

A Guidance on  
Complex  
Emotional  
Needs Carers:

*Involving  
CEN Carers  
as Partners  
in Care*

LONDON CEN PROGRAMME  
JUNE 2022

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*This Guidance on CEN carers is dedicated to all those carers, who are determined to better understand themselves and their loved ones, so together, they can learn, mentalize and thrive.*

&

*With many thanks for all the beneficent comments from CEN carers, members of the Making a Difference Alliance, a lived experience advisory body to The NWL Mental Health and Wellbeing Transformation Board, and, members of the CEN Clinical reference group, London CEN Programme.*

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## **LONDON CEN PROGRAMME**

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# Background

Despite mental health carers being increasingly recognised by healthcare services, carers of people living with Complex Emotional Needs (CEN) receive virtually no attention directed towards their particular characteristics, needs and requirements. As such, this Guidance provides evidence-based reasons for them to be supported in their caring role so they can become confident and effective partners in care.

## Highlights

- CEN carers experience much higher levels of distress and impaired quality of life and wellbeing compared to carers of other severe and enduring mental health conditions.
- The caregiving role has been evidenced as important for effective treatment and outcomes of the cared-for person.
- The provision of an appropriate support offer for CEN carers is required. This includes creating posts for practitioners with lived experience of caring and educating all healthcare staff on CEN caring so that in turn, carers can support their loved ones more effectively and, therefore, meet the demands placed on them by the care in the community policies.
- According to the Centre for Mental Health (2015):



# 1. CEN Carer definition

1.1 For the purpose of this Guidance, a Complex Emotional Needs (CEN) carer is defined as a person providing informal care for another person needing such care.

People who provide care, however, do not always recognise themselves as 'carers'. This may partly be due to the nature of CEN difficulties as many such persons do not realise that they need help or struggle with seeking help. It can take many years before the person gets diagnosed by which time their carers may provide an increasingly wide-ranging amount of practical and emotional support such as advocating on their behalf, accompanying them to appointments, encouraging them to seek help, checking they are safe, discouraging them from addictive behaviours or supporting them financially.



## 2. CEN Carers in research

2.1. Given the fairly ubiquitous nature of CEN, research on carers of people with CEN is steadily growing. Most research on CEN carers is qualitative with studies reporting persistent distress, prolonged hopelessness, feelings of guilt and grief as well as unhelpful, stigmatising mental health services. Quantitative studies indicate that CEN carers, compared to general population, report more traumatic stress and higher rates of psychological symptoms.

2.2. An overview of CEN carers’ characteristics from a recent survey of CEN carers based in England is provided in Table 1.

**Table 1**

*In brief: CEN Carers’ characteristics from a sample of 131 respondents*

<b>Characteristic</b>	<b>%</b>	<b>Characteristic</b>	<b>%</b>
<b>Age</b>		<b>Caring for</b>	
35 - 44	20.6%	Spouse / partner	30.5%
45 - 54	23.7%	Adult child 18 or over	44.3%
55 - 64	26.0%	<b>Co-habiting</b> 55%	
65 - 74	10.7%	<b>Years of caring</b>	
<b>Gender (F)</b>	64.1%	1 - 5 years	28.2%
<b>Ethnicity (White)</b>	65.4%	5 - 10 years	29.0%
		> 10 years	40.5%
<b>Education</b>		<b>Hours of caring (wk)</b>	
College	21.4%	1 - 19 hours	34.4%
Undergraduate	53.4%	20 - 49 hours	41.2%
Master’s degree	21.4%	50 ≥	24.4%
<b>Employment status</b>		<b>No intervention or carer support</b> 59.5%	
Caring full-time	17.6%	<b>Feeling unsupported by services</b> 79.2%	
Working part-time	16.8%		
Working full-time	32.1%		
Retired	13.0%		

(Hinksman, 2021)

- 2.3. In CEN carer studies, ethnicity has been either omitted or white participants dominate. A recent study found that White British carers have far lower mental wellbeing than their mixed-race counterparts. The lack of data around ethnicity in studies on CEN may be down to under-detection and poor understanding of CEN in ethnic populations.
- 2.4. There is also a divergence in research on carer ethnic characteristics. Whilst carers from ethnic minorities provide more care, they report worse physical health. Moreover, studies have found that carers of certain ethnicities experience less stress and find caregiving rewarding. Hence, there may be cultural or individual differences in how some carers express the meaning and motivation around care.
- 2.5. A recent study investigated CEN carers' mental wellbeing as underpinned by interpersonal mindfulness and mentalizing capacities and found that all three dimensions were on a par with clinical cohorts. This does not necessarily mean that carers may suffer from a diagnosable mental illness but rather this may be indicating the level of stress they experience.
- 2.6. Research indicates that there is a lack of general understanding of CEN in adolescents which may be explained by inconsistencies in clinical responses and clinicians digressing from established diagnostic guidelines.
- 2.7. CEN carers report a perceived absence of understanding about their role and support for the challenges they face. This creates barriers to receiving support for both, themselves and the cared for person which may be tangible during times of crisis in particular.
- 2.8. Factors that can impact CEN carers' wellbeing:
- Frequency of crisis days per month experienced by the cared for-person
  - The length of caring
  - Secondary education
  - Caring for a young person
  - Cohabiting
  - Not in employment
  - Feeling unsupported by healthcare services
  - Having no specific support or intervention

*Carers report that, on average, the cared for person experiences 6 crisis days per month*

## 3. Obstacles CEN Carers face regarding services

3.1. CEN carers experience significant exclusion and discrimination when attempting to interact with healthcare services. Whilst there has been lots done in terms of health professionals improving their knowledge, understanding, skills and attitudes in working with people with CEN, the same needs to be done with their carers. Training on CEN carers for all health professionals is needed, including in primary care as GPs, in particular, are likely to come into contact with carers.

3.2. Numerous studies report the following obstacles CEN carers face:

- ✗ Services often do not recognise carers' supporting role and their difficulties
- ✗ Lack of knowledge of CEN and CEN caring, especially in primary care
- ✗ Inconsistent or non-existent assistance from services at times of mental health crises
- ✗ Carer support services are unavailable or difficult to access
- ✗ Fear their loved one will lose mental health support
- ✗ Not knowing where to find help
- ✗ Lack of communication from mental health professionals
- ✗ Being treated as the cause of the person's difficulties
- ✗ Discrimination because of the diagnosis
- ✗ Poor communication between services
- ✗ Feeling stigmatised
- ✗ Lack of education about CEN
- ✗ Not being taken seriously
- ✗ Long waiting lists
- ✗ Lack of long-term & consistent support
- ✗ Feeling blamed for the person's behaviour

## 4. CEN Carers in health policy

### 4.1 The Personality Disorder Framework “No longer a diagnosis of exclusion”

The Personality Disorder Framework “No longer a diagnosis of exclusion” was a landmark policy that set out the development of personality disorder services, and, recognised systemic failures of statutory services to meet the needs of this clinical cohort in the UK.

*✘ Yet, there was no reference to carers.*

### 4.2 NICE Clinical guideline [CG78] on Carers

NICE Clinical guideline [CG78] subsequently mentions carers but only so as far advising that carers be provided with information and signposted to support from other carers.

*✘ However, it does not offer a systematic approach of capturing the views, values and needs of CEN patients, let alone their carers. Moreover, CEN carers require specialist psychosocial support and psychoeducational input, but services in the UK are largely unable to fulfil such needs.*

### 4.3 The 2019 NHS England’s Community Mental Health Framework for Adults and Older Adults

Due to transfers of mental health care to the community, the burden of care now largely lies with carers. The 2019 NHS England’s Community Mental Health Framework for Adults and Older Adults outlines that people with mental health difficulties will be enabled to “manage their condition or move towards individualised recovery on their own terms, surrounded by their families, carers and social networks, and supported in their local community”.

*✘ However, without a systemic and psycho-social approach to carers, they cannot feel empowered, or be well enough to provide the quality and amount of caregiving placed upon them by such policies.*

## 5. The case for change

A decorative graphic consisting of overlapping blue shapes, including a large triangle and a trapezoid, positioned to the left of the main text block.

*Health outcomes for persons with CEN are poor and improving awareness and understanding of CEN is needed. This applies to CEN carers too. Societal costs associated with CEN are substantial. Thus collaborative, holistic, and systemic approaches to CEN are essential – including caring for CEN carers. CEN carers require specialist assistance that addresses their distinct information, education, and support needs.*

- 5.1 It has now been well-established that compared to carers of other severe and enduring mental health conditions, CEN carers experience much higher levels of distress, grief, feelings of powerlessness, undermined wellbeing and diminishing social networks.
- 5.2 Whilst most carers come into contact with health professionals, they only identify one in ten carers. GPs, specifically, only identify 7% of carers. 66% of carers feel that healthcare professionals do not signpost them to relevant support or information. When information is provided, it largely comes from charities and support groups. 84% of carers say that caring has had a negative impact on their health. There is an increasing prevalence of ‘sandwich’ and ‘hidden’ carers.
- 5.3 CEN carers living in London are in a difficult position as Londoners with a diagnosis or emerging personality disorder do not have access to dedicated support across both primary and secondary care. The threshold and provision of appropriate and wide-ranging interventions are a barrier to people accessing support. As such, it is left to CEN carers to provide high levels of care.
- 5.4 Whilst being diagnosed may initially bring a sense of relief, CEN is not only a hard condition to treat, but specialist treatment is a postcode lottery and subject to long waiting times in the UK. It is inevitable that without treatment and adequate support, both the persons with CEN and their carers’ wellbeing may be further undermined.

- 5.5 Most mental health treatments tend to focus on the patient. This is becoming insufficient, however, as thanks to the increasing care in the community policies, the strain of mental unwellness and the bulk of care largely lies with the patient's broader family and social environment.
- 5.6 Contrary to early research studies, many people with CEN report supportive relationships in their personal lives and find a support network of understanding and caring relationships as crucial for alleviating distress.
- 5.7 Not involving CEN carers as part of CEN treatment could make patients' involvement in therapy superficial and a reason for premature dropout. Evidence shows that, depending on a treatment modality, between 16% to 67% clients with CEN drop out of treatment, with the rate being almost 80% when CEN is comorbid with a substance misuse disorder.
- 5.8 CEN carers feel often overlooked by mental health services. Yet, CEN carers tend to be the only consistent resource for the cared for person. Crucially, they are also amongst key facilitators in their loved ones acquiring hope and psychoeducational skills, evidenced as essential mechanisms of therapeutic change.
- 5.9 CEN carers have been identified as having a unique opportunity to help their loved one's with gaining mentalizing skills. Research shows that when such skills are incorporated into the daily lives of people diagnosed with CEN, their wellbeing improves.
- 5.10 Therefore, paying attention to the social ecologies of a person with CEN is vital for a number of reasons: a) in order to provide effective treatment for the individual; b) because those who constitute their social ecologies often require support in their own right - after all, The Care Act 2014 put carers on a par with patients in terms of meeting their needs and wellbeing; c) so carers can be empowered and skilled up to offer effective support to their loved ones.



## 6. Involving CEN Carers as partners in care: A transformational approach

Transforming mental health care entails pro-actively involving carers in orienting the system of mental health care towards recovery - where recovery is perceived as a personal journey of discovery. Including carers as partners in mental health care is essential when the concept of clinic-based practice shifts to a community-based service approach. As such, carers should have access to timely and accurate support and information, which promotes learning, self-monitoring, and accountability. For this, Figure 1 indicates what is required:



*“If we are to build an NHS that is fit for the future then carers must be full partners in the way we deliver that care.”*

Dr Churchill, N., NHS England, 2019

*Had it not been for his partner’s care and advocacy, the patient would have been made homeless and subsequently been in and out of hospital, or even worse still.*

Dr.T.B., a GP

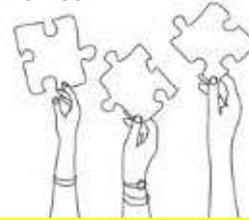
**Figure 1**

*Involving CEN Carers*



## 6.1 Recognising carers

The Triangle of Care was developed to highlight the need for better involvement of carers and families in the care planning and treatment of people with mental ill-health. Best practice suggests that the Triangle of Care model with open and frequent communication between the family, patient and carers leads to best outcomes for all involved.



*“Better recognition that carers are key partners in the planning and provision of mental health care also makes sound economic sense. Both commissioners and providers of mental health services need to recognise that supporting carers through initiatives such as the Triangle of Care is a sound investment in safety, quality, and continuity of care at relatively little financial cost. That said, supporting carers should not be used as a means, intentionally or otherwise, to substitute necessary statutory support and responsibilities. Carers support should not be seen as a means to reduce support to service users, or to legitimise inappropriate assumptions from services about how much carers can take on.”*

Carers Trust, 2013

## 6.2 Carers assessment

Because mental health difficulties are not ‘seen’, and the support needed can be often more emotional than practical, many friends and family members do not see themselves as carers. Therefore, they may not realise they are entitled to a Carers Assessment, which should happen even if the person with CEN is not receiving any service themselves.

Notably, all too often CEN carers find the assessment tokenistic, traumatising, and a box-ticking exercise as the assessors may not have the skills and/or understanding of mental health carers’ emotional and practical needs. Nor is there usually any follow-up, continued support or signposting provided. Instead, providers of assessments for carers should see this as an opportunity to help carers meaningfully by ensuring the assessor has the following competencies:

- a sound understanding of CEN and the impact this has on social and family networks
- a sound knowledge of the mental health and social care systems
- a lived experience of being an informal carer

- counselling skills to provide on-going support through one-to-one counselling
- group facilitation skills to deliver carers psycho-social support groups and psychoeducation - both should be seen as opportunities for co-production
- ability to ensure that carers are aware of the range of local mental health services and signposted to relevant voluntary sector organisations through the provisions of appropriate advice and information
- ability to provide advocacy as and when appropriate

*“Our home situation reached a point where it was almost unliveable for myself and our kids because of my husband's reluctance to seek help. Being told during a carers assessment that there is help I can access was such a relief. On a weekend psycho-edu course I learnt how to interact and communicate with him to prevent his distress from escalating which made our family life so much better. “*

M.F., CEN Carers focus group, 2021

### 6.3 Involving CEN cares in co-production

It has widely been recognised that CEN carers’ needs and views have been neglected by the system so this could be changed by supporting and empowering CEN carers to have their voices heard by involving them in, for example:

- co-producing & co-delivering services
- treatment approaches
- policy
- research
- training and education
- carers forums

*“My partner prefers the concept of discovery rather than recovery in mental health. So, when I sat on an interview panel choosing the new head of the local mental health service and one of the candidates thought a recovery meant for a person to adhere to their medication and going for a walk, whereas another one saw recovery more like a journey of discovery, I knew instantly who’d receive my vote.”*

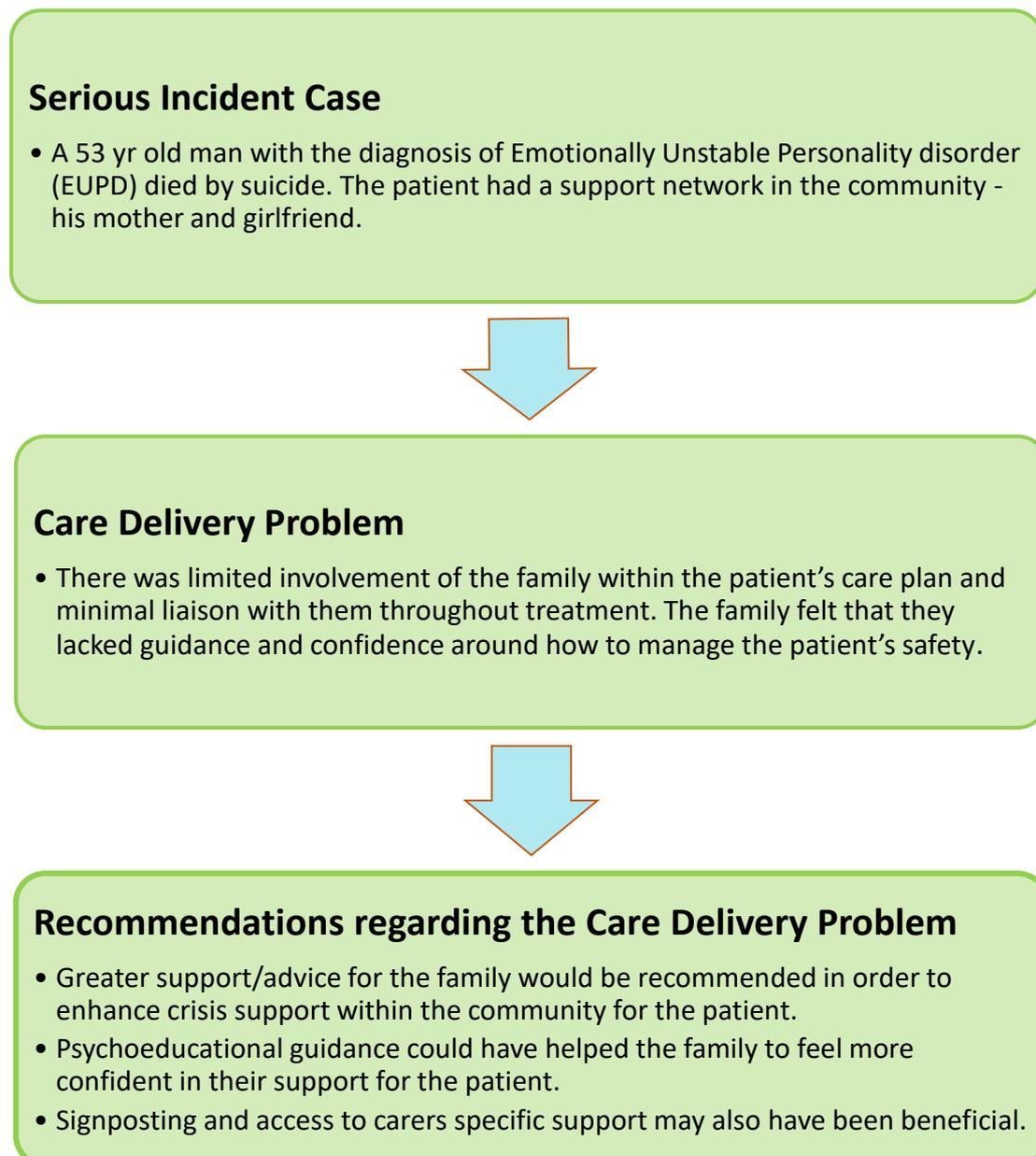
J.D., CEN Carers focus group, 2021

## 6.4 CEN carers as part of the cared-for person’s Care Plan

CEN carers may often be considered as a protective factor by the person living with CEN. Where the cared-for person explicitly agrees, CEN carers should be part of their Care Plan and provided with a copy thereof. However, even if the person with CEN would prefer to cope on their own, CEN carers should still be offered support and an assessment of their needs. Whilst in some circumstances there may be reasons for family not to be involved, it is a good practice to keep reviewing this. Figure 2 shows a Learning Note from a recent Serious incident where the patient’s carers were not pro-actively included in the patient’s care.

**Figure 2**

*A Learning Note from a Serious Incident*



## 6.5 Information sharing and confidentiality

CEN carers need to be encouraged to allow sharing of their information so support is tailored, sensitive, effective and joined-up. Information sharing also needs to be appropriate and avoid carers having to repeat information. As and when appropriate, professionals should also encourage people with care and support needs to share information about their needs with carers so that they too can participate in care and support planning. Confidentiality is amongst the core competencies for working with people with CEN. Most of the time carers would like to learn how to care with confidence e.g., deal with crises, life-threatening behaviours, and how to improve the quality of life for themselves and the person they care for.

### To note:

- At times, a person with CEN may not feel comfortable for their relative/carer to access programmes e.g. psychoeducational ones in the same service or trust they are treated in. As such, there should be a reciprocal arrangement between trusts to accept carers from different areas, or trusts should provide carers support regardless of any geographical constraints.
- Services need to have a written consent from the patient regarding information sharing with their family though this should be reviewed periodically. Even if the patient declines to give permission, this should not prevent services from, for example, signposting the carer so they can receive appropriate support elsewhere.

## 6.6 Skills for caring

Please see section 7 *CEN Carers Interventions* for evidenced-based information on how to provide CEN carers with skills for caring through a number of interventional approaches.

## 7. CEN Carers interventions

*For CEN Carers to become confident partners in care, they have to be provided with the right skills for caring. Plurality in psychological approaches to CEN carers is needed as Figures 3 indicates. If CEN carers feel supported, they report improvements in their caring role and relationship with their loved one alongside the overall family climate. Once CEN carers feel skilled, they can become an effective resource as well as an essential source of hope for the person they look after. Notably, as persons with CEN may not have a diagnosis or be in treatment, it is important to provide support for their carers regardless.*

**Figure 3**

*CEN Carers Interventions*



## 7.1 Information and advice

At a minimum, CEN carers need to be provided with:

- information in an accessible, non-judgmental and non-stigmatising manner about the condition and its prognosis
- what to expect from treatment
- how they can contribute
- as appropriate, advice on, e.g., benefits, debt, housing, employment, legal rights and Lasting Power of Attorney
- where and how to obtain further help and support

## 7.2 Family therapy

Family therapy can be a helpful addition to CEN treatment depending on the patient's history and status of current relationships. This approach may particularly be helpful for adolescents or other individuals who may still be dependent on their families e.g., living at home or getting significant support from family members. Family therapy is usually suggested when CEN symptoms significantly impair family functioning. This type of therapy can lead to better communication, fewer conflicts, reduction in self-harming, and less guilt felt in families. Of note, family therapy is not recommended as the only form of treatment for persons with CEN.

## 7.3 Individual psychotherapy / counselling / IAPT

If a systemic approach is not feasible, CEN carers could be referred to an individual psychotherapy/counselling service or advised to self-refer to IAPT. However, most CEN carers' distress is due to disempowerment stemming from a lack of understanding of CEN and not having the right skills for caring e.g., how to prevent and deal with crises and communicate effectively with their loved ones.

## 7.4 Recovery colleges

Recovery colleges are based on a recovery – focused psychoeducational model aimed at persons receiving services, carers, staff and volunteers. However, more proactive, thought-through approaches are needed to attract carers to them, such as courses solely for carers. Carers report they prefer the emotional safety of fellow carers, they would like the content of the courses tailored to them and delivered in a more convenient time. Those new to caring prefer to be close to clinicians in the pathway the cared-for person is treated in.

## 7.5 Psychoeducational programmes

Programmes combining psychoeducation and skills have proven most effective for decreasing and preventing emotional burnout amongst CEN carers. Further, they decrease stigma, alienation, relieve family distress, burden on the services, and improve communication and wellbeing. CEN carer interventions can improve the effectiveness of CEN treatments, the long-term prognosis, and reduce those interpersonal factors maintaining CEN symptoms.

The majority of research has been carried out on dialectical behaviour therapy (DBT)-based carer programmes. Some programmes are designed as peer-led whereby programme graduates volunteer as facilitators. Whilst this can be empowering for some, it may place unreasonable demand on carers, nor do they have sufficient clinical knowledge. There is a gap in longitudinal studies and more research is required for assessing impact of such interventions on the cared for person.

Innovative Examples: Psychoeducational programmes from England & abroad	
Example 1	Example 2
<p><b>Family Connections™ programme NEABPD, USA</b></p> <p>A 12-week programme based on DBT. It provides latest information and research on CEN and family functioning; individual coping skills; family skills and group support that builds an ongoing network for all family members. The programme also runs internationally and now started to be offered by some NHS Trusts in England.</p>	<p><b>The Oxford Friends &amp; Family Empowerment; Oxford Health NHS Foundation Trust</b></p> <p>Clinician-led support carer groups and psycho-education weekends open to CEN carers even outside of the trust. Carers are provided with information, education, and theoretical frameworks to enhance their understanding of CEN and accompanying difficulties such as self-harm. Carers are enabled to explore feelings, learn coping strategies, and effectively support their loved one.</p>
Example 3	Example 4
<p><b>Families &amp; Carers Training and Support (FACTS), Anna Freud Centre</b></p> <p>A volunteer carer-led 5 weeks-long course stemming from a randomised controlled trial of an MBT-FACTS pilot programme, which showed that a mentalization-based psychoeducational intervention resulted in a decrease of crises as carers gained confidence and skills around CEN.</p>	<p><b>Cygnus, Leeds &amp; York Partnership NHS Foundation Trust</b></p> <p>A 6-week pilot trial based on the principles of schema therapy. Volunteers for carer-consultant group facilitators were formally recruited, trained and received weekly supervision throughout the pilot. Outcomes showed significant improvements in carer wellbeing, understanding, capability and emotional responses regarding caring for someone with CEN.</p>

## 7.6 Psycho-social CEN carer support groups

Support groups are essential for CEN carers but there is no systematic approach to a provision of specialist support groups considering that CEN carers often provide care and support for many years, decades even. CEN carers do not benefit from general carer support groups or general mental health support groups.

*“I appreciate the stories, support and useful tips members of the group give each other in such meaningful ways. To learn that behind all that anger my daughter, actually, feels vulnerable and that I can emotionally validate her in that moment rather than crumble or chastise her was simply ground-breaking for our relationship. I have a hope and no longer feel a nervous wreck. This also enabled me to reflect on my own upbringing and some of the difficult situations I experienced.”*

K.M., CEN Carers focus group, 2021

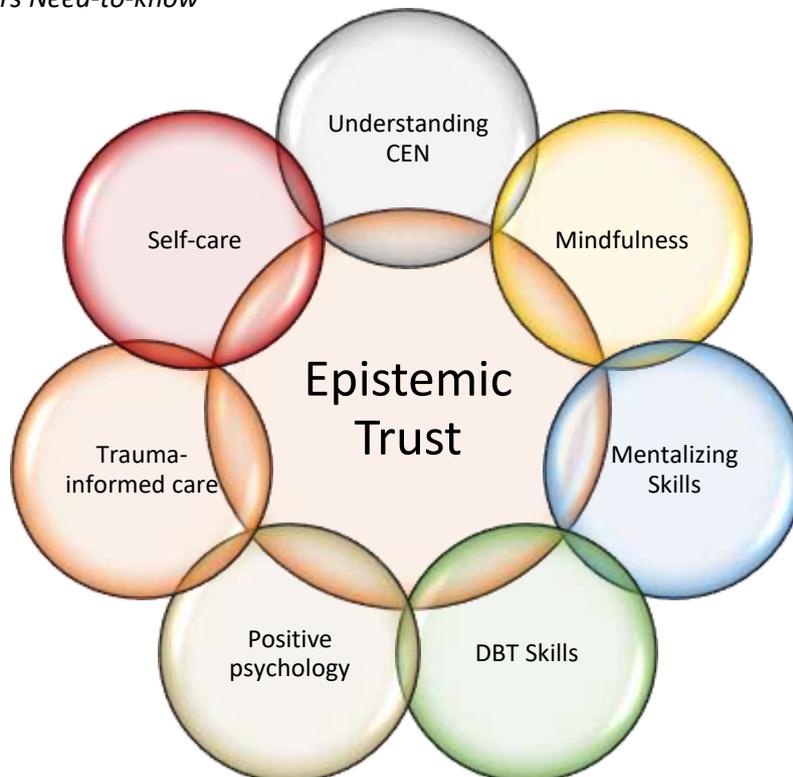
Pioneering examples: Psycho-social CEN Carer Support groups in London	
London BPD Carers Group	Harrow BPD Carers Group
<p>The Group began as an eight-week course cca 20 years ago at the Henderson Hospital in Sutton, a residential community for people with CEN. Carers were provided with information, knowledge of CEN and met with people in recovery. When the hospital closed, the Group was supported by Emergence, a lived experience charity, which also closed so now the Group operates under Rethink. Lottery grants enabled the Group to employ facilitators with lived experience. The group now runs three online groups monthly. Recently it closed its waiting list as it could not meet the demand from new carers. The Group organises conferences, talks, psycho-educational events, is involved in research and co-production with services.</p>	<p>A sister group which was established after members of both groups undertook an MBT-FACTS randomised controlled trial in 2018 aimed at CEN carers. The group also operates under the Rethink umbrella, is supported by local Harrow Carers charity and before the pandemic was provided with a community meeting venue. In the recent transformation, it was included in the local community mental health services Trauma pathway. The group is also expanding, organises talks, takes part in conferences, runs two online groups and FACTS.</p>

## 8. What CEN Carers need to know

*This section outlines essential components CEN carers ideally would be trained in if they are to help their loved ones – and themselves - meaningfully. All the elements as shown in Figure 4 are interconnected and all elements are bidirectional meaning they can each help the cared for person as well as carers themselves. In fact, they can also help professionals – after all, there is no “us and them” when wellbeing is concerned.*

**Figure 4**

*CEN Carers Need-to-know*



## 8.1 Epistemic trust



'Epistemic' refers in Greek to the 'roots of knowledge' and is an ability to learn socially. It serves as the foundation for flourishing interpersonal functioning and overall wellbeing. We need to learn from trusted others otherwise it would be too difficult to work out life, relationships, and the societal know-how. This helps us develop a shared view of ourselves and others which gets cultivated throughout our lives and even transmitted across generations. Epistemic mistrust, on the other hand, is characterised by inflexible, circular thinking patterns, a difficulty to learn from the social environment and seeking/accepting help from others. As such, it lies at the core of carers' know-how.

## 8.2 Understanding CEN



Accurate understanding of the condition and familiarity with the latest research is paramount for professionals, let alone carers. The condition tends to be subject to stigma and is often misunderstood by many, including some mental health practitioners. This can impact and influence the way that people, including their carers, are perceived, and treated. Misconceptions, including that the condition is not treatable, it affects only women and stems exclusively from child abuse, can discourage people from seeking, and receiving help. Carers should learn how to deal with and prevent life-threatening and quality-of-life-interfering behaviours, crises, and even how language matters when it comes to CEN.

## 8.3 Mindfulness



It is well-established now that that mindfulness brings about various positive psychological effects. Whilst more research is needed to fully establish the effectiveness of mindfulness training for persons with CEN, findings suggest that it may be an effective tool for alleviating certain symptoms of CEN. Mindfulness interventions enhance executive attention, a core component of mentalizing and person understanding. Notably for CEN caregiving, there is growing research into interpersonal mindfulness with its awareness of self and others and qualities of nonjudgment and nonreactive presence. Interpersonal mindfulness has been shown to be beneficial for relationship quality, encouraging effective communication, and navigating negative emotions and contentious situations. Importantly, a person mindful during a challenging situation within an intimate relationship is more likely to respond more appropriately as they are more likely to accurately perceive the moment.

## 8.4 Mentalizing



Mentalizing is, essentially, what makes us human. Mentalizing is about understanding oneself and others and is learnt through epistemic trust. As an imaginative mental activity of perceiving and interpreting human behaviours, it is intertwined with intentional mental states (e.g., beliefs, feelings). It leads to a better chance at getting objectives met in life. It is vital for our wellbeing, awareness of self and others, and for the sake of relationships. As such it is considered the foundation for emotional regulation and a fundamental mechanism of mental resilience and healthy functioning. Stress gets in the way of mentalizing. Importantly, mentalizing can also get impaired via developmental trauma which may predispose a person to being prone to stress and vulnerable to developing mental health difficulties. Mentalizing brings about mentalizing so it is vital that CEN carers know how to develop and maintain efficient mentalizing family culture.

## 8.5 DBT skills



DBT offers a practical approach focused on problem-solving. Its primary interventions such as skills training in emotion regulation and a straightforward approach to unhelpful behaviours are beneficial for many people. Because DBT is so comprehensive and practical it may appeal to professionals and carers alike. However, it may not suit those who may need more relational focus that mentalization-based approaches offer. In fact, research suggests that combining mentalizing and dialectical behaviour skills may be most beneficial to people with CEN. After all, mentalization skills may be a common factor underlying all psychological therapies.

## 8.6 Positive Psychology



Positive psychology assumes that within the limitations that exist in every human being, the largest potential for one's flourishing lies in discovering, appreciating, and developing opportunities, strengths, and sources of meaning. Its aim is to promote well-being, enrichment of one's own strengths and values so a person can lead a meaningful life. Importantly, the field of positive psychology was developed to counterbalance the medical model, with its immersion in the deficiencies of a person and looking for what is wrong with them. Research shows that positive psychology interventions have a broadening effect of thought that enables people to develop a repertoire of sustainable physical, cognitive, and social resources which in turn, helps them deal with difficult situations in the future, feeling more connected to others and resilient.



## 9. A case study

An Innovative example:

### Together, we can work it out

An 8-week psychoeducational programme for CEN carers utilizing all of the elements in Figure 4

CEN pathway, CNWL NHS Foundation Trust

Initiated and co-produced by a CEN carer, this psychoeducational, skills-based programme is currently under way at a CNWL CEN pathway. This was in response to a few serious incidents where Care delivery problems were identified and it was recognized that carers were not systematically included in the patients' care despite CEN carers having been considered a protective factor by the patients. Quantitative data is collected before and after the course, alongside planned post-intervention qualitative interviews.

The following feedback has been, thus far, received:

"I hadn't thought about CEN in any kind of positive way before. Now that's shifted. You mentioned a deep sensitivity. That made so much sense. Different ways of being, of experiencing - a different tuning. Obviously, and, because of intersecting factors, immensely challenging but suddenly there is light. No longer a tunnel but a journey! And that's after one session - how exciting!! We're both very glad to be on this course."

"I just wish I'd known these things twenty years ago."

"I don't think I can find the words to say how deeply I am affected and how meaningful this course is to me."



“So glad things are moving on from where they were.”

“I wanted to express my gratitude to you both. I felt that I was lucky enough to have these resources for myself and the people who are on the course. A massive thank you to you for putting the course out there, it has definitely paved the way for Carers and the differences they are making for people who have mental health difficulties. It is the differences that you guys make in NHS which will start and have positive effects on people.

*Thank you 🙏* “

“It was inspiring to hear you both effectively removing CEN from the deficit model where it's usually situated.”



“I really enjoy your sessions and your insights and stories bring it to life. I believe giving examples of how to deal with certain scenarios is vital and is the most supportive aspect of the programme once we realise what our loved ones are dealing with.”

“I am writing this email as I want to thank you and acknowledge the important work both you ladies are doing. I am indebted to you both. Really, I am in awe of you both. I just hope you realise that you are doing an amazing job and filling a real need, and you both deliver it exceptionally well. Well done and a huge thank you from me”

## 10. Final take-home reflections

### CEN DIAGNOSIS – NO LONGER A DIAGNOSIS OF EXCLUSION – FOR CEN CARERS EITHER

This Guidance outlines essential knowledge on CEN caring in the context of the current Transformation of community mental health services and care in the community policies. Given the plethora of research on CEN, better understanding of its causes, healthcare services becoming increasingly trauma-informed, and growing research on CEN carers, it is evident that CEN carers can no longer be routinely overlooked by services, especially when CEN carers are considered as a protective factor by the person with CEN.

As such, all health professionals need to improve their knowledge and understanding of CEN carers. This can help them realize that with effective support, CEN carers can prove valued, and, much needed, partners in care. The majority of CEN carers are eager for guidance from mental health professionals on how best they can support their loved ones. Evidence shows that CEN carers need specialist carer support that addresses their distinct information, education, and support needs so they can confidently be at their loved ones' side throughout their personal journey of discovery. And, vice versa, persons with CEN need to feel also confident that their carers can provide the right help when/if required.

The field of CEN has seen so much progress since the original NHS framework was published in 2003. However, standards on CEN carers in particular have been found wanting. By outlining the case for change, it is hoped that this Guidance will help services to find the right balance when providing support to persons with CEN and their carers. If services employ a timely systemic, relational approach in treating CEN, it can prevent CEN complexities becoming even more complex and, in many instances, intergenerational trauma being needlessly perpetuated. Such an approach can help all parties involved connect to themselves and each other so they can together learn, mentalize, and ultimately thrive.

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