The Introduction of Carers Support within a Learning Disability Forensic Community Team

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Overview of Presentation

- Background literature and guidance for working with and supporting carers
- Introducing our community forensic learning disability carer strategy
- Future steps

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USER AND CAREGIVER PERSPECTIVE ARTICLE

Supporting Carers Within a Forensic Intellectual Disability Community Team: The Development of a Carers Strategy

**Charlie Freeman · Gisela Perez-Olivas ·
Elizabeth Patteril · Verity Chester**

Received: 28 June 2023 / Accepted: 7 September 2023

Abstract The needs of carers of those discharged from inpatient forensic intellectual disability (ID) services are under researched. The role of the carer changes significantly during the transition from the person being cared for by the inpatient service, to a community setting. The carer may feel responsible for managing mental, physical and forensic needs. Therefore, carers of those with ID and forensic needs in the community require specialist support and understanding. Following the establishment of a new community ID team in Norfolk, the lack of guidelines for

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This paper describes the implementation of a carers strategy within a community forensic intellectual disability (ID) service. Due to the limited literature focusing on the characteristics and needs of this group of carers, related research is reviewed to provide context, including the evidence base on carers of those with ID, carers of those within inpatient or forensic services, and research on carers of those within inpatient forensic ID settings.

Background Literature

- When it came to reviewing the background literature to ensure our new community forensic learning disability carer strategy was evidence based, we found research on:
  - Family/carers people with learning disabilities (adults and children)
  - Family/carers experiences/needs if their relative is admitted to an inpatient or forensic service.
  - Nothing on the needs of the community forensic learning disability carer group.

Carers and ID

- Family carers of those with ID play an important role in their relative’s lives.
- Compared other conditions, the care of a person with ID is usually for the carer’s whole lifetime.
- Families are the most stable support network throughout the life course of adults with ID (Seltzer & Krauss, 1994).
- Research has often framed the experiences of families with a relative with ID negatively, in terms of burden, lower levels of psychological wellbeing, self-esteem, and chronic levels of stress (Chester et al., 2020).
- Carers can experience emotional difficulties such guilt and worry about who will look after their relative when they pass away (Chester et al., 2020).
- Overemphasizing stress and burden creates an overly negative perception of having a relative with ID.
- Most families talk about their child with ID in the same terms as their children without ID, as a source of joy and happiness (Chester et al., 2020).

Carers and ID

- Families report that their main sources of stress are external factors, e.g.:
  - negative experiences from support services (Hill & Rose, 2009; Llewellyn et al., 2010),
  - lacking acceptance, negative attitudes, feeling blamed for their relative's behaviour, being stared at in public, therefore restricting their activities ->
  - loneliness, isolation, helplessness, stigma, and reduced quality of life.

- Research highlights the pressing need for carer support initiatives (Deville et al., 2019), as good access to information and resources is predictive of greater well-being for relatives of those with ID (Resch et al., 2012).

Carers for People in Inpatient Settings Including ID

- When a person with ID develops mental health issues, carers often face difficulties accessing services, due to the barriers to healthcare experienced by those with ID (Chester et al., 2020).
- If the person requires treatment in an inpatient setting, this process can be distressing for carers, causing anxiety and uncertainty about the future (James, 2016, 2016).
- Families may remain in a crisis state due continuing concerns about their child’s vulnerability and that they will not be cared for in the same way (Gavois et al., 2006).
- Carers often cite communication issues with services and feeling excluded from care planning (Chester et al., 2020).

Carers of Patients Within Psychiatric/ ID Forensic Settings

NHS England

Carer support and involvement in secure mental health services

A Toolkit

Start

This toolkit is meant to be used in any way that is most helpful. You can find your way through the document by clicking through the pages or going directly to content that interests you by following links.

This document is only compatible with adobe acrobat and some elements will not display/function correctly whilst using other pdf views Click here to download the latest version

uclan University of Central Lancashire

- Forensic carers report experiencing stigma, due to the crimes committed by their relative, losing friends and becoming isolated.
- There are cases where the carer is the victim of abuse by their relative (Larch, 2016).
- Carers of those detained in inpatient settings who maintain relationships report anxiety, guilt and stigma, alongside practical challenges and self-sacrifice to support Section 17 leave.
- Carers want to be included as partners in the care process but often feel excluded from the system.
- Difficulties often relate to communication, with carers outlining how important communication was to them, voicing how much they valued receiving calls from staff, having access to information and their questions answered.
- Working with families is important in helping prevent relapse of mental illness, which in turn reduces forensic risk.
- As such, the Forensic Carers Toolkit (2018) was developed to support carer involvement within forensic secure hospitals. The toolkit has best practice principles for services to follow when involving carers.

Forensic community learning disability carers

- The discharge from a forensic secure hospital to the community can be challenging for carers.
- Any life change can add strain to the relationship between the carer and the person cared for.
- The carers in this study emphasized that discharge from hospital “is not the end of the story” for them (Chester et al., 2019).
- They raised concerns about ensuring the discharge placement had the correct level of support/supervision to mitigate ongoing risk, alongside the responsibility of observing their relative’s health and behaviour and reporting concerns to professionals.
- As such, it is possible that the time of approaching discharge is anxiety provoking for carers.
- Despite this, there is no research exploring the needs of carers supporting patients with ID being discharged from an inpatient forensic setting to a community forensic team.

Article

Treatment outcomes from forensic intellectual disability services: The perspectives of patients and their family/carers

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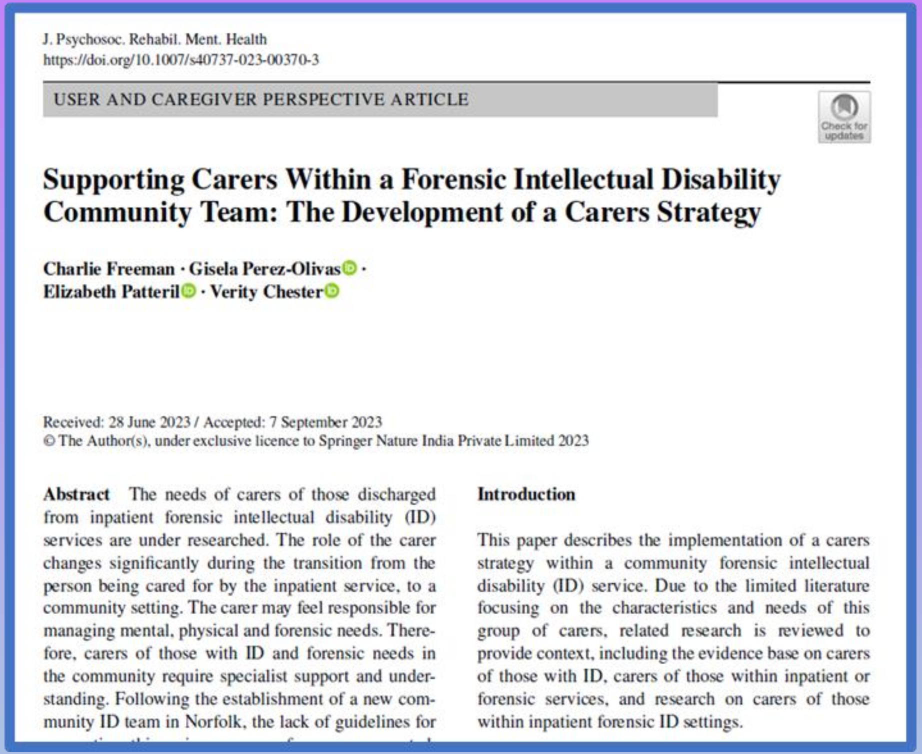
Abstract

Introduction: Research investigating the treatment outcomes of forensic intellectual and developmental disability (FIDD) services has largely focused on the perspectives of clinicians and researchers. This study sought the perspectives of patients and family/carers on the outcomes important to them. Methods: Semi-structured consultation groups were conducted with patients in FIDD services ($n = 21$) and family carers ($n = 6$). Interview data were content analysed, and outcomes identified fell into three main domains (effectiveness, safety and patient experience). Results: The consultations identified outcome domains not considered in the published literature. Patients and carers also had differential perspectives on treatment outcomes commonly reported within literature. Illustrative quotes are used to evidence the domains. Discussion: This study is the first to investigate the outcomes of relevance to patients and their families. These views have been incorporated into an outcomes framework which will form the foundation of future prospective outcome studies.

A brief overview of our paper

- When the new community ID team was set up in Norfolk, the lack of guidelines and research for supporting this unique group of carers was noted.
- As such, a carers strategy with multiple components was initiated.



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Norfolk Forensic Community Team

- We work with adults who have a learning disability and who have or are at risk of coming into contact with the criminal justice system.

- Carer awareness is vital to our role within the community, our carers have unique experiences and combat different stigma, for example, caring for a loved one who has committed serious offenses, we can offer tailored support and signposting.

Norfolk Forensic Community
NFC-LD
Learning Disability Team

Definition of a Carer

The Care Act 2014 states:

- “A carer is someone who helps another person, usually a relative or friend, in their day-to-day life. This is not the same as someone who provides care professionally, or through a voluntary organisation. “

Definition continued:-

A carer is someone of any age who provides unpaid support to family or friends who could not manage without this help due to illness, disability, mental ill-health or a substance misuse problem.

They may or may not live with the person they support

Useful to make distinction between Carers and Careworkers

Some context

- 3 in 5 of us likely to be a carer
- Up to 100,000 carers in the county of Norfolk
- 61% have faced depression because of their caring role
- 49% struggle financially because of their caring role
- Carers are twice as likely as non-carers to suffer from ill health

Where it all began

- A training event was held by Local Mental health trust
- Charities attended
- UEA attended to showcase their new research project
- Carers Voice launched their carers identity passport
- It was a great networking opportunity
- Realised that HPFT were not a part of the carers voice passport project, unlike every other trust in Norfolk
- Realised that there was no carers champion within community teams at Little Plumstead Hospital

Creation of Carers Lead/Champion Role

I began by looking at the available guidance within HPFT

Five Steps to good Carer Support

1	IDENTIFY
2	WELCOME
3	SUPPORT
4	INVOLVE
5	TRANSITION

IDENTIFY

- Carers should be identified at first meeting or at first available opportunity

Welcome

- Welcome letter and carers pack from the team that includes guidance around confidentiality
- Phone call soon after to discuss with the carer

Support

- Offer 1:1 face to face meetings, phone calls, ask the carer what they need. Signpost them to other services

Involve

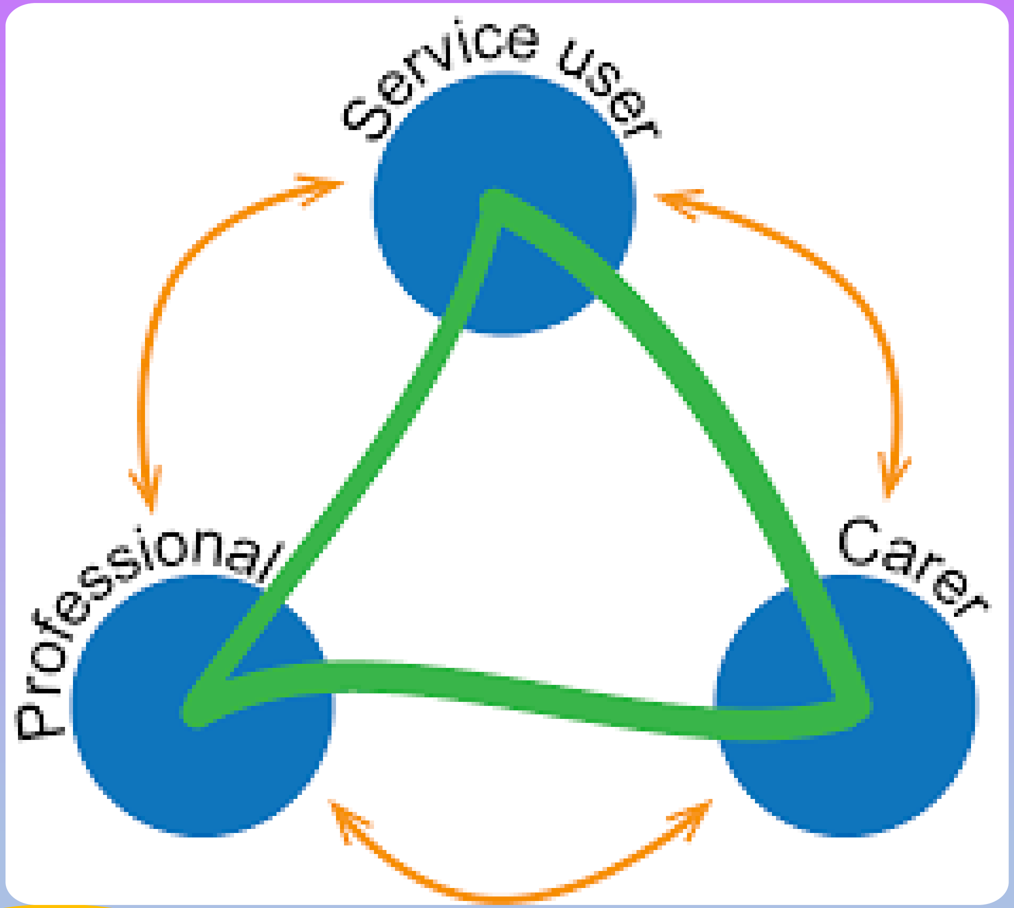
Carers have the right to be involved with their loved ones care. Service users should always be asked, just because they say no does not always mean we have to completely keep the carer away. Ask what can be shared.

Carers should always be involved with care plans that affect them, and we should work towards involving them in all aspects of care, even if they are just consulted.

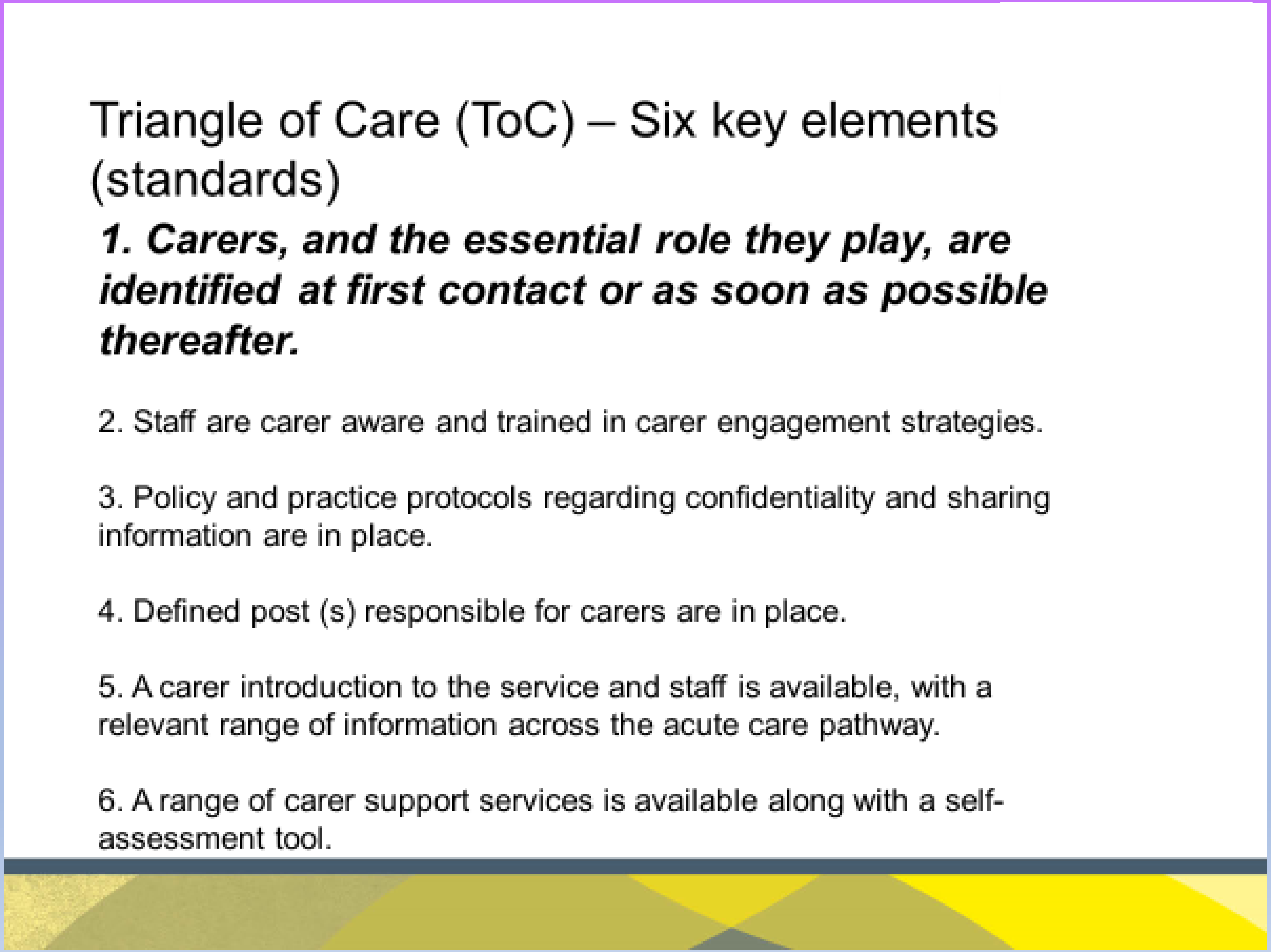
Transition

When the service user is discharged, work with the carer to develop a discharge and or crisis plan.

HPFT is a member of The Triangle of care



Triangle of Care MEMBER



Triangle of Care (ToC) – Six key elements (standards)

1. Carers, and the essential role they play, are identified at first contact or as soon as possible thereafter.

2. Staff are carer aware and trained in carer engagement strategies.

3. Policy and practice protocols regarding confidentiality and sharing information are in place.

4. Defined post (s) responsible for carers are in place.

5. A carer introduction to the service and staff is available, with a relevant range of information across the acute care pathway.

6. A range of carer support services is available along with a self-assessment tool.

Working with Caring Together

- Caring together is a leading charity in Norfolk that offer support to carers.
- They offer an award called the Carers friendly tick, which is endorsed by Norfolk County Council.

Carer Friendly Tick
Health
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Valid until 2025

Caring
Together
so that carers have choices

What was Completed

CARERS ARE IDENTIFIED AT FIRST AVAILABLE OPPORTUNITY. THERE IS A SECTION FOR THEM ON THE REFERRAL FORM.

CARERS WERE ADDED TO THE TEAM MEETING AGENDA EVERY WEEK

CARER AWARENESS TRAINING WAS CREATED AND GIVEN TO COMMUNITY TEAMS

Carers Pack

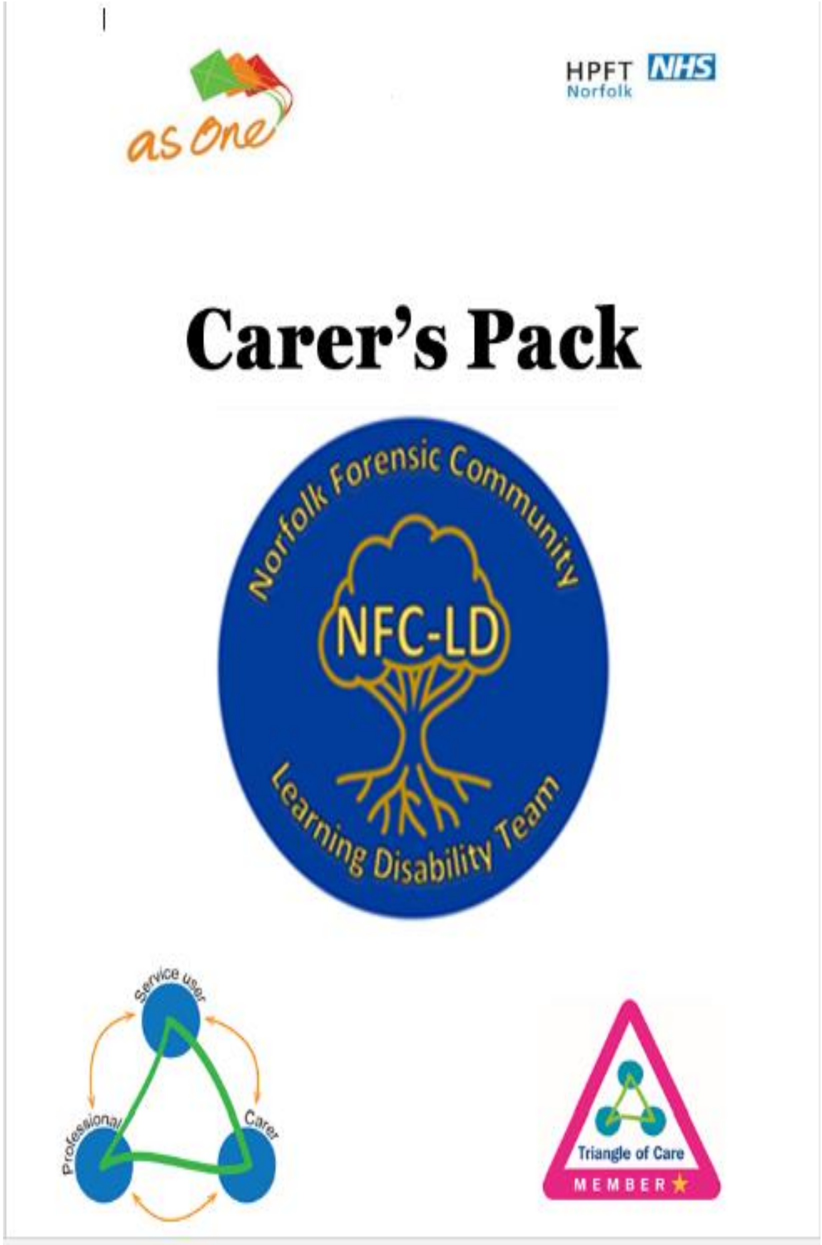
This includes

welcome letter, explaining the service and outline what they can expect for their loved one, who their named practitioner is, with contact details.

Carers Matters Norfolk handbook, Carers Matter are the service that is commissioned to offer carers assessments and carers support in the Norfolk area.

HPFT Carers Guide

Carers Charter

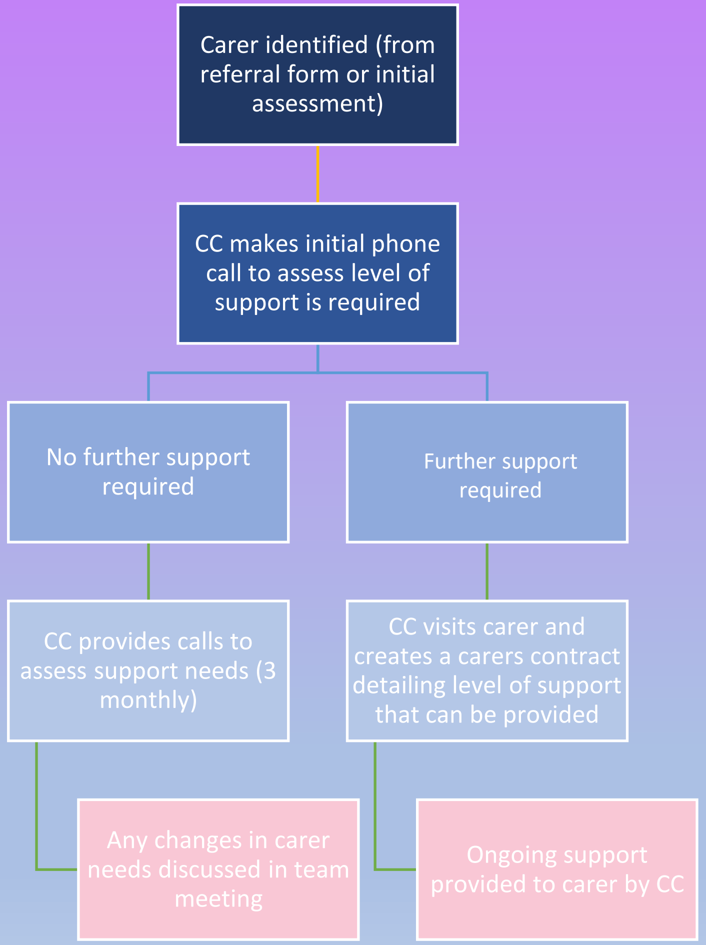


Carer's Pack

Carers Board

- This sits pride of place in our reception and comes out on training events too

Carers Contact and Support Process



Carer identified (from referral form or initial assessment)

CC makes initial phone call to assess level of support is required

No further support required

Further support required

CC provides calls to assess support needs (3 monthly)

CC visits carer and creates a carers contract detailing level of support that can be provided

Any changes in carer needs discussed in team meeting

Ongoing support provided to carer by CC

By Completing all of this we were awarded

Carer Friendly Tick
Health
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Achieving the Carers Friendly Tick Award

The Carer Friendly Tick Award is an accreditation designed to provide organisations with an emphasis on standards to support carers within healthcare settings (Caring Together Charity, 2021). The Carers Friendly Tick Award criteria is made up of five key elements:

1) Have a named member of your organisation/team as a champion for carers.

2) Have a carers' agreement developed to help identify and support carers.

3) Cover issues relating to carers in staff training and staff meetings.

4) Display information about carers, as well as projects that support them locally.

5) Raise awareness in Carers Week and on Young Carers Action Day and Carers Rights Day.

Feedback

display board shows imagination and also offers people an opportunity to respond.

very impressed by this application. There is a clear indication of her enthusiasm and concern for Carers. She is developing training, using the experience of colleagues in another centre where experience has already been gained. She is making inroads into social media and using modern methods of communication. This shows great promise and I hope she will be much encouraged by this assessment.'

"Things are going well, everyone turns up on time, they are friendly, all input is good, people are approachable. I went away for a week and had a brilliant time, she was looked after, I did not need to worry, it was lovely thank you"

The panel were really impressed by Charlie's passion for the role, with one member commenting that she doesn't just talk the Triangle of Care talk but 'walks the walk' as well! They liked that Charlie has experience of being a carer and there seems to be a good support network that work closely together when needed.

Conclusions

- Anecdotally, this project has been received very positively by the carers involved, and by staff within the team. The carers strategy is in constant review and development, based on ideas from carers, the team, and other stakeholders.
- For example, a plan is to introduce an assessment tool to provide a quantitative overview of carer needs, which could also be used to evaluate the impact of the programme.
- Similarly, there has been the suggestion to make the resource pack available online, via a website or app, to facilitate accessibility. Finally, the need to provide carer awareness training to the care providers of community ID placements has been highlighted as an area of demand.
- The limitations of this paper relate to lack of data to evaluate the carer strategy. Future work to formally evaluate the impact of the carer strategy is in development, with a broader aim of informing strategies which could be generalised to other services.

Conclusions

- It is hoped that the initiative described in this paper will contribute to a model of practice to support carers of patients supported by forensic community ID settings.
- Community based care for offenders with ID is becoming increasingly common following implementation of the Transforming Care programme. It is therefore likely that the need for effective involvement strategies for this group of carers will increase.
- While research from related populations may extrapolate, there are concerns and issues that uniquely affect this group. For example, increasing demands on the caring role following the transition from secure settings to community placement, with feelings of responsibility for managing complex health and forensic needs (Chester et al., 2019; Clibbens et al., 2019; Tingleff et al., 2022).
- Further co-produced qualitative work is warranted to explore the voices of the carers in community ID forensic settings.

Any Questions????????

Special Thanks to:

Corrina Saville- HPFT Carers Lead

Rose McCloskey- Carers Lead for Forensic inpatients

Caring Together- Clare Rogers

Caring Together- Carers panel