

# YOUR STROKE, YOUR FUTURE, YOUR LIFE Feedback Event

Wednesday 28<sup>th</sup> September 2011

9.30am – 1pm

at

The Clare Foundation

Wycombe Road

Saunderton, Wycombe HP14 4BF

Event report from Carers Bucks and  
Buckinghamshire County Council



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# 1. Introduction

Strokes can happen in an instant and have a devastating effect on an individual and their loved ones. Every year in the UK, around 150,000 people have a stroke. As the third most common cause of death in the UK, and also the leading cause of severe disability, it is vital that we get stroke prevention, treatment, services and support right for the people of Buckinghamshire.

In recognition of this, Buckinghamshire County Council commissioned Carers Bucks to host a stroke conference in November 2010 entitled **Your Stroke, Your Future, Your Life**. One of the aims of the conference was to truly hear and understand the experience of services by stroke survivors and their carers. By understanding people's experience of the stroke patient pathway, we aimed to be in a stronger position to influence and effect change and improvements in future service delivery and stroke care.

Carers Bucks were invited again by Buckinghamshire County Council to host a **Feedback Event**, as a sequel to the conference, in September 2011. The aim of the event was to highlight the progress made in improving stroke services by health, social care and the voluntary sector in Buckinghamshire since the first conference.

This report summarises the main findings and content from the event. A broad programme of speakers and themes was offered to with the hope that there would be something of interest and value to everyone who gave up their time to join us. Councillor Carl Etholen, the Cabinet Spokesman for BCC Adults and Family Wellbeing kindly opened the event, followed by an engaging Keynote Speech by Trevor Boyd, Head of Service for Commissioning and Service Improvement (BCC Adults and Family Wellbeing). An informative, stimulating and often moving programme of speakers then followed, which will be summarised in this report.

Buckinghamshire County Council and Carers Bucks would like to thank all the contributors who presented, and all the professionals, stroke survivors and carers that joined us also. Excellence in stroke services is clearly

something many of us are passionate about, and in working together we can reach our shared ambitions for stroke care in Buckinghamshire.

## 2. Speakers' Presentations

Brief summaries of the speakers' presentations follow below to give an orientation to the 'flavour' of the programme. A full transcript is available of each presentation if further detail is required. If you would like to receive a full transcript of any, or all, of the speakers' presentations, please contact Ann Whiteley on [ann.whiteley@carersbucks.org](mailto:ann.whiteley@carersbucks.org) or telephone 01494 463536. The event agenda can be found at Appendix 1.

### **Councillor Carl Etholen – Cabinet Spokesman for Adults and Family Wellbeing (Buckinghamshire County Council)**

Councillor Carl Etholen opened the stroke event and warmly welcomed attendees to the event. Cllr Etholen introduced the programme of speakers to orientate those present to the structure and content of the day, and chaired the event.

### **Trevor Boyd – Head of Service, Commissioning and Service Improvement, Adults and Family Wellbeing (Buckinghamshire County Council)**

Trevor Boyd delivered an engaging and personalised Keynote Speech which reflected on his own personal experience of stroke in the family, and the devastating impact that this can have on the individual themselves, their carer and the wider family. Trevor outlined the national and local picture in relation to stroke services and gave an overview of recent improvements in Buckinghamshire, including the launch of the Stroke Patient Portfolio, stroke web pages on the county council website, investment in speech and language therapy telecare, the recruitment of 2 community stroke co-ordinators and a Joint Action Plan. Further improvements to come locally include the development of a stroke specific expert patient programme and improved personalised support services.

### **Dr Amulya Misra – Consultant in Stroke Medicine (Bucks Healthcare NHS Trust)**

Dr Misra next delivered an informative and interesting presentation on the implementation of best practice for stroke in the acute hospital setting. Dr Misra opened his presentation with a definition of stroke and some statistics. Signs and symptoms of stroke were explored and the importance of 'time is brain' stressed. Dr Misra explained the importance of best practice in the stroke pathway both pre and post arrival at hospital. Dr Misra explained the way emergency crews alert the stroke team should they suspect stroke and the role of telemedicine in prompt assessment and treatment. Dr Misra discussed the TIA (transient ischaemic attack) pathway and also shared some real life examples with attendees to illustrate the impact best practice can have on the outcome for the individual, their carer and their family.

**Todd Kaye – Clinical Specialist Physiotherapist (Neurology and Rehabilitation) (Bucks Healthcare NHS Trust)**

Todd delivered an interesting presentation on the recent development and launch of the Early Supported Discharge service in Buckinghamshire for stroke survivor and their carers. Todd explained that evidence based research has shown that a service such as this can reduce length of stay in hospital by 8 days, improve quality in life and reduce costs. An explanation of the Early Supported Discharge service was shared and the history to the development of the service given. An opportunity arose earlier this year to progress the hospital based Early Supported Discharge service into a seamless and integrated community service. With commitment and enthusiasm, the project group worked hard to define their project goals and implementation plan and were successful in the recent launch of the Early Supported Discharge community service for stroke.

**Alison Rimmer – Technical Officer for Speech and Language Therapy (Bucks Healthcare NHS Trust)**

Alison delivered a lively presentation on the stroke and language therapy telecare programme which has been financially supported by Buckinghamshire County Council. Alison explained the background to the project and showed attendees one of the touch screen computers on which the programme can be run. The project hosts 7 touch screen computers and 3 laptops on which the software can be run, but licenses are also available should stroke survivors wish to install this on their home computer. Alison stressed that the software programmes do not replace professional speech and language therapy support, but work to maximise and complement the direct therapy support. The therapists are

able to devise and recommend exercises for the stroke survivor to practice, which can then be monitored by the therapist to support optimal rehabilitation. Anna Chalk, Stroke Specialist Speech and Language Therapist, supported Alison in a demonstration of the software.

### **Stroke Patient Portfolio – Specialist Stroke Nurses and the Patient/Carer Experience**

Stroke specialist nurses Emma Gurney and Verity Hook delivered a very interesting presentation on the implementation of the Stroke Patient Portfolio on the stroke wards. The nurses explained the previous ways of disseminating information to patients and carers and compared these with the launch of the Stroke Patient Portfolio. The development and implementation of the Stroke Patient Portfolio has helped patients and carers in a number of ways; by providing information, supporting improved communication between staff, patients and carers and helping to support a seamless discharge home. As part of this presentation, two stroke survivors generously shared their experience of the Stroke Patient Portfolio and confirmed the value and help this resource offers to both stroke survivors and their carers.

### **Community Stroke Co-ordinators – Clare Cheney and Nicole Plattner**

Nicole Plattner and Clare Cheney introduced themselves to attendees as the recently recruited Community Stroke Coordinators. With Clare employed by Buckinghamshire Healthcare NHS Trust and Nicole by Buckinghamshire County Council, the local ambition is for stroke survivors to experience a seamless, supported and co-ordinated discharge back home from hospital. The co-ordinators explained that they will contact every stroke survivor within 2 days of discharge from hospital. The co-ordinators will support with information and guidance for 6 months and will ensure GP review takes place.

### **Adey Varley – Paramedic (Bucks Healthcare NHS Trust)**

Adey gave a moving and powerful account of his personal experience after his mother experienced a stroke, and how this has also had an impact on his professional practice. Adey described the chain of events which is set in motion once a 999 call is made and the importance of speed and efficiency in assessment, treatment and handover at hospital as 'time is brain'. Adey explained all the aspects that the ambulance crew have to attend to, and then shared one final issue of importance on the emergency crew list:

*“And I left one thing out on that list. TLC. Tender loving care. Our patient is not a sack of spuds or just a medical condition. He or she is a very individual and unique human being. I really, really believe this. Who like my mother may well be going through the most terrifying experience of their life and to the people round just as precious. ”*

### **Jean Morris – WI Federation Chair**

Jean Morris delivered a rousing and inspirational presentation on the WI's mandate to campaign within Buckinghamshire for improvements in stroke services. Jean explained the role and campaigning activity of the WI and the democratic process by which campaign decisions are taken. Bledlow WI undertook much research and hard work to demonstrate the need for improvements in post hospital care and rehabilitation of stroke patients, whether they are at home or in residential care, and as a result this campaign has been adopted within Buckinghamshire. Jean explained that there are 210, 000 WI members in England and Wales and that if this campaign is taken on board in their areas too, this will make a huge difference to the lives of stroke survivors.

## **3. Question & Answer Panel**

In the Question and Answer Panel, attendees were invited to pose their questions to representatives from a number of disciplines and agencies. The Panel members were Clare Cheney, Maxine Foster (Bucks County Council Commissioning), Adey Varley, Todd Kaye, Alison Rimmer, Stephen Archibald (Carers Bucks CEO), Dr Misra and Veena da Souza (Public Health Consultant). An illustration of some of the questions and answers are reproduced below. Should you wish to read a transcript of all the questions and answers, please contact Ann Whiteley at Carers Bucks ([ann.whiteley@carersbucks.org](mailto:ann.whiteley@carersbucks.org)).

### **Q How is my GP informed of my stroke?**

“We now have an electronic discharge summary which we do on the computer. Unfortunately it is not electronically linked to the GP surgery, so we print it out and then we fax it to the GP surgery. But the electronic discharge is in the process and I think in a few months we will be able to electronically send these summaries to the GPs. But if there is any concern or any thing which especially needs to be done apart from the routine treatment, then we prefer to give the surgery a call and tell them

personally about any special things that need to be looked at." (Dr Misra)

**Q During the pre discharge planning will the stroke survivor have an assessment of his/her care needs?**

"I suppose the short answer is yes. On the stroke wards both at Stoke Mandeville and High Wycombe hospital there are specialist therapist and nursing staff that work there who will do the required pre assessments for discharge. This may include an assessment by an occupational therapist that goes out and we'll do a home visits with the patient to see what the needs are there; likewise a physiotherapist in terms of what specialist therapy might be required after the discharge. Amongst all of that will be the multi-disciplinary team getting together and sorting out what level of care the patient might need once they get home to be provided by our services." (Todd Kaye)

**Q Funding was available for setting up the portfolio and other new services, but will funds be available to sustain these improvements and to develop further therapy and community services in the future?**

"As far as funding of the portfolio goes, we are committed in the acute trust to printing more of the portfolios when the initial funding runs out. As far as further improvements for community services and community therapy, we have heard some of the services that are being started now like the early supported discharge service. There has also been a review of more generic community rehabilitation, physiotherapy and occupational therapy, and new adults and community healthcare teams and neuro rehab services are being set up. And I think we still need to look at other gaps there are after that." (Susie Mactavish, Specialist Stroke Nurse)

**For information:** the Community Stroke Co-ordinators will be identifying unmet need in the community as part of their role.

**Q What is there for patients who have had strokes some years ago and what sort of support?**

"As we mentioned earlier when we talked about the community stroke co-ordinators, they are predominantly there to support people who have just had a stroke and will continue to support as necessary for the first 6 months. However we did say we would be able to sign post other people through but other services which are available would be very much in the voluntary sector eg Stroke Association, support groups, Carers Bucks, they will all have links to support people in this way."

Unfortunately we ran out of time to hear all the questions which were submitted during the event! Some of the unanswered questions are listed below, with our suggestion as to who may be best placed to respond. We will collate further responses provided by the speakers/Panel members and ensure these are circulated when received.

**Q1** "Stroke co-ordinators will be active with new stroke survivors for six months – the issue is how the thousands of stroke survivors get access to portfolios in Buckinghamshire?"

**Suggest response from:** Susie Mactavish and Maxine Foster

**Q2** "Do you liaise with other hospitals in the area regarding all these new innovations?"

**Suggest response from:** Veena da Souza

**Q3** "What measures have been taken to ensure that patients are taken to the correct hospital? Are all ambulance staff aware of the new developments in stroke services? Could you please assure us that all ambulance staff are aware of the hyper acute services in High Wycombe?"

**Suggest response from:** Adey Varley

**Q4** "I believe my stroke from 8 years ago is causing me progressive disabilities including loss of balance and severe mobility problems. Is there anything that could be done to prevent further damage?"

**Suggest response from:** Dr Misra

**Q5** "The therapy I received at Amersham has been very satisfactory but I would like to criticise the design of the washroom and WC which appears to be designed by an accountant making hard work for the patients and the staff. My therapy was cancelled as I was making progress and improving and I feel that more treatment would be successful."

**Suggest response from:** Todd Kaye

**Q6** "If brain surgery is required post stroke ie removing blood clots after a 'bleed' stroke, is this carried out at Wycombe Hospital or is the patient transferred to Oxford?"

**Suggested response from:** Veena da Souza

**Q7** "My wife had a severe stroke in May 2009. We moved from Beds to Bucks in June 2010. What services should we be getting?"

**Suggested response from:** Clare Cheney and Nicole Plattner

**Q8** "What is there for patients who have had strokes some years ago? For support services?"

**Suggested response from:** Maxine Foster

**Q9** "What obstacles are there in the way of a faster roll out of Early Supported Discharge and is the money available to fund this?"

**Suggested response from:** Todd Kaye

**Q10** "How will staff at the hospitals manage stroke patients if they are admitted for something like falls? How will general staff be educated in the needs of someone who has experienced a stroke eg if they have speech problems?"

**Suggested response from:** Veena da Souza

**Q11** "Can you reassure me that care will be available and ready when stroke survivors are discharged from hospital, especially if they don't fit the Early Supported Discharge stuff?"

**Suggested response from:** Trevor Boyd

**Q12** "Will a social worker come to see me on the ward to help me with care?"

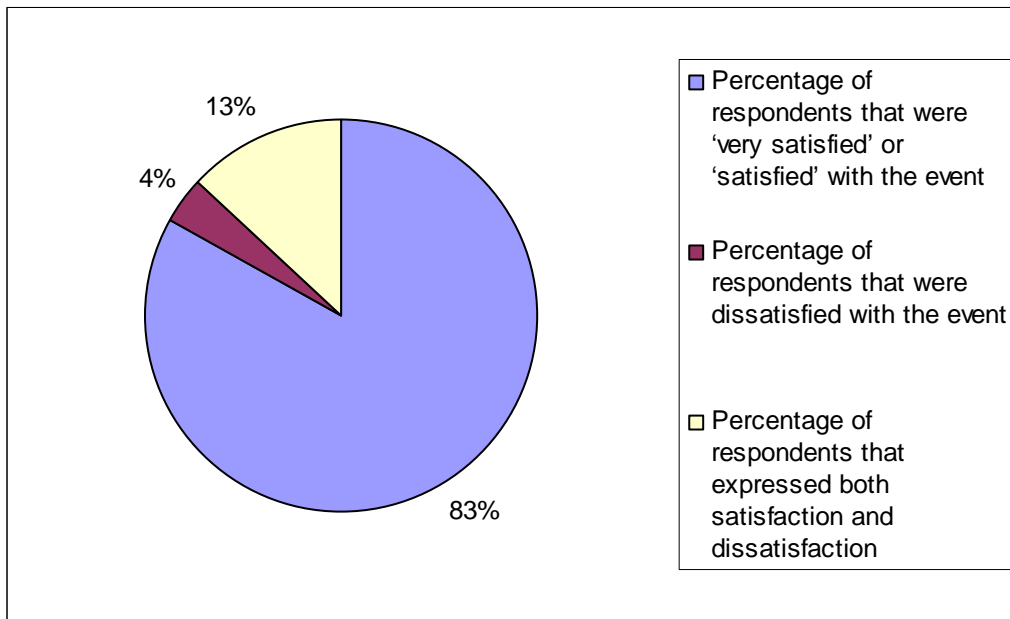
**Suggested response from:** Trevor Boyd

A network of stroke survivors and carers meet on a regular basis to ensure the user and carer voice is heard in service developments going forward. Carers Bucks also are also involved with this network group. Any queries can be directed to the group via Carers Bucks which will then be passed on to the Chair.

## 4. Evaluation

### Satisfaction with the event

Overall 24 evaluation completed sheets were received. There was a balanced representation in the evaluation sheets from professionals, carers and stroke survivors. Of these, 83% said they were very satisfied or satisfied with the event (13 very satisfied, 7 satisfied), with one evaluation sheet expressing dissatisfaction and 3 expressing both satisfaction and dissatisfaction. Whilst satisfaction was expressed by almost every respondent in relation to the content of the programme, some dissatisfaction was expressed in relation to organisational issues ie insufficient printed handouts, coffee and tea arrangements, insufficient signage, difficulty seeing the screen, difficulty hearing presenters and lack of greeting on arrival.



### The programme

The speakers and sessions that were most frequently highlighted as most useful in the evaluation sheets included Dr Misra (Stroke Consultant), Jean Morris (WI), Adey Varley (Paramedic), Alison Rimmer (Speech and Language Telecare) and the patient/carers experiences of the Stroke Patient Portfolio. Generally, all the sessions were well received overall, with some of the same speakers being identified as 'most useful' by some respondents and 'least useful' by others. Some views were expressed in

relation to individual presenters where respondents felt presentation was unclear or too hurried or could not be heard at the back of the room. One respondent indicated that although the event was very welcome, it would have been better if planned across a day programme.

### **Improvement in stroke services over the last year**

58% of respondents clearly indicated on their evaluation sheets that stroke services in Buckinghamshire have improved over the last year. (10 answered 'Yes' whilst 4 answered 'Very Much'.) None of the respondents indicated that stroke services have not improved over the last year. Where this question was left unanswered, evaluation sheets included comments such as 'we have only just moved here', 'unable to say' and 'do not know'.

Individual comments in relation to the improvement of stroke services included the following:

*"From what I have heard today, there seems to have been a significant improvement in stroke services"*

*"Services now seem more 'joined up'"*

*"Services may be better, but are still inadequate!"*

*"Acute services have improved...long term care is now the next goal"*

### **Priorities for further improvement**

Respondents' priorities for improvement in stroke services over the next year included the following contributions:

- Stroke Co-ordinator posts to be fully functioning
- Stroke Patient Portfolio to be fully implemented
- Better communication between hospital and services for home care
- Longer term follow up support and help for stroke sufferers
- Input for patients after therapy finishes ie social input/support
- Less use of jargon such as 'signposting' and 'facilitating'
- More education for GPs
- More GP surgery based services
- More Community OT for speedier response to requests for equipment and adaptations post discharge
- TIA to be treated more seriously
- More events such as this
- Better dissemination of information eg through press/TV
- Make sure everyone in Bucks knows what is available and how to access it. Review of services
- Remember people in residential care who should have the same entitlements to therapy as everyone else.
- Help in the nursing homes

- Expand rehab/physio – no 6 week window, provide in hospital on Saturdays as a minimum at weekends
- Greater access to a wide variety of community support and for this to be accessed readily when required, even if long term.
- Ensure seamless service between health and social care occurs; good communication is essential.

### **Further comments**

Other comments raised included the following:



*"The event was useful to a point but of very limited use to long term stroke patients and their carers"*

*"There did not appear to be a single GP present, yet they are going to control the finances in the future"*

*"Not enough answers given as to the emergency treatment of people in Buckingham"*

*"Next time attendees in wheelchairs could sit at the front rather than the back"*



*"Thank you for an excellent seminar. Very much appreciated."*

*"All the speakers were excellent"*

*"All the speakers were useful and together gave a fuller picture of stroke services"*

*"All sessions were useful and well done for such variety – maybe longer versions next time?"*

Interest was also expressed by respondents in a similar event being held next year to check again that services continue to improve

# Your Stroke, Your Future, Your Life

## Feedback Event

### AGENDA

<b>9.30 – 10.00</b>	<b>Coffee &amp; Registration</b>	
<b>10.00 – 10.10</b>	<b>Welcome</b>	<b>Councillor Carl Etholen</b> <b>Cabinet Spokesman for Adults and Family Wellbeing</b>
<b>10.10 – 10.25</b>	<b>Keynote Speech</b>	<b>Trevor Boyd</b> <b>Head of Service, Commissioning and Service Improvement for BCC Adults</b>
<b>10.25 – 10.40</b>	<b>New centralised stroke services at Wycombe Hospital including the TIA High Risk clinic</b>	<b>Dr Amulya Misra</b> <b>Consultant in Stroke Medicine - Wycombe Hospital</b>
<b>10.40 – 10.55</b>	<b>Early Supported Discharge for Stroke – leaving hospital and back in the community</b>	<b>Todd Kaye</b> <b>Clinical Specialist Physiotherapist</b> <b>- Neurology and Rehabilitation</b>
<b>10.55 – 11.10</b>	<b>Telecare Demonstration - Speech and Language Technology</b>	<b>Alison Rimmer, Technical Officer for Speech Therapy</b>
<b>11.10 – 11.20</b>	<b>Break – tea/coffee</b>	
<b>11.20 - 11.35</b>	<b>Patient and Carer experience of using the stroke portfolio.</b>	<b>Facilitated by Specialist Stroke Nurses</b>
<b>11.35 – 11.45</b>	<b>The role of the Community Stroke Co-ordinator and how to refer</b>	<b>Clare Cheney and Nicole Plattner</b>
<b>11.45 – 11.55</b>	<b>Paramedic responses to strokes</b>	<b>Adey Varley</b>
<b>11.55 – 12.10</b>	<b>Women’s Institute campaign to improve stroke services</b>	<b>Mrs Jean Morris, W.I. Federation Chairman</b>
<b>12.10 – 12.45</b>	<b>Q &amp; A Panel</b>	<b>Maxine Foster BCC Emma Haffenden Health. Dr Amulya Misra, Todd Kaye, Alison Rimmer, Stephen Archibald Carers Bucks</b>
<b>12.45 – 1.00</b>	<b>Closing comments and Next Steps</b>	<b>Councillor Carl Etholen</b>