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The Cygnet Journal

Improving lives together

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Artwork created by service users at Cygnet Services

Contents

Introduction

The Second Edition

In this second edition of the Cygnet journal we focus on the experiences of carers, including those with lived experience, and ambassadors who help promote the rights of carers across our organisation.

The initial concept for The Cygnet Journal was to provide a platform for showcasing some of the collaborative work which takes place within Cygnet and to ensure that this is accessible to carers, stakeholders and anyone else who shares an interest in our practices.

As a peer reviewed journal, its aim is to share research, quality improvement and developments that are professionally relevant, in addition to welcoming discussion and special interest pieces from people affiliated with the company.

We would like to thank our authors for their patience and everyone who has supported us in putting together this publication.

The Cygnet Journal Editorial Team

Dr Lorraine Bobbie Turnbull

Bobbie is a Consultant Clinical Psychologist working at Cygnet St William's, which is one of Cygnet Health Care's Neurological Rehabilitation hospitals. She is also the Cygnet Lead for Research and Development, as well as a member of the Greater Manchester Research Ethics Committee, and a reviewer for one of the UK Psychology peer review journals.

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Sarah is a Forensic Psychologist working within Cygnet Health Care's Neuropsychiatric service line. She has a passion for clinical research, with over 30 publications including academic articles, book chapters, manuals, and academic posters. She is regularly invited to act as a peer reviewer for academic journals and presents her work at national and international conferences.

Raf Hamaizia

Raf's role as an Expert by Experience sees him using his perspective as a former service user in a variety of organisations within the public and independent sector. This has included the development of policy and guidance with NICE (National Institute of Health and Care Excellence), the Royal College of Psychiatrists and the NHS.

He is currently the Expert by Experience Lead at Cygnet, leading on the organisation's engagement and involvement initiatives.

Writing for The Cygnet journal

If you would like to write an article for the journal, we welcome any of the following:

- Research / QI / Audit projects
- Reviews
- Opinion pieces
- Articles around innovation
- Service user / carer perspectives
- Book or training reviews

Submissions should be emailed to the editorial board at **TheCygnetJournal@cygnethealth.co.uk**

Foreword

It gives me great pleasure to introduce the second edition of The Cygnet Journal, a collection of articles written by our dedicated clinicians, colleagues and carers across the organisation. This publication continues to shine a light on the exceptional expertise, innovation and compassion that define Cygnet.

In this edition, we focus on an area that lies at the very heart of recovery and wellbeing - the vital role of carers and families in mental health care. The support, insight and lived experience of loved ones are invaluable in shaping meaningful, person-centred care.

Getting this right matters deeply, not only because it improves outcomes for those we support, but because it reflects our values of Care, Respect, Empower, Trust, and Integrity.

At Cygnet, we know that care does not begin and end with our clinical teams. It extends to the people who stand alongside our service users every day. Building strong, trusting relationships with families and carers ensures that we truly understand each individual's needs and aspirations. It allows us to work together in ways that promote dignity, continuity and hope.

This journal highlights how our teams are working to strengthen those partnerships, whether through co-produced care planning, family liaison initiatives, or innovative carer engagement programmes. Each article demonstrates the commitment and creativity of our colleagues, as well as their drive to share learning and improve practice across the sector.

Our growing focus on research and development continues to underpin everything we do. By grounding our work in evidence and learning, we ensure that the care we provide is not only compassionate, but consistently of the highest quality.

I would like to thank all contributors to this edition for their insight and dedication. Your work exemplifies Cygnet's mission, to help those in our care, and those who care for them, to lead fulfilling and meaningful lives.

Dr Tony Romero, CEO, Cygnet

A Carer’s Journey

About the Author

Julian de Takats
Cygnet Carer Ambassador

This article discusses his personal perspective of being a Carer, and how this led to him becoming an ambassador for other carers.

A couple of months ago, I attended an event at a Cygnet Hospital, and met three new carers; the husband, sister, and the mother of a new service user who had recently been admitted to the hospital - and they were in a state of shock. Everything happening to them was a new and frightening experience - they didn’t know what was going on with their loved one - their wife, sister and daughter respectively. They simply didn’t know where to start or who to speak to about her, and the last thing on their mind was being told they were ‘Carers’.

The whole world of mental health is brand new territory to most of us; with its language, labels, systems, processes, job titles and acronyms, diagnoses and medications. And then the difficulties with the illness itself - it’s bewildering when the person you love changes unrecognisably and is behaving in strange new ways and thinking odd new things, things we simply find it hard to relate to and can’t comprehend.

I was in a similar state myself for years - shocked by my son’s strange beliefs and irrational fears: he started hearing voices and feeling threatened by unknown forces, believing that everyone was plotting to hurt him and living in constant fear. I later discovered this was psychosis and these thoughts were delusional thinking - but trying to communicate with and respond to this new character was a startling new process.

Finally, my son was sectioned after a six-month period of escalation of his psychosis with crisis after crisis - it seemed we just couldn’t access help anywhere - until his third appearance in court in less than the space of a month. Finally, the Youth Intervention Team at the Magistrates’ Court stepped in and asked ‘What’s going on at home?’ We both burst in to tears and explained that our son was experiencing voices and paranoia, and escaping in to substance abuse and dangerous, reckless and violent behaviours.

This was the very start of my 10-year journey in the mental health world, where I, as a now single parent, am navigating my son’s changing persona, his interactions with his mental health and Community Teams (and Probation Officers), his ins-and-outs of A&E, Police holding cells, Acute and PICU wards and along the way Supported Housing and attempts to live together at our new home by the sea. After two years of this, following on from my wife’s sudden death, my son was finally diagnosed with underlying conditions rather than ‘substance-induced psychosis’ and it was decided that a long-term placement should be found for him.

The next steps on my journey began, as after seven long months of looking, a specialist rehabilitation unit was found in London within Cygnet for him - and this brought with it some hope and respite, but not for long. I had moved back to London to be nearer accessible services and support for my son, and this worked with his new placement too as I was able to visit him every week. But a few short months after he was moved to Cygnet Hospital Harrow, the country went into COVID-19 lockdown, and visits became difficult and then impossible as the ward went into isolation.

My son didn’t respond well to not seeing me in person, he couldn’t cope with the separation and increased restrictions, and his behaviour worsened into physical aggression, disruptive abuse, and very visual and destructive self-harm. During this time my only communication with him was daily phone-calls, weekly online meetings and the odd Teams Ward Round. It was during one of these online events that I was told that my son was “too challenging to be managed on the ward” and that they had referred him to a medium secure unit. However, with the ongoing restrictions with travel and so-on, that this probably wouldn’t happen in the foreseeable time.

It came as a surprise then, when less than a fortnight later a place for him had been found - in Bury (North of Manchester). "Where on earth is that?" I asked, and on hearing the reply, I said "He can't move there that's ridiculous - how on earth am I supposed to visit him there?" "Don't worry, it won't be for long", I was told. "Well, it's not happening", I said, and the reply was, "He's already on transport, he left an hour ago…"

And so a new chapter in our journey began. My son entered a secure ward some 230 miles away from home, with new restrictions, environment, characters to get along with and new personnel. There were also new travel arrangements (and expenses) that added up to a 6+ hour journey each way or a 16+ hour travel day to come to terms with.

After a year it also opened up another chapter when I was invited to a 'Carers Event' at Cygnet Hospital Bury. My immediate response was 'But I'm not a Carer', and was told, "Well, you're a parent and you're invited too - and we'll contribute towards your travel by getting you a hotel for the night." This was a game-changer, and I said "Great, I'll be there!"

A few months later at a second Carers' Event in Bury, where the term 'carer' was beginning to sound relatable, I actually involved myself in some of the discussions, and no doubt came across as angry, frustrated, and belligerent. But watching in the corner of the room was a member of the Cygnet Head Office team who came up and spoke to me afterwards – "You have a lot of energy and passion," she said, "but it's all negative - if you really want to make things better you need to use that energy more positively. Why don't you come to our next Carers' Event in London?"

This was the real beginning of my story as a 'Carer'. Up to this point I had always been simply 'the parent' looking after his son as best he could, but now I started to realise I was part of something far, far bigger. I was a Parent Carer - one of the one million plus parents, husbands, wives, children, brothers, sisters, lovers, friends or others caring for their loved ones suffering from mental health illnesses or conditions - and all largely unpaid. It took me a long time to come to terms with the fact that I was a Carer despite my son actually being 'cared for' in hospital by others. I was still caring on a daily basis - the worry, the emotional support to my son provided in daily phone calls and monthly visits, the life and financial admin on his behalf, the team meetings and the Teams meetings, the mental health and medical admin and arrangements, and the constant stress and anxiety about his life and his future.

I was first invited to share my 'Carer's Journey' back at Cygnet Hospital Harrow in September 2023. Given our history there, as my son's first long-term placement and the traumatic time we'd all been through with COVID-19 lockdowns, it was incredibly moving and nerve-wracking for me seeing many of the same staff there who remembered my son with kindness and sympathy.

This was my official start as a Carers' Ambassador - a role I have now been in for just over a year, and in that one year I have learned far, far more than I ever did in the previous nine years. I have learned the difficulties and challenges faced in keeping very ill people safe and well, alongside other people with equal difficulties and I have, as I did in Harrow that time, come to deeply respect the members of staff who support and care for my son, and the thousands of others with challenging and complex needs.

Next time I will go in to the detail of being a Carers' Ambassador, but for now, back to our friends I met at the start. This was the start of their journey - and they had question after question. They were going through everything I had; anxiety, stress, bewilderment and confusion about what on earth is happening and how do we fit in to this new reality? They sat opposite the hospital mental health team at a Carers' 'Drop-In' event and they didn't know where to start. I'd like to feel that I made a difference that day using my experience to bridge the 'gap' between the new carers and the professionals and made them both feel comfortable with each other. It was important to let them know that there were no silly questions, and start to break down that gap, letting them know that these professionals and support workers were also caring and kind individuals who also wanted the best for their loved-one.

More importantly, I hope they came away from that event beginning to see themselves as Carers too and realising they are not alone. A million of us have been through similar journeys, we've been there before, and although we might be one step, or many miles further down the road, we are still travelling the same route, and can offer support, companionship, community, and the benefit of our shared experiences - it's all there, but for one small step - saying **I'm a Carer too!**

Being a Carer Ambassador - How Did the Journey Start and Why Do It?

About the Author

Lesley Mellor
Cygnet's Expert by Experience Carer Ambassador

This article discusses her experiences as a parent carer at Cygnet, how the Cygnet Carers' Network has developed and the value that it brings.

I am a parent of two sons who have both been deemed by the school and health systems to have additional needs. Despite this, the label of Carer did not feel as though it applied to me. This changed when the needs of one of my sons increased and Social Care became involved. And so it began, as it does for so many carers, each has a different story about this realisation that life will always be different for our loved one and ourselves.

Whilst in this turmoil of daily coping, decisions and planning about his future were suddenly taken away when, as he hit crisis, a place was found at a Social Care home over 60 miles away and he moved in. As he struggled to accept his new environment, so did we as his parent carers. We went through those universal feelings that so many carers talk about; grief, relief, anxiety, and helplessnesss.

It was during this period that I felt I had lost my role in his life. I was now used to the term of Carer but what use was that to me now? It was when completing the annual survey on my opinions on the home that I made a comment which resulted in a phone conversation with a lead person at Cygnet's Head Office.

She invited me to be part of a Carers' Network that Cygnet were setting up. The plan being was that by working together and being a recognised part of the team of support around the service user should and would make a difference. I already ran a Special Educational Needs and Disabilities (SEND) parent carers' forum, for newborns to 25-year olds, in my area. We have 900 members and so having the opportunity to understand the daily issues and practices of a big health organisation would be helpful to understand the world that many children and young people may step into.

What a wonderful experience it has been. Firstly, there was sign up from the very top at our first meeting. The CEO sat in with us for two hours just listening and that's when I realised that Cygnet were going to embrace a different emphasis on our caring role. We started looking at strategies, policies, handbooks, and accreditation of this work known as the 'Triangle of Care'.

I have had the opportunity of visiting many hospitals to meet Carers' Leads and carers at network events and I sat on an interview panel for a new hospital. We all are part of working groups and so it progresses. Following conversations with staff, the idea of a Staff Carers Group was raised. This is because as well as working in a caring profession, some people are also carers in their private lives.

The next steps will be encouraging more carers to be part of the network. By supporting their loved ones and coming together with the hospital or Social Care site, we all work better, preferably informally with a cake and cuppa. As an Ambassador, I love talking about what I learn every time I meet with any Cygnet employee and their interaction with me as a Carer. My feedback to families demystifies that scary world of mental health hospitals or homes because of how Cygnet is now working. So thank you staff, team leaders, and directors. It's been wonderful and feels like a partnership with solid foundations.

Celebrating Allied Health Professionals (AHP) Day at Cygnet Heathers

About the Authors

Ryia Farrow
Occupational Therapist

Ryia has been working for Cygnet since 2021 as an Occupational Therapist. She has worked across our service in the West Midlands including Cygnet Sedgley Lodge, Cygnet Raglan House and is currently working in our Neuropsychiatry service Cygnet Heathers.

Alex Scordis-Hutchinson
Clinical Lead Occupational Therapist for Neuropsychiatry

Alex joined Cygnet in 2015 at Cygnet Heathers and took on the role Clinical Lead OT for Neuropsychiatry in 2019. Rehabilitation and Neurology have been Alex's passion throughout her career as well as supporting service users to fulfil their goals. She works to support the development of OTs within the Neuropsychiatry service to ensure that they are providing the most up-to-date and evidenced-based service to service users.

Who are AHPs?

Allied health professionals (AHPs) are a diverse group of healthcare professionals who work in collaboration with each other and other professionals within a Health and / or Social Care setting to deliver comprehensive patient care. They bring specialised skills and knowledge that complement the work of each other to address specific patient needs. Their primary focus is on improving health and wellbeing of patients.

Professionals within the AHP group include: Art Therapists, Dietitians, Drama Therapists, Music Therapists, Occupational Therapists, Operating Department Practitioners, Orthoptists, Osteopaths, Paramedics, Physiotherapists, Podiatrists, Prosthetists and Orthotists, Diagnostic and Therapeutic Radiographers, and Speech and Language Therapists. Each of these are professionally autonomous practitioners educated to at least degree level standard (NHS England, 2022).

What do AHPs do?

According to NHS England (2022) AHPs are involved in assessing, treating, diagnosing and discharging patients across Health, Social Care, housing, education, the criminal justice system, independent and voluntary sectors. AHPs can support and manage people's care from birth to end of life across mental health and physical health specialities. They focus on improving health and wellbeing by maximising the potential for people to live full and active lives within their family circles, social networks, education/training settings and the workplace. This is achieved using an holistic approach, focusing on patient led goals and collaborative interventions with other professional within the Health and Social Care sectors.

What is AHP Day?

Allied health professionals are a vital force within the healthcare system, making up the third-largest clinical workforce. They are celebrated annually on AHPs Day, both in England and internationally. This day serves as a platform to recognise the remarkable contributions of AHPs to the delivery of care, with an opportunity to:

- Shine a light on the unique and essential roles of each individual AHP
- Showcase the impactful achievements of AHPs in local services and their positive influence on patient care and public health
- Foster collaboration and integrated working across different services, organisations, regions, and nations
- Inspire the next generation of healthcare professionals by highlighting the rewarding career paths within allied health

AHP Day is a chance to celebrate the AHPs dedication and expertise, and to reinforce their importance in providing high-quality, holistic healthcare.

AHP Day is a social movement to champion the exceptional qualities of AHPs (NHS England, 2024).

The theme of AHP Day 2024

The theme for 2024 was Quality and Safety influenced by the AHP strategy for England (2022-2027): AHPs Deliver.

An integral element of the care delivered by AHPs is ensuring that it is evidence-based and focused on improving health outcomes to ensure safe and high-quality care is achieved consistently across all sectors. This approach by AHPs aligns with the NHS AHP strategy which highlights "people first" and "optimising care". To ensure that everyone has access to the best possible care, AHPs embrace research and innovation to address health and care inequalities (NHS England, 2024).

How we celebrated AHP Day 2024 at Cygnet Heathers

At Cygnet Heather's Neuropsychiatry services our AHPs are Occupational Therapists, Physiotherapists and Speech and Language Therapists. Within our service, we collaborate on developing interventions, groups and research to enhance the delivery of care to our service users.

To demonstrate the theme of safety and quality, we planned a collective of activities for the day which included;

Hazard Hunt

Being a rehabilitation service, the collaborative goal between professionals and patients is to achieve a safe discharge into community living, whether that be home or supported living. We identified that the majority of our service users have goals around increasing their independence, like being able to live independently or use the gym autonomously. With this in mind we identified common hazards that could be present in each of these environments. We created a hazard hunt to support the service users to be able to identify potential hazards within these environment which could impact on their ability to remain safe.

Therapy Room

The therapy room is a space that is often utilised by all service users and features various areas designed to resemble a home environment. We set up common hazards that they could experience within the room and provided a worksheet to complete. Focusing on those essential teamworking and social skills, the service users were encouraged to work together to find the hazards.

These involved:

- A spilt drink
- Cigarette on furniture, representing a forgotten, lit cigarette
- Cupboards left open
- Wires exposed on floor
- Furniture knocked over
- Game piece on floor
- Marbles on the floor
- Tap running
- Pool cues and table left unkempt
- Scissors left open

Gym

The gym is commonly used supervised by staff, therefore, this activity allowed us to identify what levels of understanding each service user had of potential risks in this environment. The same rules applied, where the service users had to work as teams to identify the hazards:

- Running machine left on
- Tissue on the floor
- Balls cluttered on the floor
- Therabands left around
- Different trip hazards
- Equipment not put away properly
- Plinth left at highest setting
- Water spilt on floor

Overall, the task specifically encouraged service users to work collaboratively to identify what they would need to consider being safe or unsafe when they move onto the community. The task also allowed the service users to develop their teamworking skills. Each service user took on a different role within the group and worked together, having to use social skills to listen to each person speak, and make a collaborative decision. This allowed AHPs to observe how different individual's abilities within a group setting differed and what possible interventions could be proposed to maintain and or develop this further. As well as this, the activity provided opportunity for service users to work in a group to achieve a task and use social skills.

Bostin Bingo

The next activity was a game of bingo to demonstrate and create discussion with our service users as to what the role of the AHPs involved within their care were. In particular, this was helpful as we had new admissions and new staff members into the service and we were able to showcase our roles within their rehabilitation through this game.

The bingo consisted of the following:

- Who the AHPs were (Occupational Therapists, Speech and Language Therapists and Physiotherapists)
- What assessments are completed to identify service user's skillset throughout their rehabilitation such as; community and road safety, cooking, hot drinks and use of gym
- What specific groups were ran by AHPs

The activity sparked conversation about what AHPs were, who they were and what input each speciality had into the service user's care. The game influenced motivation around potential new groups and interventions that service users wanted. For the new admissions the game presented what opportunities are available and what they should expect to be completed in the admission and assessment phase of their rehabilitation in particular.

Pizza Making

The final activity of the day was pizza making. Although this was a fun and practical activity that encouraged engagement, it was also an opportunity for a practical demonstration of the rehabilitation process to be showcased to service users. The aim of this session was to highlight the need to engage within each stage of the process to achieve the end of goal.

The first stage was making the dough and letting it prove, this representing the initial assessment phase of the Cygnet neuropsychiatry rehabilitation model. The service users needed to make the dough by following clear instructions, and leaving it for some time to prove. This was replicable of the importance of receiving the input from all members of the MDT, not just AHPs, and understanding how it may take time to develop skills to be able to continue with rehabilitation. The service users had to practice sequencing skills and patience to ensure that the dough was formed properly and left long enough to warrant that it would be ready for the next stage.

The next session was rolling out the dough and adding toppings. The service users were given rolling pins and baking trays; working on their motor skills and ability to identify what size they would need to roll the dough out to fit the tray. This step represented the results coming together. In particular understanding that if the recipe was followed correctly above then the pizza dough now would roll out properly. This demonstrated that if we hadn't been able to complete the initial stages the quality of the next result would have been impacted. In relation to the rehabilitation model this step signified the development of skills and work with professionals to develop abilities, leading to the increase of independence and readiness for next steps.

Why we celebrated AHP day this way

The day's activities showcased the collaborative efforts of allied health professionals in enhancing the quality and safety of service users' rehabilitation. In our Neuropsychiatry service line, the interdisciplinary approach is essential for addressing the complex needs of our patients. This collaborative model fosters open communication, shared decision-making, and streamlined information sharing, minimising duplicated efforts and ensuring consistent, coordinated care. Research demonstrates that this interdisciplinary approach improves patient outcomes, leading to better symptom management, increased functional capacity, and higher patient satisfaction. Furthermore, it effectively addresses the multifaceted needs of our patients, including medication management, social support, physical and cognitive rehabilitation, and family education (Wade, 2015).

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Developing a Principled, Person-centred and Consistent Approach to Consent and Information Sharing with Carers in Mental Health Settings

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On 31st January 2025, Cygnet organised a stakeholder meeting as the first step towards developing a principled and coherent approach to consent, confidentiality and information sharing with carers in mental health settings. The cross-sector meeting, which included participants from diverse communities and perspectives, was a testament to the collective effort and commitment to this cause. Dr Jon Van Niekerk, Cygnet Clinical Director, and Laura Sheridan, Cygnet Head of Service User and Carer Engagement, hosted the meeting. Contributions came from representatives of Cygnet and other independent mental health care providers, alongside professional bodies such as the Royal College of Psychiatrists, the voluntary mental health sector, NHS Trusts, and academic institutions. Importantly, the voices of carers and those with lived experience were represented from across the country. With nearly 30 people in the room and a dozen more online, each voice was heard and contributed to the process of producing a standardised and accessible approach to consent and information sharing with carers.

The opening session focused on the fact that, all too often, the views and voices of carers are excluded or unheard in patient care and treatment decisions or discharge planning. For example, a 2015 Care Quality Commission survey of carers found that fewer than 35% reported they were listened to by mental health services or given the advice and support they needed. Researchers have also identified that carers often feel excluded and their views are not sought or valued by professionals in care planning (Wilkinson & McAndrew, 2019; Cree et al, 2015).

Karen, a mother and unpaid Carer for her son, shared a deeply personal and poignant experience at the meeting about her son's discharge from hospital without her knowledge or input. She explained the challenges she faced in managing her son's care at home, with little or no information about his ongoing treatment or care needs.

Unfortunately, this scenario is all too common. Too often, confidentiality and consent are used by mental health professionals as a barrier to involving family or carers in crucial decision-making about their loved one's care and treatment. This problem has been identified by Laing et al, (2024), who looked at the experiences of family members acting as a 'Nearest Relative' in Mental Health Act assessments and admissions. The researchers interviewed nearest relatives and found they are not routinely consulted or given information about hospital admission or discharge. Furthermore, information-sharing was generally viewed as poor, with requests for information often refused due to issues of confidentiality.

Staff also need to be aware, when an individual is formally admitted under the Mental Health Act (1983/2007), of the rights of family members as a nearest relative, which are distinct from their legal rights as carers under the Care Act (2014).

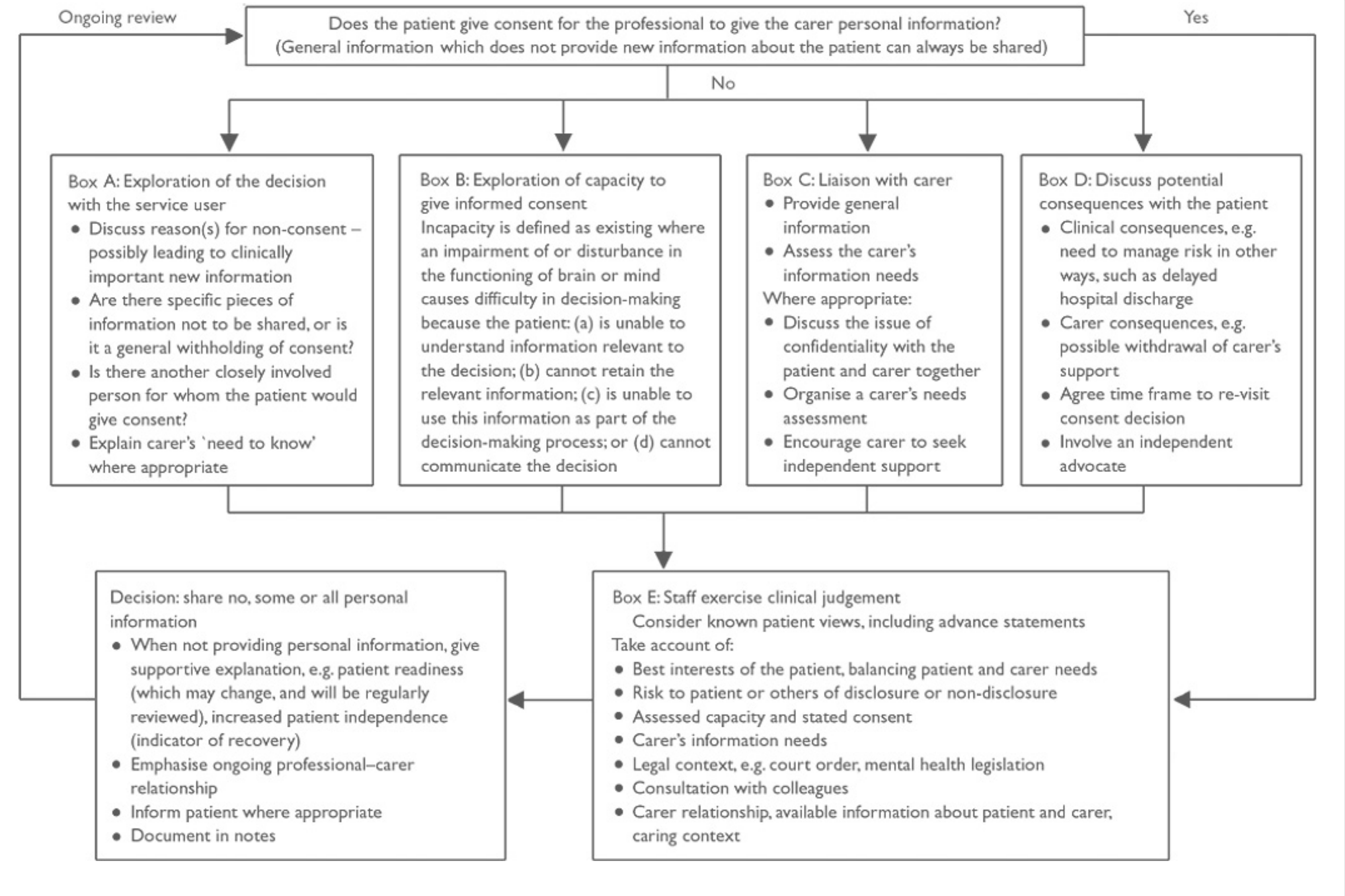
Carers and other members at the meeting also highlighted persistent confusion arising from diverse consent and information sharing practices across services. Staff often interpret the boundaries between 'personal' (confidential) and 'general' information differently, leading to uncertainty about what can be shared appropriately with carers. This leaves patients, professionals and carers unsure of their rights and responsibilities. These challenges highlight the need for better alignment with the Care Act, which places a legal duty on services to involve carers and share information, in line with the Caldicott Principles (2020). These principles emphasise the importance of sharing information when it is in the best interests of the patient to provide care and for safeguarding.

The stakeholder forum was divided into sub-groups to delve into the issues in more depth. Our group looked at existing consent forms and discussed how these could be adapted and improved. We were presented with two different forms; one featured a basic tick-box menu of options for sharing specific types of information, such as medication, diagnosis, and care plans,, and the other was broader and more detailed, aligning the disclosure of information with levels of sensitivity, low, medium, and high, based on the consent of the service user. The group discussed the advantages and disadvantages of both forms and made suggestions as to how they could be refined to provide greater clarity and better reflect the legal position about information disclosure. This open and collaborative process allowed us to gather diverse perspectives and insights, leading to more comprehensive and holistic solutions.

The group discussion kept coming back to the fundamental challenge that every situation is unique, and a person-centred approach is crucial in mental health care. It requires a degree of flexibility and adaptability, acknowledging that the level and nature of information that patients want their carers to know will vary considerably. The group also emphasised the need to reinforce to staff the differences between ‘general’ and ‘personal’ information and the degree to which these can be lawfully shared without the patient’s consent.

This is a complex area of law that staff often find difficult to navigate. It was suggested by one group member that a flowchart developed by a team of researchers could be used as a practical guide to assist staff in these situations. Central to this approach is the need to develop a clear set of principles to guide information sharing and provide clarity to staff, patients and carers on the applicable legal framework.

Figure 1 – Flow chart for consent and information disclosure, taken from Slade et al (2007)



Does the patient give consent for the professional to give the carer personal information?
(General information which does not provide new information about the patient can always be shared)

Box A: Exploration of the decision with the service user
- Discuss reason(s) for non-consent – possibly leading to clinically important new information
- Are there specific pieces of information not to be shared, or is it a general withholding of consent?
- Is there another closely involved person for whom the patient would give consent?
- Explain carer’s ‘need to know’ where appropriate

Box B: Exploration of capacity to give informed consent
Incapacity is defined as existing where an impairment of or disturbance in the functioning of brain or mind causes difficulty in decision-making because the patient: (a) is unable to understand information relevant to the decision; (b) cannot retain the relevant information; (c) is unable to use this information as part of the decision-making process; or (d) cannot communicate the decision

Box C: Liaison with carer
- Provide general information
- Assess the carer’s information needs

Where appropriate:
- Discuss the issue of confidentiality with the patient and carer together
- Organise a carer’s needs assessment
- Encourage carer to seek independent support

Box D: Discuss potential consequences with the patient
- Clinical consequences, e.g. need to manage risk in other ways, such as delayed hospital discharge
- Carer consequences, e.g. possible withdrawal of carer’s support
- Agree time frame to re-visit consent decision
- Involve an independent advocate

Decision: share no, some or all personal information
- When not providing personal information, give supportive explanation, e.g. patient readiness (which may change, and will be regularly reviewed), increased patient independence (indicator of recovery)
- Emphasise ongoing professional–carer relationship
- Inform patient where appropriate
- Document in notes

Box E: Staff exercise clinical judgement
Consider known patient views, including advance statements
Take account of:
- Best interests of the patient, balancing patient and carer needs
- Risk to patient or others of disclosure or non-disclosure
- Assessed capacity and stated consent
- Carer’s information needs
- Legal context, e.g. court order, mental health legislation
- Consultation with colleagues
- Carer relationship, available information about patient and carer, caring context

Our discussions underscored the ongoing nature of the dialogue in this complex area. We focused on the person who has been admitted to hospital, and how they might be feeling about sharing information with those family and friends who are close to, or care for, them. On admission, patients are often in crisis, feeling angry, confused, or distressed about their situation, and might not understand everything that is happening. At that stage, staff should engage with the person as an individual, to gauge how they are feeling and continually review throughout their admission how they feel about disclosing information.

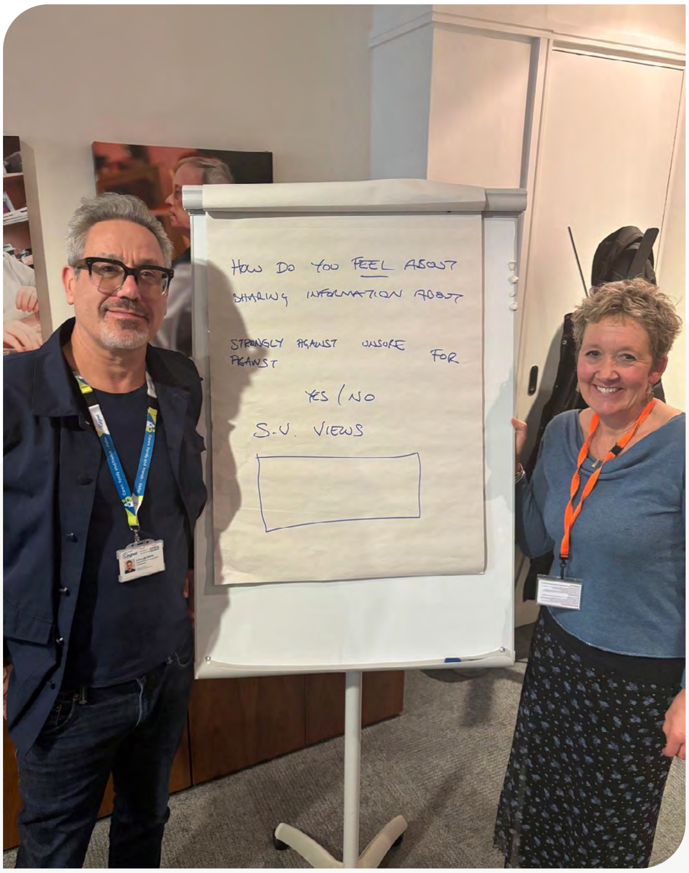
This is essential for a person-centred approach to consent and information disclosure. The group suggested two consent and information sharing forms could be developed to acknowledge that patients might be feeling confused and distressed on admission and not able to process large amounts of information – a short and simple admission consent form could be developed (Form A), and a more in-depth and tailored consent form (Form B) could be completed after the first Multidisciplinary Team (MDT) meeting and clinical review.

Form A could be as simple as: 'I am happy to share my personal information about my safety and location with the following…' and Form B would be more detailed, enabling staff to reassess capacity and patient preferences about the nature and level of disclosure in more detail. This approach recognises that consent is an ongoing process and that individual preferences and wishes, as well as capacity, may fluctuate over time.

Accordingly, it is vitally important for staff to include discussions with patients about consent and information sharing as part of an on-going dialogue throughout their care and treatment journey, including discharge planning.

A common theme in the group discussions was the need for staff to acknowledge and listen to the views of carers as they have expertise and personal knowledge of the patient, which should be valued by the clinical team. The involvement of carers in discharge planning was considered vital in cases where patients are returned to their care in the family home.

All in all, it was an incredibly worthwhile and constructive session, in the company of dedicated and passionate stakeholders, sharing a common goal to develop a clear framework for information sharing and carer involvement in decision making. We were delighted to be invited to participate in this important project. And we look forward to the ongoing dialogue and playing a part in bringing the guiding principles and consent forms to fruition.



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“I have Learned that I am Stronger than I Thought”: A Reflective Piece

About the Authors

Pam Egar
Wife of Service User

This article is a reflective piece written by Pam, whose husband suffered a cardiac arrest that resulted in him sustaining a brain injury, and subsequently requiring inpatient care.

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“It has often been said that brain injury affects whole families, not just individuals.” (Headway, 2025).

A brain injury can have a ripple effect for the individual, and the people in their lives. The cognitive, emotional, and behavioural changes can cause disruption to daily life, cause financial stain and affect relationships. Family members may experience loss, stress, anxiety, anger, worry, and sadness. Support, reflection and intervention can be essential factors to help families adapt and cope with these challenges.

This article includes a reflective piece written by Pam, whose husband suffered a cardiac arrest that resulted in him sustaining a brain injury, and subsequently requiring inpatient care.

Her husband is not referred to by name, as he is unable to agree to his name being used due to the impact the event had upon his cognitive functioning, but Pam has agreed to share her experience.

It is a thoughtful piece, where Pam reflects upon the events that led to her husband coming to stay with us at Cygnet Grange a neuropsychiatric rehabilitation, care and treatment facility for those affected by acquired brain injuries. The foreword has been written by Ella, a staff Nurse, and Sarah, the unit Psychologist to provide context and background.

Introduction

The team at Cygnet Grange support not only those who have suffered a brain injury, but also their family members, their carers, and loved ones. They strive to use a collaborative approach that emphasises the partnership between staff, the service user, and their family. This approach aims to improve safety, promote recovery, and sustain wellbeing by recognising and supporting all three parties involved in the care process. This is sometimes known as The Triangle of Care (Carers Trust, 2025).

As soon as Pam’s husband was admitted to Cygnet Grange, the team started working together to provide the best possible care. The doctors made sure he was on the right medication, and that his physical health was looked after, whilst the nurses and support staff helped him with his activities of daily living, supporting him as best they could.

Regarding therapies, the Occupational Therapist supported him to take part in activities he would enjoy and find meaningful, the Speech and Language Therapist helped him to communicate his wants and needs, and the Psychologist made sure he was safe, and looked at the things he was good at and the things he struggled with. This helped staff to build on his strengths and support him with things he found difficult.

As the team at Cygnet Grange got to know him, they also got to know Pam, and other members of the family, including their dog, Trixie. As his wife, Pam was one of the people who knew him best. His key Nurse, Ella, worked particularly closely with Pam. The team kept family members up-to-date with his care, explaining aspects of his condition and treatment, signposting for further support. They also involved the family in decision making as much as possible, and listened to the things that were important to the family as a whole.

After Pam’s husband had been at Cygnet Grange for over two years, the team thought it would be positive if Pam had an opportunity to reflect upon and share some of her experiences as part of his journey. Ella and Sarah thought that it might be helpful to use some sort of structure to help guide Pam in her reflections, as she had never done anything like this before.

The Gibbs Reflective Cycle (Gibbs, 1988) was used, as it provided a structured approach to reflecting on experiences. It is a six-stage process: Description, Feelings, Evaluation, Analysis, Conclusion, and Future.

The result is a moving reflection about the challenging realities family members sometimes face after a loved one sustains a brain injury.

Reflective piece

Description of what happened

On the 21st December 2021, my husband had an at home cardiac arrest[1]. After doing chest compressions, two ambulance crews arrived and took over. They struggled to stabilise him and the result was a hypoxic brain injury[2].

He was in an induced coma[3] for a week and when he came around, he was very confused and agitated. He couldn’t sleep and wanted to walk up and down. His words were all jumbled up, which made him angry and upset.

He was moved to a head injury ward and here he became very unsettled and would bang on windows and actually broke a computer. He was then sectioned[4] and moved to a mental health hospital.

Two weeks later, he was taken to a locked rehabilitation unit where he thought he was in prison.

A few weeks later, he was moved to Cygnet Grange, where they tried their best to make him well enough to come home. His is calmer now but has little interest in doing anything.

Feelings and thoughts about what happened

My feelings are of loss. I have still got him but he isn’t my husband as I knew him. The loving and caring husband has gone and he is now confused and frustrated.

My feelings are of anger. Why us? What have we done to deserve this?

My feelings are of worry. I worry what will happen to him. I know he is getting excellent care at Cygnet Grange. I worry he will have a heart attack or another cardiac arrest.

Evaluation of what happened, both good and bad

If there is any good, it will be my family and friends and Trixie that have kept me going. I’m not alone whilst I have Trixie and she gets me out.

My family have been amazing, with my children driving me down to Bristol to see him. Including me in their plans.

My friends for being at the end of the phone and getting me to go out with them.

The bad – my loving husband is not the same person. Sometimes I wonder if he still knows me.

Analysis to make sense of what happened

I cannot make sense of what happened. I still think I will wake up from this nightmare.

Conclusions about anything you have learned

I have learned that anything can happen at any time. He was a fit man.

I have learned that I am stronger than I thought. I have had to learn to be brave without him by my side. I can drive into Nottingham and back. I can speak to officials.

Everything he did I have to do now. I have had to trust other people to look after him and Cygnet Grange staff have helped me to do this. They are there for both of us.

Any thoughts for the future

I just want him closer to home so we can all see him more.

End note

This reflective piece has been written in loving memory of Trixie (RIP).

References

1. Cardiac arrest is when the heart suddenly and unexpectedly stops beating. When the heart stops beating, blood cannot properly circulate around the body and the blood flow to the brain and other organs is decreased.
2. The brain needs a continuous supply of oxygen to survive. If the oxygen supply is interrupted, the functioning of the brain is disturbed immediately and irreversible damage can quickly follow. This is known as hypoxic or anoxic brain injury (Headway, 2025).
3. An induced coma, also known as a medically induced coma, is a temporary state of deep unresponsiveness caused by administering sedative drugs to a patient. It is used to protect the brain from further damage, reduce swelling, or allow the body to heal after a severe injury or medical event.
4. Being sectioned means being admitted to hospital whether or not you agree to it. The legal authority for your admission to hospital comes from the Mental Health Act rather than from your consent (Royal College of Psychiatrists, 2025).

Untangling Trauma: DTD and its Distinctions from PTSD and CPTSD

About the Authors

Wesley Cooks
Assistant Psychologist

Wesley Cooks has been an Assistant Psychologist at Cygnet Appletree, female PICU / Acute service for the last year. He completed his undergraduate training in South Africa and aspires to study further in clinical psychology in the coming years. He is passionate about trauma informed care, delivering trauma informed training with the Lead Consultant Clinical Psychologist as well as being involved in a research project on service user experiences.

Dr Samuel Parker
Consultant Clinical Psychologist

Sam is a Consultant Clinical Psychologist who completed his professional doctorate at University College London. His career in mental health has spanned working across various settings since 2012. This includes forensic inpatient wards, community complex care teams, specialist clinical CAMHS in Social Care and looked after children's teams. Prior to working in psychology, Sam worked as a Project Manager in the third sector within drug and alcohol services. He was also a Non-executive Director at a mental health CIC specialising in 'Personality Difficulties' and training mental health staff in this area for around three years.

Sam specialises in trauma and complex mental health difficulties and offers an integrative approach which draws on models including but not limited to Compassion Focussed Therapy, Acceptance and Commitment Therapy, CBT and Trauma informed practices. He is also trained in Eye Movement Desensitisation and Reprocessing (EMDR). Sam is dedicated to the training and development of staff in trauma informed approaches and is highly involved in Cygnet's drive to become a trauma informed organisation.

Introduction

In their study on the epidemiology of trauma, Lewis et al., (2019) found that approximately 31.1% of people under the age of 18 in the UK have had exposure to trauma. Trauma can be understood as any experience that an individual is unable to cope with, leading to emotional and behavioural responses that can cause lasting alterations that are pathological and compromise functional capacity (Richter-Levin & Sandi, 2021).

Al-Attar and Worthington (2024) explain that early attachment difficulties and trauma can "reshape all aspects of development from childhood to adulthood". This can impact physiological, emotional, cognitive and behavioural functioning which may resemble a range of other conditions such as emotionally unstable personality disorder or autism (Lyons et al., 2020; Whitwell, 2014). Therefore, unless the origins of these difficulties are understood, it can easily be attributed to other conditions. Treatment of symptoms without a full understanding of their aetiology can potentially lead to the offer of ineffective treatment options highlighting the need for a 'trauma-informed' perspective to understand individual's behaviours, difficulties and underlying needs (Cosci et al., 2019).

Developmental Trauma (DT)

DT refers to "the complex and pervasive exposure to life-threatening events" (Cruz et al., 2022) during critical developmental periods which disrupts "interpersonal attachments, compromising an individual's safety and security operations, and alters foundational capacities" (Cruz et al., 2022) for cognitive, behavioural, and emotional control. According to Lyons et al., (2020), early trauma can occur from "things happening that shouldn't have happened" (including things such as abuse, separation from primary care-givers, bullying and childhood maltreatment) and from things that didn't happen that should have happened (such as cognitive, emotional and physical neglect).

According to Reid (2024), mental and physical health outcomes can be traced back as early as the critical foetal period, where the foundations of brain and organ systems develop. The foetus is sensitive to important in-utero exposures, such as maternal psychological, nutritional, and endocrine signals. Zhou and Ryan (2023) and Reid (2024) agree that psychoneuroendocrinology has long understood that a history of severe trauma in parents can impact unborn babies' epigenetics. Furthermore, unborn babies can suffer trauma to their mind and body whilst developing in the womb (Lyons et al., 2020); for example, if there is a disruption in bonding during pregnancy, if the mother uses alcohol and substances, or suffers with serious mental health difficulties (Cortizo, 2020).

The considered literature suggests that there are other critical developmental periods post birth when the brain's "plasticity" is highly dependent on experiences and environmental influences, where a child may be more susceptible to the effects of interpersonal trauma (Cioni, & Sgandurra, 2013). Lyons et al., (2020) suggest that the first eight weeks post-birth are the most influential to development; however, other researchers, such as Shilliday, (2022) extend this to the first 1001 days post-birth. There appears to be a gap in the literature concerning when exactly these critical developmental periods may be, and the impact that these periods may have on the development of DTD.

Differences in PTSD, CPTSD and DTD

Post-Traumatic Stress Disorder focuses on specific traumatic events and their immediate aftermath (Hiller et al., 2023). Complex PTSD arises from traumatic experiences that are chronic, repeated, prolonged, and interpersonal during childhood or adolescence and typically manifests in adulthood (McDonald et al., 2014). CPTSD still requires a person to meet criteria for 'standard' PTSD but also includes additional symptoms that comprise "disturbances of self-organisation" such as emotion dysregulation, negative self-concept, and interpersonal difficulties (De Jongh et al., 2016).

Developmental Trauma Disorder (DTD) is a new diagnostic criterion which is posited to capture a fuller scope of difficulties facing traumatised children in particular (Hiller et al., 2023). DTD can be understood as a childhood syndrome that complements and extends the PTSD diagnosis, including a wider range of symptoms such as emotional dysregulation, somatic symptoms, attachment disturbances and negative self-concept which are consequences of the cumulative impacts of chronic interpersonal trauma and disrupted attachment bonding with primary caregivers (Spinazzola et al., 2021).

DTD occurs during critical developmental years in childhood and overlaps with the "disturbances of self-organization" component of CPTSD diagnostic criteria but with adaptations consistent with the developmental psychology of childhood (Morelli & Villodas 2022), including "self-other boundary confusion, reactive aggression, negative self-appraisals and relational detachment" (Spinazzola et al., 2021). Cruz et al., (2022) assert that "DTD emerges from prolonged and cumulative interpersonal trauma that disrupts the development of secure attachments to caregivers and dramatically alters core assumptions and beliefs about one's vulnerability to danger in the world". Most of the current research agrees with Spinazzola et al., (2021) that CPTSD may reflect the impact of threats to physical safety on neurodevelopment, whereas DTD reflect the impact of threats to attachment security in early life (Cruz et al., 2022; Ford et al., 2020).

Distinguishing between CPTSD and DTD is argued to provide broader conceptualisations of the complex mental health needs of young people who have experienced trauma (Hiller et al., 2023). Much of the available research advocates for establishing DTD as a recognised diagnostic criteria, citing that it aptly describes the effects of chronic early trauma on children (Silberg, 2021). Conversely, professionals argue that a new diagnostic category may weaken the power of existing diagnostic systems (Schmid et al., 2013). It is also argued that many of the diagnostic criteria related to experiences of trauma are already superseded by different diagnoses, such as attachment disorder and emotionally unstable personality disorder (Hiller et al., 2023; Schmid et al., 2013). Still, the DTD diagnosis offers an all-encompassing conceptualisation that may limit "over-pathologizing" individuals who would instead receive a single diagnosis to capture their broad array of symptoms rather than three or more disparate diagnoses (Cruz et al., 2022). It may also increase the likelihood of more accurate assessments, treatment, and prognosis for these individuals, likely leading to better short and long-term outcomes (Cruz et al., 2022; Silberg, 2021; Schmid et al., 2013).

Results from the current research

Spinazzola et al., (2021) discovered that age, sex, ethno-cultural background, and living apart from one's birth family were unrelated to the presence of DTD or PTSD, but that these factors increased the likelihood of experiencing different types of traumas, such as rape or gang violence.

Kisiel et al., (2014) and Spinazzola et al., (2021) both found that PTSD—but not DTD—was associated with non-attachment-based trauma such as loss or rape, whereas DTD was significantly associated with traumatic emotional abuse and caregiver separation. Spinazzola et al., (2021) report that around two-thirds of all cases that met the symptom criteria for DTD also met the full criterion of lifetime contemporaneous exposure to both interpersonal victimisation and traumatic disruption in attachment bonding with a primary caregiver.

Traumatic victimisation is an important component in the development of DTD and affects children's neurodevelopment, learning, relationships, and physical and mental health (Spinazzola et al., 2021). Multiple forms of victimisation occurring can have a complex impact on an individual which can last for years and even intergenerationally (Thoma et al., 2021; Greene et al., 2020, cited in Spinazzola et al., 2021). The combination of victimisation and insecure attachment is associated with PTSD, depression symptoms in children and symptoms of complex PTSD symptoms in adulthood (Noonan & Pilkington, 2020, cited in Spinazzola et al., 2021). Spinazzola et al., (2021) found that the variables that most correlated to DTD were caregiver separation, caregiver impairment, and family violence. Spinazzola et al., (2021) further argue that "victimisation and attachment disruption should not be limited to any specific type of victimisation or attachment trauma" and that different combinations of each of these domains may be antecedents of DTD.

DTD and PTSD are highly comorbid, and both are associated with multiple other comorbidities such as suicidality, anxiety, and depression (Hiller et al., 2023). Ford et al., (2020) found that DTD was associated with more comorbidities than those with PTSD only. Young children with a presentation consistent with DTD were more likely to experience difficulties regulating emotions and behaviours, had more complex presentations, experienced more hospitalisations, and showed poorer functioning in a range of social and academic settings (Kisiel et al., 2014). There is also evidence that conventional mental health treatments are less likely to be effective with these more complex presentations in children (Hiller et al., 2023; Teicher et al., 2021).

Zhang et al. (2019) found that children separated from their parents showed higher DTD symptoms than their non-separated peers, demonstrating that attachment trauma plays a crucial role in the development of DTD.

According to Cyr et al., (2010), cited in Spinazzola et al., (2021), "traumatic emotional abuse may be a form of attachment trauma when it occurs in the context of a primary caregiving relationship." According to Gander et al., (2020); Goulter et al., (2019); Riva Crugnola et al., (2019), cited in Spinazzola et al., 2021), "childhood emotional abuse is also associated with insecure attachment and identity, intimacy, empathy, and self-direction problems" and can also extend to "adult insecure attachment and dissociation, hopelessness, substance abuse, psychosis, and borderline personality disorder" (Frias et al., 2016; Goodall et al., 2015; Kong et al., 2018; Scott et al., 2020 cited in Spinazzola et al., 2021). Traumatic separation from care-givers is also associated with amygdala–prefrontal connectivity and attachment insecurity in adulthood as well as with personality problems in adolescence and adulthood (Gee & Cohodes, 2023; Cruz et al., 2022).

The available research agrees with Lyons et al., (2020) that the most influential factor for a child's wellbeing, even more influential than early trauma, is the quality and quantity of their safe relationships (Schmid et al., 2013; Hiller et al., 2023; Calvo et al., 2020; Birrell et al., 2025). Safe attachments are instrumental in influencing resilience, emotional intelligence, and overall psychological wellbeing (Gee & Cohodes, 2023; Birrell et al., 2025). Similarly, Cruz et al., (2022) suggest that secure attachments can be a protective factor against the development of DTD during interpersonal trauma.

Adverse Childhood Experiences (ACE)

ACE scores are a tally of the extreme, traumatic, or repetitive stressors an individual has undergone during their childhood (Loveday et al., 2022; Anda et al., 2006). Anda et al, (2006) describe ACEs as common, kept secret, and generally unrecognizable to others. Cprek et al., (2020) found a dose–response relationship between ACEs and the risk of developmental, social, or behavioural delay, "with results ranging from 24.2% among children with 0 ACEs to 42.2% among those with 4 or more ACEs." Additional ACEs increased risk of developmental delay by 17%. Anda et al., (2006) similarly discovered that co-morbid outcomes nearly tripled between ACE scores of 0 and ACE scores of 7–8.

Bloomfield et al, (2021) found that the chances of experiencing a psychotic disorder are three times higher in adults who survived DT. Anda et al., (2006) found that for persons with 4 ACEs or more compared to those without any, the risk of panic reactions increased 2.5 times, depressed affect increased 3.6 times, anxiety increased 2.4 times and the risk of experiencing hallucinations was increased by 2.7 times. The risk of impaired memory of childhood was increased 4.4 times. The risk of sleep disturbance increased 2.1 times, the risk of severe obesity increased 1.9 times, and the risk of multiple somatic symptoms was increased 2.7 times.

For persons with 4 or more ACEs, the risk of alcoholism increased 7.2 times, illicit drug use increased 4.5 times, and the risk of injected drug use increased 11.1 times. The risk of difficulty controlling anger increased 4 times, and the risk of intimate partner violence (IPV) increased 5.5 times (Anda et al., 2006).

Neurological and neuro-psychological effects

The monoamine neurotransmitter systems, norepinephrine, dopamine, and serotonin, act within a primary regulatory system of neural networks to orchestrate complex neural functions (Anda et al., 2006). They originate in the lower regions of the brain and connect throughout the brain and "receive input from the autonomic nervous system and peripheral sensory apparatus" (Foote, 1983, cited in Anda et al., 2006). Anda et al., (2006) elaborate that "monoamine dysfunction has been hypothesized in a host of neuropsychiatric syndromes, including aggressive and violent behavior, suicidality, alcoholism, substance abuse and dependence, depression, anxiety disorders, and social / relational problems". Interestingly, experimental manipulation of these systems in young animals can produce behaviours like those seen in abuse victims, such as aggression, stress-response dysfunction, hyper-reactivity and eating problems (Anda et al., 2006).

According to Bloomfield et al., (2021), "DTD can cause structural and network connectivity alterations between key regions involved in memory and emotional processing including the hippocampus, amygdala and anterior cingulate cortex". McEwen (1992); Sapolsky (1990), (1996); Gould and Tanapat (1999) cited in Anda et al., (2006), discuss that "substantial research has focused on the relationship between development, early stress, the HPA axis, and the hippocampus, a stress-sensitive brain region that plays a critical role in learning and memory". Lightsey and Hulsey (2002); Knight, Waal-Manning, Spears (1983) cited in Gorka et al., (2014) explain that early abuse affects the hippocampus which is critical in shaping emotional responses to environmental challenges through its "regulation of the HPA axis and encoding of contextual memory for emotional experiences".

The hippocampus has the capability of growing new neurons in adulthood (neurogenesis), but stress inhibits neurogenesis (Nibuya 1995; Duman 1997; Gould 1997 cited in Anda et al., 2006) and memory function (Diamond 1996; Luine 1994 cited in Anda et al., 2006).

Sensitisation to environmental stressors through hyperactivity of the HPA axis has also been found to precede the onset of psychotic diagnoses and is associated with abnormal dopaminergic activity and structural changes in the brain (Mikulska et al., 2021).

Psychological trauma activates dissociation, an automatic coping mechanism which mediates the effects of trauma and psychotic features (Bloomfield et al., 2021). According to Bloomfield et al., (2021), trauma memories are stored as "unintegrated fragments, which are prone to involuntary retrieval" and are re-experienced in an emotionally unprocessed form in the present such as hallucinations or voice hearing.

ACEs may also "disrupt the ability to form long-term attachments in adulthood as animal-studies show that early stressors result in long-term changes in peptides such as oxytocin that regulate pair bonding and social attachment" (Insel and Winslow 1998; Francis, 2002, cited in Anda et al., 2006), with attachment disruption being a key component in DTD. Alterations in serotonergic and GABAergic receptors also contribute to deficits in social attachment and regulation of mood and affect following early stress. Smaller hippocampal volume and corpus callosum volume and alterations in the structure of the cerebellum and frontal cortex are found among adults with early abuse-related PTSD (Young et al., 2019). Consistent with deficits in hippocampal function are deficits in verbal declarative memory and failure of hippocampal activation with memory tasks. There is evidence of dysregulation of the sympathetic nervous system in humans with increased cortisol and norepinephrine levels in children, and low baseline and increased stress-induced cortisol responses and increased norepinephrine at baseline in adults (Anda et al., 2006). Early trauma can also impact the dopamine circuit, which is the reward system of the brain, leading to increased risk of depression, schizophrenia and addiction (Mikulska et al., 2021).

Discussion:

Traumatised children can develop a range of unhealthy coping strategies as an adaptation to interpersonal threat (Silberg, 2021). They may also not develop the essential daily living skills needed, such as being able to manage impulses, social interactions, solve problems, or learn new information (Al-Attar & Worthington, 2024).

Steven Porges's polyvagal theory is often criticised for being too vague and broad to empirically test (Silberg, 2021; Giroux et al., 2023), however is widely accepted by the literature as being a useful conceptualisation for understanding trauma responses (Giroux et al., 2023; Lyons et al,. 2020; Silberg, 2021). The theory explains how the stress management system in humans has developed a pathway through the ventral vagus nerve, which allows social engagement to help regulate physiological stress reactions.

Stress can cause activation of the sympathetic nervous system, leading to a 'fight' response, such as anger and aggression, or to a 'flight' response, like fleeing from the source of stress. This theory also explains the survival utility of immobilisation, which can be seen in the collapse response which is related to the dorsal vagal system (Silberg, 2021).

Using this conceptualisation, a traumatised child, who may have never known safety, can be understood as primarily 'living' in their fight / flight / freeze / fawn / collapse responses to survive real or perceived danger (Lyons et al., 2020). All their mental resources may be 'used up' on staying alive physically. This means there are little resources left over for the development of 'luxuries' such as processing, emotional development, retaining new information, reasoning, empathy or a sense of social awareness (Ormel et al., 2020; Silberg, 2021). Traumatised individuals may become 'developmentally stuck', with their presentations reflecting an emotional age rather than their actual age (Ormel et al., 2020; Al-Attar & Worthington, 2024).

Teicher et al., (2021) and Bloomfield et al., (2021) agree that there remains a scarcity of research surrounding the impact of DT on mental health difficulties, which is a barrier to the development of effective secondary preventative measures for survivors of DT and adults with mentally ill health. According to Cohen and Mannarino, (2019) cited in Spinazzola et al., (2021), the "association between traumatic separation from caregivers and DTD underscores the need for therapeutic interventions targeting separation-related childhood traumatic grief" as well as what Owen (2020), cited in Spinazolla et al., (2021), calls "traumatically disrupted childhood attachment security". People with mental health difficulties are infrequently asked about their DT histories (Read et al., 2018, cited in Bloomfield et al., 2021).

This may be a contributing factor to low service engagement amongst adult DT survivors (Bloomfield et al., 2021). Read et al., (2018), cited in Bloomfield et al., (2021), state that the situation is "compounded by poor responses to initial disclosures of DT, including low referral rates for trauma-related interventions".

When researching DTD, there are several limitations. Anda et al., (2006), explain that one of these limitations is "retrospective reporting of childhood experiences and self-reporting of the outcome measures". Respondents often have difficulties recalling certain childhood events (Edwards, 2001, cited in Anda et al., 2006) or may choose not to disclose certain experiences or personal behaviours (Bloomfield et al., 2021). DellaFemina (1990) and Williams (1995), cited in Anda et al., (2006), state that "longitudinal follow-up of adults whose childhood abuse was documented has shown that their retrospective reports of childhood abuse are likely to underestimate actual occurrence".

Spinazzola et al., (2021) further explain that exposure to DT may be "underreported by children due to their reluctance to disclose information in a caregiver's presence or to some caregivers' lack of knowledge of events prior to caring for the child".

Understanding the impact of DT has the potential to expand our understanding of co-morbid health and social problems (Anda et al., 2006). The above discussion suggests the need for an integrated perspective on the origins of health, mental health and social problems throughout the lifespan (Anda et al., 2006).

What can professionals do?

Most of the available literature agrees that social connections buffer the impact of early adversity (Schmid et al., 2013; Hiller et al., 2023; Calvo et al., 2020). In particular, the presence of safe and available adults at the time of the trauma (Gee & Cohodes, 2023; Birrell et al., 2025). Anda et al., (2006), states that "early environmental deprivation inhibits hippocampal neurogenesis; conversely, neurogenesis is enhanced by enriched environment (Kempermann, 1997), learning (Gould, 1999a) and, at times, some antidepressant treatments (Malberg, 2000; Czeh, 2001)". DTD requires developmental and relational approaches such as trauma-informed care giving, attachment repair and therapies that promote self-regulation, whereas CPTSD is typically treated through trauma-focused therapies, including EMDR, Compassion-focused therapy (CFT), Acceptance and commitment therapy (ACT), and DBT-PTSD (Bohus et al., 2019; Cruz et al., 2022).

What professionals can do include early, compassionate interventions, promoting safety, secure relationships and co-regulation (De Jong et al., 2016). If practitioners can respond to their clients' emotional age rather than their actual age, the client can be co-regulated and learn the skills they need over time (Lyons et al., 2020) and when ready, clients can access the aforementioned therapies.

Recommendations:

Whilst DTD and related concepts were originally rejected for inclusion for the DSM-V in 2013, it continues to be used prolifically (Silberg, 2021). This review agrees with Teicher et al's., (2021) assertion that DTD represents an "appealing unitary diagnostic category" and that it would be beneficial for this to be reviewed again for inclusion in the DSM-5. While current evidence suggests there are distinct aetiological pathways between DTD, PTSD, and CPTSD, more research is needed around the utility of distinguishing these diagnoses early on, identifying attachment disruption, and which treatment methods are most effective (Spinazzola et al., 2021). This literature review made use of broad search criteria, and the studies included were not limited in terms of language, location, or year of publication.

Because of this, it is possible that articles may have been missed, and therefore a more focused and systematic literature review may be beneficial to accurately synthesise the current research. The reason for poor engagement between people with DTD and service users is not well understood but may involve attachment disruptions and poor reactions to initial disclosures, warranting further research. Whilst critical developmental periods are highlighted in the literature, more research is needed around which developmental periods may be more susceptible to the development of DTD, which represents a novel area for further study.

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The Role of the Carer: A Personal Reflection

About the Author

Linda Bennett
Speech and Language Therapist

Linda has a professional background, having worked in and around neurology and neurosurgery since 2014, in a range of roles. Linda qualified in Speech and Language Therapy in 2024 (University of Strathclyde, Scotland) and since May 2024 has worked in neuropsychiatry services. Linda has a professional interest in forensic/secure care, and the provision of trauma informed therapy in these environments. In her spare time, Linda enjoys family history research and collecting sea pottery.

My name is Linda and I qualified as a Speech and Language Therapist in 2024, with a background of work in acute medical and surgical neurosciences as a healthcare Support Worker. Throughout my career, I've been struck by the immense need for holistic management in neurosciences care. The brain's central role in the body's functioning, and that of our interpersonal relationships, means that those working in this field must adopt a full-person approach, considering not only the patient but their families and carers as well. This holistic model, especially from a trauma-informed perspective, is crucial in providing comprehensive care.

Cygnet has embraced this holistic approach, with many of its sites now accredited under the Triangle of Care. This initiative highlights the importance of collaboration between staff, patients, and carers. While we professionals bring expertise in our disciplines, the true experts in the room are always the patients and their carers. They experience the illness, recovery, and challenges first-hand, and their input is vital in shaping the care process.

My personal connection to this concept comes from my experience as a Carer for my mum, who has Fronto-temporal Dementia (FTD - behavioural variant, sometimes known as Pick's Disease) . Prior to her diagnosis, my mum had been living with Functional Neurological Disorder alongside Emotionally Unstable Personality Disorder, and I was her primary Carer for many years. This role has deeply influenced my career as a Speech and Language Therapist and shaped my understanding of the importance of carer involvement in the therapeutic process.

My mum's story is not mine to tell, and as such I have tried where possible to minimise details and experiences, focusing mainly on my own perspective of being 'on the other side', as it were.

Growing up, my mum's health struggles created a chaotic and confusing environment. Support was limited, and care in the community was still a bit of an 'ideal' that hadn't yet really come to fruition. As a young person, I had no framework to understand her condition. It wasn't until I was 14 that it was suggested I was a 'young Carer.' Even then, explanations were limited. I remember hospital visits and medical appointments, but I often felt left in the dark about what was happening to my mum. The lack of information and child-friendly resources often left me feeling unsure and anxious, and I'm now aware of how important it is to consider the experiences of children involved in caregiving.

Reflecting on this, I believe there is a gap in how health care providers communicate with young carers. For example, in speech and language therapy, we often create easy-read materials for patients. But I wonder if we could extend this to include resources for young people who may not fully understand the situation. It is important to consider how we can ensure they feel supported in difficult situations, such as when a loved one receives a new diagnosis or is facing challenging behaviour due to an illness.

In 2022, my mum's diagnosis shifted from Functional Neurological Disorder to Fronto-temporal Dementia. The process of getting a clear diagnosis took over six years and was fraught with challenges. I was asked to document symptoms, attend meetings, and take her for tests, all while trying to make sense of a progressively changing reality.

One pivotal moment was during a multidisciplinary meeting in early 2022, where I felt both overwhelmed and exhausted. The Zoom meeting was full of professionals – my Aunty counted 26 people - and I worried they were scrutinising my ability to care for my mum. While everyone present was more than kind, I remember feeling isolated and consumed by guilt and fear.

This experience has made me more empathetic when considering the role of carers in healthcare settings. I think it's important to ask ourselves: how do we support carers in meetings or ward rounds? It can be very intimidating walking into a room full of unknown people – people who have the ability to decide what happens to your loved one. Sometimes, carers might be perceived as working 'against' the therapeutic process, but could this be due to fear or anxiety about being judged? When discussing difficult news, we must acknowledge that for carers, these conversations can be life-altering, and they may not have the same emotional resources as the professionals involved.

The process of my mum finally receiving a dementia diagnosis was emotionally devastating. My mum's diagnosis came in three stages: first, a phone call from the GP to inform me of concerning MRI results. I knew then that it was serious – she told me she had been phoned on her day off, and she asked me to sit down before she spoke.

Second was a face-to-face meeting with two consultants and a nurse, during which I was asked numerous questions about my mum's symptoms and behaviours at home. I was left in tears as I was told in great detail about FTD. They knew me from my previous job, so I was told about amyloid proteins and cerebral atrophy. I already knew the prognosis for FTD from my university lectures – I did not need this reiterated in so much detail yet again. I wonder how people with less medical knowledge would cope. I remember in particular being asked, "Has anyone else in the family ever died like this?" – honing in on the fact that this was obviously a terminal illness and this could be inherited. Good, effective communication at these stages is so vitally important – it seems like such a small thing, but when talking with patients and carers I try to be mindful of what I am saying – when we are anxious for information, we tend to zoom in on the scariest details.

Thirdly and finally, a phone call from my Uncle late on a Tuesday evening, about six weeks later. The consultants, having finally carried a PET scan, had asked my Uncle to come in. The job was given to him to inform me.

By the time of the third phone call, my mum was in hospital as an inpatient. I knew deep down she would never be coming home. I was living away in university accommodation, far from family, and had to navigate the aftermath of this largely on my own. My university were wonderful beyond words, but it was so very hard.

Looking back, I believe that the way the news was communicated could have been handled differently. In a case like mine, where the diagnosis is serious and life-changing, the health care team could have done more to ensure that support was readily available for me. Simple measures, like a follow-up call from the ward to check on my emotional wellbeing, could have made a world of difference. Likewise, providing written information would have been helpful, as we know that emotional distress often makes it hard to process information in the moment. I struggle now to remember most of what I was told.

The emotional toll of my mum's diagnosis was compounded by a sense of anticipatory grief, a term that wasn't widely used at the time but that describes the loss we experience when a loved one is diagnosed with a terminal illness. Now, parts of the NHS are providing training for staff, and I cannot express how valuable this is . Even just to be told that what I was feeling was normal, would have made a difference. I had never had a panic attack before, but with grief they became a regular event. Anticipatory grief is a profoundly lonely experience fraught by confusion and guilt. It isn't unusual for the logical and emotional sides of the brain to be in a continual conflict of wanting to spend every moment with the person, but realising that doing so would ultimately make no difference to the future outcome.

The shift in my relationship with my mum has been one of the hardest aspects of this journey. When a loved one enters any sort of care home or hospital, the dynamic changes. At Cygnet, for example, there are generally strict protocols in place for safety reasons, including CCTV and at times, staff presence during visits. These measures, though necessary, can make the experience of visiting a loved one feel very strange, especially in the beginning. I found it difficult to adjust to seeing my mum. Where we once spent most of our lives together – my mum, my sister and I – suddenly we were always joined by someone else. In hospital, this was especially difficult – not only were we not alone, but we had the noise of others, alarms and hospital routines for example. Our time together always had to be organised, and was restricted in terms of what we could do, or say. The loss of the ability to have anything resembling a mother-daughter relationship was and is very jarring – particularly when the notion of 'limited time' is very pertinent in one's mind.

Visiting, or not visiting, is a very personal decision, and given my own experiences and private emotions, I could never question a carer's choices. When my mum was first admitted to hospital, I did not visit for 10 days. Admittedly I had somehow caught COVID-19 in the process of her admission; however, I recall at that time feeling otherwise utterly depleted of all resources, regardless of COVID-19.

I was exceptionally lucky in that everyone around me fully, and wholeheartedly, appeared to respect the fact that I needed to meet my own basic needs first and foremost. I often hold this experience in mind during the day. If a carer wishes to visit, I will do everything I can to professionally support that continuing relationship in that manner. If a carer wishes to be less involved, or not to visit; we must refrain from judgement. We can never know for sure what's on a person's mind – and none of us can say for sure what relationships were like pre-injury or illness. Sometimes visiting is just too hard, or inappropriate. Exhaustion, fatigue, other pertinent responsibilities and priorities, distance, illness, fear and trauma, can all play a role. Respect, and kindness, should always be our first response.

It's vitally important to consider that my experiences are my own. When we work with individuals and carers, we meet people from all parts of society and, indeed, from all corners of the world. They bring with them their own lives, stories, and cultural norms – all of which can impact a carer's ability to engage with services. It's important from the outset to build up a relationship of mutual trust and support, without judgement – if we are to truly support a person, the whole person, we must be able to genuinely empathise with those around them. In doing so, and in finding ways in which all can collaborate, we allow for true co-production between service users, carers, and professionals.

As I reflect on my mum's care, I've come to understand that the needs of carers must be recognised. It's important for external services to provide support to those caring for individuals with complex needs, both emotionally and practically. Cygnet are well positioned to signpost, and I strongly believe that providing written resources about support organisations, and offering access to therapy or counselling, can be crucial for carers. When I was in need of support, I was made aware of resources available through the NHS and voluntary organisations, and indeed I was supported. However, not all carers are aware of these services, and offering information early on could make a significant difference to future outcomes.

As a Speech and Language Therapist (SLT), I get to see first-hand the importance of including carers in the therapeutic process. As SLTs, we can offer practical support, such as modelling social skills and interactions, role-playing scenarios, and using tools like Talking Mats™ to help patients communicate their needs . All of this can contribute to better, healthier relationships. We can support with adjusting to a new way of life and with navigating through trauma, change and loss. We can support with finding a way to communicate in psychological therapy, or increasing independence in daily living through stronger, or alternative, communication.

We also encourage the involvement of carers in creating personalised materials like "About Me" books, which provide a comprehensive look at a patient's life and preferences. These materials are not just helpful for the patient; they also help carers feel more involved and valued in the process. An excellent example I have seen was a scrapbook a service user could keep forever and continue adding to with photographs and souvenirs of life. This is something that external services could become involved with; for example, supporting the family to select photographs to aid in creating a timeline of sorts. All of this recognises the vital role of carers, families and loved ones in supporting the therapeutic process.

Being a Carer is not a negative thing in and of itself. With the right support, empathetic response and persons around who fully understand - or make every attempt to do so - carers can play an absolutely vital role as part of the team facilitating the model of care. Where carers exist, their role is an integral part in the recovery and wellbeing of the patient. Absolutely then, they deserve the full respect and support of the staff team. Working as part of a multidisciplinary team, we can ensure that carers do feel supported and that their input is valued. This collaborative approach, embedded in the Triangle of Care, can improve outcomes for both patients and their families, as they navigate the often complex and emotionally challenging path of care.

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My Story as a Carer

About the Author

Christine Clarke
Cygnet Carer Ambassador

Christine is mum to a 26-year-old service user at Cygnet Nield House, a 29-bed mental health hospital in Crewe. This Carers' Rights Day, she shares her story and what it means to now be a Carer Ambassador for Cygnet.

Every day, 12,000 people become unpaid carers for a partner, family member or a friend – many of whom don't see themselves as carers, often unaware of their legal rights and what they're entitled to in terms of support and benefits.

Since July 2023, our daughter has been a service user at Cygnet Nield House. Unfortunately the care our daughter needed couldn't be provided close to home so we accepted a placement in an area unknown to us, 70 miles from home, onto a ward for women with a dual diagnosis of personality disorder and disordered eating.

For my husband Jon and I, we really believe she is in the best place possible on her journey of recovery. She is finally getting the physical and mental health support she needs, all under one roof. She is making progress at her own pace, of which we are all benefitting as a family.

She has built trusting relationships with the staff there and they have really gone the extra mile for her. She is now able to engage with her treatment plan and has started to see a future for herself out of hospital.

It feels like we are getting our life back a little bit and I'm finally in a position to share my experiences and help others.

It was only when my daughter was admitted to the Cygnet Health Care service that I heard myself referred to as a carer for the first time. I never saw myself as a carer for my daughter, I was just a mum doing what mums did.

I still find it difficult considering myself a carer for my daughter. She is 26 years old now and before her mental health declined to the point of admission, she was working, owned her own house and lived a fully independent life with dreams and aspirations for her future.

I supported and continue to support my parents with their various needs as they get older. Considering their age, I found it easier to be viewed as their carer. But accepting that I was a carer for my daughter meant I could receive support myself. I have a background in nursing and have worked for 35 years with children and young people in the community, as a school nurse.

Despite this experience and knowledge of how mental health can impact people, seeing my daughter struggle was something I felt ill-prepared for.

Watching someone you love struggle with their mental health can impact on your own mental health over time, you just don't see it yourself. My husband Jon is incredibly supportive and we gain strength from each other. However despite this, I was too busy concentrating on my daughter and wanting to make everything better for her to consider support for myself.

The emotional impact was no easier for me despite being more aware of the support there was available.

When you care for someone, your own life gets put on hold. Making sure you have cancellation insurance on holidays, not booking them in the first place, being too worried to go too far, the phone ringing when out and saying number withheld, giving up work and constantly feeling like you are on call, just in case.

When my daughter first got admitted into Cygnet services, I didn't feel able to talk to anyone about what it was like being a carer. I was totally exhausted due to the struggles to get her the right support away from the acute sector, worried about the transition, and the fact that she is 67 miles away from home.

In 2023, Cygnet introduced Expert by Experience Carer Ambassador roles. These roles – fulfilled by people with lived experience as a carer – help shape Cygnet's carer plan and have the opportunity to improve how Cygnet interacts and involved loved ones.

Seeing how settled my daughter was becoming in hospital, I felt strong enough to take on the role and support others. Now my daughter has staff who understand and care for her in the best way possible. I finally know she's safe and supported managing her ups and downs and that makes me feel reassured enough to put myself in a position to help others.

I share my role as Carer Ambassador with several others whose lived experience is very different to mine. We support Cygnet Carers' Network, Cygnet Carer, Family and Friends Strategy and promote Triangle of Care and Carer Advocacy Service.

Personally, I identified the negative impact on service users of alarms constantly going off and as an improvement silent alarms are now being used at Cygnet Nield House. I recently hosted a Carer Stress Masterclass along with Matthew, Carer Ambassador, and am attending a face-to-face drop in for carers at Cygnet Nield House in November. I attend meetings to share my story and give a voice to carers across Cygnet.

If you aren't used to mental health services, it can be really confusing and overwhelming, trying to understand the clinical language and know how to best advocate for your loved one.

It can be very isolating when your loved one is moved to an out of area placement, miles from home. I feel I have a lot to offer family members who are just starting that journey of navigating services and admissions and I can reassure other parents and carers to see that you are not on your own and support is out there.

My experience of Cygnet is that I have been involved at every step when appropriate with my daughters care. I have attended ward rounds, been listened too, challenged decisions and they have been very transparent. As a carer I have a voice but am respectful that at 26 years old, my daughter has her own voice too. Previously she's not been well enough to advocate for herself but she's now finding her voice and is more involved in what she needs and how her care plan should look. Together we are making a difference to the ward environment and she's proud of my ambassador role.

As parents, we are so proud of how far she has come and that she's seeing a future for herself. Although discharge is many months away, I'm hopeful that a bright future exists for her when she returns to independent living. We will take it one step at a time but she's in the best place she can be at Cygnet.

She's 26 now and I am enjoying being her mum. Not her counsellor, not her therapist, or indeed her carer. When she was struggling, it was a constant battle I had to help her get to the right place, she was too unwell to fight for herself. As her discharge gets nearer, it becomes more stressful but we feel supported both by the Multidisciplinary Team at Cygnet Nield House, not forgetting her local case manager whose involvement is vital to us to all.

Now it's time to start enjoying being Mum and Dad again.

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