

## Interim Report - CQUIN 2b -Recognised, Valued , Supported - Identify the causes of carer breakdown

### 1 Introduction

- 1.1 This CQUIN is aimed at recognising early those carers at risk of crisis, in order to facilitate early intervention. The paper 'Carers as Partners in Hospital Discharge' (ADASS 2010) highlighted the period immediately after a 'cared for' person is discharged from hospital as very stressful for the carer.
- 1.2 This CQUIN involved a literature review and development of a carer survey to identify those factors that most help carers and reduce likelihood of crisis or breakdown. This report sets out those findings and proposes a number of interventions in response to the learning. These interventions will be tested out to see whether they can improve carer support in the community.
- 1.2 A key outcome of the vision set out in government's Carers Strategy - 'Recognised, Valued and Supported' (2010) is that "carers will be supported to stay mentally and physically well and be treated with dignity". It is well recognised that some carers do not receive the support they need until they reach crisis. This CQUIN aims to develop a mechanism whereby those at risk of breakdown are recognised early and receive the support they need and deserve.

### 2 Lessons from Literature Review

- 2.1 The findings from studies have, over a long period, evidenced the importance of carer breakdown in admission / readmission to hospital or long term care:
- One study found that problems associated with the carer contributed to readmission in 62% of cases. Carers of people readmitted were more likely than other carers to be experiencing ill health, fatigue and interrupted sleep and be conducting at least one intimate task .  
*A Williams, E, Fitton, F (1991), 'Survey of Carers of Elderly Patients Discharged from Hospital'. British Journal of General Practice, 41, 105–108.*
  - A four year study of 392 carers and 427 people who were not carers aged 66–92, found that carers who were reporting feelings of strain had a 63% higher likelihood of death in that period than people who were not carers or carers not reporting strain.  
*Schulz, R, Beach, S (1999), 'Caregiving as a Risk Factor for Mortality'. Journal of American Medical Association, 282 (23), 2215–2219.*
  - Carers providing high levels of care are associated with a 23% higher risk of stroke.  
*Haley, W et al (2010), 'Caregiving Strain and Estimated Risk for Stroke and Coronary Heart Disease Among Spouse Caregiver*
  - A whole systems study tracking a sample of people over 75 years old who had entered the health and social care system, found that 20% of those needing care were admitted to hospital because of the breakdown of a single carer on whom the person was mainly dependent.  
*Banks, P (1998) 'Carers: Making the Connections'. Managing Community Care,*
  - Witherington, Pirzada and Avery (2008) examined reasons for hospital readmissions. They attributed poor communication between hospital and community support organisations as a main reason.
- 2.2 Positive involvement of Carers in Hospital discharge and re-ablement services has been shown to have significant benefits:
- Evaluations of four re-ablement programmes in England found that carers play a crucial role, and involving and supporting them can improve chances of long-term patient re-ablement.  
*(2007), 'Homecare Re-ablement Workstream'. Care Services Efficiency Delivery Programme.*

- An RCT found that training carers of stroke patients reduced hospital days of patients, contributing to lower annual treatment costs of £4,043 per person, *Kalra, L et al (2004), 'Training Carers of Stroke Patients: Randomised Controlled Trial'. British Medical Journal,*

### 3 Findings from local Torbay evaluations

3.1 The results of two local evaluations have been used to identify areas for improvement in relation to this CQUIN:

- An analysis of 11 Discovery Interviews with carers of patients discharged between January and April 2012 where the patient was readmitted within 3 months of discharge (CQUIN 2b Quarter 2)
- An evaluation of Hospital Based Carers Services in Torbay Hospital completed in June 2012

3.2 Analysis of Carers Discovery interviews (CQUIN 2b)

The Discovery Interviews consisted of a spine of questions that enabled the carer to share their experience from the point of discharge from Torbay Hospital or a Community Hospital and for the three months after discharge. Appendix 1 for Carers ratings to answers in interviews.

The three top themes (in order of most frequent) were Communication, Attitude of staff and Accessibility (of services):

Questions relating to the day of discharge:

- Were you valued as a Carer? This question was answered almost universally as No – carers described not being included or consulted in the hospital setting ( RAG rating Red)
- Were you able to get information? – only one interviewee answered positively ( RAG rating Amber)
- Were you listened to? 2 responded positively and 3 reported mixed experiences. A common problem was Hospital staff not listening to explanations about the patients needs, particularly confused patients ( RAG rating Amber)
- Were you offered choices about your input? 7 responded negatively. Many said that joined up information was not forthcoming, each service seemed only to know about their own sphere ( RAG rating Red)
- Were you offered a Carers Assessment? Most were but not all were clear about its purpose or value. ( RAG rating Amber)
- Did you feel prepared? Although many of the carers interviewed were experienced, there was invariably anxiety. ( RAG rating Amber)

Questions relating to when back at home:

- Were you contacted by Health professionals? ( RAG rating Amber)
- Were you referred to community services? ( RAG rating Amber)
- How do you rate their input? 3 responded positively none negatively. Critical role of District/Community Nurses. ( RAG rating Green)
- Was it a positive engagement? ( RAG rating Green)
- Did the Hospital / GP etc work properly with each other? This did work in the main although mix ups with medication were cited ( RAG rating Amber)
- Did anyone check if you were coping OK? ( RAG rating Red)
- Were there support options which weren't forthcoming? Sometimes Carers had to fight for support( RAG rating Amber)

Questions about the carer:

- Was the Carer support adequate? A mixed response with some 'too busy' to access support ( RAG rating Amber)
- How has being a Carer affected you? ( RAG rating Red)

**In summary, it is clear that the issues for many participants in the interviews related back to their experience while the patient was in hospital and not in the community**

### 3.3 Evaluation of Torbay Hospital Carers Services 2012

In 2010 a Carers Support Worker was funded within the Hospital Discharge Team to support the most complex cases and facilitate smooth discharges where carers are involved. The evaluation of Carer support consisted of a staff questionnaire, interviews with carers, and analysis of admission and delayed discharge data.

Relevant findings:

- Carers are not involved as often as they should be in discharge planning. There was a gap of 51% between staff opinion of the involvement carers should have, compared to their actual involvement.
- 27% of carers interviewed said that their views were not respected
- First time carers seem particularly neglected – not receiving information and 88% said no one had discussed their willingness to take on the caring role
- 82% of Staff felt that Carers support reduces or delays readmissions
- 92% of carers said that follow up after discharge was or would have been useful
- According to carers, in the cases where discharge had not gone according to plan, 30% were due to carers not managing

## **4 Good practice guidance for Hospital Discharge**

4.1 The themes from a range of policy papers, reviews and guidance can be summarised as follows – “If carers and the people they support are informed, involved and supported along the care pathway the likelihood of good outcomes rises, risk of readmission falls and the financial and emotional costs this incurs avoided.” ADASS 2010.

What is clear is that it requires a consistent approach across whole care pathways and recognition of how actions and changes in one area can influence the whole system.

4.2 In good practice Carers need the following:

- to feel valued as partners in the discharge process;
- belief that their knowledge has been used appropriately
- awareness of their right to have their needs identified and met
- confidence in continued support of their caring role and receiving support before it becomes a problem
- the right information and advice to help them in their caring role
- to be given a choice about undertaking their caring role;
- understanding of what has happened and who to contact

## **5 Proposed Actions for CQUIN 2b Quarter 4 Torbay & Southern Devon Health and Care NHS Trust January – March 2013**

**The 3 areas for improvement are**

- 1 Raising Carer awareness amongst key staff**
- 2 Follow up phone calls for carers of patients discharged from Community Hospitals**
- 3 Providing Carers with contact details for support post discharge**

### **5.1 Carer Awareness for staff**

- to maintain the existing awareness raising activity in Torbay Hospital by Steve Black Carers Support Worker
- to reinstate weekly visits to Brixham and Paignton Community hospital wards by the Signposts Information Officer from January 2013
- to undertake a programme of Carer Awareness training for Intermediate care teams, IHSS and CRT, District Nurses and Community Hospital staff (Jan – March 2013)

### **5.2 Follow Up calls**

- Carers / patients to be contacted by phone 48 hrs after discharge of patient from Paignton and Brixham Community Hospitals to identify if further support is needed and appropriate action taken

### **5.3 Contact Card for Carer**

- Produce a Carers Contact card with key information of where to get support if needed. Card to be given to Carers (or patients) at point of discharge from Torbay Hospital and community Hospitals

Review of actions March – May 2013

**James Drummond**  
**Lead Officer Integrated Carers Services**  
**December 2012**

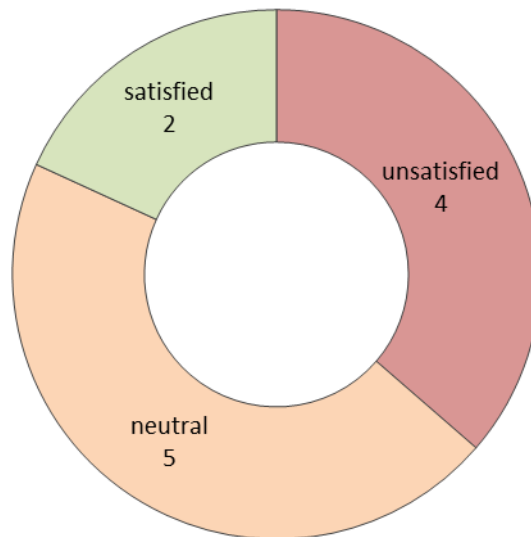
## CQUIN 2b Appendix 1 – ratings to answers/comments on interview questions

In order to quantify the results, a [subjective] interpretation was placed against those interview questions which were adequately addressed in the transcripts. These were ranked as:

- negative (unsatisfied) – 1
- neutral (neither strongly one or the other) – 2
- positive (satisfied) – 3.

In this way the results were displayed as a Red, Amber, Green to highlight which questions gave an overall negative (or positive) score. In addition, it also shows (crudely) how many of the 11 carers responded as satisfied (or unsatisfied) overall:

unsatisfied	4
neutral	5
satisfied	2



	1 - On the day of discharge...						2 - When back at home								3 - As a carer		
	Were you valued as the carer?	Were you able to get information?	Were you listened to?	Were you offered choices about your input?	Were you offered a carer's assessment?	Did you feel prepared?	Were you contacted by health professionals?	Were you referred to community services?	How do you rate their input?	Was it a positive engagement?	Did you get support outside the family?	Did Hospital/GP/etc work properly with each other?	Did anyone check if you were coping ok?	Were there support options which weren't forthcoming?	Was the carer support adequate?	How has being a carer affected you?	Overall carer satisfaction rating
4.9.12 Transcription	1	2	1	2		1	2	2	2	2	1	1	1	3	1	1	2
6.9.12 Transcription	2	3	1	3	3	3	3	3	3	3	2	3	2		3	2	3
9.8.12 Transcription Pauline	1	2	1	1	3		2	3	2	3	3	2	1	2	2	1	2
10.8.12 Transcription Pauline	1	1	1	1	3	1	2	3			2	2	1		1	1	2
17.8.12 Transcription	1	1	1	1	2	1	2	1	2	2	2	1	1	1	1	1	1
A Tape	1	1	2	1	2	1		1							1	1	1
B Tape	1	1	2	1	1	2	1	1			2		1		2	1	1
C Tape	1	1		1	2		2	1				2			1	1	1
D Tape		2		2	3	2	2	2	2	2	3		2	3	2	2	2
Interview - J T 8.8.12		2	3			3	2	1	3	3	3	3	3	3	2	2	3
Interview - WW 7.8.12	1	1	3	1	1	1	2	3	3	3	2		1	1	2	1	2

Overall question RAG rating

1	2	2	1	2	2	2	2	2	2	3	2	2	1	2	2	1
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