

PATIENTS AND CARERS TELL US

WHAT SUPPORT IS NEEDED SIX MONTHS AFTER A STROKE?

The SLCSN held an extremely successful event on 28th July for stroke patients and carers. The event aimed to gather their thoughts on the support needed by stroke patients six months after a stroke, in line with Quality Marker 14 of the National Stroke Strategy.

PATIENTS AND CARERS WANT TO IMPROVE STROKE CARE

The South London Cardiac and Stroke Network held an extremely successful event on 28th July for stroke patients and carers.

Thirty patients and carers attended the event, which aimed to find out their thoughts on the support needed by stroke patients six months after a stroke, in line with Quality Marker 14 of the National Stroke Strategy.

After receiving an overview on the current state of stroke services in London, participants broke into seven groups to give their views on what kind of support would be required in the following areas as part of a six-month review:

- Medical
- Physical
- Emotional
- Leisure and Social
- Work

Each group covered two topics and all participants had strong views, which are being collated by the Network team to develop service specifications for the delivery of six-month reviews. A brief summary of key themes has been collated below.

Experiences of follow up

Stroke survivors across South London had extremely varied experiences of follow-up after their discharge from hospital. Some:

- Were offered follow-up at 6 weeks post-discharge by a hospital consultant
- Were reviewed again at 6 months, again by hospital consultant.
- Were offered no review at all.

This led to frustration and confusion in the stroke survivors concerned, and the majority of attendees felt that a six-month review would have been extremely helpful. Please see findings below for further detail.

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Delivery of review: group responses

Where should the review take place?

Attendees felt that patients should be able to choose where they feel most comfortable, no matter what location that may be.

Suggestions included:

- Home
- Hospital
- GP practice

Who should be involved in delivering the review?

One member, reflecting on her experience, noted that no matter who delivers the review, that person must be more knowledgeable about stroke than the patient attending review.

Specific suggestions included:

- Health and social care
- GP (though this raised concerns about GPs' stroke knowledge and communication issues between hospital, GP and community services)
- Every professional working with stroke patients should be part of the review (this provides a more holistic approach and ensures that no one "falls through the net")
- All decisions should be made jointly by patient and healthcare staff
- Carer should be included

Practicalities of the review

- Transport provision for patient
- Multi-format information (post, phone, email)
- A holistic approach that addresses medical and emotional needs
- Appointments should be flexible, with extra time allotted for questions
- Opportunities to share ideas with other patients

POSSIBLE AREAS TO ADDRESS

(As suggested by South London patients and carers)

Medical

- Informing patient about correct medication, whether there are more suitable drugs available and what length of time patient can expect to be on the medication
- Give patient a clear explanation of medication purpose and side effects and give a clear choice about which medication to take
- Secondary prevention information (e.g. diet or healthy eating)
- Information about how to react if patient goes back into Atrial Fibrillation
 - When, where, how, from whom to seek advice
- Raising patients/carers awareness of symptoms and effects
- Cholesterol check, full health check to ensure patients have no other linked conditions, INR check
- Time for patients to discuss worries and fears
- Signposting to further support

Physical

- Showing/providing video clips of how to do the exercises would assist with remembering them
- General advice on becoming more active
 - Going to the gym, swimming
 - Combination of physical and mental stimulation
 - Offer support to family
- More frequent physiotherapy and reviews
- Being able to start rehabilitation at a later date if the patient has turned it down when first offered
- Referral to exercise programme at local leisure centres
- Setting goals for personal and physical improvement
- Discussion about the frustration caused by a reduction in mobility
- Communication problems
- Importance of finding out about the person and tailoring help to their needs (i.e., practical help)
- Evaluation of whether the patient needs stairlift/additional household support
- Timely access to household adaptations
- Patients need regular assessment of their independence (whether they can shop/cook/clean etc)
- Review is an opportunity to look at what care package is in place
- Providing access to domiciliary care/ review if it is needed
- Reviewing current domiciliary provision/access

- Striking the right balance between keeping independence versus accepting help
- Access to assistive technologies/computers

Emotional

- Opportunity to discuss feeling of having had a narrow escape last time and that the consequences would be worse if it happened again
- Opportunity to address fears about becoming helpless if patients were to lose lucidity or become comatose
- Review to be fixed at a time when patient is not fatigued. There is currently not enough consideration for a patient's body clock (e.g. physical therapy at 2pm may not suit the patient who may thus become labeled as depressed).
- Depression can be a big issue and formal screening of mood should take place at 6 months. Need to increase the amount of information provided. A patient's level of depression can fluctuate and options for medicating depression, Cognitive Behavioural Therapy or counseling should be discussed where needed
- Emotional support for family and/or carer of impact of stroke to avoid feelings of isolation/stress/anxiety
- Feeling isolated may be due to:
 - Transport
 - Lack of group support.
 Therefore signposting to these services must be available as part of the review.
- Help in controlling emotions – techniques for doing this and adapting
- Greater support in working environment
- Need laughter therapy!
- Buddy/befriending
- Good questions to ask:
 - How have you changed?
 - How have your emotions changed?

Leisure and social

- Advice on how patient can get out and about. This is important for their general well-being and to encourage independence. Social activities are enabling and empowering. Compare leisure activities pre and post stroke and link leisure habits assessment with changes to cognitive/physical skills
 - Assess how patient is getting out and about
 - Assistance with getting out to do the things that patient is interested in
- Ability of transport services (including public) to provide appropriate/timely transport (e.g. opportunities to pre-book to avoid waiting for bus and then unable to board as no room for wheel chair)
- Greater communication between NHS and local authorities
- Information on transport services/local options
 - Dial a Ride
 - Church groups may offer transport

- COMCAB/dial a ride: patients get subsidised fares, but needs greater publicity
- Discussion/information about the alternatives to driving/transport provision
- When driving licence has been cancelled due to condition that may improve (such as peripheral vision), patients need to know:
 - When can I drive again?
 - What processes must I go through?
- Using time banking system (where you volunteer time to the community and get the same amount of support in return) to support carers
- Provide information on local resources to look up on hobbies or activities regularly to ensure easier access to people/organisations who provide information and advice
- Discussion about short and longer break holidays
- Peer support – Offering opportunities to link into groups networks of people who have gone through a similar experience. ('Stroke clubs are really good.')
- GPs need to be clear about where extra support in the community is available
- Help/support/assistance may be available from other places (e.g.links with church groups)
- Need regular links between tertiary care, GP centres and community groups to ensure that additional care/support post stroke is in place
- Sheltered housing schemes need additional support/need to be looked into
- Social workers should have more knowledge about stroke and the services available
- Provide local information packs for patients. Information can be sent out via stroke/GP registers. Need to ensure that every borough has this.

Work

- Review needs to be tailored to the individual stroke survivor ie needs to cover impact on job for younger people and possible adaptations for return to work
- Need to discuss how the patient's work has been affected
- Communication with employer about progress
- General information about what has happened and the severity
- Communication with employer about whether role can be adapted to get patient back to work
- Linking OTs with employers
- Discussion of vocational rehabilitation needs
- Talking about finances - Review needs in relation to benefits
- Currently a lack of information about financial support available to patients/carers