

MS Education Café: Learning and Connecting

Sarah Lawrence (MS Specialist Practitioner, Homerton Healthcare NHS Foundation Trust, City and Hackney)



Serving East London and the City



Homerton Healthcare NHS Foundation Trust



Background

- City and Hackney are 2 North East London boroughs with an estimated 3844 people living with MS (pwMS) in them.
- The MS specialist practitioner (MSSP) works with anyone living in City and Hackney with a confirmed diagnosis of MS and is based in the community neuro therapy team.
- August 2022:
 - A listening event was held by the MSSP and the MS society, to review current MS services and identify unmet needs within City and Hackney.
 - pwMS who attended reported wanting to be more connected with other pwMS living locally.
- April 2023:
 - A focus group with pwMS was held to discuss ideas about how to address these unmet needs. It was agreed to trial monthly MS education café to see if it meets this need.

Aims

- To provide an opportunity for pwMS living in City and Hackney to meet and connect with others living with MS and their carers.
- To provide reliable and evidenced-based sources of information about different topics relating to living well with MS to help self-management.

Method

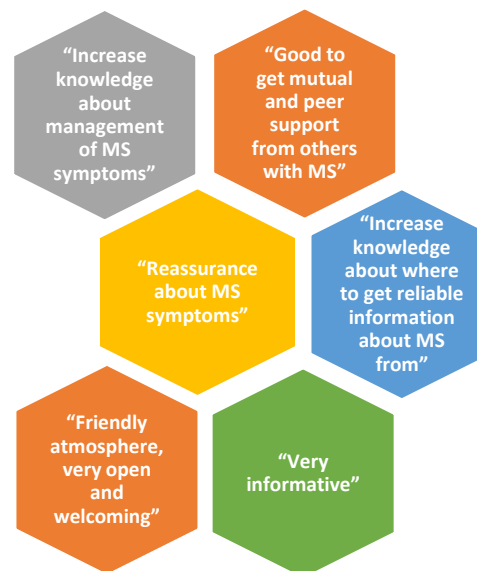
- 6 MS education café's were funded by the MS society and hosted monthly by a Hackney hospice (the hospice run a weekly neuro support group that many pwMS living in east London attend).
- 2 hour in person cafés (refreshments provided) during the working day:
 - 1 hour of formal education (including Q&A)
 - 30minutes before and after the formal teaching for informal socialising.
- Education topics covered: "Living with MS", "Work", "Bladder and Bowels", "Emotion and Mental wellbeing", "Cognition" and "Benefits" by a range of specialist speakers.
- Basic demographic details were gathered about attendees and evaluation forms given out after each café.

Results

Qualitative data was collected from evaluation forms given to those who attended. NB: Some forms were either partially or not at all completed. October was an evening online group due to the topic being "work and MS" - no evaluation form or details of attendees was collected.

Total number of pwMS <i>(for all 6 cafes)</i>	84 <i>(On average 10 pwMS attended each of the in-person cafés. 40 pwMS attended the online group)</i>
Total number of carers <i>(for all 5 in-person cafes (data not collected for Octobers online group))</i>	16
Type of MS <i>(for all 5 in-person cafes (data not collected for Octobers online group))</i>	RRMS = 22 SPMS = 21 PPMS = 1
EDSS <i>(for all 5 in-person cafes (data not collected for Octobers online group))</i>	EDSS 0-3.5 = 12 EDSS 3.5-6 = 0 EDSS 6-8 = 32

What did you like about the café?



Would you come again? – 100% of people who responded said "Yes"

Would you recommend the café to family and friends? – 100% of people who responded said "Yes"

What did you think of the venue?

- "Very accessible"
- "Local to where I live"
- "Very convenient"

What did you think of the content?

- "Very relevant"
- "Sensitive to different stages of MS of people in the room"
- "Puts things into perspective that I'm not going mad"

Conclusion

POSITIVE FEEDBACK from those who attended

- People enjoyed feeling more **connected** with others with MS.
- People felt more **informed** about living with MS (both from information provided from professionals and from peers)
- People felt **reassured** about their MS symptoms.
- People felt the topics covered at the café were **relevant** to them.

LOCATION

- People liked being able to attend a group nearer to their home and liked the disabled accessibility of the café hosted by the Hospice.

ATTENDEES

- The café was well attended by pwMS and some brought carers/family/partners/friends.
- Most people who attended had more advanced disease with higher levels of disability.
- Possibly the location of a hospice meant certain people (e.g. those who have been newly diagnosed) did not feel comfortable attending.

COLLABORATION with the MS Society and St Joseph's Hospice provided benefits

- Expertise and ideas from different professionals, backgrounds and sectors.
- Expanded relationships and networks.

FUTURE

- This group clearly meets an unmet need and people want to return to the group and would recommend it to others.
- There are potentially people who missed the café due to weekday timings and its location. Further work is needed to address this.

References

- Ennis, M., Thain, J., Boggild, M., Baker G., Young CA. (2006) A randomized controlled trial of a health promotion education programme for people with multiple sclerosis. *Clinical Rehabilitation*, 20(9) pp. 783-792, Available at: <https://doi.org/10.1177/0269215506070805>
- McCabe, M., Ebacioni, K., Simmons, R., McDonald, E., Melton, L. (2015) Unmet education, psychological and peer support needs of people with multiple sclerosis. *Journal of Psychosomatic Research*, 78 (1) pp. 82-87, Available at: <https://doi.org/10.1016/j.jpsychores.2013.02.002>
- Wakefield, J., Bickley, S., Sani, F. (2013) The effects of identification with a support group on the mental health of people with multiple sclerosis. *Journal of Psychosomatic Research*, 74 (5) pp. 420-426, Available at: <https://doi.org/10.1016/j.jpsychores.2013.02.002>