

# **The SUN Network Cambridgeshire and Peterborough**

## **Review of Day Services for Acquired Brain Injury**

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## Introduction

The SUN Network is an independent Community Interest Company based in Huntingdon and covering Cambridgeshire and Peterborough. Its main business is ensuring people who may use or need mental health and/or drug and alcohol support services across Cambridgeshire and Peterborough are being heard by commissioners and service providers and influencing service delivery. This work is completed through, amongst other things, involvement, and co-production. The involvement and co-production model is transferable, and The SUN Network was commissioned by Cambridgeshire County Council to review day support services offered by Headway Cambridge and Peterborough for individuals with an acquired brain injury.

Headway Cambridge and Peterborough offers support for people whose lives are impacted by a brain injury acquired through, but not limited to stroke, road traffic accident or trips/falls. Some of the individuals receiving support from Headway have their support funded by Cambridgeshire County Council. It is these individuals that The SUN Network has been commissioned to engage with for the purpose of gathering their feedback.

## Overview of the project

The SUN Network and Cambridgeshire County Council commissioners met to consider the questions to be asked. It was agreed that it is important to know what options of support individuals and families are aware of, what works well at Headway and what could improve, along with exploring whether a needs-based option would be considered suitable for individuals with an acquired brain injury.

Headway Cambridge and Peterborough is a service that delivers support specifically for individuals with an acquired brain injury and the Cambridge service is based at the Trinity Methodist Church on Green End Road in Cambridge. The SUN Network staff (Lois, Agata and Anne) visited these premises on three occasions to speak with the individuals accessing the service. We also contacted some individuals by telephone as they receive outreach support from Headway or were not present on the days that we visited. Some of the individuals we spoke with requested that a member of their family or a support worker were present during their conversations with us.

Of particular note is how supportive and welcoming every staff member at Headway was to The SUN Network staff. We were given a room to speak with people privately, were able to observe some of the activities to help the clients understand who we were and why we were there. The staff collected individuals to speak with us and offered us support in how to engage in a way that would be appropriate for each individual's needs. A big thank you to Emilie for the insightful lesson in Acquired Brain Injuries and how people can be impacted, prompted by our own desire to understand.

We were able to speak to sixteen individuals, three of whom were family members of individuals that attend Headway day services.

There were four questions to ask individuals, and these are outlined in the report below with the responses given in summary and then qualitative responses.

## Report

### Q1: When you were offered a day service, what choices were you offered? (such as where you could go and who delivered the support)

**Summary:** Many of the respondents were only offered Headway as an option for support. Some of the family members recall not being given much information at all about what support could be available to them. The individuals and family members that met Emilie from Headway at Addenbrookes hospital have described the information and support offered as invaluable, and that it has helped them navigate the system of support options available to them, including funding options.

#### Qualitative Responses:

- 'Nobody offered me anything. A neighbour told my wife about Headway'
- 'Just Headway. I've been coming for a long time, since it was on Mill Road'
- 'I was only told about headway as I met Emilie in Addenbrookes, and she told me about it. I went to CAB (Citizens Advice Bureaux) upon discharge from hospital as I had nowhere else to go. I went to my GP surgery and was sent to a Mental Health Community Connector, and they have been quite helpful too. Headway helped me to access funding through the Cambridgeshire County Council'
- 'I went to Camsight. (This individual lost their sight) to learn to use a computer but I only went a couple of times. They told me about Headway, and I come here now as it is much better for me'
- 'I don't think I was offered anything else'
- 'Due to my memory, I can't remember that far back'
- 'I didn't have any support for ages. I finally was told about headway'
- 'I had hospital support workers to start with'
- 'Fen House brain rehab centre. Social worker recommended Headway'
- 'Used a previous Headway out of county so wanted to continue the same level of support here'
- 'I felt this was the only place suitable for me. I take two buses to get to Headway'
- 'During Covid, it was hard to find support as not many places were doing anything'
- 'We were not offered anything and couldn't find anything out there. We were approached by Headway in Addenbrookes hospital, and it was such a relief to know that there was some support out there'

## Q2: What is important to you about the day service you go to? What works well or helps you?

**Summary:** People feel safe here at Headway. The environment is non-judgemental. The staff are trusted, consistent (low turnover) and really take the time to get to know individuals. The activities are popular, and the organisation and the staff within are really geared to understanding and supporting those with an acquired brain injury. Peers with similar injuries or understanding was important and friendships were being made. The service is credited with being the most important thing in people's lives.

### Qualitative Responses:

- 'I really like Brian (staff member) because he talks to me normally. There is no patronising here. We are all treated as equals'
- 'I have made friends here. I really look forward to coming here. I am in bed all day every day unless I am here'
- 'I like the bowls and the boxing activities. It really helps my mental wellbeing coming here. I was so active before (the brain injury) and it's so depressing to be how I am now. I think I would have nothing to feel good about if I didn't come here. I am in bed all day doing nothing if I am not coming here. (This individual is in a wheelchair) I have made friends, good friends'
- 'It gives my family member purpose. He talks about being making friends and doing activities. He has a group of people who understand him'
- 'I really, really, really like the staff. They understand me and give me hope. I had a really good job before and don't like to rely on the staff. They help me because they really take the time to understand me. I have made friends which is important to me as this is the only time I speak to other people. They all understand me because they have all had a brain injury too. I like the staff consistency and the routine here. It is understood how change is difficult for some people, but they still encourage me to learn change. It's good'
- Mixing with other people. His head has improved as the exercises are easier. He did not go out for four years prior to finding Headway. It also gives me a break from carer responsibilities'
- 'I really like coming here as it is challenging. They are always stimulating my brain and pushing me to use it in ways it doesn't get used anywhere else. The activities are tailored to brain injuries. We play scrabble which pushes my thinking. I hate scrabble but I understand and can feel that it is making my brain work thinking of words. I feel like I am making progress when I am here'
- 'Headway is a lifeline for me and my family member. My family member could not be anywhere else as no-one would be able to accommodate

their needs. It provides a different for my family member, it improves their life and helps them to accept their needs'

- 'I live in an isolated area, so I like to come here to be sociable, make friends, play games, and do activities. The activities are specific to improving cognitive progress'
- 'The staff are quality and do a superb job. They take the time to understand my individual needs such as needing the toilet urgently. When I need to go, I have to go quickly, and they don't make me feel bad about that. I have made a few friends here that are like me but have different brain injuries. But we all get the help we need. We learn about the brain here and it is good to understand more about how it works and what has happened'
- 'It's a really good distraction coming here. I am normally in bed all the time hearing the TV (this individual has sight loss) and here I can play games, meet new people, and get to know them. Dues to not being able to see, feeling safe and knowing my surroundings is important to me and the staff tell me everything and then they become familiar voices, so I know who is there. I like the physio (this individual is also in a wheelchair) and the movement activities that we do. I have made friends; we are all close. The staff are close, they are like family. They know me so well'
- 'My family member likes coming here as it's 'His place' to come to. A place where he can be around people who are all experiencing similar things and understand' He really likes doing projects and enjoys the boxing. He likes the independence being here brings him. It's his time away from me and it is my time away from him too. There is lots of cognitive stuff which is focused towards improving brain function and memory. There is a farm, and he loves going there. The support here is holistic and well connected to other services or they know a lit about other services. Headway has been the lynchpin of good care for him. He likes the physio as well'
- 'The staff are lovely. Nothing is too much trouble for any one of them. They go above and beyond to help me. Anything I need, they help me. They push me cognitively and make my brain work. I really like this as when I work my brain and get something right or do something, it makes me realise I'm not as useless as I thought'
- 'Headway literally saved my life. Not physically, but emotionally and mentally they have saved my life. I am so excited to come here. I can make mistakes, and no-one cares because they understand. I can take my time to think about what I want to say. If I can't think of it, the staff have gotten to know me so well that they can offer suggestions if I am struggling, and they always get it right. They know me so well. I can just be me. I love coming here so much'
- I really like the community here. I can't remember much when I get home but I do know that it feels familiar when I am here, and I feel safe. There is a comfort to me about being here. It is a learning space and a space to

talk, chat, and make friends. They offer wellbeing support and some independence away from my family'

- 'I can do stuff I can't normally do elsewhere. Activities, boxing, cognitive groups, games. I really like the physical training with Sophie. I love the farm; I really want to drive one of the tractors. I love being there'
- 'Staff are really nice. I can say what I want in front of them, tell them what I need or if I don't like something and they help me as much as they can'
- 'I like being with other people, I feel less lonely. The staff are good. Friendly and helpful. I like the activities, drawing and painting, poems, and rhymes'
- 'They have services personalised to me. They cater to my needs, and they treat me like I am normal'
- 'I like the organised outreach which is helping me to ride a bike and gain some independence. Boxercise and keep fit. Coming to Headway helps me develop my speech and language. I also have made friends'
- 'I like the creativity of the art therapy, and the gym and physical therapy in my one to one'

### Q3: What do you think could improve here at Headway?

**Summary:** Most people felt that Headway was already meeting their needs and did not need to improve in any way. The suggestions made for improvements were mostly about various activities.

- 'A more purpose-built building for Headway to operate from'
- 'More Headway hubs closer to where I live'
- 'They are doing a great job so wouldn't change a thing'
- 'I don't see how they could improve'
- 'It's great as it is'
- 'I would welcome more practical activities'
- 'Nothing'
- 'A wider variety of games and activities'
- 'A language class would be nice, or a real artist who could come and really teach us how to do art properly, but that is not a negative, they are brilliant here'
- 'A speaking quiz'
- 'If we could do some model building'
- 'If someone came in to check and repair hearing aids'
- 'It would be great if there was a befriending service with people of a similar age just to take my family member to a football game or something. I thought he should be around people his own age, but he doesn't seem to mind. He has made friends here'
- 'Make it so that I can come here on more days and spend more time here. I really enjoy it'

- 'It doesn't need improving as it is great as it is, but I do want the staff to stay the same. I don't want the staff to leave or change'
- 'I don't think it can improve. It does everything it needs to do'
- 'I wouldn't change anything'
- 'No improvement needed. Happy with the support provided'

**Q4: Would you consider using other local day services based on needs, not diagnosis if it was closer or more convenient than the support you currently use? (For example; this could be alongside people with learning disabilities, or older adults)**

**Summary:** Four people were, in essence, not opposed to being with people with learning disabilities but it was on the understanding that they didn't lose the support they had here at Headway. Ages of group members was not seen as an issue, but alternate needs for older people with for example dementia was seen as not comparable to the needs of older people with an acquired brain injury. People didn't want an alternative service. The majority (twelve people) saw the differences in needs to be too great to be able to combine needs-based care for acquired brain injury, learning disabilities and/or older people. Overall, it was considered that the support needed to be specifically for acquired brain injury as it was so different to anything else in terms of need.

**Qualitative responses:**

- 'It wouldn't work for my family member as he is unable to communicate his needs. I have explored other options but was unable to leave him which defeats the object. With Headway, they do understand him despite him being unable to communicate his needs'
- 'No. They understand me here because of my diagnosis, which is essential'
- 'No, because half my brain is gone, and that loss is understood here. Headway has a really good understanding. There is too big a difference between someone with an acquired brain injury and someone with learning disabilities'
- 'We (people with acquired brain injuries) are all dealing with similar things, so it is important to be with people who understand'
- 'No. He does not have learning disabilities; he has got an acquired brain injury, and the needs are very different. Headway has an excellent understanding of acquired brain injury and the very specific needs of each individual. I can leave him here with them because I can trust them to give the very best care'
- 'I would be open to other things, but I wouldn't want anything to change here'
- 'It is good to learn from others, and I also attend the Bedford Headway, but this one is much better for me'
- 'It (Headway) offers what I need'



- 'Yes. It could work for physical activities like horticulture'
- 'If it was extra sessions that were complimenting this one then yes. If I had to drop Headway for something else, then no. It would be great to have Headway extended to more days'
- No. It is important to me to be around people who understand my needs. I used to be a solicitor and enjoy the activities that push me to speak'
- 'He is familiar with Headway and feels too embarrassed to go to a centre closer to home'
- 'I would consider it'

## Conclusion:

Awareness of support options for people with an acquired brain injury is low. This could be because there are so few options, or because information is not being given to people about possible support and funding options. Or the professionals that people encounter at the beginning of their search for support are not themselves fully informed about options. Headways in-reach work at Addenbrookes seems to work well in terms of raising awareness of options for support.

Headway is described as a safe and trusted environment with excellent understanding of acquired brain injury. Non-judgemental, accepting, and supportive. A place with a good social element and appropriate cognitively stimulating activities.

There was very little suggestion of how Headway could improve, with just a few preferred activities requested.

The question around whether groups should be needs based rather than diagnosis based invited a lot of conversation around the needs of people with acquired brain injuries being very niche and incomparable to people with learning disabilities as people with acquired brain injuries are all impacted in such unique ways with some not having much sense of awareness of their injury and the impact it has had, some whose intellect has not been impaired at all and still require high intellectual stimuli, and most have an awareness and understanding of who they were prior to the acquired brain injury and feel a sense of being patronised and condescended if someone were to liken their injury to having a learning disability due to the fact that there has been a 'before' and 'after' for the individuals who have an acquired brain injury, whereas individuals experiencing a learning disability do not have a 'before' and 'after' and cognitive needs of acquired brain injuries are very different to cognitive needs of people with learning disabilities and also older people with a diagnosis of dementia. Several of the individuals were in very challenging, academic or highly intellectual careers prior to having an acquired brain injury and felt that there is no comparison on a needs basis.