

People's  
Experiences of  
Stroke Services in  
Oxfordshire

Healthwatch Oxfordshire

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Healthwatch Oxfordshire would like to thank those people who gave time to share their experiences and to tell us how stroke services could be improved.

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# 1 Executive Summary

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## **Stroke services in Oxfordshire: feedback on current services and what a good stroke support service would look like**

Since October 2016, Healthwatch Oxfordshire has visited and spoken to the members of four different stroke clubs around Oxfordshire. These were located in Wallingford, Banbury, Witney and Abingdon. In all around 40 people were engaged and listened to. <sup>1</sup>

There was agreement that stroke services seemed to have improved in recent years and people who had strokes more recently (2013 onwards) seemed more satisfied with their care than those who had had their stroke more than a decade ago.

People we spoke to told us their experiences and also gave us their thoughts on how they felt services could be improved.

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<sup>1</sup> While people attending all the clubs gave feedback, we were able to gather the most detailed feedback on stroke services from the Abingdon Stroke club on 14<sup>th</sup> August 2017.

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## 2 Main Themes

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The main themes that emerged around stroke care are:

### 2.1 Good care at the John Radcliffe (JR) stroke unit and community hospitals

People stated that the care they received at the JR was good. The length of time people stayed varied from a day to a few weeks. Some were then sent to community hospitals in Witney and Abingdon. Some were discharged back home and some were sent on to the Oxford Centre for Enablement. Comments received about care at the JR and community hospitals were that people were satisfied with the care they had received there including physiotherapy provided at the community hospitals. But many people said there was too long a wait for physiotherapy following discharge from hospital.

### 2.2 Excellent care at the Oxford Centre for Enablement (OCE) though delays in access

People praised the OCE and unanimously said that the care provided there was very good. However people pointed out that there was no support following discharge from the OCE. Some also said that it could take a few weeks before they could access the OCE. This meant there was a delay in starting physiotherapy which they pointed out was far from ideal in terms of recovery after stroke. One person said he was sent to Abingdon hospital for two weeks following his stroke and then was told there would be a further two week wait for access to the OCE. He said that would have meant a month before he could have started physiotherapy which is too long to wait after a stroke.

### 2.3 Praise for occupational therapists and social services

People commented on the good follow up provided by social services. Occupational therapists (OT) were praised. One person said the OT support at the Witney hospital was good- they came daily and really helped him get back on his feet. People appreciated the support they received in terms of help with assessments at home and hand rails.

### 2.4 Mixed experiences with GP follow up support

Some people said their GPs were proactive in providing support and care in the weeks



following their discharge from hospital while others said there was no follow up at all, other than an invitation to an annual check-up. Many people said they would have appreciated more regular contact with their GPs after their stroke.

## 2.5 Lack of support at home following discharge

Overwhelmingly people mentioned the lack of support once they were discharged from hospital. As one person said, it felt almost like they had *“been dumped at home. You get all this attention in the hospital and then nothing [at home].”*

Another said that he had been discharged from the OCE because they were satisfied he could go up and down the stairs once a day but he quickly realised that that wasn't quite enough.

When he left OCE, he said he was enthusiastic about the things he could do but says *“You realise how hard things are - getting up, getting dressed etc. OCE were satisfied I could go up the stairs once a day - but it was really hard if I needed to go more than once -for e.g. if I'd left my glasses upstairs.”*

People returned to this theme time and again - the feeling that one *“fell off a cliff edge”* after discharge with no support or follow up at home. People used the word *“abandoned”* frequently to describe how they experienced the time after their discharge. One person said that they had to wait three to four weeks for physiotherapy once they were home but she was so worried about deteriorating in that time that she chose to pay for physiotherapy privately.

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## 3 What people told us a good stroke support service looks like

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### 3.1 Prompt access to sustained physiotherapy without delay is critical

People reiterated this many times - physiotherapy should start immediately after a stroke and the current delays that come with transfer to the OCE (or home) and the wait for physiotherapy is too long. People also said that physiotherapy should not be short-term or time-limited to a few weeks but should last as long as the person needs. Some people said the ability to directly access the OCE without having to wait for referral would be good.

### 3.2 Support at home following discharge

This was one of the most oft-repeated themes. People said they felt abandoned at home and there was a complete lack of support once they got home. They said information should be given to people who have had a stroke in hospital before discharge on the kinds of support available to them.

They said this support should include:

- A named contact to be able to go back to as new challenges emerge at home and who can provide them with information about the different sources of support.
- More information on how to access the stroke clinic if relevant, the early supported discharge service, support from the Stroke Association, Stroke clubs.
- Information and advice on financial support, benefits, how to get a blue badge, what to do with your driving licence, how to access the regional driving assessment centre. People said it was overwhelming to have to try and navigate through the systems without any support or advice. People said they found out about a lot of services through word of mouth rather than one source of information. One person pointed out that if you were referred to the Regional Driving Assessment Centre from the hospital the service was free but if you approach it directly, you had to pay £90. People need to be given this kind of information.



- Information on what other support services are available for people who have had stroke. This information needs to be centralised and tailored to individuals. People said being directed to a website is not adequate, especially if you have a visual impairment that makes accessing information online harder.
- Help in accessing social groups with other people who have had a stroke as having a stroke can be a very isolating experience and people can struggle with depression.
- Exercise groups, gym classes, swimming pool access and swimming classes for people who have had stroke.

### **3.3 Regular follow up appointments with GP not just an annual check**

People said they would like to have regular contact with their GP initially after discharge from hospital that could then tail off to an annual check once they feel more stable and secure in their recovery. Many said that they did not get any follow up care from their GP after their stroke and this was a gap in services for them. Some people reported changes in their medication and wanted an opportunity to discuss both the changes and the impact the changes in medication were having on them with their GP. One person said their GP was meant to change her medication for stroke but never did and she did not have much faith in the system of after care.

### **3.4 Better coordination between GPs and other support services**

Some people said that there was not enough coordination between their GP and other stroke services. One person reported that he requested his GP to refer him for physiotherapy at the start of 2017 but didn't hear anything for eight months. He then went back to his GP who has now said they will chase this up for him as they had not heard anything either. He said people have to be quite proactive in their care and not assume the different services were communicating well between themselves.

Another person said that she needed help with podiatry but was told by her GP that they could not refer her and that she would have to seek help from the Red Cross on this directly. Yet another person living in the same town was referred to podiatry and was extremely satisfied with the care she had received from them.



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## 4 Information on the Early Supported Discharge service

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The Oxford Early Supported Discharge (ESD) Service for Stroke aims to speed up the discharge of stroke patients by continuing their rehabilitation in their home after they leave hospital, providing the same level of rehabilitation in the community as that provided on an inpatient Stroke Unit.

The team comprises:

- Stroke Consultant
- Physiotherapists
- Occupational Therapists
- Speech and Language Therapist
- Dietitian
- Rehabilitation Assistants.

Each patient is set specific goals, which take into account the needs and abilities of their carer or carers.

### **Patient eligibility criteria**

Patients must:

- have a diagnosis of a new stroke
- live within the area of Oxford City and North East Oxfordshire PBC consortium
- be registered with a GP in the stated area; any medical needs should fall within the remit of the GP
- consent to ESD
- be environment-assessed as safe by referring MDT
- be continent, or have a continence plan in place
- need no assistance that their family / carers cannot support; care needs should be assessed prior to referral and will need to be supported by family or community support agencies (e.g. SHDS, Re-ablement Service, private care)
- be engaged with rehabilitation programme; goals should be identified prior to discharge from hospital
- be able to mobilise and transfer safely independently, or with support from a trained carer, with or without equipment
- be visually or verbally assessed by an ESD team professional, prior to acceptance into the ESD programme.

They cover Oxford City, Kidlington and Bicester areas.

Oxford University Hospitals also provides daily TIA clinics (Monday to Friday) and a weekend service for high risk patients. This service is for:

- suspected TIA or minor stroke patients who do not need admission to hospital.
- suspect TIA in any patient with sudden onset focal neurological deficit, most commonly, weakness of the arm, leg or face, speech disturbance or visual loss. TIA is unlikely in those with loss of consciousness, non-specific dizziness or gradual onset symptoms.

This is an outpatient service for the 'walking wounded' and does not replace the inpatient pathway for those with acute, major or disabling stroke who need hospital admission and stroke unit care.