



HARROW ASSOCIATION OF VOLUNTARY SERVICE (HAVS) STROKE RESEARCH PROJECT REPORT

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Abstract

This research report provides up to date information of current stroke provision in Harrow for stroke survivors and carers. It also provides details from focus group meetings the HAVS Stroke Research Coordinator had with stroke survivors and carers, and makes relevant recommendations from the information gathered.

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Introduction and Background

Stroke is London's second biggest killer and the most common cause of adult disability (Healthcare for London 2009). Harrow has one of the highest stroke prevalence rates in the capital. Harrow has a growing elderly population and a large BMER population, both of which are factors associated with higher stroke incidence (Harrow Council 2009). As with other London Boroughs, Harrow is giving more attention to stroke issues.

As one of the stroke initiatives funded by Harrow Council, HAVS's Stroke Research Project began in June 2009 and was funded for 6 months. The project was coordinated by HAVS's Stroke Researcher, Adam Gahhu.

Aims of the Project

- Researching up to date information of the provision in Harrow for stroke survivors and their carers.
- Providing up to date information and signposting via focus group meetings and outreach to 8-10 additional stroke survivors and carers.
- Providing networking opportunities for stroke survivors and carers.

Methodology

I researched provision using a number of means. Firstly, I publicised the project through HAVS's monthly mailout. The project's leaflet was also included in the mailout and put up on the HAVS website. The publicity clearly stated the aims of the project and encouraged any service providers, stroke survivors and their carers to make contact with me. From this I was able to meet with many members from different organisations through whom I gathered relevant information regarding stroke provision in Harrow.

HAVS's monthly mailout reaches 220 voluntary and community organisations in Harrow. HAVS's affiliation to such a large number of organisations proved very useful and suited to this project.

Secondly, I met up with different members of statutory and health services in Harrow, all whom provided me with useful information regarding stroke provision in Harrow. I also conducted research using the internet and liaised with colleagues.

I provided information of stroke provision and signposted through different ways. Firstly, I created a list of useful contacts which I put up on the HAVS website

<http://www.harrowcvs.org.uk>). The HAVS website is accessible to all organisations affiliated to HAVS and to the general public. Secondly, I distributed the useful contacts list and other stroke provision information sheets in my outreach work and meetings I attended in Harrow. This included for instance Harrow Stroke Club sessions and Aphasic Self-Help Group sessions. Stroke survivors and carers also contacted me after seeing the publicity in the HAVS mailout, on the HAVS website, and through health professionals.

I also provided information sheets during my focus group meetings with clients. I met with a total of 18 stroke survivors and carers, 11 of whom were female and 7 were male. Clients were from a variety of ethnic backgrounds and age groups and their disabilities also differed. I provided networking opportunities to clients by putting them in touch with different service providers. This helped clients with a host of issues, such as welfare benefits and respite care.

My meetings assured stroke survivors and their carers that confidentiality was to be maintained, and due to this the report does not reveal any individual names, their nationalities, age, or contact details.

USEFUL CONTACTS

Useful contacts for Harrow stroke survivors and their carers

1. Admiral Nursing Service

Bentley House, 15-21 Headstone Drive, Harrow, Middlesex HA3 5QX

Tel: 020 8424 7728

2. Aphasia Self-Help Group

The Lodge, 64 Pinner Road, Harrow HA1 4HZ

Tel: 020 7261 9572, 080 8808 9572

3. Age Concern Harrow

3rd Floor, Premier House, 1 Canning Road, Wealdstone, Harrow HA3 7TS

Tel: 020 8861 7980

Website: www.acharrow.org.uk

4. Carers Direct (NHS)

Information, advice and support for carers.

Freephone: 0808 802 02 02 (7 days a week)

Website: www.nhs.uk/carersdirect



5. Children with Disabilities Service (Harrow Council)

Tel: 020 8966 6481

6. Citizens Advice Bureau

Harrow Citizens Advice Bureau: Adjacent to Civic Centre, Civic 5, Station Road,

Harrow, Middlesex HA1 2XH

Tel: 0844 826 9711

Website: www.citizensadvice.org.uk

7. Dial-A-Ride Ltd

Progress House, 5 Mandela Way, London, SE1 5SS

Tel: 020 7309 8900

8. Different Strokes (Harrow)

Contact Gerrie Norcross

Tel: 020 8361 0247

Email: DiffStrokesMiddx@aol.com

9. Harrow Association of Disabled People (HAD)

Ground Floor, Bentley House, Headstone Drive, Harrow, HA3 5QX

Tel: 020 8861 9920

Website: www.had.org.uk

10. Harrow Association of Voluntary Service (HAVS)

The Lodge, 64 Pinner Road, Harrow HA1 4HZ

Tel: 020 8863 6707

Website: www.harrowcvsvs.org.uk

11. Harrow Bereavement Care

The Lodge, 64 Pinner Road, Harrow HA1 4HZ

Tel: 020 8427 5720

Email: harrowbereave@btconnect.com

12. Harrow Carers

25-27 Pinner Green, Pinner, Middlesex HA5 2AF

Tel: 020 8868 5224

Website: <http://www.carers.org/local/london/harrow/>

13. Harrow Community Transport

The Lodge, 64 Pinner Road, Harrow HA1 4AZ

Tel: 020 8427 6619

Website: www.harrowcommunitytransport.org.uk

14. Harrow Crossroads

Milmans Resource Centre, Grove Avenue, Pinner, Middlesex HA5 5PF

Tel: 020 8868 0903

Website: www.harrowcrossroads.co.uk

15. Harrow Mencap

3 Jardine House, Harrovian Business Village, Bessborough Road, Harrow HA1 3EX

Tel: 020 8869 8484 (core team), 020 8423 7382 (community team)

Website: www.harrowmencap.org.uk

16. Harrow Shopmobility

Main office: 37 St. George's Centre, St. Ann's Road, Harrow HA1 1HS

Wealdstone office: Peel House, Gladstone Way, Wealdstone HA3 7QT

Tel: 020 8427 1200

Email: harrowshopmo@tiscali.co.uk

17. Harrow Stroke Club

The Lodge, 64 Pinner Road, Harrow HA1 4HZ

Contact Norman Garber

Tel: 020 8863 6707

Website: www.harrowcvs.org.uk/harrow-stroke-club.asp

18. Headway North West London (Brain injury care and support)

PO Box 1025, Harrow HA1 9FY

Tel: 07726 325 222, Headway UK Helpline: 0800 800 2244

Email: headway.northwestlondon@hotmail.co.uk

19. Learning Disabilities Team (Harrow Council)

PO Box 161, Civic Centre, Station Road, Harrow HA1 2UI

Tel: 020 8424 1019

20. Mental Health (Harrow Council)

Crisis Team Telephone: 020 8869 2690, 020 8869 2484.

Community Mental Health Team Telephone: 020 8424 1352.

Tel: 020 8951 3770 (East)

Tel: 020 8422 9443 (West)

Website: www.harrow.gov.uk/mhs

21. Mind in Harrow

Mental health organization working for a better quality of life for people in Harrow who are experiencing mental distress.

8 Havelock Place, Harrow, Middlesex HA1 1LJ

Tel: 020 8426 0929

Website: www.mindinharrow.org.uk

22. NHS Direct

Health advice and information

Tel: 0845 4647

Website: www.nhsdirect.nhs.uk/

23. NHS Harrow (PCT)

The Heights, Fourth Floor, 59-65 Lowlands Road, Harrow HA1 3AW

Tel: 020 8422 6644

Website: www.harrowpct.nhs.uk/index.html

24. North West London Cardiac and Stroke Network

Website: <http://www.nwlcn.co.uk/>

25. Northwick Park Hospital

Watford Road, Harrow HA1 3UJ

Tel: 020 8864 3232

26. Older People Services (Harrow Council)

Tel: 020 8424 1234 (West)

Tel: 020 8951 3811 (East)

Email: socialservices@harrow.gov.uk

27. Oshwal Elderly Welfare Association (OEWA)

Association which assists older people to make more effective use of services provided to help them as independently and comfortably as possible.

Scouts Hall, 1A Walton Road, Harrow HA1 4UX

Tel: 07900 911074

Website: www.oewa.org.uk

28. Physical Disability and Sensory Services(Harrow Council)

PO Box 167, Civic Centre, Station Road, Harrow HA1 2FR

Tel: 020 8424 1694

Textphone: 020 8861 1824

29. Physical Disability Support Team (PDST)

PDST, P Block, Northwick Park Hospital, Watford Road, Harrow HA1 3UJ

Tel: 020 8869 3303

30. Rethink (Harrow)

Charity which works with those affected by severe mental illness to help them regain a better quality of life.

Rethink Recovery House, 13-17 Roxborough Road, Harrow HA1 1NS

Tel: 020 8974 6814, 0845 456 0455, 020 8861 3717

Website: www.rethink.org

31. Speakability (Aphasia Group, Hatch End)

Contact Mary Mahoney

Tel: 01923 223 473

Email: marymahony@hotmail.co.uk

32. Taxicard

Tel: 020 7934 9699

Email: taxicard@londoncouncils.gov.uk

Website: www.taxicard.org.uk

33. The Disability Foundation

Tel: 020 8954 7373

Email: info@tdf.org.uk

34. The Harrow Kingfisher (Swimming club for disabled people)

Tel: 020 8427 8126, 020 8204 1919

Website: www.kingfisherse.org

35. The Stroke Association

Contact Gillian Dunne

Tel: 020 8906 0073, Mobile: 07799 436049

Email: Gillian.Dunne@stroke.org.uk

Website: www.stroke.org.uk

For more information please contact: Adam Gahhu (Stroke Researcher), Harrow Association of Voluntary Service (HAVS), the Lodge, 64 Pinner Road, Harrow HA1 4HZ. Tel: 020 8863 6707. Email: adam.gahhu@harrowcvs.org.uk



Focus Group Meetings

I had meetings and conducted informal interviews with 18 stroke survivors and carers during the project. Some meetings had both the stroke survivor and carer present, whilst some had just the stroke survivor present, and some had just the carer present. This depended on a number of factors, such as what the clients were comfortable with.

I provided stroke survivors and carers with useful information on service provision, as well as providing them with networking opportunities. I also asked them about their experiences in Harrow and their information and support needs. The list of the questions which guided the informal interviews is in the appendix of this report.

The following bullet points are the main issues which stroke survivors and carers raised:

- Lack of sufficient information with regards to available services and support at different stages after the stroke. Clients complained that they had to look for a significant amount of information themselves, both in the short term (before survivor was discharged from hospital) and longer term (after survivor was discharged from hospital). This was not easy.
 - One carer said; *“I was totally lost after my husband was discharged from hospital. I did not know what support was available. I struggled to look for information and this made the situation even tougher to deal with.”*
- Aftercare issues. Both survivors and carers complained about lack of sufficient support after discharge. Particular focus was placed on the lack of stroke specific emotional and psychological support for both stroke survivors and carers. The need for this was highlighted as crucial, considering the change of circumstances following a stroke and issues involved in coming to terms with this. Stroke survivors and carers experienced feelings of depression.
 - One stroke survivor said; *“The stroke changed my life significantly. I can no longer do most of the things I used to do before the stroke. Due to this I experience a myriad of emotions such as feeling depressed and worthless. Stroke specific counselling would help me come to terms with things.”*
- Carers strongly highlighted the need for more respite care and information around this issue.

- Carers felt they did not have enough support as most of the information they received was more relevant to the needs of the survivor.
 - One carer said; *“The help we have been receiving has mainly been focused around my mother’s needs. My mother’s stroke has also significantly changed my life but hardly any attention has been given to my emotional and other needs.”*
- Clients felt that physiotherapy and speech and language therapy did not go on for long enough after discharge. A number of clients mentioned for instance how fortunate they felt to have come across aphasic self-help groups which helped them improve their speech significantly.
- The need for more peer support networks such as stroke clubs. Clients complained of limited availability and access to these in Harrow.
 - One stroke survivor said; *“I wish there were more clubs for me to attend. I can not describe just how mentally refreshed I feel every time I go to the stroke club.”*
- Survivors under 65 years of age felt that they do not receive as much attention as those over 65 years of age following discharge, despite also having complex needs of their own.
- Clients complained of long waiting times for wheelchairs.

General Recommendations

Following the 6 month research project, the main areas that need to be highlighted include the following:

- It would be useful to have a stroke coordinator in Harrow who would bring all the relevant service providers together. This would increase awareness of who is operating in Harrow amongst the service providers, as many of the ones I came across were not aware of other providers.
- Service providers should be encouraged to work in partnership and network.
- Stroke survivors and carers should be given thorough information about support available to them in the community after discharge.

- Following discharge stroke survivors and carers should have regular reviews and assessments of their needs. This requires a holistic approach which should include medical, emotional, social and financial needs.
- A psychology and counselling service specific for stroke survivors and carers would be extremely useful for reasons and examples I have given in the preceding Focus Group Meetings section. This includes the problems of depression and isolation experienced by stroke survivors and carers.
- Work needs to be done to increase the number of stroke clubs and other social support. This would benefit both stroke survivors and carers. Clients who attended stroke clubs and aphasic self-help groups referred to how attending these improved their confidence, speech, and general wellbeing. It also reduced their sense of isolation.
- More attention should be given to carers' issues than is the case at present. This includes looking at their emotional and respite care needs, amongst others.
- Having a stroke specialist community rehabilitation service which deals with all age groups and has clearly defined processes would significantly improve the post discharge experience of stroke survivors and carers.

Conclusions and Future Scope for this Project

Coordinating this project provided me with an opportunity to meet with many stroke survivors and carers. Clients found the stroke provision information I gave them very useful and they emphasised how much of it they were unaware of. They were also very grateful for the networking opportunities which enabled them to receive the support they required. I found this very motivating and rewarding.

The up to date information of current provision will also be useful for the relevant and responsible authorities in Harrow in their work on stroke. Authorities can also take measures with regards to the issues raised by stroke survivors and carers.

With 6 months being a relatively short period, evidence shows that there is scope for this project to reach more stroke survivors and carers to provide them with support, information, and networking opportunities. This is demonstrated by the increasing number of clients who I have been in touch with and saw as time progressed, even in the final month of the project. This strongly supports the need for

the project to continue for the benefit of more stroke survivors and carers in Harrow, more so considering the current prevalence of stroke. It will also provide the opportunity to make further follow up with clients I have met and assisted.

Experience also shows that one can not rule out the possibility of coming across more non mainstream service providers, particularly from BMER groups. Relatively more time tends to be required to reach these groups. I would therefore strongly recommend that funding for this project is extended. I would also like to restate what I mentioned earlier in this report and that is HAVS's suitability in running this project.

References

- 1) Harrow Council, 2009. *Vitality Views*, October 2009. Harrow Council
- 2) Healthcare for London, 2009. *The shape of things to come; Developing new, high-quality major trauma and stroke services for London Consultation document*. NHS

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Thank you to all the service providers for their time, information and support. I would also like to sincerely thank all the stroke survivors and carers I met for their time and contributions. I would also like to thank Harrow Council for funding the project.

Appendix

Focus Group Interview Questions:

- 1) Date of Interview:
- 2) Name of Interviewee:
- 3) Survivor or Carer?
- 4) Carer or Cared for present?
- 5) Contact details:
- 6) Year/age stroke happened:
- 7) Services/Provision in Harrow currently used/received by interviewee
- 8) Services out of Harrow (if any) currently used by interviewee:
- 9) Was the interviewee given enough information and support for the different stages after the stroke happened? If not what was missing?
- 10) Has the interviewee experienced any problems accessing and/or using services? If yes what are/were they?
- 11) Current information and/or support needs (if any) of interviewee:
- 12) Interviewee's ideas (if any) on what may help them with their situation:
- 13) Provision information/advice provided to interviewee by interviewer:
- 14) Any other comments: