



SPOTLIGHT ON DYSCOVER

HEALTHWATCH KINGSTON UPON THAMES

Healthwatch Kingston is an independent charity - its aim is to listen to what people have to say about their health and social services and feed this information back to the service providers.

This is a benefit to everyone involved, because it shines a light on what's good about services, and also involves the people at the heart of the services to make suggestions and provide ways which could help make them even better. Spotlight is just one of the ways which Healthwatch Kingston does this.

In this Spotlight, Healthwatch Kingston visited Dyscover on Tuesday May 17th 2016 at the Kingston Quaker Centre to find out what is good about the services provided by Dyscover from the members who use it. Our findings are presented below.

WHO ARE DYSCOVER? WHAT DO THEY DO?

Dyscover is an organisation that provides long-term support, opportunities and strategies for communicating to people living with Aphasia. Dyscover sessions are led by professional speech and language therapists and are designed to help people adjust to living with aphasia. There are 8 different support groups designed for different stages of recovery and for different needs.

The sessions are run in two locations: Walton on the Hill and Kingston Quaker Centre. Sessions are priced at £12.50 for a 2.5 hour group. Most people attend one group per week.

Dyscover also provides family support with regular opportunity to meet the group's speech and language therapist, a chance to meet other relatives and members at outings and coffee mornings, and a professionally-led counselling and support service.

WHAT IS APHASIA?

Aphasia is a communication disability that is caused by damage to the language processing centres of the brain, most commonly through stroke. It can affect the ability to speak, read, write and understand what is being said. Aphasia can

range from mild to severe, depending on the type and extent of damage to the brain. It can be a very frustrating and isolating condition.



DYSCOVER SESSIONS AT KINGSTON QUAKER CENTRE

Three Dyscover sessions are held at the Kingston Quaker Centre every Tuesday. Three separate groups meet between 10.00 am to 4.00pm with a focus on communication and participation. Sessions are aimed at supporting people with aphasia to engage in conversation through a termly programme, which is planned jointly by therapists and group members. Activities include:

- Conversations on planned topics,
- Sharing of experiences and strategies for coping with life after stroke,
- Debates, quizzes, current affairs,
- Spot lights - where members talk about something they are interested in,
- Projects (including fundraisers),
- Art,
- Games

The structure of the programme runs like an academic year with three term times. However, since members said they miss the group over the holidays activities are organised for the holiday period. These activities range from informal drop-in conversation sessions to art and photography courses and sailing.



Picture Description: Chatting over tea and coffee



Picture Description: Art session

On our visit

Healthwatch Kingston visited the Dyscover sessions at Kingston Quaker Centre on 17th May 2016 from 10.15am to 3.30pm - different members attended the morning and afternoon groups.

Our aim was to find out what aphasia members, family, volunteers and staff thought about the service provided by Dyscover.

It would also provide a useful opportunity to hear more about local health and social care support members receive in Kingston, and how they could be improved.

We visited three different groups at different stages of their recovery:

- First group: members living with aphasia for a long time,
- Second group: younger members living with aphasia for a short time,
- Third group: members living with aphasia for a short time,

We spoke to 13 members, 4 volunteers and 2 members of staff.

Healthwatch Kingston received very positive feedback about the Dycover service from members, volunteers and staff. On the whole, members were very happy with the services provided by Dyscover.



Picture Description: Activities during outing

What members and volunteers told us

“EVERY SESSION IS DIFFERENT...”

- “Dyscover is one of the very few charities that has speech and language therapist led conversation groups for people with aphasia.”
- “The sessions helps lift our moods up and makes us more relaxed.”
- “I get to sing which makes me happy”

- “I enjoy the games sessions, it is fun and competitive”
- “We really enjoy spot-light sessions by fellow members especially the one on India with all the pictures.
- “Spot-light activities boost our confidence and helps with communication.”
- “We really like the outings at Kew Gardens and the companion cycling.”
- “I really like the tea and coffee sessions.”



Picture Description: Members enjoying tea and cake

“I FEEL SUPPORTED AND UNDERSTOOD...”

- “It is a supportive and understanding environment that makes us feel more comfortable to speak”
- “I feel more relaxed and confident to talk openly”
- “The group has helped form a new family after stroke”
- “The group has helped reduced my nervousness and anxiety.”
- “I have the opportunity to meet other people which makes me happy”
- “It’s interesting to meet and share experiences with different people - even though we have all had a stroke, every one is unique and different.”
- “I get an aphasia identity card which is helpful to navigate around places when I go out.”



Picture description: Outing

“I ENJOY COMING BACK...”

- “I come back because it’s a break from normal surroundings like my home”
- “I enjoy seeing fellow members improving which also helps me judge my own recovery.”
- “I start to appreciate different people but also myself and my own situation.”

- “The location in Kingston Quaker Centre is better than other locations.”
- “I wouldn’t want to change anything about the service.”

“IF I COULDN’T GO TO DYSCOVER...”

- “Dyscover groups are something to look forward to. I would feel terrible if I could no longer attend sessions.”

“AS A VOLUNTEER I LOVE COMING...”

- “I have volunteered at Dyscover for 10 years. When members see me they smile and it inspires me.”
- “I feel welcomed, it feels like family here.”
- “Quaker Centre is the perfect place - it is clean, it has easy access, I can walk easily to the kitchen and bathrooms”
- “I come to maintain continuity for the members - they form a close and strong bond. We are like a family”

- “I love the strong bond members have - when one member doesn’t attend the session, other members are concerned and ask about them.”
- “It is humbling - members are so positive despite having had the stroke”
- “I always volunteer - I pick up people who don’t have family and wouldn’t be able to get to Dyscover if I didn’t pick them up and bring them.”



We asked people what Dyscover could do to help members more

a) Challenges around transport:

- Dyscover sessions is only run in 2 locations Kingston Quaker Centre and Walton on the Hill. Most of our members come from Surrey, although some members will travel from far such as Worthing, Haslemere and Egham. Members who don't live near Kingston said they can find it harder to get to sessions.
- People said transport to get to the sessions can be an issue, especially for members who have wheelchairs and must rely on someone else to bring them. Using public transport can be difficult for them.

b) Communication Support:

- Some members said the activities suggested by therapists can be challenging (for example summarising a 20 minute TedTalk)

- One member said they had very limited speech therapy and would like more from Dyscover

c) Dyscover could explore how to support members to communicate outside of their sessions and increase their wellbeing

- Some members said communicating to people outside the Dyscover group can be difficult because the public do not understand the different communication style needed for aphasia individuals - for example calling a taxi cab can be difficult if you find it hard to talk.
- Some members live alone, so it's harder to have the conversations which would help improve speech and communication.
- Some members said they feel embarrassed about their lack of communication so they can feel uncomfortable talking to people outside of Dyscover sessions.

- One member felt frustrated they couldn't express themselves by telling people how they feel - it would help to have more links between mental health support and speech therapists.
- Many members have limited opportunities to communicate after the Dyscover sessions. But majority of the members enjoyed the outings such as to Kew Gardens. Dyscover could have more social activities outside a formal setting / session for example coffee mornings, lunch, and outings to bring members together more often. This would help improve people's mental wellbeing
- The majority of members said they would like to have more physiotherapy but find it difficult to get this. Dyscover could explore options for physiotherapy for their members, by making better use of resources already available such as Stroke Association resources, or by contacting Stroke Support Groups who can sign post.

Feedback from Dyscover members around health and social care provided in Kingston

1) Support Equipment for people with Aphasia accessibility

- Equipment (wheelchairs) maintenance varies depending on health setting such as nursing homes that don't respond quickly when wheelchair breaks down,
- Fire doors in public spaces (including Kingston Quaker Centre) are too heavy for members who have paralysis, even mild paralysis,
- Toilets are poorly designed in public spaces - not conscious of the fact that some people have paralysis down the left hand side whilst others have paralysis down the right hand side, so toilets have to be designed accordingly,
- Tolworth Hospital Neurogym is helpful, but directions to get to gym were either not given or when they got to the hospital and it was difficult to find.

- One member said he couldn't find a quiet place to go to, noise was very overwhelming.

2) Transportation

- Transportation and access for getting around was a major concern for many members - one member needs a ramp from his flat to help get around - stopping him from having an independent life.
- Lack of appropriate transport was preventing members from getting to physiotherapy
- Some members need their partners to bring them in for therapy - rely heavily on others for getting out and about. Some partners are elderly themselves.
- With aphasia, some members find it difficult to navigate the transport systems - it needs to be more user friendly for aphasia users.
- Senior railcards are great as discounts encourage some members to go out.

3) Mental Health

- For some younger members who have had a stroke, the stresses of family life are challenging especially with young children.
- Some members get frustrated and can't say what they think, there is a lack of aphasia trained psychiatrists / psychologists who understand their needs.
- Many members said they don't talk a lot at home, which lowers the speed of recovery.



NEXT STEPS FOR HEALTHWATCH KINGSTON...

We really value the feedback about local health and social care provision for stroke survivors.

Healthwatch Kingston will use this feedback to raise awareness of the challenges people are facing and to try to influence improvements via:

- The Healthwatch Kingston Hospital Services Task Group
- Kingston Health and Wellbeing Board
- Kingston Health Overview Panel

We will discuss further steps and procedures to bring positive changes to services.

Healthwatch Kingston would like to give a big thanks to all the members, volunteers and staff at Dyscover for their feedback and for taking the time to talk to us. Thank you.