Experiences of Stroke Patients in Waltham Forest

Focus Group Findings
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Background

About Stroke
In the UK and in London, strokes are a major health problem. Every year, around 110,000 people have a stroke in England and it is the third largest cause of death, after heart disease and cancer. The brain injuries caused by strokes are a major cause of adult disability in the UK.

Older people are most at risk of having strokes, although they can happen at any age - including in children.

(Source: http://www.nhs.uk/Conditions/Stroke/Pages/Introduction.aspx/).

Stroke Association Waltham Forest
The Stroke Association is the UK's leading stroke charity. With a local office at Resource Hub South, staff provide stroke survivors in Waltham Forest with much needed support, information, advice and advocacy.

The team has developed a personal relationship with its service users and also a close working relationship stroke services in the Borough. In facilitating regular peer support groups, and working with professionals, the team has an insight into the challenges facing stroke survivors locally.

Healthwatch Waltham Forest
Healthwatch is the official health and social care 'patient voice' across England. Part of its core work is to gather views and understand the experiences of patients and the public through systematic engagement and analysis of information. In doing so, it is empowered through statute with promoting and supporting the involvement of people in the commissioning and provision of local care services and how they are scrutinised.

Stroke Focus Group, 26th September 2014
The Stroke Association and Healthwatch Waltham Forest co-hosted a focus group on Friday 26th September 2014, to record stroke survivors' views on their experiences of health and social care services as a whole.

The event was attended by around 15 service users and carers, plus stroke nurses from Whipps Cross Hospital (Barts Health).

From the comments recorded, 185 issues have been identified.

This report identifies clear trends and offers suggestions on what could and should be improved, what is failing, and what is working well.

Overall Sentiment
The focus group engaged participants in open, impartial discussion. Of the 185 issues recorded, 26% were positive, 5% neutral and 69% negative. From the outset, this suggests that service users were clearly feeling negative about their experiences as a whole.
Hospital Inpatients

25% of issues overall were about hospital inpatients/nursing care provided and sentiment was 80% negative.

We identified clear issues around communication on the ward, with patients not feeling involved or engaged in their care. Poor communication has wider effects on welfare during the stay, with nutrition and personal hygiene, as well as emotional wellbeing affected as a result. See comments on Page 12.

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<tr>
<th>What ‘could and should be improved’</th>
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<td><strong>Issue Identified</strong></td>
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<td><strong>Patients not being engaged by staff for long periods of time, therefore without access to information and support.</strong></td>
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<td><strong>Patients not being able to communicate due to their condition and/or shock.</strong></td>
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<td><strong>Patients often did not know who to speak to.</strong></td>
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<td><strong>Patients sometimes are not able to interpret medical advice, due to their condition.</strong></td>
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<td><strong>Some patients had lost control of their hands due to the condition and were not assisted to eat.</strong></td>
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<td><strong>Personal hygiene was an issue, with one patient having to wait 2 hours to be washed, and another falling over on the way to the toilet.</strong></td>
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<tr>
<td>‘The most important thing for stroke patients is to see others’ commented a patient. Being able to interact could aide wellbeing.</td>
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<td>One patient commented that ‘There was a bell for support, but it didn’t register I had to press it’.</td>
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<tr>
<th>What ‘works well’</th>
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<td>Patients were complimentary about the consultant clinics.</td>
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Hospital Discharge

9% of issues overall were about discharge from hospital and sentiment was 73% negative.

Issues were identified around the timing of discharge, and provision of support following discharge. See comments on Page 13.

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<td></td>
<td><em>It is accepted that patients will have to be discharged as soon as is clinically possible. However, emotional as well as physical needs should be addressed (‘I was petrified at the prospect of going home, as that’s where I had my stroke’).</em></td>
<td><em>9. At discharge, provide the patient with information on how to access emotional support.</em></td>
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<td><em>Some patients were discharged without any care in place at home. A wife stated that ‘my husband didn’t know a toothbrush from a razor on discharge’. Without the family/carer support, such incidents present risk.</em></td>
<td><em>10. Hospital staff liaise with Social Services and family members/carers to ensure that support is available as required when returning home.</em></td>
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<td></td>
<td><em>One patient commented ‘I didn’t know my condition until discharge’.</em></td>
<td><em>11. Vital information on condition should be communicated, if possible, in advance of discharge.</em></td>
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<td></td>
<td><em>One patient was made to feel ‘relaxed and comfortable to receive rehab at home’ and left hospital in a good mental state.</em></td>
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<td></td>
<td><em>Physical ability assessments are carried out ‘before they discharged me they made sure I could walk up/down stairs and they tried to get me to make a cup of tea’.</em></td>
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Community Services

47% of issues overall were about community services and sentiment was 61% negative. Issues were identified around home support, access to information/advice, care assessments, emotional support/personal development and transport/isolation.

Community Services - Social Care Assessments & Eligibility

Issues around care package assessments were identified. See comments on Page 14.

What ‘could and should be improved’

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<tr>
<td>Several comments suggested that assessments are not explained clearly, with uncertainty arising.</td>
<td>12. Provision of advocates would help residents understand questions, and the potential consequences of answers.</td>
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<td>13. Assessors should take extra care when assessing people with neurological conditions. Staff training would be beneficial.</td>
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What ‘is failing’

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<tr>
<td>One person commented that ‘if you can walk you’ll be considered alright, but real capacity - memory and energy for example - do not appear to be considered.’</td>
<td>14. Check that neurological conditions are being weighted as required.</td>
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Community Services - Care at Home

Clear issues were identified around the ability to cope at home, with many finding it difficult to prepare meals, look after their personal hygiene and grooming, and get by generally. See comments on Page 14.

What ‘could and should be improved’

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<tr>
<td>Preparation of meals can be difficult, with some people having to rely exclusively on packaged meals (‘I can’t butter a slice of bread’).</td>
<td>15. Signpost to services that can provide specialist equipment and training.</td>
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<td>16. Promote the services that already exist to known stroke patients.</td>
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<tr>
<td>Personal hygiene/grooming can be difficult for some people (‘I’ve stopped wearing socks as I can’t get them on’).</td>
<td>17. Signpost to services that can provide specialist equipment and training.</td>
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<td>18. Promote the services that already exist to known stroke patients.</td>
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### Community Services - Access to Information

Access to information is a clear issue, with comments suggesting that not enough information is making it ‘out into the community’, and that a ‘central place’ to access information is desired. *See comments on Page 15.*

### Community Services - Emotional Support & Personal Development

There is a sense that emotional wellbeing and personal development can be overlooked, impacting on long term health and quality of life. *See comments on Page 15.*

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<tr>
<td>Many people said they do not receive any help or support from the Council. It may be the case that they are entitled to funding, or a care package.</td>
<td>19. Send leaflets on available support to known stroke patients, to encourage uptake. It is known that many people will not act on their own initiative.</td>
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<td>Comments indicate that ‘information about services is very hit-and-miss - they need to get information out into the community’.</td>
<td>20. Disseminate information to community hubs including libraries, community centres and groups.</td>
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<td>It was thought that ‘a central place’ to access information would be a very useful resource (‘it is difficult to deal with fragmented information’).</td>
<td>21. Produce a directory/guide of stroke services and make available in a range of formats.</td>
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<td>People indicated they did not currently receive emotional or psychological support.</td>
<td>22. Encourage patients to discuss emotional and psychological issues with their GP, for referral to appropriate services.</td>
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<td>23. Ensure that peer support groups are available and widely advertised.</td>
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<tr>
<td>One person commented that ‘I need help getting into employment, I feel unsupported and don’t have much hope’.</td>
<td>24. Stroke services to liaise with DWP to see if specialist support exists.</td>
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Community Services - Home Therapy and Testing

Comments suggest that speech and physiotherapy are greatly valued, but would be more effective if offered for a longer period. See comments on Page 15.

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<tr>
<td>Comments suggest that 6 weeks of speech and/or physiotherapy are not enough to ensure long term benefit.</td>
<td>25. If extension to 8 weeks is not possible - consider referral or signposting to any complimentary services that exist.</td>
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<tr>
<td>Some people commented that the therapy could be more ‘in-depth’.</td>
<td>26. Offer holistic therapy if possible.</td>
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What ‘works well’

Some people were satisfied with the physiotherapy received.

Community Services - Transport and Isolation

According to comments, people can find it difficult to travel by public transport, resulting often in isolation. See comments on Page 16.

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<tr>
<td>There was a consensus that ‘a lot of stroke victims are trapped in their homes’. One person could not get from Walthamstow to London Bridge, where useful community services are located.</td>
<td>27. Promote local advocacy/buddying services to known stroke patients.</td>
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<td>Many stroke patients live in isolation, but the Local Authority and Health Service does not make an effort to reach out and improve life chances.</td>
<td>28. Promote local groups and activities to known stroke patients. 29. Utilise existing community centres, or vacant community buildings to host activities.</td>
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GP Services

There is an assumption that GP’s will contact stroke patients after hospital discharge, but this often does not happen. Comments suggest that GP’s could be more supportive generally. See comments on Page 14.

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<td>Patients are at their most vulnerable in the days/weeks after discharge, yet many report that they are not contacted by their GP.</td>
<td>30. GP’s should act on discharge summaries that indicate stroke and call patients in as soon as possible, to assess physical and mental health, ability to cope, and refer to social services where required.</td>
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<td>There is no routine contact with the GP.</td>
<td>31. Regular review meetings would ensure that patients welfare is monitored in the long term.</td>
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Community Stroke Team

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<tr>
<td>There is a long waiting list to access the Community Stroke Service, which has a negative effect on health and wellbeing.</td>
<td>32. Look at capacity and reduce waiting times where possible. 33. Utilise any other existing services.</td>
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Community Organisations

Community Organisations, such as the Stroke Association and Age Concern are regarded as an essential support service by users. See comments on Page 16.

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<tr>
<td>Referrals from health and social services could be more frequent.</td>
<td>34. Literature on the Stroke Association (and other appropriate groups) could be issued on discharge. 35. GP computer systems could flag up appropriate community groups when seeing a stroke patient.</td>
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**What ‘works well’**

*The Stroke Association in particular is providing essential support daily, including peer support groups. One person commented that ‘if the Stroke Association wasn’t here it would be terrible and a disaster’.*
Focus Group Comments

Topics Covered

**Hospital Admission**
Admission/Diagnosis, Distance/Travel/Choice

**Hospital Inpatients**
Communication/User Involvement, Nutrition, Facilities/Personal Hygiene, Staffing Level, Carer Involvement, General Comments

**Hospital Transfer**
Communication/User Involvement, Timing, Choice

**Hospital Discharge**
Communication/User Involvement, Planning/Care Package, Timing, Transport

**GP’s**
General Comments

**Social Care Assessments and Eligibility**
Access to Information and Support, Assessment Criteria

**Care at Home**
Grooming/Personal Care, Nutrition, General Comments/Ability to Cope

**Carers**
General Comments

**Access to Information**
General Comments

**Emotional Support and Personal Development**
General Comments

**Home Therapy and Testing**
Physiotherapy, Speech Therapy, General Comments

**Transport and Isolation**
Transport, Isolation

**Community Organisations**
Stroke Association, Other CVS

**Hospital Admission**

*Admission/Diagnosis*
1. I had 3 strokes. First stroke went to Royal London Hospital, they didn't recognise the stroke and the doctor sent me home. They called me 4 weeks later to see if I’d had a stroke.
2. I remember getting in the ambulance, seeing my son and granddaughter, but that’s all I can remember.
3. I didn’t know what was happening on admission as I was in a daze. I don’t remember much about Whipps Cross or Royal London. I do recall some staff were nice, and others not so nice.
4. Had the stroke at home and paramedics came. Thought he was okay but then lost consciousness so they took him to hospital.
5. Had stroke. Went to hospital. Doctor sent him home. Not admitted after second stroke. Admitted after third stroke with severe dysphasia. Care was difficult because staff didn’t understand. Seen by SLT - frustrating at first.

Distance/Travel/Choice
6. We live in Chingford - why do we have to go to the Royal London, which is some distance further than Whipps Cross. Royal London is better for stroke, but this could be better communicated to patients and Carers.
7. It’s a ‘far longer’ journey (Royal London).
8. I’d much prefer my treatment to be at Whipps Cross.
9. The choice is limited - Romford or Whitechapel, but my friends assumed I’d been taken to Whipps’s Cross and went there by mistake to see me.

Hospital Inpatients

Communication/User Involvement
1. It’s difficult when the nurses don’t read the doctor’s notes and we can’t talk.
2. The most important thing for stroke patients is to see others.
3. Staff need to know more about the condition. Stroke patients can be very confused.
4. They didn’t ask me if I needed a nicotine patch, no user involvement. They didn’t tell me I had pneumonia.
5. It would be nice for people to say ‘are you alright’, but it doesn’t happen as people are busy.
6. It is nice to be spoken to.
7. A bit more 1-2-1 would make a lot of difference - the personal touch.
8. Communication - I had fallen out of bed twice on the ward and the doctor and seen to me, but nobody told my Carer.
9. They gave me an oxygen mask at one point, and didn’t tell me what for or why.
10. There was a bell for support, but it didn’t register that I had to press it, this was not impressed on me.
11. Staff need training on communication difficulties.
12. Poor communication on the ward.
13. Staff did not inform me as to progress, I had no idea of my condition.
14. It’s all very well if you’ve got a voice in hospital, but many stroke patients have not.

Nutrition
15. I lost 2 stone after the stroke, the doctor didn’t seem too worried. I went from a size 12 to a size 6.
16. I needed help with feeding but the food was just left there. I couldn’t move my hand at all.
17. I noticed some patients could not feed themselves and trays were left.
18. I didn’t like the mashed up stuff, so had milkshakes instead.

Facilities/Personal Hygiene
19. The ward shower didn’t work, but the occupational therapist took me to the bath.
20. There was no personal toilet, had to call for help and kept bumping into things as my co-ordination was gone.
21. I needed changing and smelled, but had to wait until 2 staff members were available.
22. I wasn’t allowed out of bed to go to the toilet!

Staffing Level
23. I was staying on a large ward (I think 2 wards combined) but staff seemed thin on the ground (the service was ‘diluted’).
24. There are more staff on the rehab ward now.
25. There should be more staff downstairs.
26. There should be more staff generally and what about the quality of staffing?
27. There weren’t enough staff at Whipps Cross.

Carer Involvement
28. Would struggle to leave family member on the ward.

**General Comments**
29. Did not like Wavel ward.
30. One nurse on the ward was exceptionally good.
31. Being moved to rehab on my own was quite daunting.
32. Not very happy with my experience on Peace ward.
33. The consultant clinics are fine.
34. More help is needed in hospital.
35. It’s nice to know you’re in good hands.
36. One of the sisters was excellent and even gave cuddles!
37. It felt like some staff members didn’t care.
38. The night staff are not as good as the day staff.
39. Fantastic care in hospital for 3 days.
40. First couple of days found it very hard to walk, then had severe headache. Eventually fell asleep - doctor came and didn’t wake him. Woke up 15 minutes later with a headache. In morning was good. Sent home next day.
41. Had stroke at home, headache and reduced movement in arm and foot. Went to Whipps Cross and had scans. Good care in hospital. Seen by therapists - very happy with care.

**Hospital Transfer**

*Communication/User Involvement*
1. I had a disconcerting move from Whipps Cross to Royal London. I was moved for a very good reason, but this was not communicated at all, adding to my anxiety.
2. Taken to Royal London without any explanation. I know it is a specialist stroke centre, but the communication there could be much better.

*Timing*
3. I was moved from Whipps Cross to Royal London in the middle of the night, why is that necessary? I was also discharged gone midnight and told to get a cab.
4. Moved from one hospital to another and my shoulder/collar bone was broken.

*Choice*
5. You get more help at Royal London, but was moved to Whipps Cross.

**Hospital Discharge**

*Communication/User Involvement*
1. They made him feel more relaxed and comfortable to receive rehab at home.
2. Staff at Royal London should have communicated with me more (and more effectively) and I should not have been discharged at 12 midnight.
3. I didn’t know my condition until discharge - the summary said pneumonia. I was quite concerned when reading it.

*Planning/Care Package*
4. Nobody to help me at home.
5. Before they discharged me they made sure I could walk up/down stairs and did tests at home. At Whipps Cross they tried to get me to make a cuppa!
6. My husband didn’t know a toothbrush from a razor on discharge, so without me around it could have been a disaster at home.
7. I was petrified at the prospect of going home, as that’s where I had my stroke. Thankfully my son stayed with me for 2 weeks.

*Timing*
8. Did not feel ready for discharge - scared stiff. Did not have any carers on return home.
9. Second stroke - my time in hospital was too short - should have been a week, not 2 days.
10. I spent 2 weeks in hospital.
11. I spent 1 month in hospital.

Transport
12. Could therapists take patients home, instead of hospital transport? Now that would have been nice.
13. I had arranged to be dropped off to my son’s, as I was staying with him for a fortnight. However, this information never made it to the transport crew and they dropped me home. I had a problem with speech so couldn’t correct things.

GP’s

General Comments
1. The GP said I’d had a stroke because I hadn’t taken my medication.
2. There was not enough support from my GP. I was on aspirin but changed to a stroke drug without explanation from the GP.
3. The GP changed my chemist, who supplied a pill box. But I changed back to my original chemist after a lack of customer service.

Social Care Assessments and Eligibility

Access to Information/Support
1. I may have been assessed for needs during therapy, but is it explained clearly? I find it difficult to get in the bath for example, but this was not one of the assessment questions. The physio should explain things clearly and impress important points.
2. Are we entitled to home help? I only found out about the service through the Stroke Association.
3. I often miss the point, get lost, daydream, I can’t help that.
4. Benefits and Carers Allowance - my disability money was cut back. The full amount was reinstated, but only because I fought hard for it. What about those who are unable to fight?
5. What is available on a care package is not explained. Can I get specialised equipment/gadgets to open cans?

Assessment Criteria
6. There’s a perspective that ‘if you can walk you’ll be alright’, but real capability (memory and energy for example) is does not appear to be considered.

Care at Home

Grooming/Personal Care
1. I can’t cut my fingernails and there is no help for this.
2. Getting dressed is hard.
3. I’ve stopped wearing socks as I can’t get them on. I have to wear felt lined boots.
4. I can’t wash my hair - I have got the strength, and I can’t rinse.
5. Getting in-and-out of the bath is quite difficult and I might slip one day.
6. My bathroom is upstairs, it’s very hard to get up there and can be very stressful.
7. I’ve largely had to fend for myself at home. Got special commode and bath equipment but my daughter had to take time out to collect - why can’t they be delivered?

Nutrition
8. I can’t butter a slice of bread. I get no help from the Council or social services.
9. I have to improvise on meals as I can’t use my hands that well. All cooked meals have to be ready-done and microwaved.
10. Used to cook but can’t any more.
11. I struggle at home and can’t prepare meals. I buy tinned potatoes etc but had to be proactive and improvise.
12. The occupational therapist suggested things to try - using special cutlery for example.

**General Comments/Ability to Cope**
13. I wouldn’t cope without a carer.
14. Help from the Council or social services ‘would be a god-send’.
15. Since having the stroke I can’t write, so I can’t write to complain - which is a challenge in itself.
16. I’m on my own every day, but manage to get to the door to let the Carer in.
17. I still fall over at home. Help would be good.
18. People don’t understand if they don’t know you so well.
19. Support once a week is important.
20. It’s difficult at home as I live on my own, I get by on my own resourcefulness, but others may struggle.
21. It’s fortunate I can cope, but a lot of people can’t.
22. I’m glad I live in a flat!

**Carers**

**General Comments**
1. Carers deserve a lot more support.

**Access to Information**

**General Comments**
1. Information about services is very hit-and-miss. They need to get information out into the community.
2. My cousin works at the Council and he says I’m entitled to a disability care package, though nobody in an official capacity has mentioned that to me.
3. I don’t know what benefits are available (one participant had not heard of Community Care Grants).
4. It would be good to have a central place to access information.
5. I need a central point of access, it is difficult to deal with fragmented information and multiple agencies.
6. After 1st stroke the information provided was not as good or useful as it could be - there could have been more tips on lifestyle changes.

**Emotional Support and Personal Development**

**General Comments**
1. I do have a voice, but some people do not, they just have to ‘get on with it’.
2. There is no emotional support. I saw a psychiatrist once, but not again.
3. We just need somebody to talk to - somebody who we can explain the implications of what we’re going through.
4. I need help getting into employment, I currently feel unsupported and don’t have much hope.
5. Mental attitude is important. Positivity and not accepting defeat. Have to encourage people to do as much for themselves as possible. Promoting independence.
6. Having a good support network helps. For the first 2 weeks daughters wouldn’t allow visitors to promote rest.

**Home Therapy and Testing**

**Physiotherapy**
1. I was told very little at the physio assessment.
2. Gesture therapy is ‘useless’.
3. I had physio after the second stroke. I went to the ‘Rehab Centre’ after the third stroke.
4. I had physio at home, but only for 6 weeks.
5. The home physio and speech therapy was good.

Speech/Language Therapy
6. The level of service was not adequate - a visit once a week to test writing etc. It could be more in-depth, with more advice and access to information.
7. I got speech and language therapy and physio when I went home. Nice girls and a lovely service. They pushed me as hard as I could go!
8. The service was for 6 weeks, but I would have preferred 2 months.
9. Being read to aloud is very useful for my speech therapy.
10. I’m going to the hospital for appointments about my speech.
11. Could be worse but it’s okay. Communication can be difficult but have adapted because you have to.
12. Still doing speech language therapy independently at home.
13. 3 months of speech therapy would have been much more effective in my case, it’s a shame there’s a limit.

General Comments
14. It took a long time to get to the rehab team but the services were very good.

Transport and Isolation

Transport
1. I have trouble travelling - I cannot touch my Oyster card on the scanner. I can’t even get from Waltham Forest to London Bridge.
2. I walk slow and have to get 2 buses to the centre (a fit person would only need 1). If I had somebody to take me to appointments, that would be an enormous help.
3. Half the bus drivers don’t bother putting the disabled ramp down. Recently 2 ladies had to help me off the bus. Most people won’t stand up for me (relinquish their seat), as they can’t tell I’m disabled.
4. Can walk and access public transport.
5. Could hardly walk to the bus stop to get on the bus.

Isolation
6. A lot of stroke victims (perhaps most) are trapped in their homes. If they live on their own they are particularly isolated. The Council does not deal with isolation.
7. Living in temporary accommodation and has to move again but is awaiting housing. Frustrating. Lonelier now - doesn’t go out anymore. Can’t walk properly - gets nervous and walking gets worse. Doesn’t participate in nightlife anymore but sees friends during the day.
8. Some relationships with friends change but depends on the individual person. Daughter abroad calls every day, local daughter communicates less. Can be a lack of understanding.
9. Have a 5 year old daughter. Couldn’t wash self. Lives with parents - best thing that has happened to him. Lack of speech was very frustrating. Worked as a counsellor - can’t now. If I hadn’t had a stroke life would be very different. Don’t talk to friends as often now because of speech problems.
10. I need a food bank referral but my GP refuses referral.
11. My condition is often not recognised within society.
12. It can be difficult to communicate with professionals. There is a lack of awareness of what stroke is and what the effects are (some are not visible).

Community Organisations

Stroke Association
1. I was signposted to Age Concern through the Stroke Association, which is very useful.
2. The Stroke Association helped me to understand what is happening, especially for me as a Carer.
3. The Stroke Association is a very important place to come to. If the Stroke Association wasn’t here it would be ‘terrible and a disaster’. We would not get basic support.
4. Speech Therapy - I was referred to the Stroke Association within 3 weeks of the stroke.
5. I went to a speech school with Jacqueline (SA).
6. It’s good to meet people with the same condition and to hear their stories and views.
7. I came back to the country in December 2013 and saw the Stroke Association 2 months later. Brilliant support once in contact.

Other CVS
8. Waltham Forest Vision sometimes help me do my shopping. It’s very useful as I cannot use my hands.
9. The Connect Service at London Bridge is very good, but with my condition I can’t get there.

End.