

**Enfield Carers Conference
Summary Report
Mental Health Awareness
Week 2024**

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Introduction

Every year, in May we honour Mental Health Awareness Week, to highlight and try to address and identify the issues of those struggling with their mental health. But, in tandem with those struggles, there is the often, hidden story of the army of unpaid Carers, who work tirelessly to support their loved ones and to give them the chance of living a full and happy life. To support those Carers, and to provide advice and help, in May 2024 Enfield Carers Centre (ECC) held their inaugural Mental Health Carers Conference. With over 50 attendees, there was a clear need and enthusiasm for this opportunity to share, learn and build awareness.

The overarching aims and objectives of this Enfield Carers Centre Mental Health Action Week Conference were:

1. To actively co-produce and involve Family/Unpaid Carers in the improvement of borough-wide support for Carers who are supporting people with mental health conditions
2. To gather feedback on mental health services in Enfield, help to identify any unmet areas of need and to facilitate improvement in existing services

Part 1

Conference

The conference was opened by **Pamela Burke**, Chief Executive of Enfield Carers Centre (ECC), who welcomed everyone and explained the objectives of the conference.



In her introduction to the Conference Pamela Burke, Chief Executive of Enfield Carers Centre, spoke of the sad fact that there are so many repeated issues for Mental Health Carers. Pam emphasised the determination of Enfield Carers Centre to listen to Carers and help adapt services to meet their needs.

There is a lot of existing support available for Mental Health Carers both from Enfield Carers Centre and other organisations, including advice on financial and practical matters, advocacy, respite and facilitating mutual support among Carers. However, many Carers attending the conference felt that their involvement as key providers of care wasn't recognised (or sometimes wanted) by statutory providers of Mental Health services.

An emerging theme, from Carers at the conference was the need for better co-operation and partnership to support the wellbeing of both Carers and the cared for person (Mental Health Service User). In this spirit, Enfield Carers Centre welcomed the support, involvement and contributions to this conference from colleagues at Carers Trust, Mind in Barnet & Enfield, North London Mental Health Partnership, Enfield NHS Talking Therapies, PohWER, Healthwatch Enfield and Working Well Trust.

Sharon Spurling, Triangle of Care Programme Lead at Carers Trust (national umbrella body for Carers Centres) delivered a presentation on the Good Practice Key Elements of the Triangle of Care. The Triangle of Care is a strong model of partnership that had been adopted by Barnet, Enfield & Haringey Mental Health Trust many years ago. The model emphasises the need for three-way communication and involvement between the cared for, professionals and Carers. With the full involvement of Carers, much more can be done to prevent hospital admissions and re-admissions. Such an approach was warmly welcomed by Carers, although some said that it did not echo their actual experiences. All present at the conference agreed that the Triangle of Care is a useful model and one that should be adopted again by the North London Mental Health Partnership. It was generally agreed that there was more work to do to achieve its aims within Enfield.

Speakers at Mental Health Conference

Danny Newland and Mark Warwick from Enfield Carers Centre introduced the conference agenda and the aims of the day. All Carers were encouraged to participate, ask questions and network with other Carers.

Andy Hofmann, Diren Incedal and Aimee Macleod, Psychological Wellbeing Practitioners delivered a short workshop on Mental Health Awareness with a focus on Enfield NHS Talking Therapies. This also involved an interactive quiz on the topic of depression.

The Practitioners explored the nature and causes of mental health problems, and strategies for helping Carers to deal with their own stresses and concerns. Carers were asked what they felt would help them, what works and what doesn't in the current support network. For so many Carers, the problem of having the opportunity to take time to discuss and share views is difficult. Enfield Carers Centre recognise this and will be trying to make services more accessible by varying event times, hopefully to include evenings, and offering online access.

Also, recognition needs to be given to the specific needs of family Carers, combining this with more general support, and opportunities for respite and social interaction to help avoid feelings of isolation. Balancing the need for peer support was seen as important, as some Carers felt that constant discussion of the same issues could end up as "one big moan" and be depressing.

Perhaps unsurprisingly, Carers expressed frustration at the failings of the systems which are meant to support them. While there was a general acknowledgement that services were under resourced, and that many professionals provide a good service, delays, lack of proper advice and bureaucracy all came up many times as making life difficult for Carers. In particular, Carers were angry that so often the urgency of their problems wasn't responded to. Caring for someone with mental health issues can often lead to difficult and threatening situations, and they felt unsupported and isolated when this happened.

Another theme from Carers was the need to promote understanding of what Carers have to cope with. Clearly some Carers felt that their challenges were trivialised by others, suggesting that someone had "a bit of OCD" or "a bit of depression". Such reactions, failed to understand the profound effects of such conditions, and the impact that they had on so many lives, including, of course, Carers.

Mark Pritchard, Interim Managing Director for Enfield Community Mental Health Services provided an overview of Enfield's local community support offer.

Ellie Crawford, Head of Services Mind in Enfield and Barnet, provided an overview of services offered by the local branch of Mind including their Sanctuary Crisis Hub which is open Monday to Friday 5pm to 9.45pm Saturday & Sunday 12pm to 4.45pm. Enfield – 020 8906 7509

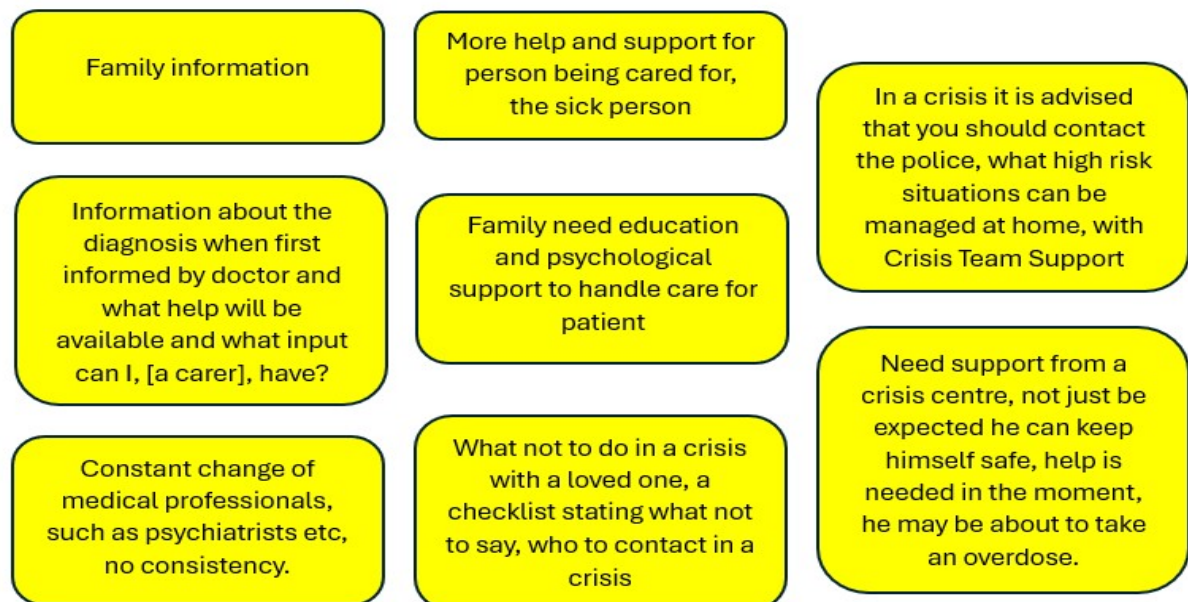
**Copies of Presentations can be requested via
info@enfieldcarers.org**

Part 2

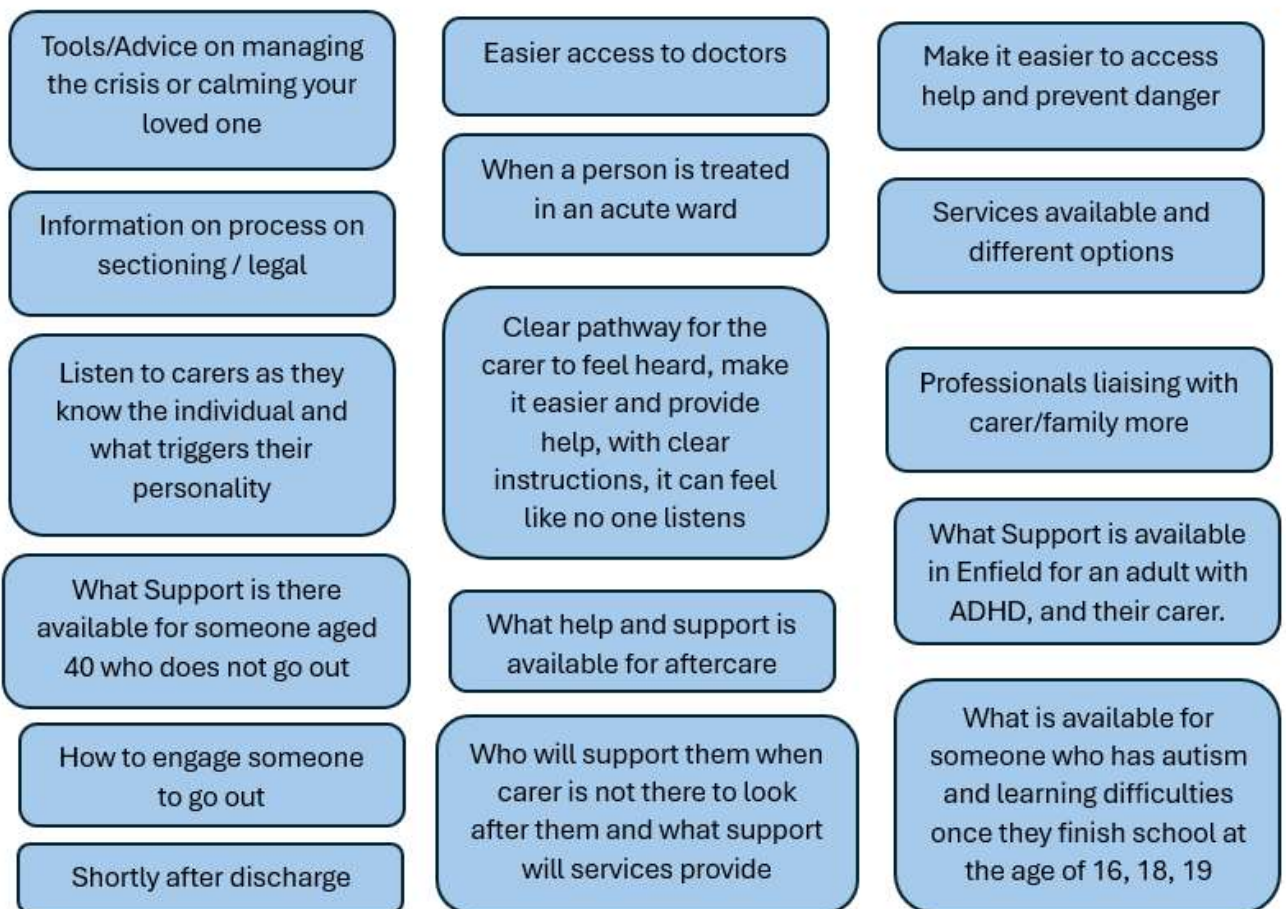
Tabletop Discussions – Outcomes and Feedback

Carers were asked to give feedback within small groups on the following topics.

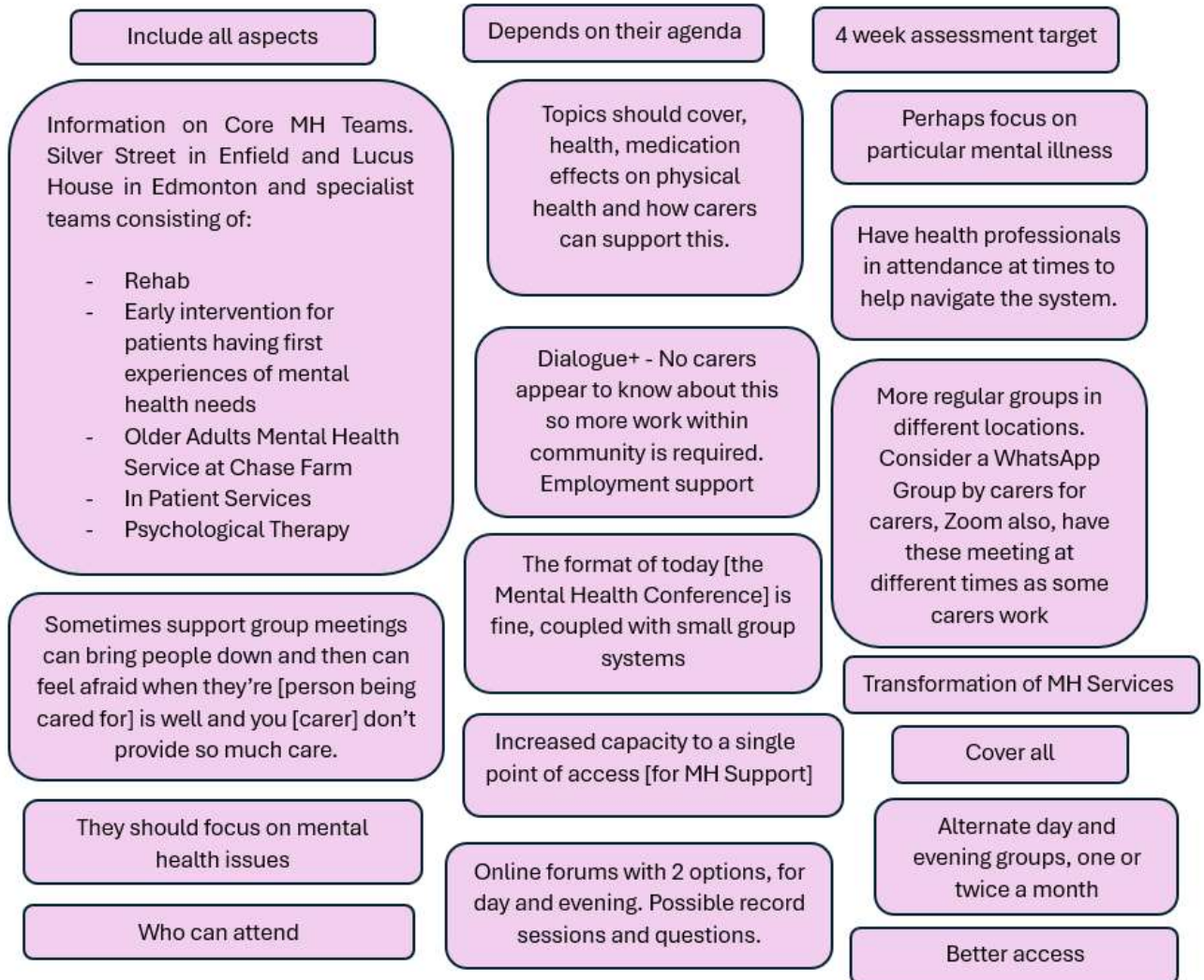
1. **What training or information do you think should be provided to Mental Health Carers when the person they care for first becomes unwell and generally, as that person goes through various stages of recovery and relapse?**



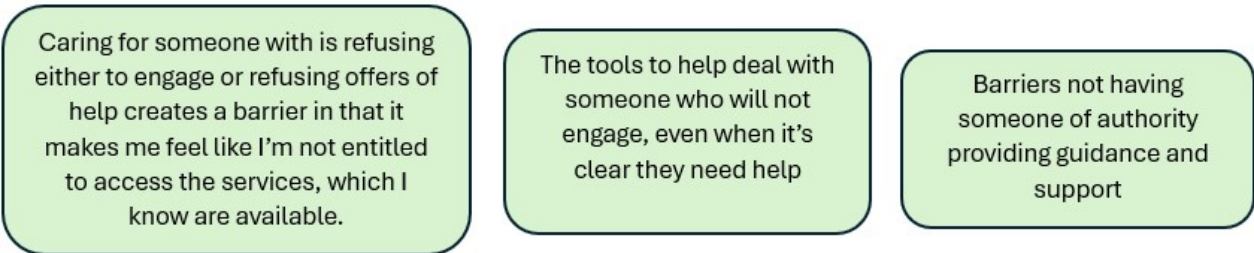
2. If Enfield Carers Centre was speaking to, or training, Mental Health Professionals about improving the experiences of Carers, what information would you say was essential to convey? Would there have been different information you would have found useful at different times, from professionals? (E.g. if the person you care for was being treated in an acute ward, or shortly after being discharged?)



3. How often should Enfield Carers Centre groups be held, and what time of day/evening would be best? Should the focus be on one-off big events or regular smaller groups? What formats should these take? Should they focus on Mental Health topics only, or include social, relaxation or other aspects; or rotate through these different options?



4. Do you feel there are barriers to accessing services from Enfield Carers Centre or other organisations. Based on your experiences of caring for someone with mental health, what would help positive engagement?

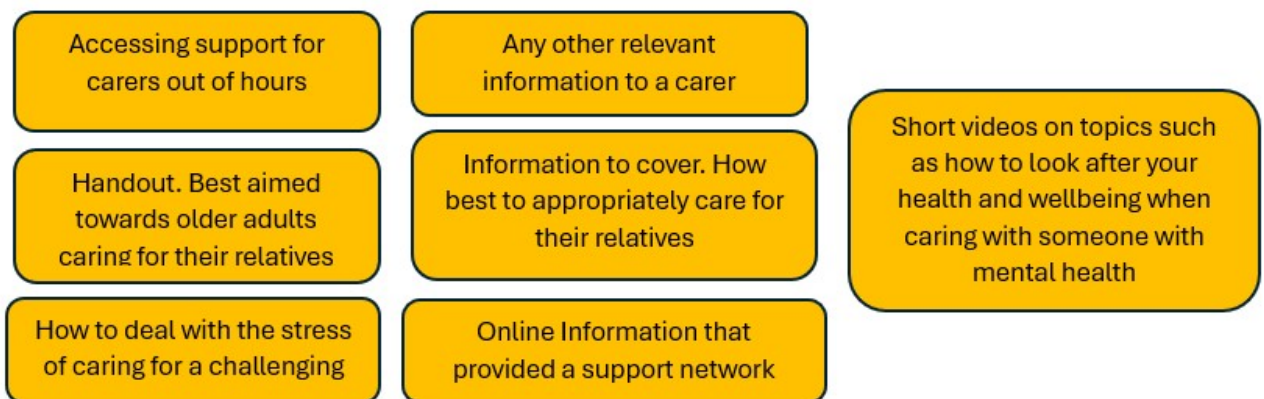


Caring for someone with is refusing either to engage or refusing offers of help creates a barrier in that it makes me feel like I'm not entitled to access the services, which I know are available.

The tools to help deal with someone who will not engage, even when it's clear they need help

Barriers not having someone of authority providing guidance and support

5. If Enfield Carers Centre were to create an information pack/webpage for Mental Health Carers, what should be included in this? Would it be best to be a handout or online, or short information videos? Would having an online drop in with ENFIELD CARERS CENTRE Staff and key mental health professionals be something you would find useful? If so, what areas should be covered?



Accessing support for carers out of hours

Any other relevant information to a carer

Handout. Best aimed towards older adults caring for their relatives

Information to cover. How best to appropriately care for their relatives

How to deal with the stress of caring for a challenging

Online Information that provided a support network

Short videos on topics such as how to look after your health and wellbeing when caring with someone with mental health

Part 3

Question & Answer Panel

The Question & Answer session concluded the conference, providing a lively and informative exchange of views, information and advice. Linking back to the comments made by Pam Burke at the opening of the conference, many of the questions referred to long-standing problems, and Carers' struggle to access helpful and consistent advice.

Panel Members:

Erasmus Tacconelli	Consultant Clinical Psychologist – Barnet Enfield & Haringey MH NHS Trust
Dilek Demur	Systemic & Family Psychotherapist – Barnet Enfield & Haringey MH NHS Trust
Jon Robson	Senior Operations Manager – Enfield Primary Care Trust
Lucy Omezi	Head of Service – Rehabilitation Team, Barnet Enfield & Haringey MH NHS Trust
Saffron Lee	Early Intervention Psychosis Team – Barnet Enfield & Haringey MH NHS Trust
Florence Fendarmas	Early Intervention Psychosis Team – Barnet Enfield & Haringey MH NHS Trust
Andrea Morkah	Enfield Community Transformation Pharmacist – Barnet Enfield & Haringey MH NHS Trust

Questions posed to the Mental Health Panel and their responses

Q. How do you approach someone self-medicating with drugs/alcohol. How can a family offer support.

A. There are a range of teams available to help. Clients may have co-morbidities, such as depression and substance abuse. The MH Trust has a Dual Diagnosis Worker to help with this. If someone is under the influence of a substance, it may be that that needs to be addressed first before looking at other issues. In primary care, consent is needed from the client to be helped. If they don't want to engage, legally they have that right. The key issue is whether or not they have 'capacity'. It may be that they move towards full capacity as the effects of the substance wear off. It's a complex area, requiring a wider understanding of neurodiversity and an integrated approach.

Q. I have not been able to get a diagnosis for autism over an extended period. Only The Maudsley offered support, and there was a 4 year wait for this.

A. There may be a need for a further diagnostic, and there is a clear need for ongoing support here, as well as different routes for diagnosis. This is an issue that still requires a strategy to address appropriately.

Q. Mental illness means my cared for resists therapy, sometimes leading to a threat of discharge. This causes stress to me, and re-referral can cause delays. This has been made worse by moving from another borough. Care is available, but hard to access due to bureaucracy.

A. There is a real need for the client to engage, but there should be a number of ways to engage available, not just "on the couch" therapy. There has been an investment in more community support and, in the move towards more person centred, aim driven support via Dialog+, it is hoped that support can be tailored more to the preferences and needs of individuals.

Q. Can you say more about Dialog+?

A. When compared to Care Plan Approach Support plans, Dialog+ is more focused on the changing circumstances of the service user, creating a constant "dialogue" to reflect on progress and move towards desired goals. The carer can be part of the discussion (as can the family) as long as the service user agrees. **It was noted by Enfield Carers Centre that no attending Carers were aware of Dialog+ and so it will arrange sessions regarding this for carers as an outcome of this conference.**

Q. What happens if a client is incapacitated (unable to make best interests for themselves)?

A. You should contact an advocate to ensure that decisions taken are in the best interests of the service user.

Q. Is it true that Enfield Barnet & Haringey MH Trust is merging with Islington & Camden?

A. Yes, but Enfield services will remain local. The aim is to level up services across boroughs, and to give a wider access to beds.

Q. Are there any resources for carers in the MH Trust?

A. Families can be included in therapy, as they're affected as well. However, if therapy is individual there may be other support for families, for certain conditions, such as OCD. After there has been an intervention for someone with psychosis then there is a support group for their carers that can be accessed. In regard to information about medication, there are website and leaflet resources to explain how medications work and the effects they can have.

Q. Continuity of care is a big issue, we always seem to see different doctors.

A. A Care-coordinator should provide a bridge between professionals. Ideally there would be continuity for consultants, but staff move on for a variety of reasons and this is not preventable. Professional teams should try to make a transition as seamless as possible but understand that this can be distressing.

Q. How can a Carer get help with a new issue or crisis?

A. The Crisis Team should respond. There's a single point of access at Crown Lane, Southgate. They assess and offer a pathway forward, or discharge. This service can be accessed via self-referral, but ideally through the GP.

Q. What happens when a young person with mental health issues moves from CAMHS (Children & Young Persons) to Adult Services?

A. CAMHS is a more family focussed service, and Adult Services may seem strange at first. The Transition Service will provide a bridge and pass on an understanding of service user needs to try to reduce the any stress during the transition process.

Q. If a Carer is not mentally robust themselves, where is it best for them to go for help?

A. Talk to the team caring for your loved one. They may be able to arrange respite etc. or possibly refer you on. A carer may sometimes need their own mental health support, as a service user. The voluntary sector may also be able to assist. Mind in Enfield and Enfield Carers Centre offer a range of services and are a very useful first point of contact to understand your rights and options.

Q. What can I do if my cared for is not taking medication, but won't allow information about this to be shared?

A. Professionals can't legally share information without consent. However, you can share any information that you feel the team should be aware of, as it is still useful for them to hear from the carer, even if they can't respond. A Care-coordinator may also be able to help by engaging the cared for and discussing how they are managing generally.

Q. Dialog+ is a holistic system, but if a cared for is not engaging, what should carers do?

A. Work together with the professionals. Never feel that you're alone.

Q. I was ignored as a Carer and told as my cared for is an adult I couldn't be involved unless there is a crisis.

A. The panel all felt that it is not acceptable to be excluded in this way, although the law on patient confidentiality does make it difficult. A professional should still be able to listen to the concerns of a family Carer even if they cannot divulge information about treatment or care plans.

Owing to time constraints, some questions/comments submitted could not be put to the panel. However, these are listed below have been responded to by the Support Team based at Enfield Carers Centre.

Q. Please advise on activities available for both loved one and carer to get involved together.

A. Occasionally Enfield Carers Centre provides trips and events for both Carers and cared-for people. Carers are advised to check local events and activities organised by voluntary and community groups in Enfield such as Mind in Enfield.

Restrictions on staff time and funding often result in organisations focusing on the essential needs of service user, or core services; which can mean things like social activities for Carers and their cared for persons are a secondary consideration, even though recognised that these can be highly beneficial. If carers feedback that they want more of these types of service via evaluations and consultations, this can help shape the services offered.

Q. We need early diagnosis and prevention of dementia (early MRI scans).

A. This question appears to be more a comment than a question and has been passed to the Integrated Partnership Board as feedback from the conference.

Q. My husband, aged 82, has had treatment for resistant depression for 7 years. He doesn't want to stop his SSRIs, (Selective serotonin reuptake inhibitors), in case he gets worse. He is reluctant to ask GP. What next? The Priory? NHS?

A. It can be difficult when the person we care for is making, what we consider to be, unwise decisions. Carers may strongly believe that the person they care for would be much better if they took specific actions and feel that their decision is being guided more by their declining mental health, rather than personal choice.

However, the law does not allow for a service to interfere with a person's choices if that person has capacity to make those choices. In this case, as the cared for doesn't want to speak to his GP, then it is unlikely that he will choose to discuss this need with any service.

Perhaps they could be encouraged to speak to their GP, just to talk about potential alternative treatment as a first step. As trying to persuade someone to do something they don't want to do can cause friction in relationships, and this is another factor that needs to be considered. Perhaps gentle suggestions would work better than trying to debate or reason with them, should they continue to refuse support.

Q. In a maze of professional help, how do Carers/patients find a route to greater help?

A. Services such as Enfield Carers Centre and Mind will do their best to support Carers and service users to understand their rights and would support communication with Mental Health Teams. The outcome is heavily dependent on each individual situation and although resolution can't be guaranteed, these services would do their best to assist throughout.

Although, it is recognised that more holistic, family-based approaches, would also be beneficial. The focus for the mental health team will be on the patient and their wishes and sometimes the voluntary sector is in a better position to provide help for carers.

At the moment, it is highly likely that someone with a variety of needs will have to access various services from different sources and it is often left to the individual to find these and cobble them together. It is hoped that with better partnership working that this experience can be made easier for carers.

Q. Are there no services in Enfield catering for ADHD?

A. There are clinics that support those with ADHD, it would be recommended that this be discussed with their GP for a referral to an appropriate service. There is also information on the North London Mental Health Partnership website. There are also online resources to help families better understand ADHD; such as www.youngminds.org.uk

Q. About the Crisis Team. Why are we told to call the Police? What do I do if the cared for won't take their medication?

A. If you are concerned about someone having a mental health relapse during normal office hours you are advised to call the team that oversees their care. If out of hours (after 5pm or before 9am), then you would be directed to call the Crisis Team. The advice to call the police is for situations where there are concerns that there is a risk of harm to self or others if there is no rapid intervention. The advice to call police would always be given if there is any potential risk of harm to someone.

Regarding someone not taking their medication(s), a Carer should be able to raise this with the cared for person's mental health team. Owing to confidentiality, the team may not be able to comment back but can take note of any concerns raised. The mental health team should also not tell the patient that a Carer has been in touch, as this may cause bad feelings.

How the team react would be dependent on the situation. They may find a reason to reach out to the patient and invite them for a wellbeing appointment, for example. However, if a patient has capacity, then they have the right to choose not to take their medications, even if all those involved in their care consider this to be an unwise decision.

Q. It would be helpful if there was a website that Carers could access basic information e.g.:

- a) Structure of the service.**
- b) Who's who.**
- c) Therapies available and a definition of them.**
- d) Definitions of different conditions.**
- e) How to get in touch.**
- f) Our rights as parents (although it's becoming clearer!).**

A. You can find information on the website for North London Mental Health Partnership with details about services available in each borough. There is a section for Carers and a section explaining what to do in a crisis.

Q. What is Dialog+ and how, as a Carer, can I ask for it to be implemented by the Care-coordinator to involve me in the process?

A. Dialog+ is a new assessment-based support plan. Patients used to have a Care Plan Approach (CPA), which looked at all their needs to help form a support plan to address these. Dialog+ is more focused on the key aims that the patient wants to achieve and so support is more tailored towards what is important to the individual than just general in nature.

For example, if someone was eager to find work their support would primarily focus on assisting them to achieve this. The patient also gives themselves a score of where they feel they are at the start of the process and again after having the support, allowing evaluation of any improvements that the patient feels they have achieved towards their personal goals. As the person progresses in their recovery their aims may change and so their support, via Dialog+, would also change to focus on meeting the new desired outcome.

In theory, the person you care for should be able to request a Dialog+ assessment from their supporting Mental Health Team. If the cared for consents, then there shouldn't be any issue with a carer being involved in the process. However, as this assessment focuses on the patient's priorities it should be anticipated that their views are considered more essential than those of the carer.

Q. How do I communicate with CPN, psychiatrist and Crisis Team?

A. Carers should be able to call, or arrange a call, with professionals supporting the cared for; we do understand that professionals can often be difficult to contact. Carers are asked to be understanding that sometimes key professionals have heavy caseloads and a lack of time in which to respond. If you are finding constant barriers when trying to reach a professional, or team, then the Trust's Patient Experience Team, Enfield Carers Centre or organisations such as Mind or POhWER can support advocacy, comments or even the making of complaints, in cases where Carers are finding they are not being heard or treated as an expert partner in care.

Q. How do you deal with patients who are suspected with another condition, e.g. autism in addition to mental health issue? What services are provided to clients with both mental health issues (schizophrenia) and autism?

A. In the majority of cases a person with high functioning autism and schizophrenia will be treated the same as other patients with the same mental health diagnosis by the Trust; although there should be reasonable adjustments made to support them to access their treatment to minimise additional distress.

A person with high level of autistic needs may be eligible for support from the Integrated Learning Disability Team (ILDT). This team has a multidisciplinary team, which includes psychologists and psychiatrists.

Q. Is there a crisis centre that can help instead of calling the Police?

A. We recommend that if there are issues during normal working hours – the team that already oversees the care of the cared for person is contacted. If out of hours then the Mental Health Crisis Team, 0800 151 0023; there is also the Sanctuary, which is run by Mind, 020 8906 7509, Mon–Sun, 12–10pm.

There are also Crisis Prevention Houses that a patient, already known to mental health services can self-refer to. This would be organised by speaking to a mental health professional about their concerns. The advice to call police will always be given if there is any potential risk of harm to someone if the situation is not dealt with promptly. The police have powers to take a person to a “place of safety” and to hold them temporarily to allow time for follow up assessment.

Conference Feedback/Carers' Comments

32 Carers completed and returned evaluations. Not all questions were responded to, explaining why percentages do not total 100%

Did you find the event worthwhile?		Was the event well planned?		Did the event provide relevant/useful info?			Did the event help you feel less isolated?			Did you meet other carers to share experiences?	
Yes	No	Yes	No	Yes	No	Little	Yes	No	A little	Yes	No
30	1	30	0	19	5	7	19	3	6	26	2
94%	3%	94%	0%	59%	5%	7%	59%	9%	19%	81%	6%

Feedback on the types of services that should be offered at Enfield Carers Centre for Mental Health Carers.

Services needed:

- Be there for questions to be answered when needed.
- Get the new policies advertised and explained.
- Provide some social events to cheer us up and socialise.
- Advocacy and wills.
- Going on holiday when the person you care for is not joining, therefore breaking family up.
- Respite care for both carers and cared for.
- Help with support in communicating with the Crisis Team and Lucas house, psychologist, CPT etc.

Perhaps offer a variety of access to support.

- A weekly or fortnightly Carers Support Group, face-to-face held at ECC to share experiences and to socialise.
- A physical break from caring responsibilities.
- Input from professionals.

Emails from the Centre telling me what you're doing (I won't check website weekly to check what you might have)

Buddying would be really appreciated, as my cared for has been refusing to leave the house. A reachable target would be for a befriending buddy.

Could there be workshops and services that engage with specific mental health conditions?

Stay in contact with carers by phone call on a regular basis (moral support, "agony aunt").

Help in directing carers to the most appropriate services in their circumstances.

Is there a service that can help with autism, where the person is refusing to leave the house for days on end?

Support services for carers of loved ones with mental health disorder, but it needs a facilitator with psychotherapeutic skills, or at least different outside speakers with specific skills in mental health or knowledge.

Attendees' responses to question:

Which part of conference was most useful?



Attendees' General Comments



Conclusion

No one event will ever solve the many challenges that were highlighted on the day. However, the general feeling was that the Enfield Carers Centre conference was very worthwhile, and a useful start towards hopefully strengthening the support network that Carers want, need and very clearly deserve. Hopefully next year's conference will exhibit the evidence of progress being made towards this.

Ongoing Commitment by Enfield Carers Centre

In consideration of the feedback provided by Carers at this conference, Enfield Carers Centre will re-introduce a monthly Mental Health Carers Support Group. This will initially be at a set time, during the Centre's normal opening hours and there will be discussions about specific mental health topics, such as medication, overviews of mental health conditions; as well as sessions that just focus on social inclusion and wellbeing.

The Centre will continue to work with the mental health teams to provide a more holistic support network for Carers and to ensure that any information requested by mental health carers is accurate and up to date.

The focus of this work will cover what to do in a crisis, Dialog+ and positive communications between Carers and professionals, as these appeared to be the area that Carers reported concerns about.

Enfield Carers Centre's ultimate aim is to continue to make mental health Carers feel welcomed and supported by the Centre, so we are able to understand the challenges that are repeatedly faced. Wherever possible, we will work in partnership with Carers, mental health professionals and other members of the voluntary sector to resolve these challenges.

