CV 014

The Challenging Behaviour Foundation

making a difference to the lives of people with severe learning disabilities

INFORMATION SHEET

Timeline of changes to family visiting during COVID-19 - *Based on a real person (name changed)*

1. Care Review Meeting before Coronavirus / lockdown

Discussed that things were generally going ok for Craig. He loves visits to his family home.

Some behaviours being displayed, some of sensory nature. In the past Craig was physically held, now he has not been held for around 2 years. Only having paracetamol medication – no other medication for the last few years.

2. Beginning of lockdown

Craig presented with increased behaviours that challenge including considerable self-injurious behaviour.

Due to Coronavirus the care provider stopped family visits. Craig values visits to his parents.

In terms of health risk due to coronavirus Craig is a young man with no known underlying physical health conditions. He has a learning disability, and this is one of the groups that are identified as possibly being more vulnerable. He is not able to understand guidance and will not follow handwashing guidelines.

3. Blanket decision

Family received a letter from the care provider saying no visits across the board - visiting the home or meeting in a public place. Family decided to comply, but were concerned about how this would impact on Craig who was already quite unsettled.

4. Risk assessment

Care Provider produced a plan and risk assessment to try to support Craig to maintain some contact with his family. This involved meeting for two walks a week.

5. Medication

Prescription of PRN (as required) medication was agreed in Craig's Best Interest at this difficult time to aid him to cope with the changes and less family contact due to Covid-19.

6. Multi-disciplinary team

Craig was discussed by Learning Disability Nurse in a multidisciplinary team meeting, to make staff aware of his possible escalating risk.
Speech and Language Therapist involvement.

7. Challenging behaviour

Following initial contact with his family (2 walks a week), Craig's self-injury went down. He continued to have behaviours that challenge but his support team were able to manage these and did not need to give him any PRN medication.

There was then an increase in Craig's self-injurious behaviours and PRN medication was used. This appeared to be in relation to ongoing reduced contact with family and Craig asking for family members.

8. Professionals meeting

Discussion about an increase in family contact and for Craig to be able to visit his parents' homes.

Learning Disability Community Nurse felt that his visits were part of his care plan and that his parents could be seen as unpaid carers.

Social services' position was that family contact in their homes would not be advised. If it was thought necessary then a mental capacity assessment would need to be completed, a best interest decision and sent to court for agreement.

Provider felt it was a higher risk going to the house and were reluctant to support this at the current time.

9. Behaviour and staff support

Deterioration in Craig's behaviours that challenge. There had been a lot of staff changes which is likely to have an impact on Craig, as well as his routines being changed due to Covid-19.

Input from MDT to ensure consistency in support workers' communication with Craig, how they present choices, use visual aids and intensive interaction.

Craig's risk assessment was updated to 'high', due to the level of physical aggression to others and increase of self-injurious behaviours. Contingency plan updated.

Family and provider were concerned that 'as required' PRN medication and physical intervention has needed to be implemented. No PRN or restraint was used for almost 18 months, previously.

Family wanted him to come home for visits as they feel he is very relaxed when home and he needed this security.

10. Care Programme Approach (CPA) Review

Provider stated that they are following government Covid-19 advice. Provider did not like the situation but had to follow the guidance in place, from two legal departments and Government.

Community Nurse did some research. The Challenging Behaviour Foundation has a group of legal people giving advice. A question was raised from a parent: '*My son lives in a supported living home and we see him regularly every week. We are a critical part of his support team and need to continue to visit as usual. We are happy to adhere to stringent hygiene. Can we be considered as part of "his team" and offered test so that we can do this safely?*' Answer: *It should be as if you are providing unpaid care for your son alongside his care team.*

Discussion about concerns whether staff are putting themselves at risk (i.e., bringing Coronavirus back to the house). Parents had been self-isolating for 3 months and ensuring they followed guidance and still contact is limited.

Need to weigh up the risk of COVID-19 against Craig harming himself. Consider Craig's Best Interests and what has the lowest risk for him. Community Nurse raised Article 8 Human Rights Act (Right to family life).

Community Nurses agreed to maintain weekly contact with Manager to monitor how Craig has been and use of restrictive practices, to help inform the risk assessment. The Covid-19 Risk Assessment to be discussed with Health, Social Care, Family and Provider at fortnightly meetings and amendments made as applicable.

11. Settling down

Craig got back into a routine and was more settled. Not so much self-injurious behaviour happening. Contact with the family going from twice to four times a week really helped.

12. CPA Meeting

Provider reported all staff can see that Craig wants his old routines back. Discussed school and family contact. Craig's mum felt too exhausted to go down the legal route to reinstate family visits.

Need to look at things on an individual basis, through an individual risk assessment and in Craig's best interest. Biggest risk is emotionally, behaviours will not decrease.

He is communicating that he wants to be with his family and his behaviours will not stop until he gets this (based on historical information).

Parents agreed that their biggest concern is Craig's behaviours escalating and fear that Craig could go back to hospital. All agreed to not allow it to happen again, focus on protecting Craig.

Meeting considered the recent government guidance regarding contact with families. Provider to discuss this with senior management to see if Craig's routine could be adjusted so that it is more familiar to him.

The care provider did not change their decision in regard to the current restrictions to Craig's visits with his family.

13. No movement

Craig was spending time alone in his room. He is reliant on going to other environments to complete various activities and due to Covid-19 this was not possible. Craig was still engaging in household tasks.

He was having walks with the family but both family and Craig can struggle with these and this cannot be all they do (weather permitting). Provider looked at what they could do but were open to going back to the original care plan.

Family were concerned about prospect of a third meeting discussing the same thing and nothing moving forward. As the biggest concern from the family was Craig's readmission to hospital then the next meeting would be a Blue Light meeting so NHS Commissioner could chair.

14. Blue Light meeting and Nurse Consultant advice

Main area of discussion was around Craig's current presentation and if it was in his best interest to return to his previous contact with family.

Nurse Consultant for infection control at NHS:

Craig's visits to family can be seen under the guidelines as a "therapeutic intervention" and that the balance of risk must be taken into account, i.e., is the risk of not visiting was greater than the risk of contracting Covid 19 when visiting.

Nurse Consultant agreed that the risk from staff members contracting Covid-19 is equal to the risks of Craig's family members contracting Covid-19, and that the continuity of visiting his family is the overriding benefit.

So, as visits are a therapeutic intervention, they would not contravene guidelines. Testing would not be of benefit, as this would just provide a snapshot, rather than an assurance of continuing safety. Antibody tests would also not provide reliable evidence of safety either.

All reasonable measures would still be required, such as hand washing, maximised open air contact where possible, surface cleaning etc.

15. Risk Review meeting

Review of risk assessments re family contact, following the Blue Light meeting.

The intensity of Craig's behaviours directed towards staff decreased. More structure, routines and boundaries were introduced with good effect.

Behaviour Specialist met with the staff to provide debrief sessions. Behaviour Specialist and Provider to commence The Brief Behaviour Assessment Tool to ascertain if there any changes from the original functional analysis that was completed.

Risk assessments completed by provider for visits to family homes. Both Risk assessments were reviewed, and suggestions of amendments offered and agreed.

Agreed for family contact to commence (following the existing care plan).

16. Family visits and positive progress

Craig's family visits went well. He was very pleased to see his sister and spent a lot of time with her. There have been no problems with these visits and Craig really looks forward to them.

Report that overall Craig has more structure in his daily routine and he is less unsettled than he was a few weeks ago, however there are still some incidents where he is unsettled and requiring support and medication.

Training provided to support team by Speech and Language and Occupational Health.

There have been lots of positive developments for Craig, including person centred planning, new goals for Craig and he is now slowly settling back into being back at school.

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The Challenging Behaviour Foundation
We are a registered UK charity specifically focussed on the needs of children, young people and adults with severe learning disabilities whose behaviour challenges, and their families.
We will make a difference to the lives of people with severe learning disabilities, whose behaviour challenges, and their families by:

- Championing their rights
- Ensuring timely information and support
- Raising awareness and understanding
- Promoting and sharing best practice

To access our information and support, call 01634 838739, email info@thecbf.org.uk or visit our website: https://www.challengingbehaviour.org.uk