024

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Welcome to the **Winter 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 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 for a Merry Christmas and Happy New Year,

Jonathan.

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 confidential 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.

It is possible that in the New Year we will change the ways we support carers by email and phone. So please WATCH THIS SPACE.

- **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. It is important that this includes those who need financial help to attend courses or maybe conferences to improve their skills and knowledge as a carer.

Please contact me by email if you would like to know more.

- **Conference.**

We held our Mental Health and Families conference on Monday 21st October at the Holiday Inn Lakeview Hotel, Bridge Road, Cambridge. As a committee we are pleased about how it went.

The attendance was 60 in total with around 40 being unpaid carers and most of the rest interested professionals.

Here are some statements from people who attended about **what they learnt**:

- Very informative about a good range of topics
I thought the talk on Schizophrenia was one of the best I've ever heard. I learnt much about the importance of families and relationships
- Employment act for carers
- "What if" plans
- OCD and potential treatments
- Met other parents
- I found both Dr Peter Jones and Dr Lynne Drummond very engaging and found myself engrossed in what they had to say and the information they shared. No jargon, just straight forward speech and diagrams.
- Reminded about carer's rights; "nearest relative" and yellow card
- The insight into life as an autism person was quite emotional for me
- Gained insight and a historical perspective into the role of families in the treatment of mental health conditions
- It was so refreshing to hear Prof Jones' candid views in relation to treatment and diagnosis. I appreciated his honesty and great experience
- Valuable Insight into autism and OCD. It is always particularly valuable to hear of someone's personal, lived experience
- Carer's support rights, very important
- It was very interesting to hear about the types of expressed emotion and realised how much families would need support in dealing with this positively
- The overlap of various conditions.

Here are some statements from people about **what they will do differently**:

- Explore more the overlap between ADHD and Autism and how to interact more positively with a neurodiverse family member
- Jill's talk on Carers Rights was very informative, especially the breakdown on the various Sections under the M.H. Act. We are going to put this information into our next Newsletter

- Even though obvious, spend less time trying to fix and more just supporting
- The whole day gave an added awareness and understanding of illnesses faced by families daily and the impact that support and knowledge of professionals can provide.
- Caring Together gave a broader insight into both carers rights and the rights of the people they care for. We as professionals can pass this information onto carers, empowering them to use legislation to receive the best possible outcomes.
- Ask for a yellow card in Addenbrookes.
- Ask “what do you need” and not try and solve every issue
- Help break tasks down into much smaller steps with my daughter.
- Help her find her niche way of working, become her strengths.
- Understand the legal position more robustly.
- ‘Take a step back’ rather than patronisingly assuming my ideas were necessarily right
- Be more aware of the significance of expressed emotion

Out of 10 survey responses post-conference these were the **results**:

	great	good	OK	bad
presentations	7	2	1	0
venue	6	4	0	0



JW & Prof Peter Jones.



Making Space Team and Jill



Angela



Dr Lynne Drummond.



Dr Janine Robinson, JW and Susanna Snell

A big thankyou to all who helped before the day and on it – including David, Sue, Jean and Jill!

- **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.

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
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- **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.

We have learnt more about the struggles for Acute Hospitals to incorporate carers in whatever they do, including discharge planning. Jean recently attended a meeting to feed back about the experiences of autistic people in hospital which are often negative. The hospital has developed carers' passports and introduced "sunshine lanyards" to help carers identify themselves. However, as I understand it, those who cannot formally identify themselves as carers may get an inferior service, which doesn't seem right.

We have been invited to do a presentation to the ICB Board on the needs of all carers but do not have a date yet. There are so many competing priorities in a huge NHS Trust like Cambridge University NHS Trust (CUH). We have allies within the organization, but it is a constant battle to get carers' needs fully identified.

Through people like Mike, Sue and Kathryn, we keep up with developments and events that may help people in their mental health carer roles. Part of this is about training/learning opportunities, such as the Future Learn courses and Mental Health First Aid. Below are links to a powerful presentation about addictions and to a group for the parents of autistic children.

<https://youtu.be/66cYcSak6nE?feature=shared>

<https://www.autismcentral.org.uk/events/parents-autistic-adults-0>

LOCAL NEWS - OTHER

- **Cambridgeshire and Peterborough NHS Foundation Trust (CPFT).**

Leadership

Steve Grange has been appointed as Chief Executive Officer (CEO) at CPFT. He started without delay and has already made a big impact on the Trust, meeting around 500 staff. I met him at the recent event which celebrated the Trust services that have won the Carer Friendly Tick as evidence of working well with carers.

Steve has a massive job ahead of him and we wish him well.

Development of a Community Mental Health Rehabilitation Service

This is very important from the point of view of carers of a family member with severe mental illness including schizophrenia. CPFT are at the point of making a Business Case to the Integrated Care Board describing what the service would achieve and how much it would cost.

This can be a complicated and anxious process and I will be involved as much as I am able.

Culture of Care

This is a national project to improve the quality of inpatient care in a selection of wards around the country. 4 wards from CPFT are participating – one for older people (Maple), one for young people (Darwin), and 2 general mental health inpatient units, Mulberry 1 on the Fulbourn site and Oak 1 at The Cavell Centre, Peterborough.

Co-production underpins this work which means that several carers from our group are directly involved, sitting down with ward staff and agreeing what changes can be made. Sometimes it is about little things, like not just sitting round in a communal area on phones, but explaining that sometimes patient notes have to be completed and staff are doing this, rather than idly playing on their phones. Sometimes it is about bigger issues, like avoiding having too many rules, and persistently working to maintain an environment which is calm and confident and meets each patient's needs.

The project is led by the Royal College of Psychiatrists and includes some excellent presentations which will be shared where possible.

Mental Health Crisis Care

This is another big initiative where we as carers are closely involved. Emma Welsh from the ICB is leading a piece of work to make these vital services simpler and safer. We have spoken up about some of the most obvious issues which include:

- Delays getting through to the First Response Service via NHS 111

- A lack of CPFT inpatient places leading to very unwell people being sent inappropriately to out of area psychiatric hospitals
- Bad care in some of these private sector hospitals
- Too many different parts to the Mental health crisis system which includes FRS, A and E, the Police and section 136, the Samaritans, the Lifecraft helpline, the Sanctuaries and their outreach element, Cambridgeshire County Council and Peterborough City Council's Emergency Duty Teams, Mental Health Liaison Services at the Acute Hospitals, etc.

There is a lot of very good work that goes on within these services. I recently heard an excellent presentation from two nurses who are part of a small team going out with the Police to mental health crises which has had encouraging results. This is known as the Joint Response Car. Carers have provided evidence of when things work well but also when they don't, which is often about too many "handovers" between teams, which is experienced as too many gaps.

This is a very important project which may take years and is closely linked with suicide prevention (see below).

Suicide Prevention Group

I am still part of this group although I feel it may have lost some momentum since the excellent lead Joe Davies moved on.

Updating on what I reported in the last newsletter, I'm afraid to say that CPFT have not been able to assure me that stratified risk assessment tools (eg. where the level of suicide risk is derived from a rating scale- generated score) are not used anymore in CPFT.

I was told the Trust is awaiting national guidance about what is now considered best practice. I have made a Board member aware of my concerns.

Complaints

Salim and I are part of the Trust's Patients and Carers Experience Committee which is about many things including how well CPFT learns from feedback. The aim is always to use feedback to improve services.

Responding to complaints is part of this and it is problematic at present, with significant delays in dealing with complex complaints, where the target deadline of less than 50 working days is often not achieved. Complainants who are already unhappy with a service are becoming even more discouraged when their complaints are not handled in a timely manner.

The subjects of complaints are widespread but they fit quite well with what we report in Rethink. For example, there are quite a lot of complaints about not being able to

access the mental health services that someone needs -, whether that is REDS (for people with problems in emotional regulation) or an Adult ADHD assessment.

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.

CPFT Board of Directors

The Board reports are in the public domain and are easily accessed on the CPFT website. Some highlights for me in November were:

- At the end of Month 7 of the financial year, the Trust has a deficit of £6.2 Million. This is largely due to the pay awards to nurses and doctors made across the country by the new government. Another major financial pressure is created by the continued use of out of area placements when all CPFT beds are taken up. (CPFT has now succeeded in reopening Mulberry 3 with a full number of beds (16) which will help the situation both clinically and financially)
- The staff vacancy rate is still high – 15% of posts are unfilled at present Trust-wide, and as many as 19% in the Children and Families Directorate
- The Adult and Specialist Mental Health Directorate is described as having a total of 11,984 people on its waiting lists. If Adult ADHD and Autism are excluded from this total the figure goes down to 3,040. In September there were 6607 people waiting for an Adult ADHD assessment!
- Against a chosen target of 80% the proportion of cases where staff have recorded asking whether there is a carer involved in the case is now at 88% for the Adult and Specialist Mental Health Directorate which is a very welcome improvement

Some of these figures can seem alarming. But I mention them partly to help individual families understand the many challenges that CPFT have been facing. Of course it is right for us to continue to raise issues as necessary, and to seek the best possible care for our loved ones. But I think it can also help us cope with a situation if we appreciate this broader context, even when it seems negative.

- **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.

Sometimes it is hard to understand whether CPFT or the ICB (through its Mental Health Learning Disability and Autism Partnership) is leading on a particular piece of work.

Partly in response to the incident in Nottingham this summer, NHS England asked Mental Health NHS Trusts to review where they are at in terms of various services including Assertive Outreach. This is a way of working which is very much needed especially by those with a severe mental illness who may refuse medication and disappear from the care of community mental health services, often putting even more pressure on family to stay in touch and provide support.

Assertive Outreach Teams were closed down in many parts of the country (including CPFT) because of the financial crisis in around 2010. The ICB and CPFT have done an initial review and I am involved on behalf of carers in trying to make sure this developmental work is taken forward as briskly as possible. As is to be expected, the funding is not yet identified and I think this project will take years not months.

Mike and I are still trying to get an answer to the questions around the NHS Right To Choose. This is about when someone needs a health service and is entitled to choose the provider as long as certain criteria are met. With over 6 000 people in our area on the CPFT adult ADHD assessment wait list, it is not surprising that many people are looking into how else such an assessment can be accessed.

It is disappointing that when something is a right for patients, there is no clear communication about what the right is and how it can be exercised in our area. I am keen to hear from others who may be interested in this subject.

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

I and other Rethink members have recently been part of two Making Space meetings where Laura Green carer lead in Adult Social Care and colleagues sought our views and told us where they are up to in implementing the Carers' Strategy. New carer peer support groups are being established, young carers are being helped to get the ongoing support they need when they move into adulthood and an online tool to find resources relevant to carers called Bridgit has been introduced.

Because of the stresses and frustrations that carers sometimes feel these can be quite fiery meetings and I'm grateful to Laura for maintaining an ongoing dialogue with carers about what they most need.

Via a Freedom of Information request I have obtained some data about social care and carers' support. Here is a summary:

	2020/21	2023/24
Spend by Cambs CC on commissioned services for carers	£1.454M	£2.105M

Total spend by Cambs CC on individual carers (in house and respite)	£3.100M	£3.182M
Total Cambs CC spend on carers	£4.554M	£5.287M
Cambs carers known to Cambs CC getting help to carry on	376	394

This sort of data requires careful interpretation. At least you can say it shows that expenditure on carers is not decreasing.

- **Voluntary Sector.**

I am still a member of the Voluntary Charity and Social Enterprise Project Board led by Fiona Kerr. Our aim is to make sure that organizations outside the NHS and local authorities are fully part of and plans to develop and/or improve mental health and LD and autism services. We expect that CPSL Mind and Lifecraft will be part of the redeveloped mental health rehabilitation service, for example.

The non-statutory sector can be very good at responding to local needs and making sure it spends its time doing what is most useful for service users and their families. In a small way, I think this is what we do in Rethink Carer Support.

- **CPFT Carer Friendly Tick**

I enjoyed meeting CPFT staff at this event in November.

I talked to staff from services that have won the Carer Friendly Tick. None of them are from the Adult and Specialist Mental Health Directorate. I was struck by how easily and confidently those staff who work with older people and/or those with physical health conditions engage with carers, unlike some colleagues in Adult Mental Health.

Below you can see Steve Grange on the left, Keith Grimwade on the right, Anna Tuke kneeling in the middle and me in the red jumper!



NATIONAL NEWS

1. National Rethink.

We are part of national Rethink Mental Illness. We are not a charity in our own right, but encourage those who use our support to become a member of Rethink Mental Illness too.

The annual Poetry Competition is now open. If you win you get £100 for yourself and £900 for our group! Some people have already said they will have a go.

More details can be found on <https://www.rethink.org/>

Send your poem to groups@rethink.org or post to Rethink Groups E01, PO BOX 502, Bridgwater, TA6 9JU and don't forget to include the name of your group.

We have a good relationship with key link people such as Julie Galliford. I am part of the Eastern region group and find it helpful both to share how we operate but also to learn from other groups, although most of them are smaller than us. I generally believe that campaigning has more chance of making a difference on a local scale (which is what we do) than on a national scale and am in dialogue with Rethink Head Office about this.

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.

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

2. A New Mental Health Act.

The Labour government has confirmed it has made time for this Bill to be taken forward and enacted. It is quite likely that the role of the nearest relative, which is currently quite powerful, will be abolished and replaced by a person chosen by the patient. This is of concern to carers. However, it is not at all clear how this would work and the need to agree a new Act and then train a lot of staff to act in accordance with it means that it will be several years before it becomes “active”.

3. Call For Transformation of Mental Health Services Launch Event

I attended this conference in November It was organized by the International MH Collaborating Network and took place at Queen Mary’s University, East London.

For me, it was a chance to learn about radical ideas that some NHS Trusts are putting into practice to make care better. There was a view that current services are consistently failing people and that this cannot be allowed to carry on. Some of the 20 speakers were too radical for me – eg. wanting to get rid of psychiatrists altogether – but others were more inspiring. In several places in England now, community mental health centres have been set up in a particular neighbourhood, and these centres include the chance for people with mental health problems to walk in and be assessed, as well as a small number of acute inpatient places being in the same building.

From another perspective, people were talking about care being based on mutuality – that is, staff being much more effective if they can find common ground with patients and their families. Another way to approach this is to say that staff and patients have one thing in common - their humanity - and if staff can tap into this rather than being ground down by the pressures of their jobs, the outcomes for patients will be much better. As carers we often talk about how our loved one is unlikely to get good effective help from CPFT or elsewhere if it is not built on a relationship between a professional and a patient which is based on mutual respect and trust, and where there is continuity.

I’ve shared my notes on the event with CPFT and if anyone wants to know more about all this, please contact me.

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.

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