Stroke Pathway Project Report

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A report of evidence gathered on the stroke pathway for Surrey residents after discharge from acute hospital.

It is a simulation of how Local Healthwatch might give appropriate support to enable the Health Scrutiny Committee to carry out their scrutiny role from 1st April 2013.

Acknowledgements

Thank you to all the people who shared their story and to The Surrey LINK and its volunteers for their help in undertaking this project.

Contents

> to raise the quality of stroke care, and to audit/monitor progress and performance

Executive summary

Possible deficiencies in stroke services for the residents of Surrey detected by The Surrey LINk and the Health Scrutiny Committee (HSC) prompted this report. It was also prompted by the need to develop an effective Local Healthwatch in Surrey from 1 April that could gather evidence and communicate the views of patients, relatives and carers.

An effective Local Healthwatch will gather views, with trained volunteers who reach out and collect experience stories and carry out Enter & View visits; these will be underpinned by Freedom of Information Requests, to inform the HSC.

The Francis report 2013 has stated that Health Scrutiny Committees will need reports with comment and recommendations for actions, with local involvement in the development and maintenance of the healthcare system.

There has been an improvement in the quality of stroke care since 2008 but Surrey residents are still facing challenges in 2013. Improvements in Acute Care are not yet matched by progress in delivering more effective post-hospital support for stroke survivors and carers, progress needs to be accelerated.

Across Surrey, stroke services varied in quality and accessibility. The challenge will be maintaining and monitoring standards Surrey-wide with the way the NHS is to be organised from 1 April.

What did come across strongly was the need for timely information backed up with a care plan and a key worker. People lacked social care information; often coming across it by chance and far too late in the pathway.

Something that also came across strongly was the importance for people of voluntary services such as The Stroke Association, Headway, TALK, Strokeability, Dyscover and local stroke clubs (not all named) in the stroke pathway.

The recommendations are made to raise the quality of stroke care, and to audit / monitor progress and performance.

The Local Healthwatch stroke project approach and draft report met with the Health Scrutiny Committee's approval at their meeting on 14/3/13. The next steps agreed were to produce this final report and an action plan.

Introduction

There are many policy drivers for the improvement of stroke services: the National Stroke Strategy, Royal College of Physicians (RCP) National Clinical Guidelines for Stroke, National Institute for Clinical Excellence (NICE) quality standards for stroke and Care Quality Commission (CQC) report on stroke services.

The National Stroke Strategy published in 2007 by the Department of Health recognised that stroke was the country's third biggest killer. It was acknowledged that progress to ensure that lives are saved and disability reduced would take time to deliver but that there was no excuse for standing still. The strategy presented 20 quality markers to assist commissioners, stroke networks and service providers in judging the quality of their local services and a 10-point plan for action to guide those affected by stroke, their carers and the public in looking at the services available locally. This was the beginning of an ambitious agenda to deliver high quality stroke services from prevention right through to life-long support.

By 2010 the quality markers set out in the National Stroke Strategy were well established so during 2010 the Care Quality Commission used them to look at how services across the country helped people who have had a stroke after they leave hospital and how well services supported carers and family members, focussing on progress against the National Strategy.

In their 2011 Supporting life after stroke publication the data collected from the Surrey PCT area from the health and council services resulted in an overall assessment of performance of "Fair performing", with more areas of weakness than strength.

The 2010 NICE Quality Standards for stroke gave therapists a standard to work to deliver stroke rehabilitation, however, it was recognised by NHS Improvement that services were struggling to work out how to implement them. Their Mind the Gap report gave lots of ideas and methods to change and improve services in order to make the standards a reality with examples of how nine project sites across the country had redesigned services and the stroke pathway.

During 2012 people in Surrey who had had a stroke and their carers told The Surrey LINk that their experience of care was confusing and uncoordinated; this is also reflected in the Stroke Association's 2012 report, Struggling to Recover. Individual service users and carers were not experiencing a seamless transfer of care as stated in quality marker 12 of the National Strategy and that local service commissioners did not have an understanding of the NICE standards.

It was agreed that The Surrey LINk, working in partnership with Surrey County Council Health Scrutiny Committee, would find a way of gathering evidence on the health and social care experiences of Surrey residents so they could be heard and understood.

Project process

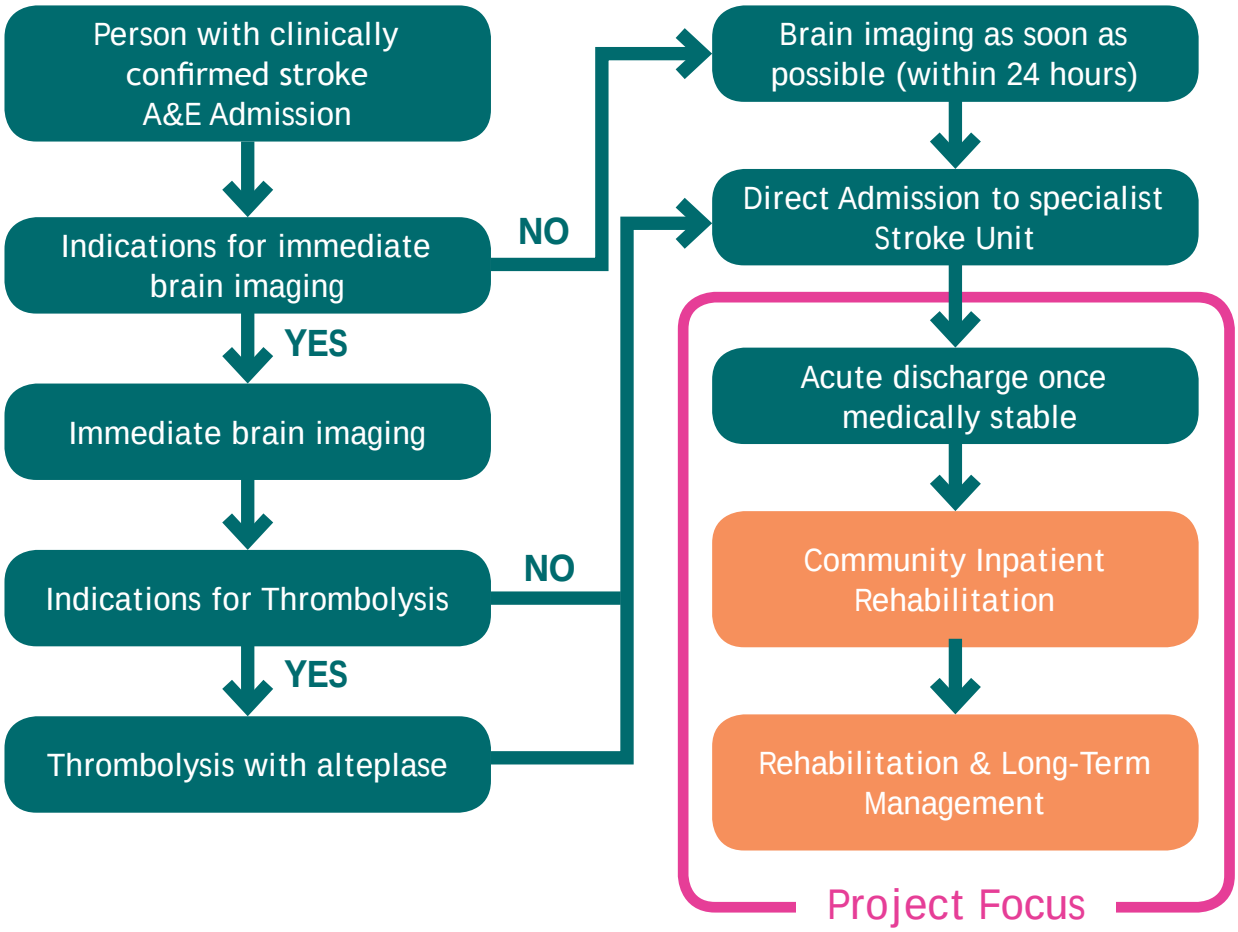
At the September 2012 Health Scrutiny Committee (HSC) meeting, the committee heard the experience of a Surrey stroke carer presented with the support of The Surrey LINk.

A proposal by The Surrey LINk to work on a project that would both look at the quality of stroke health and social care services in Surrey and simulate how The Surrey LINk might work with the committee following the changes introduced by the Health and Social Care Act 2012 was agreed. The 2012 Act is to bring about structural reforms to end LINk and introduce Local Healthwatch from 1 April 2013.

The stroke project was introduced to explore a real experience that Local Healthwatch and the health and social care system might face in Surrey. A simulation to develop and establish an open and transparent Healthwatch process, gathering evidence of the stroke pathway drawn from Surrey residents' experiences to influence and monitor the quality of stroke health and social care services in future.

A project gathering evidence for the whole stroke pathway from beginning to end with all 20 quality markers would have been too large and take too long to report. The particular part of the pathway relevant to the carer's experience story that the HSC had heard was quality marker 12 the seamless transfer of care, so this was the focus for the project. The carer's experience of the stroke pathway had been poor due to the lack of smooth transitions and transparent decisions.

Stroke pathway



To build a picture of the stroke pathway starting at acute hospital discharge and the community in patient rehabilitation provided afterwards the project gathered evidence from four different sources:

- **The individual**
- **Enter & View visits**
- **Patient stories**
- **Carers stories**.

A significant part of the project involved actively reaching out across Surrey to collect experience stories from people who had recovered from a stroke and find out their personal experiences of services. This entailed LINk volunteers and staff attending different stroke clubs and carers groups in the boroughs and meeting with individuals who stepped forward to tell their story.

Enter and View visits were carried out to the six community units commissioned by NHS Surrey to provide in-patient stroke rehabilitation in Surrey. LINk volunteers took part in visits to Crawley Hospital, Ewell Cottage Hospital (NEECH), Milford Hospital, Haslemere Hospital (Godwin Unit), Woking Hospital (Bradley Unit) and Farnham Hospital. These visits looked at hospital facilities and found out how stroke rehabilitation was experienced by patients and service users. The findings and recommendations from these visits were reported to each service provider and will be made publicly available on The Surrey LINk website.

The LINk volunteers were the authorised representatives of The Surrey LINk, they were CRB checked, had ID and had undergone training. The 20 people who shared their experience stories told us that that they were keen to talk to LINk volunteers because they were independent. The experience stories

covered eight areas of experience; with these eight quality elements present the stroke pathway would be seamless with smooth transitions and transparent decisions. These were then used to evaluate the evidence in the stories.

During the early stages of the project a press release was sent out to the local media to raise awareness and inform patients, service users and carers and the wider public.

This gained publicity in newspapers and on the radio with articles in the Surrey Comet, Elmbridge Guardian and This is Local London. An interview with a stroke carer for Eagle Radio was broadcast to listeners across Surrey and Hampshire helped to raise awareness of stroke, its effects on people and the project.

Freedom of Information Act requests were made to gather evidence of number of patients receiving in-patient stroke rehabilitation, how many were under 65 years old, how many were over 65 years old, where they had been referred from, where they were discharged to, the average length of stay, bed occupancy and the number of stroke registers held by GPs.

Quality marker 12 - seamless care

For a seamless stroke pathway of care a workable plan with the full involvement of the individual, (carer and family where appropriate) that is responsive to the individual's particular circumstances and needs should be developed by health and social care services together with other services such as transport and housing.

Stroke pathway activity in rehabilitation units

Activity 2011-2012	NEECH Epsom/Ewell	Farnham	Godwin Unit Haslemere	Bradley Unit Woking	Milford	Total
Number of patients	23	49	10	66	32	180
Patients over 65 years	14	25	7	32	30	108
Patients under 65 years	9	24	3	34	2	72
Referred from acute hospital	All	All	All	All	All	180
Discharged home	18	36	5	48	16	123
Discharged to Nursing Home	3	8	2	11	10	31
Discharged to acute care	1	4	1	6	2	14
Unrecorded	1	1	2	1	4	9
Number of stroke/neuro beds	4	6	10	12	12	44
Average length of stay	47.3 days	35 days	36 days	47 days	47 days	Average 42.3 days

No information was made available from Crawley Hospital for Surrey residents.

In a year (2011-2012), 180 Surrey stroke patients received community in patient stroke rehabilitation in 44 beds.

Stroke rehabilitation for Surrey residents who are under 65 years of age mainly takes place in the Bradley (Woking) and Farnham units with some at NEECH.

Stroke rehabilitation for Surrey residents over 65 years of age takes place at all the units.

The reports from the Enter and View visits to each of these units can be found in appendix A.

Quality marker 12 - stroke registers

Quality marker 12 of the National Strategy states that all GPs should hold a stroke register. Over 40% of GP Surgeries responded to the Freedom of Information Act request about their stroke register.

The responses showed that there are:

- 6,690 stroke patients over 65 years on a stroke register
- 1,739 stroke patients under 65 years on a stroke register.

Stroke register responses

GP Practice	Locality	Over 65 years	Under 65 years
Ashford Health Centre	Ashford	11	7
Stanwell Road Surgery	Ashford	72	20
Studholme Medical Centre	Ashford	216	54
Park House Surgery	Bagshot	88	22
Ahmad M & Partners	Banstead	177	34
Longcroft Surgery	Banstead	222	37
Gordon Road Surgery	Camberley	161	33
Heatherside Surgery	Camberley	47	12
Caterham Valley Medical Practice	Caterham	103	26
Townhill Medical Practice	Caterham	232	66
Cranleigh Medical Practice	Cranleigh	271	15
Dorking Medical Practice	Dorking	179	26
Medwyn Surgery	Dorking	137	24
Riverbank Surgery	Dorking	32	7
Ashley Centre Surgery	Epsom	109	23
Derby Medical Centre	Epsom	184	31
Old Cottage Hospital Surgery	Epsom	401	87
Lantern Surgery	Esher	38	9
Farnham Centre For Health	Farnham	58	14
Farnham Dene Medical Practice	Farnham	115	36
Ferns Medical Practice	Farnham	155	17
Holly Tree Surgery	Farnham	90	10
Frimley Green Medical Centre	Frimley Green	176	26
Binscombe Medical Centre	Godalming	146	25
Mill Medical Practice	Godalming	174	32
Pond Tail Surgery	Godstone	23	12

Stroke register responses (cont)

GP Practice	Locality	Over 65 years	Under 65 years
Fairfield Medical Centre	Great Bookham	221	27
Austen Road Surgery	Guildford	59	13
Dapdune House	Guildford	110	24
Guildowns Group Practice	Guildford	197	43
Merrow Park Surgery	Guildford	119	24
Shere Surgery and Dispensary	Guildford	78	27
Wonersh Surgery	Guildford	179	28
Stoneleigh Surgery	Epsom	13	4
Smallfield Surgery	Horley	94	27
Wayside Surgery	Horley	48	7
Horsley Medical Practice	Leatherhead	136	14
Greystone House Practice	Redhill	137	31
Hawthorns Surgery	Redhill	161	26
Holmhurst Medical Centre	Redhill	112	83
Moat House Surgery	Redhill	138	37
Woodlands Surgery	Redhill	89	33
Wall House Surgery	Reigate	184	21
Hythe Medical Centre	Staines	50	21
Knowle Green Surgery	Staines	67	16
St Davids Family Practice	Stanwell	129	51
Thorkhill Surgery	Thames Ditton	72	19
Elizabeth House Medical Practice	Warlingham	93	16
Parishes Bridge Medical Practice	West Byfleet	184	32
Whyteleafe Surgery	Whyteleafe	53	11
Witley Surgery	Witley	100	18
Heathcot Medical Practice	Woking	169	37
Sheerwater Health Centre	Woking	22	9
Villages Medical Centre	Woking	81	20
Westfield Surgery	Woking	128	35
Auriol Medical Centre	Worcester Park	42	7
Shadbolt Park Surgery	Worcester Park	51	17

Evaluation of the 20 experience stories

1. **How smooth the discharge from acute hospital was.**

   Experiences of discharge were mostly good and well organised; five poor experiences were from East Surrey Hospital.

2. **The specialist rehabilitation provided**

   The experience of rehabilitation was good at the Bradley and Farnham units.

   Provision of therapy is only five days per week at all units. Rehab provision has improved over the last five years. Some experiences were that of "fighting" for rehab in the community, two people in the east of the county had their rehab stopped at six weeks when they felt they needed more. Five people were purchasing rehab privately. Psychology provision is provided across the county except the Crawley area, this is an issue.

3. **Help for family and carers**

   The experiences of being offered help in a timely way were poor; some had received no help and had found it for themselves over time. The Stroke Association Care Support Workers were praised as the "only help" that had been offered. Carers experiences have been difficult to collect and we will continue to try for more.

4. **Care of individual needs**

   The experience was that voluntary organisations such as Strokeability and the Stroke Association Care Support Workers were doing good work with individuals. Two people were experiencing problems with advocacy for return to work. There is a need for more psychological support for people and their carers and more group activities.

5. **Help to return to family life**

   The experience was that more help is needed, the main issue was transport, one person used Dial a Ride, some people had Blue Badges and it was the Stroke Association Support Workers who had helped with this.

6. **Reviews weeks/months after the stroke**

   The experience of 6 week/month reviews taking place was poor.

7. **Information given**

   The experiences of being given information in a timely way were poor. People were missing out on vital sources of (free) support and information they wanted to be given stroke information right from the beginning of the pathway in hospital and for it to include voluntary organisations. Most information had been provided by the Stroke Association Care Support Workers.

8. **Choices given**

   The experiences of being given choice were very poor; most felt they had not had choice.

Although it was acknowledged that improvements in stroke services have been made over the last 5 years the overall experience was of a group of people who due to lack of information, a named person, a care plan and reviews did not know what support they could expect as stroke survivors and carers. Once discharged from acute care the reduction in the level of therapy causing a gap in their rehabilitation programme and progress. For all of them returning home was by no means the end of the journey.

Experience stories

A summary of the 20 patient and carer experience stories can be found in Appendix B.

Thank you to all the people who shared their story and to The Surrey LINK volunteers.

Recommendations

SSNAP Audit

Royal College of Physicians SSNAP audit that audits patient care in acute hospitals to be implemented to audit patient care in the community hospitals, Woking, NEECH, Farnham, Milford and Crawley. This should then be extended to stroke services provided in the community at home for example Early Supported Discharge.

Care plan

Implement a standard transferable care plan to provide information and support to patients and carers through the pathway from acute to community setting and an identified keyworker at all stages.

Community therapy

Increase availability of community in patient therapy from 5 days per week to 6 days.

Psychology

The immediate provision of a psychology service in the east of the county with a stroke service review to follow.

Bradley Unit

Conduct a review of the stroke rehab service to patients provided at the Bradley Unit, at Woking Hospital following the closure of the Godwin Unit.

Stroke registers

Improve the access to reviews utilising the GP stroke registers and explore the possibility of the involvement of voluntary organisations such as the Stroke Association to increase review capacity.

Service specification

Review and update the Stroke Service specification (this was due for review in November 2012 not sure if this has happened) with a standard defined pathway agreed for Surrey with the involvement of all services providers and representation from patients and carers.

Information

Improve the availability of information (the website is an improvement if the content is good). Other health and social care information sources need to be reviewed and provided at the beginning of the pathway along with a care plan.

Care Support Workers

Increase the number/hours of Stroke Association Care Support workers in the localities.

Commissioning

Commission stroke services using guidance from the Royal College of Physicians concise guide containing specific recommendations included in the National clinical guideline for stroke, fourth edition, 2012.

Appendix A

Enter and View visit reports

Enter and View Visit to Crawley Hospital Stroke Unit

Name and address of unit visited

Crawley Hospital
West Green Drive
Crawley
RH11 7DH

Day, date and time of visit

Monday 29th October 2012 at 10.30am

People undertaking visits

Colin Slatter – Chair FPH LINk Group

Jane Shipp – Stroke Project

Details of service provider

NHS West Sussex – Julia Dutchman-Bailey

Type of service/unit

In-patient Stroke Rehabilitation - NHS Surrey has advised The Surrey LINk/Shadow Healthwatch that Crawley Hospital is one of the six providers that they commission a service from for Surrey residents.

Reason for the visit to the Stroke Unit

The Surrey LINk/Shadow Healthwatch Stroke Project for Surrey County Council Health Scrutiny Committee.

Pathway Information

Activity - April 2010 to March 2011 and April 2011 to March 2012, Surrey residents.

- The number of in patients who have received stroke rehabilitation.
- How many over 65 years?
- How many under 65 years?
- Where patients are referred from and the numbers
- Where patients are referred onto and the numbers
- Number of beds?
- Average length of stay?
- % bed occupancy

Information requested none received.

First Impressions of premises

Parking was limited.

Reception was welcoming, staff were aware that a visit was to be made and had instructions of who to call. Good sign in, identity and authorisation processes. Met by Nicky Dowdswell the Admissions/Discharge Sister as the Matron was on annual leave.

Visiting times are 2- 4.30pm and 6.30 – 8pm

The Unit

Access to the unit on the 1st floor is by stairs and lift.

Ward has a conservatory and day room, there were no patients in these areas upon arrival. In this area there was a comprehensive range of patient and carer stroke information available.

There are 18 beds that are used flexibly, three 5 bedded bays and three side rooms, the side rooms do not have ensuite facilities.

The ward has its own OT kitchen and Physio gym.

There was suitable space and sufficient equipment including hoists. Boards at each bed indicated patient's therapy plan but did not have the name of the patient.

The Pathway

Surrey and Sussex patients are admitted to the ward from East Surrey Hospital. Patients below and above 65 years of age are admitted to the unit.

Therapy is available 5 days per week. There is a hairdresser and access to an interpreter.

There is no psychology service, it was funded short term and has now stopped.

There is an MDT meeting weekly and the aim is that within 2 weeks of admission the patients have their treatment goals agreed. Patients hold a copy of their care plan and they are up-dated weekly.

Patients are referred to a Stroke Association Stroke Support Worker from East Surrey Hospital.

Observations

There was one patient observed in the gym practising the stairs with a physiotherapist and another later.

By the time of leaving at noon there were many patients all sat at tables for lunch, others had the choice of remaining by their bed. There were red trays and red jugs on the food trolley.

Conversations with staff and patients

Female patient – awaiting discharge that day her stay had been a good one she had achieved her rehab goals and was to have lunch first and then go on transport. She told us she had had an OT home visit and was expecting a visit at home later that day from a carer to see if she was OK.

Female patient – was making slow progress she felt this was not because of the rehab but because she is elderly and "these things take time".

There is pressure to reduce length of stay but this expectation is difficult because many of the patients on the unit had complex needs and were older especially since the introduction of Early Supported Discharge for Stroke.

There is no neuro community service at the weekends and packages of care do not start at the weekend.

Continence is an issue when discharging patients, if not safe to toilet at night then a care home is the only option. Younger patients to have a rehab specific to them can go to a brain injury unit at Horsham but this would only be for the Sussex patients not Surrey patients.

Sussex PCT and Surrey PCT have different processes to follow, an example of this is Continuing Care, Sussex require a checklist only and respond quickly coming to see the patient whereas Surrey there is a 2 week wait, more paperwork and they don't come to see the patient.

Delayed discharge data does not show Surrey patients.

Action Points

What to address, by whom and by when

Item	Action	By whom	By when
No Psychology	Put service in place	Sussex PCT	1/4/13
No FOA Information supplied for Surrey residents	Make information available when a FoI request is received	Sussex PCT	ASAP
Be able to address patients with limited speech by name	If agreed with patient put their name on board by the bed	Sussex PCT	1/4/13

Enter and View Visit to New Epsom & Ewell Cottage Hospital (NEECH) Stroke Ward

Name and address of unit visited

NEECH
West Park, Horton Lane
Epsom, Surrey

Day, date and time of visit

Monday 29th October 2012 at 2pm

People undertaking visits

Colin Slatter – Chair FPH LINk Group

Jane Shipp – Stroke Project

Details of service provider

Central Surrey Health

Type of service/unit

In-patient Stroke Rehabilitation - NHS Surrey has advised The Surrey LINk/Shadow Healthwatch that NEECH is one of the six providers that they commission a service from for Surrey residents.

Reason for the visit to the Stroke Unit

The Surrey LINk/Shadow Healthwatch Stroke Project for Surrey County Council Health Scrutiny Committee.

Pathway Information

Activity - April 2011 to March 2012, Surrey residents.

- 23 patients received stroke rehabilitation, in a year
- 14 patients were over 65 years
- 9 patients were under 65 years
- 5 patients were admitted from Epsom hospital, 1 from East Surrey Hospital, 1 from Kingston Hospital and 2 from home
- 18 patients went home, 3 went to a nursing home, 1 to an acute hospital and 1 unrecorded
- The average length of stay was 47.3 days
- 100 % bed occupancy

Note – Central Surrey Health responded to the information request promptly and accurately

First Impressions of premises

Parking was good.

Ward reception was welcoming. Met by Mary Weller the Ward Sister.

Visiting times are all the time except meal times which are 12.30 – 13.30pm and 17.30 – 18.30pm.

Public transport for visitors could be difficult but as more houses are being built in the area more demand will be triggered for a bus service.

The Unit

The ward is on the ground floor.

There is a large dining / day room with a view, it is a lovely setting. There are 4 beds for stroke/neuro rehab, the overall bed capacity is 21 beds consisting of 3 six bedded bays and 3 single rooms. Only 15 of the 21 bed capacity is commissioned.

There is a quiet room and suitable space and sufficient equipment on the ward.

There is an OT kitchen, the physio gym is an excellent facility well equipped with In patient and outpatient activity.

The unit may have to move to Epsom Hospital because of subsidence.

Observations

On the day of the visit 19 beds were open as there were 4 beds closed at Molesey Hospital for flooring to be replaced.

The day room had tables set ready for patients to take meals together
There were several patients and therapists in the gym.

Conversations with staff and patients

Female stroke patient and her husband – she had had a home visit this week and with the OT she and her husband were making plans for her discharge with the adaptations needed. Rehab had been hard work and her speech was difficult still, S&LT would continue post discharge. She and her husband were having a good experience of rehab on the unit and praised it highly.

Male patient – had not had a stroke but was having neuro rehab for a long term condition he also reported that his rehab on the unit was excellent, the food was good too.

MDTs are not always attended by social services.

6 days per week therapy would be better.

There is a 1 year funded post for vocational rehab and return to work (funded by the network, whole system?).

Commissioning is still for historic pathway and this will be reviewed so that commissioning catches up with the integrated health and social care pathways that are being developed with a model for the whole of Surrey.

A positive aspect of a move to Epsom would be the location next to the stroke ward and co-location with the community team.

Action Points

What to address, by whom and by when

Item	Action	By whom	By when
Awaiting NHS Surrey and CCG decision to support move to Epsom Hospital due to subsidence	Ensure the good patient experience, especially the excellent gym is maintained when decision is made to move to another site. CSH have ensured there are contingency arrangements in place if condition of buildings worsens	Central Surrey Health	During 2013
Accessible Stroke patient/carer information	Currently under review to be made available in areas	Central Surrey Health	Completed, available in Poplars

Enter and View Visit to Milford Hospital Stroke Ward

Name and address of unit visited

Milford Hospital
Tuesley Lane
Milford
Surrey

Day, date and time of visit

Thursday 1st November 2012 at 10.30am

People undertaking visits

Margaret Jago – West LINk Group

Jane Shipp – Stroke Project

Details of service provider

Surrey Community Health

Type of service/unit

In-patient Stroke Rehabilitation - NHS Surrey has advised The Surrey LINk/Shadow Healthwatch that Milford Hospital is one of the six providers that they commission a service from for Surrey residents.

Reason for the visit to the Stroke Unit

The Surrey LINk/Shadow Healthwatch Stroke Project for Surrey County Council Health Scrutiny Committee.

Pathway Information

Activity - April 2011 to March 2012, Surrey residents.

- 32 patients received stroke rehabilitation, in a year
- 30 patients were over 65 years
- 2 patients were under 65 years
- All patients were admitted from RSCH
- 16 patients went home, 10 went to a nursing home, 2 to an acute hospital and 4 unrecorded
- The average length of stay is 47 days
- 13 % of total bed occupancy

First Impressions of premises

Parking was good. Public transport for visitors is difficult.

Met on Holly Ward by Angela Williamson the sister in charge who was very helpful.

The Unit

Holly Ward has 17 beds is on the ground floor with a dining room and a lovely view. There is a physio gym and OT kitchen.

The corridor in the ward had boxes etc requiring storage.

The Pathway

Surrey patients are admitted to the ward from RSCH. Patients are usually above 65 years. The minimum wait for a bed to become available is about a week.

There were 6 patients receiving stroke/neuro rehabilitation on the day of the visit, these were located amongst the rest of the patients on the ward, not as a unit, there can be up to 12 stroke patients.

There is an MDT meeting and a consultant ward round weekly.

Therapy is available 5 days per week.

There is psychology, aromatherapy and a hairdresser available.

Weekend medical cover is by GPs so transfers are avoided.

Rehab period offered is 42 days this may be longer or shorter.

Clinics to provide a 6 weeks follow up review have just started to be available at Milford.

STED team (early supported discharge for stroke patients) located at Milford Hospital. Team staffed with part time S&LT, 1.5 WTE OT, part time Physio, 1 Nurse, 3 rehab assistants and admin. At the time of the visit there was a nurse and physio vacancy. Service is provided 8-5 Mon - Fri with some visits at weekends, the maximum caseload for the service is 20 patients. The service is available for a maximum of 12 weeks and patients are then referred to social care.

STED do the 6 month post stroke review of patients who are theirs, the rest are dealt with by the Stroke Coordinator.

Patients are referred onto the Stroke Association Support Worker.

Observations

There were boards above the beds with the patient's therapy programme but no estimated date of discharges (EDD) completed.

Cedar Ward is closed.

The physio gym was busy with several therapists and patients.

Some patients having lunch together in the dining room at the end of the visit.

Conversations with staff and patients

Female patient – she was from Cranleigh, she was able to choose her food from a menu and enjoyed the food. She said her therapy was making her busy which she needs in order to get better as she had been very unwell. She needed to drink often because of her kidney condition and the water was sometimes out of reach.

Male patient – his rehab morning had been to get up and dressed and go to physio.

Care Managers are now co-located part-time to pick up social care referrals which is an improvement but still not really part of the team. A designated case manager would improve continuity – this is now in place.

Section 2 referrals have now stopped.

The OTs and physios work well together.

The gym is not big enough for 12 therapists and a room for the OTs to work with individuals and groups is needed that is quieter.

The Day Unit is not integrated with the rest of the unit and the gym was empty at the time of the visit – therapists to be made aware that this space can be used also.

Action Points

What to address, by whom and by when

Item	Action	By whom	By when
Review use of space available in Cedar Ward, as well as space available in the Day Unit	More space is required to provide rehab therapy for in patients there is need for an area quieter than the gym. Make the 6-bedded bay in Cedar Ward available for OT rather than storage. Therapists to be made aware that Day Unit space can be used also.	Virgin Care*	1/5/13
Tidy Holly Ward corridor	Remove and store boxes regularly	Virgin Care*	1/4/13
Estimated Date of discharge (EDDs)	To be filled in on boards by patient's beds.	Virgin Care*	1/4/13

* Virgin Care has taken management responsibility for the services provided by Surrey Community Health.

Enter and View Visit to Godwin Unit, Haslemere Hospital

Name and address of unit visited

Haslemere Hospital
Surrey

Day, date and time of visit

Thursday 1st November 2012 at 2pm

People undertaking visits

Margaret Jago – West LINk Group
Peter Hughes – ASPH LINk Group
Jane Shipp – Stroke Project

Details of service provider

Surrey Community Health

Type of service/unit

In-patient Stroke Rehabilitation - NHS Surrey has advised The Surrey LINk/Shadow Healthwatch that Haslemere Hospital is one of the six providers that they commission a service from for Surrey residents.

Reason for the visit to the Stroke Unit

The Surrey LINk/Shadow Healthwatch Stroke Project for Surrey County Council Health Scrutiny Committee.

Pathway Information

Activity - April 2011 to March 2012, Surrey residents.

- 10 patients received stroke rehabilitation, in a year
- 7 patients were over 65 years
- 3 patients were under 65 years
- All patients were admitted from RSCH and FPH
- 5 patients went home, 2 went to a nursing home, 1 to an acute hospital and 2 unrecorded
- The average length of stay is 36 days
- 7% of bed capacity bed is for stroke patients

First Impressions of premises

Parking was limited.

Parking was reduced due to roofing works.

Reception was welcoming with good sign in, identity and authorisation processes.

Visiting Times 2- 4.30pm and 6.30 – 8pm

We met Chris Papworth, Matron.

The Unit

The Godwin Unit has 10 beds and is split between the male and female wards which are on the ground floor with access to a garden.

Physio gym, OT Dept. There were 6 neuro/stroke patients on the day of the visit. Patient and carer stroke information was available.

There is suitable space and equipment. Boards by each of the beds indicate the patient's therapy plan with estimated dates of discharge (EDDs).

The Pathway

Patients come from Hants and W Sussex as well as Surrey.

Surrey patients are admitted to the ward from RSCH. Patients are above 65 years and below 65 years.

There was 1 male bed available on the day of the visit.

Rehab is offered for 42 days, therapy is available 5 days per week.

A psychologist and psychology student are available.

MDT meetings are weekly with a Care Manager present.

There has been no Consultant for the neuro rehab patients for over a year. All the patients are looked after by the Haslemere GPs.

The unit admits patients 7 days per week but cannot discharge at the weekends in the same way.

Observations

There were several patients and therapists in the gym during the visit

Conversations with staff and patients

Female patient – not a stroke patient, had come from St Georges Hospital described her rehab programme and the improvement she had made because of the expert therapy, she was looking forward to discharge but had encountered problems with wheelchair provision because of a Surrey/Hants border issue, provided by Hants but they would not deliver as her address was Surrey. Group exercise classes were especially good and she had done visualisation and relaxation. Had to rush off to OT.

Male patient - not a stroke patient, he praised the clinical expertise of the therapists in treating his long-term condition. Together in a unit with the other neuro rehab males had been beneficial as they compared notes and encouraged one another. He said the food was good and enough too as doing rehab increases appetite he did not approve of powdered potato.

Male patient – not a stroke patient, he praised both the rehab for his long term condition and the food and being able to sit together at mealtimes.

The experience is good for patients at the unit they expressed sorrow that it was to be moved.

Social Services have begun to return to being based at Haslemere so there will be practitioners in place.

There are some nursing vacancies with staff deciding where they might work when the unit closes and moves to Woking Hospital.

The bed number was 16 but there have been up to 24 in the past.

Action Points

What to address, by whom and by when

Item	Action	By whom	By when
Unit move to Woking Hospital	Maintain good patient experience and staff neuro expertise	Virgin Care*	2013?

* Virgin Care has taken management responsibility for the services provided by Surrey Community Health.

Enter and View Visit to the Bradley Unit Woking Hospital

Name and address of unit visited

Bradley Unit
Woking Hospital
Surrey

Day, date and time of visit

Monday 5th November 2012 at 11am

People undertaking visits

Gareth Jones – West Surrey LINk
Margaret Jago - West Surrey LINk
Jane Shipp – Stroke Project

Details of service provider

Surrey Community Health – to be branded Virgin Care from 10th December 2012.

Type of service/unit

In-patient Stroke Rehabilitation - NHS Surrey has advised The Surrey LINk/Shadow Healthwatch that the Bradley Unit is one of the six providers that they commission a service from for Surrey residents.

Reason for the visit to the Stroke Unit

The Surrey LINk/Shadow Healthwatch Stroke Project for Surrey County Council Health Scrutiny Committee.

Pathway Information

Activity - April 2011 to March 2012, Surrey residents.

- 66 patients received stroke rehabilitation, in a year
- 32 patients were over 65 years
- 34 patients were under 65 years
- patients were admitted from ASPH, RSCH
- 48 patients went home, 11 went to a nursing home, 6 to an acute hospital and 1 unrecorded
- The average length of stay was 47 days
- 17% of total number of beds are for stroke
- % bed occupancy not supplied

First Impressions of premises

Parking was good. Public transport good, railway station and buses.

Reception was welcoming with good sign in, identity and authorisation processes. There was an information board with carer's information and "recommend to a relative or friend" questionnaires available.

Met by Annie Christie the Matron.

The Unit

The ward is on the first ground floor it is secure, security is required for the more cognitively impaired patients.

There are 12 beds, 4 double rooms and the rest are single there are ceiling hoists in all the rooms.

Co-located there is a quiet room with computers, a physio gym and OT kitchen, a group day room and a new wet room.

The clocks in the unit were excellent for orientation, with date and time and very visible.

The Pathway

Surrey patients are admitted to the unit from ASPH, RSCH and FPH hospitals both under and over 65 years of age.

There is a waiting list.

Admissions are planned and at the time of the visit there were 5 patients on

the waiting list for admission, each patient is assessed for suitability before admission and there is a detailed referral form.

There is an MDT meeting weekly with social services present, there is a care manager linked to the unit from the two at the Woking Hospital site. The aim is that within 2 weeks of admission the patients have their treatment goals agreed. Patients hold a copy of their care plan updated weekly, to update more frequently is difficult. Patients have a key worker who is a therapist. EDDs are patient specific.

Therapy is available 5 days per week. The unit is Consultant-led.

Psychology is available and a Disability Councillor.

The rehab period target is 42 days it may be longer or shorter.

The community rehab team is co-located at Woking Hospital providing 6 weeks rehab at home post discharge gives continuity.

There is a patient information meeting to which carers are invited.

A carers support group is available half an hour before visiting time at 2.30pm. Families are encouraged to be around the unit.

There is vocational therapy for return to employment.

The pathway is due to change when the Godwin Unit is closed and all patients will go to the Bradley Unit instead.

Observations

At lunchtime the patients were sat together at a table in the dining room for Lunch.

Wheelchair users were able to move around the unit independently.

There was a comprehensive range of patient and carer stroke information available.

Conversations with patients and staff

Male patient – his experience of rehab in the unit was very good especially the therapy programme and the food.

The unit is fully staffed, a recruitment drive was held to fill nursing vacancies, morning shift has 4 nurses 1 trained and 3 untrained, there are 2 nurses at night.

It is not clear yet if nurses will move from the Godwin Unit.

The unit would be capable of admitting a mother for rehab, with baby and for husband to stay.

LINk had been informed that the unit did not admit smokers but this is not true, smoking cessation is encouraged during admission.

The move to Victoria Ward to accommodate more patients when the Godwin Unit closes will require such things as security and ceiling hoists to be put in place. There will be 20 beds.

The Bradley Unit name is to remain so all the patient information does not have to be changed.

Action Points

What to address, by whom and by when

Item	Action	By whom	By when
Project to change service to accommodate Godwin Unit patients	Ensure rehab service is replicated to same standard with involvement of users and carers in the project	Virgin Care*	During 2113

* Virgin Care has taken management responsibility for the services provided by Surrey Community Health.

NOTE: On 7th December 2012 the Godwin Unit moved from Haslemere Hospital to the Bradley Unit at Woking Hospital.

The action now will be to carry out an Enter & View visit to the larger Bradley Unit.

Enter and View Visit to the Stroke Ward Farnham Hospital

Name and address of unit visited

Farnham Hospital
Farnham
Surrey

Day, date and time of visit

Thursday 8th November 2012 at 2pm

People undertaking visits

Gareth Jones – West Surrey LINk
Peter Hughes - ASPH LINk
Jane Shipp – Stroke Project

Details of service provider

Surrey Community Health

Type of service/unit

In-patient Stroke Rehabilitation - NHS Surrey has advised The Surrey LINk/Shadow Healthwatch that Farnham Hospital is one of the six providers that they commission a service from for Surrey residents.

Reason for the visit to the Stroke Unit

The Surrey LINk/Shadow Healthwatch Stroke Project for Surrey County Council Health Scrutiny Committee.

Pathway Information

Activity - April 2011 to March 2012, Surrey residents.

- 49 patients received stroke rehabilitation, in a year
- 25 patients were over 65 years
- 24 patients were under 65 years
- patients were admitted from FPH and RSCH
- 36 patients went home, 8 went to a nursing home, 4 to an acute hospital and 1 unrecorded
- The average length of stay is 35 days
- 11% of bed capacity is for stroke patients

First Impressions of premises

Parking was good, a modern building.
Reception was welcoming and efficient, good sign in, identity and authorisation processes.
Visiting times 2pm – 4.30pm and 6.30pm – 8pm
Runfold ward was well signposted on the 1st floor.
We met Daphne Denhayi the ward sister, Amanda Edwards and Ruth Whiting.

The Unit

The stroke unit is on Runfold Ward, all single rooms.
There are 6-10 beds available for stroke patients, there were 10 on the unit when we visited.
There is a sitting room with a phone for patients to use it is shared with S&LT.
The OT kitchen and a second physio gym are located on another floor where there is a garden.
There is space and sufficient equipment.

Observations

The therapy gym was well used with several therapists and patients
There was one patient using the sitting room.

Conversations with staff and patients

Female patient – she had a stroke post cardiac care at FPH, was just starting rehab and felt she was doing well and that the rehab she was experiencing was good she had a rehab timetable and was to have an OT home visit soon.

Breakfast club and coffee morning are held in the sitting room; it is important for patients to come together as they are in single rooms.

At discharge better organisation between Hants and Surrey Social Services would smooth the pathway if Surrey could act as co-ordinator for Hants who are not present in the hospital.

There is much confusion about how many beds are commissioned at Farnham, by whom and what they are designated for.

Not all the beds are commissioned.

Action Points

What to address, by whom and by when

Item	Action	By whom	By when
What beds are commissioned and for what	Review and provide clarity	Virgin Care*	1/4/2013
Social services coordination	Agree a process whereby Surrey can coordinate for Hants	Surrey and Hants social services	1/4/2013
Estimated Date of discharge (EDDs)	To be filled in on boards by patient's beds.	Virgin Care*	1/4/13

* Virgin Care has taken management responsibility for the services provided by Surrey Community Health.

Appendix B

Patient and carer experience stories

Patient Experience Story – Stroke Pathway Project

Male under 65 years. Stroke in July 2012

1 How smooth the discharge from hospital was

He was in East Surrey hospital for 2 weeks. Discharged at 7pm in the evening and because the wait for drugs from Pharmacy was so long he had to return to the hospital the next day to collect them and this required him to catch 2 buses which was very difficult.

2 The provision of specialist rehabilitation

This was provided in the hospital by therapists, physiotherapy and OT. The kitchen where he made a cup of tea was the staff room and it was not clean and tidy, a poor facility for assessment.

A physiotherapist was due to visit him at home (from Oxsted) but this did not happen.

Available 5 days per week.

3 Help for family members and carers

Lives alone.

4 Care of individual needs

Return to work most important to resolve, has financial problems with mortgage payments. He has been to Access for Work advocacy help at the council and the Job Centre and is on statutory sick pay only.

5 Help to return to family life and leisure

From the Stroke Association Support Worker East Surrey

6 Reviews weeks/months after stroke

No review at 6 weeks. 6 months review would be due in Jan 2013

7 Information given

None, promised but not received from E Surrey and CAB.

8 Choices given

No choice has to return to work due to financial issues cannot live on £81 per week.

None, feels that nothing is getting done for return to work.

Patient Experience Story – Stroke Pathway Project

Male under 65 years. Second stroke in 2012

1 How smooth the discharge from hospital was

Two admissions to two different hospitals

In East Surrey hospital, Chaldon Ward is a much better stroke ward than the previous one, an improvement, discharged to Crawley Hospital.

St Peter's Hospital was good, discharged to Bradley Unit, Woking.

2 The provision of specialist rehabilitation

1st stroke, rehab at Woking, Bradley Unit, excellent all rehab should be like this, especially for the younger stroke victims.

2nd stroke, rehab at Crawley Hospital. It was too big and with too many ages, old as well as young. Not enough staff often patients had to wait a long time for bell to be answered.

Available 5 days per week.

3 Help for family members and carers

Care for 6 weeks was not enough, then there is nothing or you pay for it.

4 Care of individual needs

He has employed his own personal trainer at the Redhill stroke gym.

Has speech problems as was not told about DISCOVERY found out later.

5 Help to return to family life and leisure

He was able to return to work after 1st stroke for 3 days per week then became sick again. Has been to the CAB but needs an advocate to help with work issues and his rights as they are trying to get rid of him.

6 Reviews weeks/months after stroke

6 week review when carers stopped.

7 Information given

From the Stroke Association Support Worker.

About the YMCA in Redhill has a stroke gym and Pilates.

8 Choices given

None and there is no join up of what provided.

Patient Experience Story – Stroke Pathway Project

Male over 65 years. Stroke in Sept 2010 and July 2012

1 How smooth the discharge from hospital was

From East Surrey Hospital to Crawley Hospital and then home was good.

2 The provision of specialist rehabilitation

Physiotherapy at home and then this stopped at 6 weeks, still has poor balance and uses a stick.

The Stroke Association Support Worker visited at home.

Provided 5 days per week

3 Help for family members and carers

Lives with wife, no help offered.

4 Care of individual needs

Once you are out of hospital you are on your own.

GP has been useless.

Worries about another stroke.

5 Help to return to family life and leisure

He has been depressed. The Stroke Group (organised by the Stroke Association Support Worker) are the only ones who understand.

6 Reviews weeks/months after stroke

6 weeks attended outpatients clinic at the hospital and had to wait 2 hours.

7 Information given

At the outpatient appointment they promised to send literature but this never arrived.

8 Choices given

None. Strokes are life changing; there is a big adjustment to make.

Patient Experience Story – Stroke Pathway Project

Male under 65 years. Stroke in August 2012

1 How smooth the discharge from hospital was

Was blue lighted from East Surrey Hospital to St Peters Hospital because there were no ITU beds and then transferred back to East Surrey. Was on Chaldon Ward for 3 weeks.

Fell at home on the first day home, carers came next day after discharge but they were not needed as he has a wife and they had coped alone on the first day.

2 The provision of specialist rehabilitation

Physiotherapy at home was good but this stopped at 6 weeks, he still needs another stick and a wheelchair for long distances.

Achieved his goal of being able to do the stairs

Available 5 days per week

3 Help for family members and carers

Help to fill in forms, for example benefits. He is on incapacity benefit at the moment.

4 Care of individual needs

He wants to be able to drive.

Purchased a urine bottle for himself, it was promised but didn't happen

5 Help to return to family life and leisure

Would like a wheelchair to go out with the family further distances

6 Reviews weeks/months after stroke

6 weeks review then rehab at home stopped

7 Information given

Physiotherapist supplied information on the Stroke Association Support Worker

8 Choices given

No choice about having carers at home when they managed without, what was really needed was more rehab at home.

Patient Experience Story – Stroke Pathway Project

Female under 65 years. Stroke caused by heart condition

1 How smooth the discharge from hospital was

No problems whatsoever, all good.

Was at the Royal Surrey County Hospital – Stroke Ward, had stroke consultant and cardiologist support.

Physiotherapy and psychology sessions offered.

Excellent provision.

2 The provision of specialist rehabilitation

Excellent. Home stroke team (Stroke Early Supported Discharge) available constantly, the service offered was excellent.

Rehabilitation offered and sessions taken, all excellent.

Available 5 days per week

3 Help for family members and carers

Other help offered and appreciated but not needed as Stroke Early Supported Discharge Team helping. Had Surrey Help in Home, walking children to school, getting running and (exercise) again.

4 Care of individual needs

Good. Offered help in home and with personal hygiene.

5 Help to return to family life and leisure

Good, although not needed.

6 Reviews weeks/months after stroke

6 weeks review main question remaining is why the stroke happened. No answers as yet, understandably.

7 Information given

Personal experience is the mental side of my stroke – affected me mentally more than physically. Psychology offered.

8 Choices given

Yes, given as many choices for situation.

Patient Experience Story – Stroke Pathway Project

Male under 65 years. Stroke in October 2011

1 How smooth the discharge from hospital was

He was admitted to FPH, stayed for 10 days making good progress. Discharged to Farnham hospital all went well.

2 The provision of specialist rehabilitation

At Farnham he had physiotherapy and speech therapy. Currently attends as an outpatient three times a week, making good progress speech now normal.

OT home visit equipment and adaptations done.

Available 5 days per week

3 Help for family members and carers

None required

4 Care of individual needs

Attends Woking Strokeability, gym and hydrotherapy weekly

Has had private physiotherapy

5 Help to return to family life and leisure

Driving, assessed at Queen Elizabeth Foundation (QEF). Not eligible for a Blue Badge which is a major problem as he needs to open the car door fully to get out. He requires a wheelchair for long distances.

6 Reviews weeks/months after stroke

At Farnham Hospital when he attends as an outpatient.

7 Information given

Feels that in hospital he should have been given details of voluntary or other organisations in the area, there should be a list. Recommended ARNI a private charity for stroke.

8 Choices given

Was able to make choices himself as he is “well off”.

Patient Experience Story - Stroke Pathway Project

Male over 65 years. Stroke March 2012

1 How smooth the discharge from hospital was

East Surrey Hospital, perception of staff at hospital was that NHS care is 'free so what do you expect'. Had to fight to get therapy as often as they did, he received therapy everyday whilst at hospital and this was very disciplined.

First time he has accessed NHS and the stroke was very sudden and unexpected.

Patient was told discharge had been arranged 2 weeks prior to discharge date.

The patient had been fitted with peg for feeding & medication administration as swallowing difficult. When he arrived home food had not been organised, no key safe installed, and discharge was very disorganised.

MDT team meeting was held with all involved soon after discharge, community team quickly resolved these issues and therapy started.

No discharge letter given whilst at hospital, the patient was told it had been sent to his GP and to request copy from his GP. The patient had to phone the GP to get a copy.

2 The provision of specialist rehabilitation

Physiotherapy, OT & SALT was provided for 12 weeks 5 days a week, this then stopped with no on-going therapy provided and no Dietician oversight.

Available 5 days per week

3 Help for family members and carers

Wife has suffered a stroke and now in hospital, she has had a history of TIA since 2009, aspirin was prescribed.

She was due to be discharged from hospital to a care home on 29/11/12, choices have been given of care homes and the husband is due to visit to review choices.

The Stroke Association have been excellent in providing support, not aware of any other support being provided.

4 Care of individual needs

A Care support worker is still providing help 2 times a day but service is poor, they can turn up at any time and he has to get up early in morning in anticipation of their arrival. They are very quick and are in and out in few minutes, they blend the food and state they have fed the patient but he feeds himself and administers medication. There is no provision of household support, housework, laundry etc

Issues have been raised with carers manager but no action taken.

Stroke Association have given lots of help and support to organise benefits and disability badge etc.

5 Help to return to family life and leisure

No transport provision for community access, friend drives him on Mondays to stroke club. No access to community or help with transport to hospital appointments.

Patient takes taxi to hospital to visit wife.

6 Reviews weeks/months after stroke

None.

7 Information given

None.

8 Choices given

None.

Any other notes or comments

GP is very difficult to book appointments with and can take weeks, also problems with blood test machine patient has to get taxi (£30 return) to GP surgery to have test with machine and papers.

Patient Experience Story – Stroke Pathway Project

Male 65 years. Stroke in January 2011

As told by carer

1 How smooth the discharge from hospital was

He was in FPH, stayed there for a month. Discharged to the Bradley Unit, Woking Hospital, his stroke was very severe.

2 The provision of specialist rehabilitation

Had 5 months rehabilitation at the Bradley Unit, physiotherapy and OT, Speech Therapy began but was stopped. OT did a home visit and environment made suitable for wheelchair and shower equipment loaned.

Available 5 days per week?

3 Help for family members and carers

Wife has Disability Allowance to help with car costs, she has Multiple Sclerosis

4 Care of individual needs

Also has a long term condition Multiple Sclerosis. Has had 10 days at Bagshot Park private rehabilitation centre at a cost of £2,300, to have physiotherapy at home is not safe.

5 Help to return to family life and leisure

Wheelchair provision has been a big problem. Loaned basic wheelchair is unsuitable it has poor back support and wife had to remove right hand propelling wheel to get through downstairs bedroom door. Wheelchair service in Guildford have taken over 4 months to provide an adequate wheelchair, it is due soon.

Transport is difficult as wife cannot transfer him into a car, neighbours do help. Dial a ride comes 3 times per week to take him to Disability Initiative in Camberley.

6 Reviews weeks/months after stroke

Has an appointment with the Psychologist at FPH.

7 Information given

Yes.

8 Choices given

Yes.

Patient Experience Story – Stroke Pathway Project
Female under 65 years Stroke in 2005

1 How smooth the discharge from hospital was

She was in RSCH for 2 weeks. 4 days in ITU. Really cannot remember very much has poor memory due to the stroke.

Her balance was very affected and has vertigo so when she was sent home her husband wheeled her out of the hospital in a wheelchair that he had borrowed .

2 The provision of specialist rehabilitation

None.

It was assumed that her husband would take care of her even though he had a full time job.

She needed care as she was tired, had poor memory and could hardly walk.

3 Help for family members and carers

Her husband did not have help, when he returned to work he would make the lunch before he left and then ring her to remind her to eat it, her memory was so bad she would forget otherwise.

4 Care of individual needs

Has had hearing tested as her right ear and hearing have been affected.

5 Help to return to family life and leisure

After 4 months off work she returned and could not cope. She requested early retirement but this was refused. Occupational Health said she should not drive so she had a taxi for a while and then 8 months later she was allowed to retire.

6 Reviews weeks/months after stroke

Has not had any review, her GP is not good.

7 Information given

Found Headway in Guildford herself in 2010.

Going to the drop in at Headway as it gets her out of the house.

8 Choices given

Does not think that she has had any choice.

Patient Experience Story – Stroke Pathway Project

Male under 65 years. Stroke in November 2011 and January 2012

1 How smooth the discharge from hospital was

He was discharged from FPH followed by an admission of 5/6 weeks to the Bradley Unit, Woking for rehabilitation, no problems mentioned.

2 The provision of specialist rehabilitation

Was at the Bradley Unit for 6 weeks, the experience was good.

Had a home visit with therapists prior to discharge.

The speech therapy he received was good.

Available 5 days per week.

3 Help for family members and carers

No, was he supposed to ask for this?

His partner visited him constantly when he was at the Bradley Unit.

4 Care of individual needs

Currently he has home visits from a physiotherapist and a District nurse.

Attends hospital to see a neuropsychologist.

5 Help to return to family life and leisure

Was at home for 24 hours every day when first discharged which he did not like, he has now progressed to driving himself to shop more or less daily, the car is essential as he can only walk 50 yds. Not clear if there was help with this and for example if there had been some advocacy to obtain a blue badge.

6 Reviews weeks/months after stroke

Not clear in the report.

7 Information given

May be too soon for information on employment, not clear what other information he might have received to date.

8 Choices given

Chose to be discharged home as soon as possible from rehabilitation.

Patient Experience Story – Stroke Pathway Project

Female over 65 years. Stroke in 2008

1 How smooth the discharge from hospital was

Was admitted to RSCH, the consultant said that I was fit to leave hospital. After that I had a very long wait. I went home in a taxi organised by a neighbour (I live alone). I was told that I would need to go back for a scan sometime of the carotid.

2 The provision of specialist rehabilitation

None. I was able to walk but was not told about exercises or care I needed to take.

3 Help for family members and carers

None, but it was really not needed.

4 Care of individual needs

None. I realise that I could have done with help at the time. I have reduced resilience, I tire easily and my balance is less good. No one has ever helped me with overcoming these problems. I suppose I simply accepted the fact that the differences were inevitable.

5 Help to return to family life and leisure

I had nothing extra, except a little bit of extra help with house work.

6 Reviews weeks/months after stroke

No review, my GP was not even informed that I had had a stroke. It came out in conversation when I went to see him about something else.

7 Information given

None.

8 Choices given

None were given. I guess they were not needed

Patient Experience Story – Stroke Pathway Project

Female over 65 years Stroke in 2009 and 2010

1 How smooth the discharge from hospital was

She had a TIA and was admitted to Frimley Park Hospital for 5 days and later returned for further checks for 4 weeks and had a stroke during that period. Another 3 weeks in hospital. In 2010 she had another stroke. The second stroke also left her with epilepsy. Had Physiotherapy\Occupational Therapy following her first stroke at Frimley Park Hospital but after her second stroke "they didn't want to know" and she "felt like a leper". Transferred to Farnham Hospital for rehab.

2 The provision of specialist rehabilitation

She went to Farnham for assessment though this focussed on her speech, which is fine, and not on mobility which was not good.

She did not want to stay in Farnham so went home.

Nothing special, the OT visited and made recommendations e.g. a stairlift which her husband installed.

Provided 5 days per week

3 Help for family members and carers

Her husband is retired and acts as carer.

Limited help there was a wide selection of stroke related leaflets in Frimley Park Hospital but it relied on relatives to sort them. Not much information was given by the physiotherapist. Husband was not aware of the need for him to register as a carer with his GP. He picked up from the Stroke Association information on the Surrey Heath Carers Association which has been very helpful they should have information in the hospital.

4 Care of individual needs

Her needs were like those of many stroke victims – lack of movement is particularly difficult and she cannot now read or cook.

5 Help to return to family life and leisure

This was mainly in terms of adaptation of the house (helped by having a husband experienced in building)

6 Reviews weeks/months after stroke

The last contact she had regarding her stroke was when she was copied a letter from FPH to the GP a year ago. She attends GP surgery to have dressing changed.

A six week review and a 6 month review? No

7 Information given

They found this; discussion on what services would be available to a single person (widow) in these circumstances, with no local family and how to find things.

This is a well educated family able to use services when they are aware of their existence.

8 Choices given

The only choice was whether to recuperate at Farnham or go home.

Patient Experience Story - Stroke Pathway Project

Male under 65 years. Stroke in 2009

1 How smooth the discharge from hospital was

Was admitted to East Surrey Hospital and had major stroke whilst kept overnight for observation. Was later told that I had had suffered 3 strokes in succession. Whilst in hospital both he and his wife were very confused and nobody was sharing information about the situation and felt very isolated. Once medically stable he was then transferred from East Surrey to Crawley for inpatient rehabilitation, still not given much information or sat down and the situation explained. “We were just told it was time to go and felt we just had to go along with it. We both felt very shocked and confused and nobody seemed to be giving us any information or explaining what would happen.”

2 The provision of specialist rehabilitation

At Crawley Hospital he had approximately 4 weeks intense inpatient rehabilitation. Then told going home and next day we found ourselves at home and told the Oxsted community team would call. No information given and again we felt very isolated and lost.

Received 12 weeks rehabilitation at home, physio, OT & SLT 5 days a week.

After 12 weeks I was then told that they had done everything they could for me and that it was now up to me. If I needed any equipment to continue my exercises they suggested we buy those online. I had the same physiotherapist but people would come and go all the time and always different people. I was not offered physiological support at this time.

3 Help for family members and carers

It seems if you need anything you have to be very demanding and persisted, no help offered we were alone. My wife has had to organise everything for me from a Blue Badge to carers.

We finally found SILC and they helped us organise a Carer for me, initially we had issues with SILC and with many different people dealing with our case until we were assigned a case worker. Then 2 full time carers were found who look after me from 9 - 5 Monday to Friday using self-directed payments. This had taken 12 months as my carer started on 1st Jan 2010. I had been having fits up to this point so it was important for us I have full time carer.

4 Care of individual needs

Felt I was abandoned and no information. No key worker was identified,

My wife had to return to work to support both of us and pay the mortgage, she also became my carer. We had no visit from Social services. My Wife had to arrange for a carer who then visited me 2 times a day for 30 mins to help shower me and feed me for the first year.

Group activities are most important for me and we need more organised group activities.

5 Help to return to family life and leisure

No help I have been totally reliant on my wife. I attend the stroke club once a month. Go to gym and go swimming / water aerobics that wife had arranged with carers.

6 Reviews weeks/months after stroke

No reviews received to date.

GP has recently referred me for psychological support, not NHS I believe private.

7 Information given

Information from the NHS providers was extremely poor / non-existent both whilst there and also at discharge. Wife went to CAB and also did not have much information just directed us to Stroke Association and gave us the number.

Information has been one of the biggest challenges.

8 Choices given

No choices ever given or discussed.

Patient Experience Story – Stroke Pathway Project
Female over 65 years Stroke in 2009 and 2010

1

Female under 65 years. Stroke in 2009.

How smooth the discharge from hospital was

Admitted to hospital whilst on holiday, returned to stay with brother, once home went to see GP, had Scan taken at a London hospital.

2

The provision of specialist rehabilitation

Community team provided some Physio, OT & S&LT whilst at sisters but only for short time, she cannot remember exactly but for few months.

She feels she has memory problems but never been assessed, feel if had assessment 3 years ago this would have helped. 3 years ago I was not interested in physio, now I have been coming to the stroke club and am paying for the great physio here. Once a week I see him and I have seen progress. I had a knee operation recently and am receiving physio 2 days a week from the community team for that and it is great.

Her brother now pays for a private physio few times a week has helped to get her outside walking and building up confidence.

Would be great to get to be able to cook simple things myself and not be dependant.

Is great news about the new gym at the Walton Stroke club and she is very motivated to make progress.

3

Help for family members and carers

I had no help initially and had to rely on sisters and brother. She lived with sister for 2 years in Walton; she works so was difficult for both of them.

No intervention initially by social services has since had to fight for long time for assisted housing and care.

4

Care of individual needs

I was not and am not aware of what is available or what I am entitled to. Her sister cared for her for 2 years, had no carers until last year. Have fought for long time but she is now in assisted housing in Hersham (3 Wardens), has 2 carers a day who visit to help.

5 Help to return to family life and leisure

None except I have community transport to bring me to the stroke club once a week.

6 Reviews weeks/months after stroke

Had no reviews for 3 years until recently and the community team visited and carried out an assessment.

7 Information given

None apart from sharing information at stroke club.

8 Choices given

None.

Patient Experience Story - Stroke Pathway Project

Female under 65 years. Stroke in July 2012

1 How smooth the discharge from hospital was

Admitted to East Surrey Hospital was feeling sick and dizzy, and had seen GP few days before, she spoke to NHS Direct as symptoms had got worse. They called 999 and ambulance arrived, arrived at A&E and also did not know what the issue was. The hospital then recommended a CT scan that day and found a small bleed and thought the cause was a clot which had disappeared; she had become worse by this stage with paralysis of left side. Could not walk, talk or move arm. She was admitted onto Stroke Ward for 3 weeks receiving rehabilitation, Physio, OT & S&LT. Sister came up from Devon met her at hospital and stayed a few weeks after discharge with her. At discharge she was walking assisted and speech coming back, her son had come over from Spain to stay for 2 months. No care plan or provision was made within the community, no visit by Social services. Bungalow did have rails at front door and in bathroom as fitted for late husband who had recently died of cancer.

2 The provision of specialist rehabilitation

No Inpatient rehabilitation was deemed necessary by the hospital team.

Oxted community team phoned and after explaining that she continued to do her exercises and how her son had been caring for her, they confirmed her son was doing everything correctly and there was no more the community team could do. At this point she feels that due to no ongoing physiotherapy she may not have progressed as far as potentially she might.

3 Help for family members and carers

Only help received is from Stroke Association representative who called and gave lots of information, was the only help available post discharge.

4 Care of individual needs

Hospital care was very good but no other care provision or discussion regarding needs. No Social Services call or assessment.

5 Help to return to family life and leisure

Help from the Stroke Association and connection with Stroke club, this has been a life line. Family not close by but friends have helped and drive her to places she needs to be.

6 Reviews weeks/months after stroke

She had 3 month review at East Surrey Hospital and recently had a 6 month review with a Stroke Nurse. She has written to her GP asking for a community team referral for Physiotherapy and felt as she is still young she would benefit from some level of Physiotherapy. Forgets things and has not received any cognitive or memory assessment.

7 Information given

Only information given by the hospital was a discharge letter that stated she needed to see GP for further blood tests for high cholesterol & follow up liver function tests as results were not clear.

Has no idea long term prognosis and kept being told it was just early days and found this very frustrating. No information given other than Stroke Association. Patient felt that without them they would not have been able to cope, the Stroke Support Worker was excellent and spent a lot of time explaining how to get help. Disabled parking badge etc.

8 Choices given

No choices and no community support given so no choices.

Patient Experience Story - Stroke Pathway Project
Female under 65 years. Stroke April 2008

1 How smooth the discharge from hospital was

I had a severe headache at work and a fit, an ambulance was called and I was taken to East Surrey Hospital A&E I believe I was put to sleep for several days.

When I awoke I was not aware of what had happened and nobody explained to me that I had suffered a stroke, although I knew my left side was not working properly. I was moved from one ward to another over a period of 4 weeks at East Surrey Hospital. I did not receive any therapy although I was assessed at some point at my bed on the ward. Then suddenly one day I was taken on a trolley by ambulance and transferred to Crawley Hospital, nobody had discussed this with me prior to being moved.

2 The provision of specialist rehabilitation

The staff at Crawley were wonderful, Physios, OT & S&LT and progress was great. I was there for 4-5 weeks but after 4 weeks I caught MRSA and was on a drip for a week or so and was not able to have any therapy. I remained in a bay of 6 beds but when I had visitors they had to wear yellow aprons. I was on anti-epileptic medication but still suffering some fits. I had an OT who arranged my discharge and visited me on my day of discharge. They arranged for equipment, a commode, wheelchair, walking Stick, hand rails, bath board and for the council to fit the rails. Unfortunately I had a fit later that day and was admitted back to East Surrey Hospital. I was put on new medication and have not had a fit for 3 years.

For 4 weeks I had the same Physio from the Oxsted community team once a week, and for another 2 weeks an assistant Physio came. I was then transferred to the Crawley team for a few weeks until finally being transferred to Caterham Dean Team to receive Physiotherapy for 4 weeks. I was told after this that they had done all they could for me and I should go to Stafford School and ask for Jackie to get more Physio at £3.50 per session. I continue to go there and having Physio still helps and I see progress, just a slower improvement now, swimming is also available here.

I have had no Psychological support or therapy.

Access to community is biggest issue and it would be great to have group Physio sessions for example.

3 Help for family members and carers

No help was provided for my family; my sister in law does washing and I rely on brothers and family to support me.

4 Care of individual needs

The council visited me last year to do an assessment but said I was not eligible for any help. I just get DLA and incapacity benefit.

5 Help to return to family life and leisure

Only help I get is from my family, brothers and sister. Have to do everything for myself, I have made friends at the stoke club arranged by the Stroke Association and we help each other.

6 Reviews weeks/months after stroke

No reviews over past 4/5 years.

7 Information given

The family picked up leaflets from Crawley Hospital and most information and help came from the Stroke Association and other people I have met at stroke club.

I volunteer at East Surrey Hospital and we have a new communication point which I host with the Stroke Association.

8 Choices given

No Choices given and most of the time no information.

Patient and Carer Experience Story – Stroke Pathway Project

Male over 65 years and female carer over 65 years. Stroke in September 2012.

1 How smooth the discharge from hospital was

First TIA in 2009, admitted to ASPH, had scan and then confirmed stroke but told it was too late for thrombolysis. Was on Cedar Ward, this was very good and staff very helpful & supportive; he received Physio, OT & S&LT. He was then discharged to Ashford Hospital for further stroke rehabilitation.

2 The provision of specialist rehabilitation

At Ashford Hospital for a number of weeks, unable to recall how many, discharged home and received call from community team. No intervention by Social Services.

Was recommended White Lodge and given lots of information from them. Paid for and received Physio & S&LT for 12 weeks twice a week at home and went out for walks with Physio and this started to give him confidence. Has continued S&LT by paying for it from White Lodge but he is now 3rd on the list for S&LT from the community. Physically now OK just S&LT & memory are the main concerns and that no psychological support has been received.

3 Help for family members and carers

None, friends help to drive them to stroke club and shopping. Can only use buses, has bus pass, only gets to the stroke club with the help of friends.

4 Care of individual needs

No immediate care needs but with no psychological support for either him or his carer she felt she needed help to come to terms with what had happened.

5 Help to return to family life and leisure

None. Carer, when alone was trying to put on a brave face worried about ability to cope and the need for psychological support.

6 Reviews weeks/months after stroke

Had review after 3 weeks with GP, no other reviews so far.

7 Information given

Only information given was by the White Lodge.

8 Choices given

No Choices.

Carer Experience Story – Stroke Pathway Project

Wife. Carer for 5 years

1 How smooth the discharge from hospital was

East Surrey Hospital acute stroke ward was horrid experience, received some therapy.

Could not wait to get him home

Had to co-ordinate everything themselves, if you shouted and made a fuss you got some level of care provision.

2 The provision of specialist rehabilitation

Had to fight for rehab but once received progress was great.

Few times a week rehab provided but husband wanted more, not able to be offered at the time.

Has seen some improvement in last 5 years in the provision of services.

Available 5 days per week.

3 Help for family members and carers

No help at the time was 5 years ago though.

4 Care of individual needs

None.

5 Help to return to family life and leisure

None.

6 Reviews weeks/months after stroke

None.

7 Information given

Have picked up information and contacts over the years, had to seek it.

8 Choices given

None.

Carer Experience Story – Stroke Pathway Project

Wife. Carer for 2 years

1 How smooth the discharge from hospital was

Discharge from ASPH was smooth after 3 months there. She had to request speech therapy for his aphasia. The OT and District Nurse visited and recommended a special bed.

2 The provision of specialist rehabilitation

She had him admitted, with difficulty, to Woking, having been informed that it was full (it wasn't). He was in Woking for 16 weeks; following the inpatient stay she took him in for breakfast each day and collected him in the evening. This period was prolonged, he was able to help around the ward and this contributed to husband's recovery.

They both spoke highly of treatment at Woking. Speech therapy was good.

Available 5 days per week.

3 Help for family members and carers

Social services did visit but, once it was discovered that savings were available, no help was forthcoming.

No particular help was provided (other than the bed) but it was difficult to see what could be provided other than help with aphasia – the role of the speech therapist. No modifications to the bungalow were needed.

The GP does not appear to have been very helpful.

4 Care of individual needs

These relate mainly to aphasia, for speech therapy at home there was a 3 month wait and the quality was not as good.

5 Help to return to family life and leisure

This was via his daily attendance at Woking.

6 Reviews weeks/months after stroke

Has had a review with consultant.

7 Information given

She felt that there was a substantial lack of information on facilities available. The Stroke Association was helpful but most avenues were found by her. These included Woking Strokeabilty, Headway (charity in Guildford at £75 a day), Dyscover and Talk charities. Apart from S&LT treatment the main worry was the lack

of easily available information on sources of help – specialist in this case. There was some material on noticeboards in Woking Hospital but no tailored "pack" to be given out on discharge. Much then depends on the enthusiasm and persistence of the carer, preferably one who is prepared to "pester"

8 Choices given

None

Carer Experience Story – Stroke Pathway Project

Male under 65 years. Occurred in 1999

1 How smooth the discharge from hospital was

Admitted to Royal Surrey and then onto the Bradley Unit, whilst at Royal Surrey it was very difficult as there were a number of consultants & Dr's involved in my husband's care but it seemed at the time that no one person had accountability or took a lead role, I was speaking to many people in relation to my husband's care.

At discharge no care plan was discussed, I was just told he would be going to the Bradley Unit.

2 The provision of specialist rehabilitation

The Bradley Unit was much better for my husband than hospital and treatment was very good. I had some issues though; one example was that on one particular day I had been informed by the unit that my husband was due to go back to the Royal Surrey Hospital for some tests the following day. I took this opportunity to take my daughter out for some quality time together and we spent the day together. I returned later that day and was surprised to find my husband had not been to the Royal Surrey, it seemed I had been expected to take him and so he had not gone.

On discharge from the Bradley unit we received a home visit to ensure equipment was in place to help us.

There was no provision of therapy after this point but after some months physically my husband was independent. Although cognitively he is still has issues now and is dependent on me.

3 Help for family members and carers

There was no help provided for myself of family, we found Headway several years later and they helped to persuade social services to visit and they carried out an assessment. This proved to be of no value to us and did not meet our needs, the social worker was quite rude and made me feel like a I had failed.

In the early years I suffered from depression and have since developed coping strategies, but some days are easier than others.

My children were also affected at the time and the situation was very hard on the whole family.

4 Care of individual needs

My husband has cognitive issues and although, to many, seems now very capable this is something I still struggle with and get no support with.

I still feel I need support dealing with this and that my husband needs some kind of on-going assessment / help with this.

5. Help to return to family life and leisure

We received no help, only from family and friends. I was not in a position early on to fight or challenge decisions being made and was very much in shock myself. This had a dramatic effect on our whole family as well as myself and husband.

6. Reviews weeks/months after stroke

No reviews since the home visit and initial social services assessment.

7. Information given

We were given no information and only many years later came across Headway who have been very helpful.

The CAB also have been helpful and helped us apply for DLA, we were not made aware we were entitled to it at the time.

I have only become aware of things more recently and would like to know if I can get help for my husband's cognitive challenges and assessment.

8. Choices given

No choices given

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