



East Sussex Health Overview and Scrutiny Committee

Carers' Review

**The GP, the Carers' Assessment and
experience of hospital discharge – who
listens to the carer?**

March 2005

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EXECUTIVE SUMMARY

Introduction

i) The Carers' Review is the third in the East Sussex Health Overview and Scrutiny Committee's pro-active programme of reviews. A Project Board (the Board) was set up with the following membership: Councillor David Rogers, Councillor Beryl Healy, Councillor Tony Slack and Margaret Unwin, Chief Executive of Care for the Carers. Councillor Rogers was elected chairman at the first board meeting.

ii) The Board agreed that the following three issues should become the scope of the review:

- Carers' assessment
- Hospital admission and discharge
- GPs identification of carers

iii) This focus was chosen to ensure the review covered how carers are recognised, engaged and valued within the local health economy. It also encompasses how carers' needs are being dealt with. The review ran from October 2004 to February 2005.

iv) Key findings and recommendations are set out below.

Recognition and Support from GPs

v) Sussex Downs and Weald PCT and Care for the Carers have developed a protocol to help GP practices measure up to Management Indicator 9 (found in the quality outcomes framework of the new GMS contract). This was distributed to GP practices within the PCT on 9 November 2004, together with supporting information about carers and the service offered by Care for the Carers. This protocol has now been shared with Bexhill and Rother, Hastings and St Leonards and Eastbourne Downs PCTs, who are adapting it for their needs.

- **The excellent carers' protocol devised by Sussex Downs and Weald PCT is regarded as good practice.**
- **PCTs across East Sussex must continue to adapt and promote this protocol to ensure GPs provide a consistent and equitable approach to carers across the county.**

vi) There were mixed and wide-ranging views from the sample about support from GPs; the quality of service from GPs to carers appeared to vary considerably. In April 2004, Care for the Carers (CftCs) undertook research to quantify what CftCs outreach staff had achieved with GP surgeries, as well as community hospitals and clinics, across the county. All but 9 of the 91 (90%) practices countywide had at least some information in waiting areas, usually CareLine magazine and some Care for the Carer leaflets (N.B. The 91 practices include sub-practices). Nineteen (21%) made pro-active referrals of carers and outreach workers had regular contact with 59 (65%) practices. A handful of practices had been resistant to any contact.

- **In order to address a lack of consistency in informing carers about support and assistance, all GP surgeries across the county must, as**

a minimum, provide information from Care for the Carers and Social Services on how to access carer services.

vii) PCTs are working to improve services to carers through their local Health Improvement Plans and Programmes

- **PCTs, using their local knowledge and Health Improvement Programme work, must continue to develop the support and services carers need from primary care.**

viii) To encourage the minority that are unresponsive to the protocol to recognise and refer carers on, and unresponsive to putting information in their surgeries the new GMS contract could include a negotiated element of recognition and support for carers.

- **The new GP contract, and the Locally Enhanced Services element, should be used to give further encouragement to GP practices to recognise and support carers.**

Assessment

ix) Performance against D42 in East Sussex has been poor when compared to its nearest neighbouring group of authorities. However, there is evidence to suggest that during a Community Care Assessment of the service user carers are often assessed; a case file audit showed that the carer's needs had been taken into account when agreeing the care plan for the service user. But, critically, the vast majority of these assessments (of the carer) are not recorded on Carefirst. Indeed, the failure to accurately record and complete the number of Carers' Assessments is a major failure, which does not allow the County Council to know whether its actual performance is good or bad.

- **East Sussex County Council needs to make urgent improvements to both the completion and recording of Carer Assessments.**

x) CMHTs currently are required to enter data into two different computer systems. For instance, many CMHT bases do not have access to Carefirst while the priority inputting task is to PIMS (Patient Information Monitoring System) which is the health data base.

- **It is essential that when social care and the NHS work jointly in teams (e.g. the Community Mental Health Teams and the Single Assessment Process) joint computer systems are there to support the frontline staff struggling to meet the performance information needs of both the NHS and social care.**

xi) Up to this point it has not been possible to identify how many carers have been involved in the early days of the Single Assessment Process pilots. Furthermore, there were no mechanisms in place to identify how many carers have been referred on for a Carers' Assessment from Social Services. Carers' assessments generated by the use of the new FACE overview process will be monitored once the new version has been adopted. However, it is not clear if the carer assessment generated by the SAP overview assessment leads to an automatic referral to Social Services for a Carers' Assessment.

- **The SAP project managers and the County Carers Strategy Group must liaise to establish the mechanisms needed to ensure automatic referral to Social Services once a carer has been assessed as part of the SAP overview assessment.**

xii) The overwhelming majority of the carers in contact with this review are disillusioned with the carer assessment process.

- **East Sussex County Council's Social Services department must radically rethink the way in which the carers' assessment process is administered in order to:**
 - **Ensure that carers know where to find information about the Carers' Assessment and their rights to it.**
 - **Take account of good practice in assessing carers including a more sensitive approach to enquiries.**
 - **Always provide face-to-face assessment for carers.**
 - **Ensure the process is better understood by carers.**
 - **Ensure the process is explicit.**
 - **Ensure that carers are aware of follow-up processes and reviews.**
 - **Improve the perception that the assessment does not result in any positive support or service.**

Hospital Admission & Discharge

xiii) The East Sussex Hospitals NHS Trust has a *Code of Practice for Involving Carers*, which has been evaluated by Bungay & Alaszewski, University of Kent in 2002. However, it was reported that its implementation has lost momentum and that making sure all frontline staff are alert to the code is an issue.

- **All hospitals serving East Sussex patients should launch (or re-launch) the *Code of Practice for Involving Carers* to ensure it is put into daily practice at the ward level.**
- **Over time the Code must be monitored rigorously to address carers' concerns about hospital admission and discharge.**

xiv) The Care Passport is a card designed for carers to record the special needs, preferences, ways of communicating and behaving of the person they look after. It was reported to the Board that the East Sussex Hospital NHS Trust is not accepting Care Passports because, in their view, the Single Assessment Process (SAP) does away with the need for this document. The argument against this is that on admission SAP does not offer the same opportunity as the Care Passport for carers to contribute specific and personalised information about the patient.

- **All hospitals serving East Sussex patients, including those where the patient is referred on, must continue to use and promote the Care Passport when a patient is admitted to hospital.**

xv) Some carers reported to the Board that they put off going into hospital themselves because they either could not get a firm date for admission, and therefore could not arrange alternative care, or could not find or fund the alternative care needed for the person they care for.

- **When carers need to stay in hospital (e.g. elective surgery) all hospitals serving East Sussex patients, the PCTs and East Sussex County Council Social Services Department must support carers' efforts to arrange alternative care including:**
 - allowing sufficient time to make arrangements;
 - arranging appropriate care.

xvi) Carers reported a mainly negative view of hospital care and discharge. The Board heard of both children and older people being discharged late in the evening and at other inconvenient times.

- **In order to improve carers' experience of hospitals all hospitals serving East Sussex patients must respond to findings identified in this report. These include:**
 - Carers must be given time to arrange for the discharge of the person they care for.
 - Carer's needs must be taken into account on admission and on discharge of the person they care for.
 - Carers must be listened to by health care professionals.
 - Carers must not be required to continually repeat the same information to staff.
 - Training must be provided by health care staff for new carers.

Respite

xvii) Because of the remit of the review the Board has not heard any direct evidence on respite. However, carers and other individuals and organisations drew the Board's attention to the lack of respite beds in East Sussex.

- **Progress in mapping and monitoring of existing respite services leading to a review of the East Sussex Respite Care Strategy should be reported to HOSC in September 2005.**

Working Carers

xviii) One of the focus groups attended by the Board consisted exclusively of working carers, who had both positive and negative comments on their working lives. The consensus was that while working was a positive force in their lives and a 'lifeline' there are aspects that are negative, including giving up leave for caring responsibilities and having to reduce hours. A minority who worked in departments with a 'long hours culture' found their environment less supportive and felt their career prospects damaged.

- **All major employers, including the County Council, should identify how many working carers they employ and address their needs.**

Young Carers

xix) Because of the remit of the review the Board has not heard any evidence on Young Carers.

- **It is recommended that HOSC sets up a separate review on Young Carers to be done at a later date.**

Overall findings

xx) There appears to be inconsistent and inequitable support for carers across East Sussex; it seems to be a matter of luck as to how much recognition, support and services carers received. The QOF Management Indicator 9 is making some impact on GP management systems and should therefore make some difference to the way carers are supported and assessed by their GPs and social services. However, any work to improve numbers of carer assessments in East Sussex could be negated by an almost universal disenchantment with the assessment process.

xxi) While the review has taken place in the context of a great deal of work on delayed transfers of care, and systems are being put into place to reduce these delays, there are no mechanisms to measure the impact of this work on carers. The review was interested in hospital admission and discharge but some of the strongest views the Board heard centred around the experience of being in hospital; a dismal picture was received of neglectful and poor hospital care.

xxii) Above all the carers wanted professionals from both the NHS and social services to listen to them at every stage, and offer appropriate practical help.

INTRODUCTION

1. Project Board

1.1 The Carers' Review is the third in the East Sussex Health Overview and Scrutiny Committee's pro-active programme of reviews. A Project Board (the Board) was set up with the following membership: Councillor David Rogers, Councillor Beryl Healy, Councillor Tony Slack and Margaret Unwin, Chief Executive of Care for the Carers. Councillor Rogers was elected chairman at the first board meeting.

1.2 The Board was supported by Penny Kocher, Project Manager (Consultant); Roger Howarth, Scrutiny & Best Value Co-ordinator and Sam White, Scrutiny Support Officer, East Sussex County Council.

2. Remit of the review

2.1 Having decided that there were a number of areas of concern regarding carers, the Board agreed that the following three issues should become the scope of the review:

- Carers' assessment
- Hospital admission and discharge
- GPs identification of carers

2.3 This focus was chosen to ensure the review covered how carers are recognised, engaged and valued within the local health economy. It also encompasses how carers' needs are being dealt with. The review ran from October 2004 to February 2005.

3. Methods and approach to the review

3.1 Information and evidence gathering played a large part in this review. Between October 2004 and mid January 2005 two evidence sessions were arranged for presentations to the Board from both statutory and voluntary organisations. In addition, the Project Manager used a combination of desk-based research, survey instruments, interviews and discussion with individuals from both statutory and voluntary organisations, carers and members of the public.

3.2 Papers and memoranda were received from organisations including a report from the Sussex County Healthcare NHS Trust Patients and Public Involvement Forum (PPIF) describing a workshop on the Carers' Assessment and setting out the results of a survey.

3.3 The Board also considered that carers are expert witnesses. As a result, it heard their experience of recognition and support from GPs, carers' assessment and hospital admission and discharge. A reference group was set up that met once at the beginning of the review and again at the end to discuss the evidence and explore the recommendations with the Board. Eight carers were involved in this group.

3.4 Three focus groups were held and included:

- ESCC employees who are also carers;
- an independent support group in St. Leonards;
- a breakout session in a PPIF workshop.

3.5 It is important to note that while the evidence that the Board heard from carers was not from a random sample, the participants attending the four groups came from a wide geographical area and range of ages (from 30-80). The carers cared for children, spouses, partners and parents, and included working carers as well as those who cared for many hours a day. In addition, each focus group was recruited from a different source i.e. the Reference Group through Care for the Carers, the working carers through East Sussex County Council employees. A total of 37 carers met with members of the Board who asked questions and listened to carers discuss their experiences and recommend improvements in support from GPs, the carers' assessment and hospital admission and discharge.

3.6 In addition, members of the public and voluntary organisations were encouraged to contact the review and give their views. The review was advertised through the Care for the Carers website, a press release and an email through Voices (a network of East Sussex voluntary organisations). Several carers, voluntary organisations and other individuals have added their views to the review through this route (see Appendix 1 for a list of participants).

3.7 The project manager and the Board members would like to acknowledge and thank the many individuals and organisations that collaborated and contributed to this review; especially the 37 carers who participated in the reference and focus groups. There was much good will and co-operation and the review benefited from everyone's efforts – we value everyone's views and are grateful to you all.

4. Structure of the report

4.1 This report looks at the policy context for the Carers' Review, both at a national level and locally, and sets out the economic argument for supporting carers. The report also looks at the policy context around GPs and the new contract along with the policy context for the Carers' Assessment and hospital discharge. The views of carers on these issues along with their ideas for improvements are also set out in this report (see pages 22, 32, 39).

4.2 A summary of recommendations is on pages 47-49.

BACKGROUND

5. National Policy Context

5.1 Helping people to remain in their own homes rather than in long-term institutions has been the central tenet of successive governments since the 1960s. Over the years a number of reviews and acts have shifted the emphasis from caring for people in institutions to people being cared at home by their family, including:

- the **Audit Commission's Making a Reality of Community Care (1986)**, which highlighted the uneven pattern of local authority services, and the shift from one pattern of residential care based on hospitals to an alternative supported in many cases by Supplementary Benefits. (1986, p2);
- the **Griffiths Report, Community Care: Agenda for Action (1988)** which set out, amongst other proposals, that packages of care should be delivered to people, *"building first on the available contribution of informal carers..."* (1988, p1);
- The **DHSS White Paper, Caring for People (1989)** was published in response to the critique contained in the above two papers and acknowledged that the great bulk of community care is provided by friends, family and neighbours. One of the six key objectives for service delivery was *"to ensure that service providers make practical support for carers a high priority."* (1989, p5);
- The proposals in Caring for People were implemented in the **1990 NHS and Community Care Act**, which required local authorities to take account of carers when undertaking assessments of need, but nevertheless granted little in the way of a right to their own assessment.

5.2 Indeed, underlying these policy papers and the act, was an assumption that partners, friends and relatives would act as a resource and care for those members of the community who are ill, frail or unable to look after themselves because of a disability. Lobbying from a number of organisations including Carers National UK resulted in the implementation of:

- The **Carers (Recognition and Services) Act (1995)** which granted certain carers a statutory right to an assessment of their needs.

5.3 There were, however, limitations to this act; no rights to services were given to carers, and critically carers could not request an assessment if the person they were looking after had not been assessed or was not undergoing assessment.

5.4 As a result the **Carers National Strategy – Caring about Carers (1999)** was launched with the intention to shift the balance so that carers would not only be recognised, as the 1995 Act set out to do, but also substantially supported and respected, and given access to short breaks from their caring role. The need for

carers to have a short break or respite from caring was also described in the DoH paper, **Taking a Break**.¹

5.5 A challenge to the notion that carers should be seen as a resource came from 1999 **Royal Commission on Long Term Care** which set out its recommendations in that year, of which one was that government should “*ensure that services become increasingly ‘carer blind...’*” In other words, services should be offered whether or not there was a carer available and willing to care.

5.6 Carers were at last given a substantial right to an assessment of their own needs through the **Carers and Disabled Children Act (2000)**, even if the cared for had refused an assessment, provided the person was eligible for a service. But while previous legislation has allowed the carer to request an assessment of their own situation the new **Carers (Equal Opportunities) Act 2004** requires local authorities to inform carers that they may be entitled to an assessment under the 1995 and 2000 Acts.

6. The economic argument for supporting carers

6.1 Society owes a great deal to carers, in that when relatives take on the care of a loved one they save a great deal of tax payers money. In other words, without carers health and social care agencies would have to find huge additions to their already overextended budgets. A report in 2002 stated that in reality carers save the State £57 billion a year, a figure 70% higher than previously estimated.

6.2 This figure, the report notes, should serve as a warning that if only a few carers were to give up caring through lack of support, the economic impact could be dramatic².

6.3 To arrive at a cost of replacing the care provided by carers a new rate of care was calculated at £9.95 an hour³. If the 50,993 carers in East Sussex provided an average of 20 hours a week (see box) the cost of replacement care would be £527,675,564 per year.

Carers have their own health needs

6.4 The Board is aware that carers are often seen as a free ‘good’ or resource, but carers have their own health needs.

Numbers of carers in East Sussex

There are 50993 carers in East Sussex; 10.36% of the population.

- 9700 people are caring for more than 50 hours a week; of these 1821 are not in good health.
- 1177 are young carers under 18 years of age, 179 of these care for more than 20 hours a week.
- 4885 carers are over 75 years
- 125 carers over 85 years care for more than 50 hours a week.

Services for Carers Joint Strategy for East Sussex 2004-6 Census data

¹ Weightman, G (1999) *A Real Break. A guidebook for good practice in the provision of short-term breaks as a support for care in the community*. London: DoH

² Carers UK (2002) *Without Us...? Calculating the value of carers support*. London: Carers UK

³ For details of this costing see Carers UK (2002) *Without Us...? Calculating the value of carers support*. London: Carers UK

6.5 A new study from Carers UK⁴ shows that nearly 700,000 carers reported they were in 'not good health' according to the Census. Nearly a quarter of a million carers providing over 50 hours of care per week said they were in poor health.

6.6 In a national survey of the mental health of carers⁵, almost a third of the sample said their health was only fair or poor. Just over half the sample said that caring made them worried a little of the time and further 18% a lot of the time. A third said that caring made them depressed. (27% a little of the time and 5% a lot of the time) and almost half said caring made them tired with 11% saying it made them tired a lot of the time.

6.7 Thirteen per cent of carers in the sample had consulted a GP about being anxious or depressed or about a mental, nervous or emotional problem in the last year. But significantly, nearly three quarters (72%) had consulted a GP about their physical health at least once in the last 12 months⁶.

The benefits of preventing the breakdown of the caring situation

6.8 Indeed, there is evidence to show that if carers are not supported, not only will their health deteriorate the caring relationship may be at risk. A study in Surrey⁷ showed that 1 in 5 patients were returning to hospital because of the breakdown of the caring situation and not, as one might expect, because of the health needs of the patient.

6.9 As a result, lack of support to carers is highly likely to result in increased demands on health and social care budgets.

7. Local context

7.1 East Sussex has a history of supporting carers; in 1989 government money helped set up the voluntary organisation East Sussex Care for the Carers Council (now Care for the Carers Ltd) which has worked over the years to campaign and give a voice to carers in East Sussex. Many other voluntary organisations including Crossroads, Alzheimer's Disease Society and Mencap have also worked to support the carer and give practical help and a voice in the planning and commissioning of services. Care for the Carers, for example, worked to bring mainstream organisations together to support carers, and in 1994 health and social services signed up to the first countywide Carers Strategy.

7.2 Despite many changes in the structures of both health and social services collaborative working to support carers continues and East Sussex County Council Social Services Department, the NHS Trusts, the four Primary Care Trusts, Education, Districts and Boroughs endeavour to work in partnership with carers and their representatives to commission, develop and deliver social and community care, children's and health services.

⁴ Carers UK (2004) *In Poor Health. The impact of caring on health*. London: Carers UK

⁵ Singleton et al (2002) *Mental Health of Carers*. London: The Stationery Office

⁶ Singleton et al (2002) *Mental Health of Carers*. London: The Stationery Office

⁷ Developing a Whole System Approach to the Analysis and Improvement of Health and Social Care Services for Older People and their Carers: a pilot study in West Byfleet, Surrey. Cited in *Carers Impact in East Sussex, Brighton & Hove. Carers: Partners in Primary Care*.

7.3 The current East Sussex Carers Joint Strategy Action Plan 2004/6 targets are to:

- provide accessible and timely information
- ensure that carers are fully involved at all levels in the strategic development of services
- improve and maximise the recording of carers assessment and their outcomes
- encourage all GP surgeries to have a carers register
- review carer awareness training
- undertake a needs analysis to inform a carers commissioning strategy
- improve, develop & increase a range of reliable, flexible short break services
- develop other services that support carers
- increase awareness of the needs of young carers & develop services to meet those needs
- address the needs of parent carers
- improve carer recognition in the workplace
- implement 'The Carers (Equal Opportunities) Act 2004

7.4 The Joint Carers Strategy and accompanying Action Plan is reviewed annually by the County Carers Strategy Group; this group is chaired by the Head of Policy & Strategy, East Sussex County Council Social Services Department and has the following membership:

- Carers from the Carers Planning & Development Groups, East & West
- Care for the Carers
- Social Services
- Sussex Downs & Weald PCT
- Eastbourne Downs PCT
- Bexhill & Rother PCT
- ESH NHS Trust

7.5 The next sections look at the findings of the Carers' Review.

GPs – RECOGNITION AND SUPPORT FOR CARERS

8. National context

8.1. The General Practitioner and the Primary Care Team play a key role in the life of a carer because, when people are worried about the health of a person close to them, such as a parent, partner, friend or child, often the first to be consulted is their GP⁸.

General Medical Services (GMS) contract

8.2 Recently, major changes have been put in place regarding contractual arrangements for primary care. The GMS contract, implemented in April 2004 as a result of pressure from a demoralised GP workforce, has been referred to as the greatest change to how GPs work within the NHS since 1948;⁹ it is contract between the health service and the practice rather than an individual GP. Benefits to GPs are, amongst other details, increased investment and the right to opt out of out-of-hours responsibility and work.

8.3 Benefits to patients from the GMS contract include a potential wider range of primary care services and evidence-based indicators in the Quality and Outcomes Framework, with an attached financial reward to GPs. The Princess Royal Trust notes¹⁰ that it had been hoped that these indicators would include a “*significant element relating to carers*”. The reality is a weak incentive of 3 points out of a possible 1050 in the quality framework **Management Indicator 9**, which states:

‘The practice has a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment.’

Primary Care Trusts (PCTs)

8.4 All PCTs across England work with local stakeholders (i.e. key individuals and organisations) on a range of issues and through a variety of working arrangements and partnerships¹¹. This might be through Local Strategic Partnerships and community strategies or health improvement plans if locally appropriate.

9. Local context

9.1 There are four Primary Care Trusts (PCTs) in East Sussex; the majority of contracts setting out the services provided by GPs are General Medical Services (GMS) contracts, a minority are Personal Medical Service (PMS) contracts:

- | | | |
|------------------------|-----------------|-----------------|
| • Bexhill & Rother PCT | 12 GP practices | 2 PMS contracts |
| • Eastbourne Downs PCT | 23 GP practices | 2 PMS contracts |

⁸ Kocher, P (1989) *The Information Needs of Older People in East Sussex*. Lewes: Age Concern East Sussex

⁹ e.g. Fradd, S & Cross, J. Eds. (2004) *The Insider’s Guide to the New GP Contract*. Oxford: Radcliffe Publishing.

¹⁰ Keely, B & Clarke, M (2003) *Primary Carers – identifying and providing support to carers in primary care*. London: Princess Royal Trust for Carer. p6

¹¹ See www.dh.gov.uk/PolicyAndGuidance/

- Hastings & St. Leonards PCT 24 GP practices 2 PMS contracts
- Sussex Downs & Weald PCT 22 GP practices 2 PMS contracts

9.2 The key planning tool for local health economies is the Local Delivery Plan which covers all aspects of healthcare management, workforce training and expansion, information support, organisational development, estate management, neighbourhood renewal and community engagement including services to carers.

10. Findings

10.1 There is a view that primary care should have a much stronger and wider role than merely referring carers on to social services. The **National Strategy for Carers (DoH 1999)** for example emphasises that primary care staff should:

- identify patients who are carers and patients who have a carer;
- check the physical and emotional health of the carer whenever an opportunity arises and at least once a year
- tell carers that they can have an assessment of their own needs;
- ask patients who have carers whether they are happy for their health information to be passed on to their carer;
- signpost carers to other sources of support in the community such as voluntary organisations and support groups¹².

The benefits to the NHS and the GP of recognising the carer

10.2 The roles set out above focus on the health of the carer; an important consideration because if carers have to give up their caring role due to their ill health (as discussed in Section 6) the cost to the NHS would be prohibitive.¹³ Support given to carers by the GP and the primary care team, alongside appropriate referral, may also reduce appointment times and prescription medication to carers, although much of the evidence on these points is difficult to quantify and anecdotal¹⁴.

Research findings

10.3 A recent survey by Care for the Carers¹⁵ revealed that the most frequently provided service in the community (36% of respondents) came from the NHS through visits from a District Nurse, Health Visitor or Community Psychiatric Nurse. A survey of carers in touch with a Carers Centre¹⁶ outside East Sussex reported that of 1,346 carers who were caring for more than 8 hours per day;

- 94% helped to ensure that the person cared for took medication;
- 23% changed dressings;
- 13% gave injections.

¹² Also quoted in Keely, B & Clarke, M (2003) *Primary Carers – identifying and providing support to carers in primary care*. London: Princess Royal Trust for Carer. p5

¹³ See *Without Us...? Calculating the value of carers' support..* Carers UK 2001

¹⁴ See for example, Warner, L (1999) *Seven and half minutes is not enough.* London: Princess Royal Trust.

¹⁵ Ross, M (2003) *From Rhetoric to Reality: Are carers getting what they deserve?* Eastbourne: Care for Carers Ltd

¹⁶ Warner, L & Wexler, S (1998) *Eight hours a day and Taken for Granted?* London: Princess Royal Trust for Carers

10.4 But only 33% had received information, training or guidance. Of those carers of working age:

- 71% believed GPs were unaware of carers' needs¹⁷

10.5 The Princess Royal Trust believes that although social services has the lead on carers in local authorities, the NHS and, in particular Primary Care Trusts (PCTs), should lead on issues for carers within primary care¹⁸.

The Quality Outcomes Framework (QOF) assessment

10.6 Since the implementation of the new GP contract each PCT has to do a QOF assessment for each of their practices. An example from one PCT reveals that:

- 17 out of 22 practices are aspiring to management indicator 9 (which asks for a protocol for the identification and referral of carers)
- 11 have an agreed protocol
- 6 (possibly 7) aim to submit an agreed protocol for validation by the end of March
- 3 practices have not yet had a QOF assessment visit. Of these 3, 2 have aspired to management indicator 9 in their pre-visit submission.

The development of a protocol for the identification of carers

10.7 Sussex Downs and Weald PCT and Care for the Carers have developed a protocol to help GPs measure up to Management Indicator 9. This was distributed to GP practices within the PCT on 9 November 2004, together with supporting information about carers and the service offered by Care for the Carers (see Appendix 2). This protocol has now been shared with Bexhill and Rother PCT, Hastings and St Leonards PCT and Eastbourne Downs PCT, who are adapting it for their needs.

10.8 All Sussex Downs and Weald practices responded positively to the initiative and a follow up questionnaire (18 responses out of 22) revealed that:

- 15 practices have a protocol in place.
- 13 have adopted the suggested protocol
- 2 use a different protocol
- 1 aims to have a protocol in place by 1 April 2005
- 2 are not aiming to have a protocol in place by 1 April 2005
- 12 practices responded that they are familiar with the Care for the Carers outreach worker responsible for their area
- 14 practices responded that they do not perceive there to be any barriers to identifying carers
- 1 practice indicated that with new registrations this is not a difficulty but needs to consider how best to identify existing patients.
- There were a few concerns about privacy of the cared for if information is given to the carer

¹⁷ Also quoted in *Caring about Carers*. DoH 1999. Chapter 4 p41.

¹⁸ Keely, B & Clarke, M (2003) *Primary Carers – identifying and providing support to carers in primary care*. London: Princess Royal Trust for Carer

10.9 Four practices indicated that additional PCT support might be helpful and suggested:

- PCT staff might provide more information about carers and Care for the Carers at practice meetings
- Continued support from Care for the Carers who were considered very useful
- Resources to support initiating mechanisms for the identification of carers.

10.10 The PCT recognises that the activities surrounding the protocol of carers have to feed right through individual practices and involve all professionals, including the practice managers and the Primary Care Team, as well as the GP. The PCT intends to support this through general awareness raising and plans to re-visit the impact of the protocol in the future.

Recommendation

- **The excellent carers' protocol devised by Sussex Downs and Weald PCT is regarded as good practice.**
- **PCTs across East Sussex must continue to adapt and promote this protocol to ensure GPs provide a consistent and equitable approach to carers across the county.**

Information in and referrals from surgeries

10.11 It was suggested by carers (see below) that a good GP recognises a carer; however, it was clear to the Board that many carers do not recognise in the first instance that they are carers. For example, one third of the Working Carers focus group had not realised that they were carers until contacted by the Carers' Review.

10.12 In April 2004, Care for the Carers (CftCs) undertook research to quantify what CftCs outreach staff had achieved with GP surgeries, as well as community hospitals and clinics, across the county. All but 9 of the 91 (90%) practices countywide had at least some information in waiting areas, usually CareLine magazine and some Care for the Carer leaflets (N.B. The 91 practices include sub-practices). Thirteen (14%) had designated carers' notice boards, 19 (21%) made pro-active referrals of carers and outreach workers had regular contact with 59 (65%) practices. A handful of practices had been resistant to any contact.

10.13 By December 2004, 3 additional practices had a designated notice board and another had asked for one (3 of these are in Eastbourne, 1 in Seaford). The new Senior Outreach Worker had made contact with 7 practices in Hastings, supplied them with literature and set up referral systems.

10.14 It is important to note, however, that while (19) 21% of surgeries made pro-active referrals of carers to Care for the Carers there was marked inconsistency across the county. For example, in the Bexhill & Rother area 13 out of 20 surgeries (including sub-surgeries) made referrals to Care for the Carers while none were made in the Wealden & Seaford area.

Recommendation

- **In order to address a lack of consistency in provision of support and assistance to carers, all GP surgeries across the county must, as a minimum, provide information from Care for the Carers and Social Services on how to access carer services.**

Local partnership work

10.15 PCTs are working to improve services to carers. For example, there is a carers' section within the Bexhill & Rother PCT local Health Improvement Plan that is linked to and monitored through the Rother Local Strategic Partnership¹⁹. Sussex Downs & Weald PCT considers that a key mechanism to obtain best practice for carers is a carer's action plan being developed as part of its strategic Health Improvement Programme²⁰.

Recommendation

- **PCTs, using their local knowledge and Health Improvement Programme work, must continue to develop the support and services carers need from primary care.**

Encouraging GPs to support carers

10.16 However, to encourage the small number of GP practices that are unresponsive to the protocol to recognise and refer carers on, and unresponsive to putting information in their surgeries the new GMS contract could include a negotiated element of recognition and support for carers. This is because the new GMS contract separates services into three broad categories:

- Essential - which must be provided
- Additional - which most practices will provide
- Enhanced - which are optional

¹⁹ Questionnaire response

²⁰ Questionnaire response

10.17 Enhanced services are of three types:

- Directed Enhanced
- National Enhanced
- Locally Enhanced; that can be developed locally *in response to the needs of patients in the Primary Care Organisation area.*

10.18 The Locally Enhanced Service element of the GMS contract could, therefore, include an enhanced service level to carers. This could include, as a minimum, using a protocol to recognise carers and refer them on to Care for the Carers, and putting carer information in the surgery.

Recommendation

- **The new GP contract, and the Locally Enhanced Services element, should be used to give further encouragement to GP practices to recognise and support carers.**

11. The carer's perspective

The carer's view

11.1 As has already been discussed while the evidence that the Board heard from carers was not from a random sample, the participants attending the four focus groups came from a wide geographical area and range of ages (from 30-80). The carers also cared for children, spouses, partners and parents and included working carers as well as those who cared for many hours a day. The findings also include views from individual carers who contacted the review's project manager.

11.2 There were mixed and wide-ranging views from the sample about support from GPs; the quality of service from GPs to carers appeared to vary considerably. A minority reported that their GPs were excellent and these GPs were praised for their supportiveness and their ability to understand the dynamics of the family and the carer's role. Words used to describe these GPs were '*fantastic*', '*dead lucky to have him*', '*good nursing team*' and '*brilliant*'.

11.3 Positive comments were made about:

- Efficient appointments systems
- A call back service

11.4 But the majority of comments about GPs from carers in this sample centred on GPs failing to recognise and support the carer. Specific comments were made about the following:

- The quality of the service received depends on the assertiveness of the cared for person or carer.
- The receptionist was perceived as a barrier.

- The receptionist could also dictate the sort of service received.
- The GP did not recognise that the person is a carer.
- The GP recognised that the person was a carer but did not fully appreciate what the caring role involved.
- Appointments being offered in working hours (comment from the working carers focus group).
- The GP did not discuss the cared for because of confidentiality restrictions.
- The GP did not make a house call to attend an emergency.
- Concerns about the SEEDOC out of hours service. In particular, carers felt that the knowledge of a person's condition was limited because the out of hours service could not access the patient's full medical history.

Information for carers in GP surgeries

11.5 There was a consensus around the importance of information about caring being available in the GP's surgery, but few could recall seeing carer information. Even fewer had been given information about caring directly by the GP. For example, in the working carers' focus group, none of the carers had been looking for information but nobody had been directed to any information. Significantly, one third of the working focus group had not realised that they were carers until the contact by the review.

Carers' views on improving support for carers by GPs

11.6 The overall consensus from the sample was that what they wanted from their GP was:

- recognition &
- information.

11.7 A common theme through the discussions was that a good GP recognised a carer first and then supported them in their role over the years. It was considered essential that GPs should point them in the right direction to information about services for the cared for and support for them. There was a strong consensus that, at the very least, prominent information on carers and caring should be visible and available in the surgery.

THE CARERS' ASSESSMENT

12. National context

12.1 An assessment is an opportunity for the carer to tell social services about the things that could make life easier for them, including whether they think the person they care for is getting enough help. It is also an opportunity to think about themselves and ask whether they:

- are able to have time for themselves;
- are able to get enough sleep;
- are worried about giving up work;
- have enough information about benefits;
- have enough information about other support in the community;

- and whether their health is affected by their caring situation.

12.2 While this appears to be such a simple thing to do, unfortunately assessments take place in a highly complex political and social policy context both at the national and local level. The following sections set out the legislation and policies that affect both carers and the social service departments that provides the carers' assessment.

Legislation and the Carers' Assessment

12.3 As already discussed, previous legislation has, up to July 2004, allowed the carer to request an assessment of their own situation.²¹ The new Carers (Equal Opportunities) Act 2004 makes three changes to the law.

- First, there is a requirement for local authorities to inform carers that they may be entitled to an assessment under the 1995 and 2000 Acts.
- Second, when undertaking the carers' assessment, the local authority must consider whether the carer works, undertakes any form of education, training or leisure activity, or wishes to do any of those things.
- Third, the 2004 Act provides for co-operation between local authorities and other bodies in relation to the planning and provision of services that are relevant to carers.

Single Assessment Process

12.4 An important national initiative that may have some impact on the Carers' Assessment is the single assessment process (SAP) for older people introduced in the National Service Framework for Older People. The purpose of SAP is to ensure that older people receive appropriate and effective responses to their needs. Guidance²² stresses that:

- Individuals are placed at the heart of assessment and care planning.

²¹ See Section 1 of the Carers Recognition and Services Act 1995 (thereafter the 1995 Act) and Sections 1 and 6 of the Carers and Disabled Children Act 2000 (thereafter the 2000 Act).

²² See Website www.dh.gov.uk/PolicyAndGuidance/

- Care plans or statements of service delivery are routinely produced and service users receive a copy.
- Professionals and agencies do not duplicate each other's assessments.

12.5 The Department of Health advises that assessment systems are based on four broad types:

- **Contact assessment** – where significant needs are first described or suspected
- **Overview assessment** – carried out by qualified professionals, from either health or social services, when it is clear that more than basic personal information is needed to support the older person
- **Specialist assessment** – a way for a number of health and social care professionals to explore specific needs.
- **Comprehensive assessment** – for people where the level of support and treatment likely to be offered is intensive or prolonged, including permanent admission to a care home, intermediate care services or a substantial package of care at home²³.

12.6 See below at 13.1 and 14.14 for the SAP implementation process in East Sussex

Mental Health National Service Framework (NSF)

12.7 The Board looked at the issues for carers of people with more serious or long-term mental health problems. In the past services for people with these problems have been organised separately by the NHS and Social Service. Now specialists in mental health have been brought together to work in teams known as Community Mental Health Teams (CMHTs). Each team covers a different area in East Sussex and they work closely with GPs.

12.8 The Mental Health NSF points out that one quarter of routine GP consultations are for people with a mental health problems and around 90% of mental health care is provided solely by primary care.²⁴ To take account of the pressure on primary healthcare services (mainly GPs) the Joint Commissioning Team for Mental Health in East Sussex is proposing to commission Primary Mental Health Care Teams (PMHCTs) to help address these needs and reduce referral to secondary specialist services.

12.9 Currently, if the person with the long-term mental health problem has a carer the team is expected to make sure that the carer understands the problem and also make sure that the carer has the support that they need²⁵.

12.10 Standard 6 of the NSF states that carers play a vital role in helping to look after service users of mental health services and that individuals who provide regular and substantial care for a person on a Care Programme Approach (CPA) should have

²³ Single Assessment Process. Guidance for Local Implementation. Annex E

²⁴ DoH Modern Standards and Service Models. Mental Health. National Service Frameworks p29.

²⁵ “Your Community Mental Health Team”. Leaflet. East Sussex Social Services. September 2003

- an assessment of the caring, physical and mental health needs, repeated on at least an annual basis
- have their own written care plan which is given to them and implemented in discussion with them²⁶

12.11 See below for East Sussex CHMTs and the assessment of carers' needs. See also the carers' perspective captured at a Day for Carers organised by the Patient & Public Involvement Forum for East Sussex County Healthcare NHS Trust.

13. Local context

The Single Assessment Process in East Sussex

13.1 East Sussex Social Services and East Sussex Primary Care Trust have jointly funded a secondment for two policy officers to support the implementation of the Single Assessment Process (SAP) across East Sussex.

13.2 Because of the way services are delivered in East Sussex SAP is being applied to all adults with complex needs not just older people.

13.3 Currently SAP is being piloted in Eastbourne District General Hospital and Conquest Hospital. In addition, there are SAP pilots in:

- Firwood, Eastbourne involving:
 - Firwood inpatient beds
 - The community rehabilitation service
 - Hailsham II Ward
 - Eastbourne Contact Team
 - Independent Living Team
 - Physical Disability Team
- The Havens Locality. This pilot involves:
 - District Nurses (DN) in 4 different DN Teams
 - Downlands Social Services Team
 - The Community Rehabilitation Team
 - Health Advisor for Older People
- Thornwood Intermediate Care, Bexhill from January 2005. This includes:
 - District Nurses, Social Workers, IRT contact team, community physiotherapy

²⁶ DoH Modern Standards and Service Models. Mental Health. National Service Frameworks Standard 6 p69.

The Carers Assessment in East Sussex

13.4 In East Sussex, the number of informal carers receiving an assessment is measured by counting the number of carers assessed separately + jointly/partly with clients, as a percentage of the total number of clients and carers receiving assessments (the D42 definition). However, there has been a change in the definition:

- **D42 pre 2003 Definition:** The number of carers receiving an assessment as a percentage of the total number of all clients and carers receiving assessments.
- **D42 Post 2003 definition** The number of carers receiving an assessment or review as a percentage of the total number of clients and carers receiving assessments and reviews.

Outcomes for carers

13.5 From the 1st October 2004 the Department of Health now require Social Services to measure carer outcomes as a percentage of the number of Carers' Assessments, and have introduced a performance indicator to measure the number of carers receiving specific carer services. Only two sorts of outcomes count for the purpose of the performance indicator:

- a breaks service; which actually gives the carer a break from direct caring
- other specific services; which can be any service supporting the carer in their caring role e.g. a back care service

13.6 These measurements may make some impact over time on carers being assessed in East Sussex but it is too early to tell.

13.7 Perhaps a key issue with regard to outcomes is whether, in the first instance, a Carers' Assessment has at the very minimum an impact on the cared for person's eligibility for services rather than the presence of a carer actually reducing the cared persons' eligibility. See below at Section 15 for the carers' perception of the Carers' Assessment and its benefits and outcomes.

14. Findings

14.1 The above (at 13.4) means that due to changes in the way that Referrals, Assessments & Packages of Care submission (RAP) counts assessments and reviews, the denominator of D42 for 2003-04 includes more people than in 2002-03, giving lower Performance Indicator (PI) values – the PI is therefore not comparable with earlier years.

A poor comparative performance

14.2 However, performance against D42 in East Sussex has been poor when compared to its nearest neighbouring group of authorities. In 2001/02 East Sussex recorded a figure of 4.9% compared to an average of 20% for the nearest neighbour group and a national average of 23.4%. (It should be noted, however, that Authorities differ in monitoring methods)

14.3 The figures continue to be low in 2003/4 (although the national average for D42 dropped to 20% and the average of a nearby authority dropped to 19%) as the D42 score for East Sussex score dropped to 3.8%. But it must be remembered that using the previous definition of D42, excluding reviews, the D42 score would have actually been over 8%, showing improvement over the score in 2002/3, which was again 4.9%.

Some improvement is being achieved

14.4 East Sussex Social Services Department is working to improve scores. Significantly a case file audit in May 2003 showed that there was much higher level of Carers' Assessment activity than being recorded on Carefirst. Indeed, anecdotal evidence is that during a Community Care Assessment of the service user carers are often assessed. Furthermore, the case file audit showed that the carer's needs had been taken into account when agreeing the careplan for the service user. But, critically, the vast majority of these Carers' Assessments are not recorded on Carefirst.

14.5 However, much work has been done to emphasise the importance of recording the joint assessment of both the carer and the user (i.e. party assessments) and the figures appear to show some improvement.

- In 2002/03 - 530 Carers' Assessments recorded
- In 2003/04 - 676 Carers' Assessments (and carer reviews) recorded
- In 2004/05 - first 9 months 650 Carer Assessments (and carer reviews) recorded

14.6 This means that at 9 months there is a 62% increase on the 6-month figure and that the total is practically the same as the whole of last years total. At ten months into 2004/5 the D42 total at is now running at around 6%. However, it is too early to tell whether any improvements in recording carers' assessments will have an impact on the carers' perception of the Carers' Assessment (see below at Section 15).

14.7 Indeed, the failure to accurately record and complete the number of Carers' Assessments is a major failure, which does not allow the County Council to know whether its actual performance is good or bad. Energy and scarce resources are being invested in simply improving recording accuracy rather than focusing on improving the quality of Carers' Assessments and outcomes (see below at 16).

14.8 It is essential therefore, that rapid progress is made in improving the completion and recording of Carer Assessments so that a real baseline performance can be established.

Recommendation

- **East Sussex County Council needs to make urgent improvements to both the completion and the recording of Carer Assessments.**

Community Mental Health Teams

14.9 A review in 2003 of East Sussex Community Mental Health Teams case files with an identified carer revealed that 66% contained either a completed Carers' Assessment form or evidence that the carer's needs had been assessed. However, the files were not randomly selected so this might have distorted the figures when compared with other teams.

14.10 There was a mixed picture across the county with some areas showing a high number of completed Carers' Assessment forms in the case file review and others with lower numbers of completed Carers' Assessment forms; but these figures may simply reflect the ICT resources of different teams (see paragraph below). Managers are working to improve the performance of teams and to ensure that the Carers' Assessment is part of a holistic approach towards both mental health service user and their carer.

14.11 The Board believes the real issue here is that, when establishing joint/integrated teams between health and social care, both the accountability requirements of the NHS and County Council, and the resourcing of joint systems should be in place to enable the teams to deliver.

14.12 CMHTs currently are required to enter data into two different computer systems. For instance, many CMHT bases do not have access to Carefirst while the priority inputting task is to PIMS (Patient Information Monitoring System) which is the health data base. Teams have also been unsure about the storing of carer information with reference to the latest Information Governance. However, guidance for staff is being produced. The picture is further complicated by a likely merger in the foreseeable future with West Sussex, which has different IT systems which are also incompatible.

Recommendation

- **It is essential that when social care and the NHS work jointly in teams (e.g. the Community Mental Health Teams and the Single Assessment Process) joint computer systems are there to support the frontline staff struggling to meet the performance information needs of both the NHS and social care.**

14.13 On the positive side, there are a number of initiatives funded by the Carers Grant particularly targeted on this group of carers such as the Carers Support and Short Break Service contracted to Rethink which provides two f/t support workers and a budget to fund short breaks (£122,600) short term care for Older People with mental health problems provided by Grangemead (£11,740) and the Minders Scheme run by Lewes and Wealden District Mind which provides an outreach service for rural carers.

14.14 See below for the research done by the East Sussex County Healthcare NHS Trust Patient & Public Involvement Forum on the Carer Assessment in East Sussex

The Single Assessment Process pilots and carers

14.15 The FACE contact assessment form is now in use at Eastbourne DGH and the Conquest. FACE contact assessment and overview assessment documentation is being piloted at Firwood House, Havens Community Team and Thornwood, Bexhill. A new section of the overview assessment, which has a greatly enlarged carer element to it, is currently being agreed by the National FACE user group (see Appendix 3).

14.16 Up to this point it has not been possible to identify how many carers have been involved in the early days of the pilots. Furthermore, there were no mechanisms in place to identify how many carers have been referred on for a Carers' Assessment from Social Services.

14.17 Carers' assessments generated by the use of the new FACE overview process will be monitored once the new version has been adopted. However, it is not clear if the carer assessment generated by the SAP overview assessment leads to an automatic referral to Social Services for a Carers' Assessment.

Recommendation

- **The SAP project managers and the County Carers Strategy Group must liaise to establish the mechanisms needed to ensure automatic referral to Social Services once a carer has been assessed as part of the SAP overview assessment.**

Local research

14.18 A number of local organisations have conducted research on carers' perceptions of the carers' assessment, including:

- Care for the Carers
- Mencap
- East Sussex County Healthcare NHS Trust Patient & Public Involvement Forum

a) Care for the Carers survey

14.19 In late 2002, Care for the Carers included a questionnaire in their bi-monthly magazine, Careline; a total of 123 carers responded. The profile of carers who responded was of a group with an average age of 65, mainly female, with many having serious health problems of their own; 90% reported that they spent more than 90 hours per week caring. Most were looking after husbands, wives, partners or other close family members.

14.20 The findings report that less than half the respondents had received a Carers' Assessment and that just over half of these had felt a benefit to their caring situation, i.e. only one quarter of respondents had experienced an improvement in their caring situation from having a Carers' Assessment. Comments such as "*What is it?*" "*not worth the hassle*" and "*no point*" suggest that a number of carers were uncertain about what a Carers' Assessment is and had little faith in the effectiveness of the

process. The findings indicate that respondents were not routinely offered information on or the opportunity to have a Carers Assessment²⁷.

b) Mencap

14.21 East Sussex Parents Forum set a questionnaire on respite to a total of 950 families on the Disability Index managed by Kites, the Childcare Information Service. The results, published in May 2004 by *Including You* (a biannual newsletter) revealed that while 47.8% had had an assessment, of their own needs as carers, 76.2% of these respondents (i.e. over three quarters) had received no services as a result of such an assessment. Tellingly, 91% of respondents said that they had been close to breaking point as a result of lack of support, including respite.

c) PPI Forum Workshop – “A Day for Carers”

14.22 An objective of the Patient & Public Involvement Forum for the East Sussex County Healthcare NHS Trust (hereafter referred to as the PPI Forum) was to capture the views of carers on the Carers Assessment and deliver the results directly to the Health Overview and Scrutiny Carer Review.

14.23 A “Day for Carers” was devised and held in January 2005 with the aim of gaining the current perspective of local carers caring for older people with mental health problems, and relating especially to their personal experiences of being offered, accessing and benefiting from the carers assessment process provided by services in East Sussex.

14.24 The PPI Forum, working with UserQ and the University of Brighton, also drew up a questionnaire that could be filled in by participants and those carers unable to attend on the day. The sample was small in number (23) but nevertheless it represents a snapshot of people’s views and experiences of caring and being assessed in their own right.

14.25 For the few carers (9) who had been involved in drawing up a care plan, for the person they are caring for, most of them felt they *had* been involved in defining it and were invited to contribute their views, but few felt that within that process of identifying their role as a carer, their own needs had been recognised. 6 had been invited to be involved; 5 had felt able to contribute; only 2 felt that their help as a carer had been considered; only 3 had received a copy of the care plan of the person they care for; 3 were informed it was confidential; only 4 stated they felt that the help they gave had been acknowledged. Therefore more than half of the carers overall (52.4%) felt no recognition or support.

14.26 More than half of the carers questioned (55%) had never heard of the Carers’ Assessment. Of the carers who had heard of the assessment, 4 had heard of it from the mental health team; 5 directly from social services; 2 from a voluntary organisation; 1 from a carers support group and 3 had heard from other sources but did not state what they were. Of those who knew about the assessment only 6 carers had received an assessment.

14.27 Of the 5 carers who answered the question and *had* received an assessment, 2 had only waited two weeks and 3 had waited *more* than four weeks. Of the carers who had *been* assessed 6 had received an assessment at home and 1 in another place but *all* had been assessed in person.

²⁷ See Ross, M (2003) From Rhetoric to Reality: Are carers getting what they deserve? P18-19

14.28 The sample is small, but among those who have had an assessment, 3 out of 7 did not get personalised services in response to the assessment. 5 carers felt they had received a follow up to the assessment but 2 had not. 2 carers felt they had benefited a lot from the assessment; 4 carers felt they had benefited a little and one felt it had made no difference.

14.29 The larger PPI Forum report and its findings form part of the evidence to the HOSC Carer Review and can be found in Appendix 5. However, the report describes a valuable piece of work. It sets out important and complimentary recommendations to the HOSC report and is an example of exceptional collaborative working between carers, users of services, statutory agencies and the voluntary sector. The PPI Forum report should, therefore, be read in its own right.

Recommendations

14.30 Recommendations that take into account the above findings (from a-c) are at the end of Section 15.

15. The carer's perspective

15.1 These findings include views from carers participating in the four focus groups along with individual carers who contacted the Carer Review project manager.

15.2 The overwhelming majority of the sample, plus the individuals contacting the Carers' Review, were disillusioned with the whole carer assessment process; they reported either that they had never heard of a Carers' Assessment²⁸ or did not want an assessment, as they believed they would gain nothing positive from the experience.

15.3 Specific concerns were around:

- not knowing anything about the Carers' Assessment
- insensitive handling of telephone enquiries from carers
- being sent the form by post and being asked to complete it on their own
- a perception that they would not be listened to
- a perception that they would be offered inappropriate services
- not wanting to give any financial information to the assessor
- a perception that having an assessment was an admission of failure
- not wanting to make a 'fuss'

- and a belief that nothing would change as a result of the assessment

²⁸ It is possible that some of these carers may have had an assessment or partial assessment (see above) whilst the client was being assessed but were, perhaps, unaware that they were being assessed at the same time.

15.4 One carer's perceptions are highlighted below.

Case Study 1

Mrs A

Mrs A has cared for her husband, who has multiple health conditions, for over 20 years; he needs 24 hour care. She also has two daughters, one with mental health problems whose children she often has to supervise and care for as well. But she does not want a Carers Assessment (although she believes she might have had one about nine years ago). Her reasons for not wanting an assessment are as she describes

“ I take each day as it comes, but I don't need to be told what I need when I won't get it. It's pointless and waste of my time and theirs. The effort is ten times the productivity of the outcome [...] the consequence is that I've decided not to put in that extra ounce needed [to get an assessment]. People like me live on the edge; I'm on the edge about my husband, and on the edge for myself, and even on the edge when I think about the professionals. I don't need that, I don't need to be told I can't have it, it's too dangerous for my mental health [...] it's too soul destroying.”

15.5 Only two out of all the carers in contact with the Carers' Review said that they had had a positive experience; the experience of one of these carers is highlighted below. In this focus group discussion, the two carers who'd had a positive experience of being assessed had had recent assessments (in the last month) while the other more disillusioned carers had had their assessment some years back (e.g. 4 years and 7 years).

Case Study 2

Mrs B

Mrs B was pleased with the way she had been assessed as a carer. First of all, she had asked why she needed to be assessed because she did not want anything at that time.

“Because I said, well why do you need to assess me, I'm not asking for something, and she said, well no, it doesn't go there, it's just to know my needs, my situation, my background and everything else, so that in the form, it says something like do I need extra help now and she worded it kind of for me, ' no, I don't at the moment, but if I was ill or had to go away, I mean I've got a daughter that lives [abroad], well say I've got to shoot off there, you know, well then the first port of call, is Social Services again. [...] It's a total result and I have no complaints at all. And I've got a [telephone] number because what I really needed was somebody I could call on if I was, needed somebody to talk to, and so I shall call on this, the Social Services, what was it, the Home Care Team. And because I won't keep on with [SS assessor] because she did the assessment and now it's all set up she's not needed. But just anybody on that Team, so they've got phone numbers of friends while I'm away and whatnot. So I can't personally grumble about anything.”

15.6 Despite this example of good practice (above) one of the key findings of this Carers' Review is that carers are distinctly disenchanted with the assessment process. Overwhelmingly, carers in contact with the review reported that they wished to have an assessment of need carried out by someone with whom they could discuss all the issues. Carers reported they prefer face to face assessments, rather than completing a form in isolation or over the telephone. Carers misgivings and lack of confidence in the assessment process would be overcome, they believe, if the assessment were carried out in the presence of a professional.

15.7 Despite this example of good practice (above) one of the key findings of this Carers' Review is that carers are distinctly disenchanted with the assessment process. There was a general consensus from all the evidence received that carers wanted to be listened to and then be given practical help. Assessment was fine as long as it produced results.

Recommendation

- **The Social Services department must radically rethink the way in which the carers assessment process is administered in order to:**
 - **Ensure that carers know where to find information about the Carers Assessment and their rights to it.**
 - **Take account of good practice in assessing carers including a more sensitive approach to enquiries.**
 - **Always provide face-to-face assessment for carers.**
 - **Ensure the process is better understood by carers.**
 - **Ensure the process is explicit.**
 - **Ensure that carers are aware of follow-up processes and reviews.**
 - **Improve the perception that the assessment does not result in any positive support or service.**

HOSPITAL ADMISSION AND DISCHARGE

16. Introduction

16.1 The benefits for the carer of effective discharge are that they:

- feel valued as partners in the discharge process;
 - understand what has happened and who to contact;
 - have the right information, advice & training to help them in their caring role;
 - are aware of their right to have their needs identified and met;
 - consider their views have been used appropriately;
 - feel confident of getting support before it becomes a problem.
- and are given a choice about undertaking a caring role²⁹

16.2 Effective discharge from hospital has become more of a focus with waiting list targets. In addition, delayed transfers of care and inappropriate readmission has led the Government to press for improved discharge, and for hospitals to see discharge as a process, rather than an event, that involves the development of a plan to help the individual from hospital to the best possible setting for them, including their own home. For this to happen successfully both the individual concerned and their carer needs to be involved at all stages and kept fully informed.³⁰ Policies on continuing care have also emphasised that carers be included in the discharge procedure and the Carers (Recognition & Services) Act 1995 and the 1999 Carers National Strategy have given more priority to involvement of carers alongside patients.

17. Local context

A complex geographical picture of health service provision

17.1 There is a complex picture of health service provision in East Sussex with:

a) Four Primary Care Trusts

- Bexhill and Rother PCT
- Eastbourne Downs PCT
- Hastings and St. Leonards PCT
- Sussex Downs and Weald PCT

b) One acute trust

- East Sussex Hospitals Trust providing acute hospital services at:
 - Conquest Hospital, Eastbourne District General Hospital, Bexhill Hospital, Crowborough Birthing Centre, Memorial Care Centre and Uckfield Community Hospital.

²⁹ Health & Social Care Joint Unit Change Agents Team (2003) Discharge from hospital: pathway, process & practice.

³⁰ See Health & Social Care Joint Unit Change Agents Team (2003) Discharge from hospital: pathway, process & practice.

c) One mental health and specialist trust

- East Sussex County Healthcare Trust providing care across East Sussex

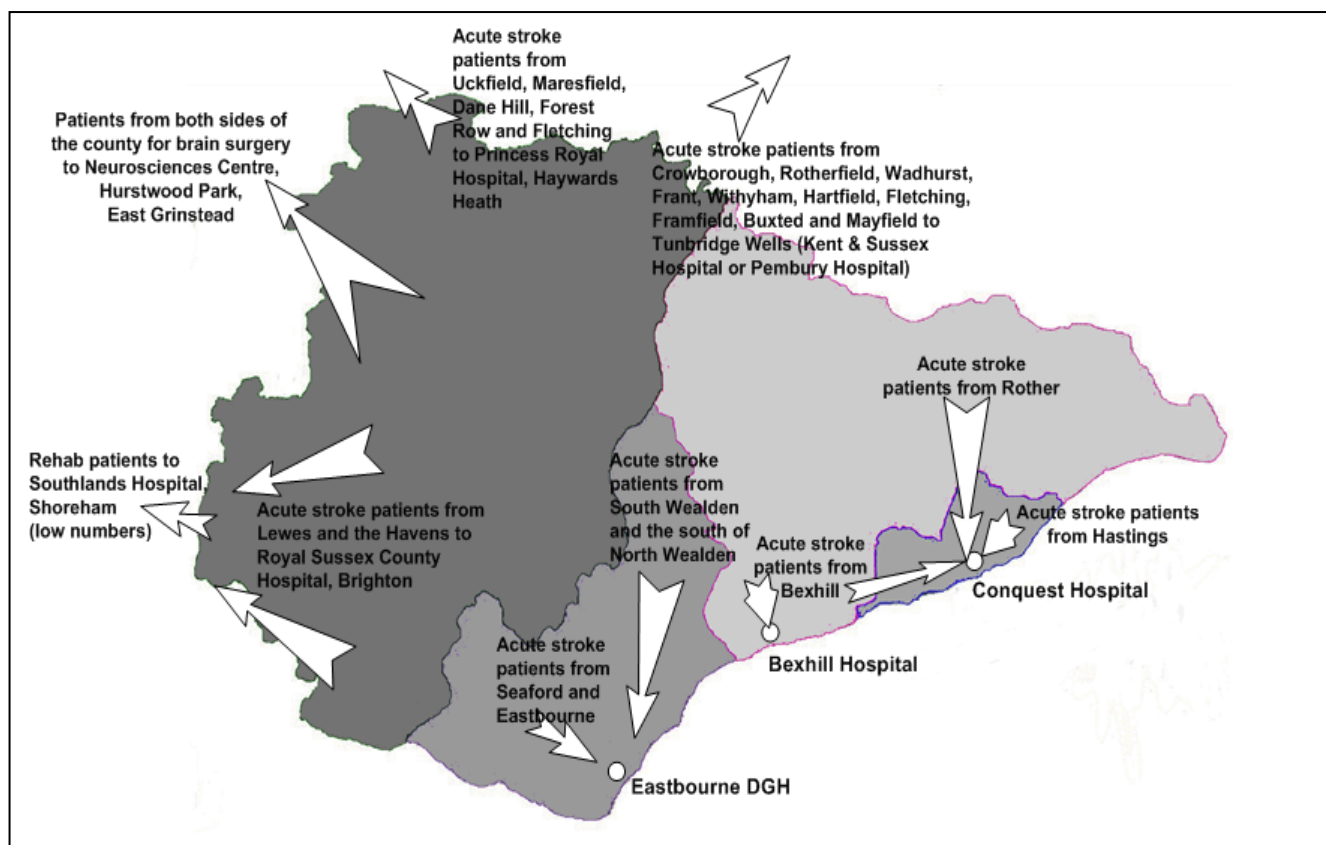
17.2 The complexity of this local health economy is best understood by focusing on one PCT, Sussex Downs & Weald PCT, which runs three local hospitals:

- Lewes Victoria
- Crowborough War Memorial Hospital
- Uckfield Community Hospital

17.3 However, the PCT may use other hospitals for local people within its boundaries, such as Eastbourne DGH, the Kent and Sussex Hospital, Tunbridge Wells and the Princess Royal Hospital in Haywards Heath.

17.4 A map (Fig 1) of stroke patient flows in East Sussex³¹ reveals how hospital treatment is often divided along geographical lines with hospitals outside East Sussex, in Tunbridge Wells, Shoreham, Brighton & Hove City and East Grinstead, providing acute services to the population of East Sussex.

Fig.1 Stroke Patient Flows in East Sussex. *Stroke Services Review, Final Report*



³¹ (2004) *Stroke Services Review, Final Report*. Eastbourne: Clinical Services Review Unit

Partnership working to reduce delayed transfers of care

17.5 The Carers' Review has taken place in the context of a great deal of work being done locally on hospital discharge. Hospital discharge marks the transition of responsibilities between the acute sector, primary care trusts and the local council. Because patients have not always been discharged into the community quickly, and delays have occurred, the government has set up a process of reimbursement (from the local council) to the NHS body, e.g. an Acute Trust.

17.6 A new discharge patient referral allocation process is being developed in East Sussex (since October 2004) at the Conquest Hospital by a jointly funded Operations Manager, building on the learning from the multi-disciplinary team Assessment, Discharge and Partnership Pilot Team (ADAPPT) that was piloted in Eastbourne District General Hospital in July 2004.

17.7 The Delayed Discharge (Community Care) Act 2003 legislation has put greater emphasis on the NHS consulting with both the patient and the carer before referral to Social Services. The hospital and Social Services have to ensure that the needs and views of the carer have been taken into consideration before discharge, i.e., it has to be established that the carer wishes to continue in their role as carer of the discharged patient.

Code of practice for involving carers

17.8 The East Sussex Hospitals NHS Trust has a *Code of Practice for Involving Carers*, which has been evaluated by Bungay & Alaszewski, University of Kent in 2002.³² Their research findings conclude that if the Code of Practice (see Appendix 4) was fully implemented it would address the main concerns and difficulties experienced by carers in hospital and at discharge.

The Care Passport

17.9 The Care Passport is a card designed for carers to record the special needs, preferences, ways of communicating and behaving of the person they look after. When a child or adult with special needs or other disabilities needs to be cared for away from home, e.g. in hospital, they may be unable to communicate in ordinary ways with staff. The Care Passport tells staff exactly what help they need, whether they have problems with making decisions or with communication, and anything else that is important to their well-being.

18. Findings

Introduction

18.1 Admission to hospital can be a frightening experience. Some patients will be prepared because it is a planned admission and everything goes as expected, but for others this is not so. The NHS should play a pivotal role in helping people understand their new situation. Babies are born who are unwell, children are diagnosed with long term conditions, people have head injuries in car accidents, parents become disabled, middle age moves on to older age and frailty - hospitals are often the places where people *become* carers.

³² Bungay, H and Alaszewski, A (2003) *Informal Carers: An Evaluation of their Experiences of Hospital Support*. Canterbury: University of Kent.

18.2 The NHS should also support the carers, who have been caring for some time, whose partner, parent, child or friend is admitted to an acute (or community) hospital. Some of these carers will need more support than before while others just need to be listened to, as they are the experts in communicating and dealing with their cared for who is now a patient. Yet a number of studies cite hospital discharge as “a key point where carers face difficulties”,³³ and that carers often report that they:

- are not listened to;
- do not understand the needs of the person they are caring for;
- are not prepared for the tasks that need to be done;
- have not been informed of the options or the support available in the community.³⁴

Hospital admission

18.3 Senior nurses reported to the Board that when a patient is admitted, especially in an emergency situation, the priorities of the hospital may differ from those of the carer and nurses involved in the immediate treatment of the patient may not follow the *Code of Practice for Involving Carers*.

18.4 If a carer is admitted as an emergency nurses would not necessarily be aware if the patient is a carer, or the circumstances at home, unless the ambulance paramedics informed them.

18.5 Senior nurses also reported that the implementation of the *Code of Practice for Involving Carers* has lost momentum, senior nurses are aware that making sure all frontline staff are alert to the code is an issue.

Recommendation

- **All hospitals serving East Sussex patients should launch (or re-launch) the *Code of Practice for Involving Carers* to ensure it is implemented and put into daily practice at the ward level.**
- **Over time the Code must be monitored rigorously to address carers’ concerns about hospital admission and discharge.**

³³ e.g. Bungay, H and Alaszweski, A (2003) *Informal Carers: An Evaluation of their Experiences of Hospital Support*. Canterbury: University of Kent.

³⁴ See, Bungay, H and Alaszweski, A (2003) *Informal Carers: An Evaluation of their Experiences of Hospital Support*. Canterbury: University of Kent. Henwood, M (1998) *Ignored and invisible? Carers Experience of the NHS*. London: Carers National Association. Kocher, P (2003) *Sit Down and Listen To Me. Focus group study commissioned by the East Sussex Clinical Services Stroke Review Group*. Eastbourne: Eastbourne Downs PCT.

18.6 It was reported to the Board that the East Sussex Hospital NHS Trust is not accepting Care Passports because, in their view, the Single Assessment Process (SAP) does away with the need for this document. The argument against this is that on admission SAP does not offer the same opportunity as the Care Passport for carers to contribute specific and personalised information about the patient.

Recommendation

- **All hospitals serving East Sussex patients, including those where the patient is referred on, must continue to use and promote the Care Passport when a patient is admitted to hospital.**

19. The carer's perspective

19.1 Some carers reported to the Board that they put off going into hospital themselves because they either could not get a firm date for admission, and therefore could not arrange alternative care, or could not find or fund the alternative care needed for the person they care for.

Case Study 3

Mrs C

Mrs C cares for her husband who has Cerebella Ataxia and Renal Failure. She reported that in 1999 she needed her first hip replacement operation but could not find suitable alternative accommodation for her husband. In the end another carer, who had a wife in a wheel chair, came in to her home to care for her husband. After her discharge her daughter, who had just had a baby the week before, came to care for both her father and mother.

Recommendation

- **When carers need to stay in hospital (e.g. elective surgery) all hospitals serving East Sussex patients, the PCTs and East Sussex County Council Social Services Department must support carers' efforts to arrange alternative care including:**
 - **allowing sufficient time to make arrangements;**
 - **arranging appropriate care.**

19.2 Carers of adults with learning disabilities reported that they had very much less opportunity to stay with their 'children' when they are in hospital. Senior nurses concurred that when a patient with learning disabilities becomes an adult, unlike children, there is less access for the carer to be with the patient.

19.3 Carers also reported that they often wished to stay overnight but it was confirmed that there are no beds for carers to stay overnight at the Conquest and limited facilities (away from the ward) at EDGH.

Poor nursing care

19.4 While the Project Board was primarily interested in hospital discharge, carers (including participants of all four focus groups and the individuals who contacted the Review separately) described to the Board a disturbingly negative view of hospital care. Descriptions of poor nursing care included:

- lack of continuity i.e. named nurse never there;
- the carer repeating the same instructions to the staff over and over again because the staff are always different;
- related to the above, too many agency nurses;
- not being allowed to put a notice above the bed saying that the person is a diabetic (because of patient confidentiality);
- (as a result) staff giving sugar to diabetic patients;
- not administering medicines correctly;
- not abiding by dietary requirements of patients (such as no dairy products);
- not feeding the patient;
- not giving enough water to the patient and, as a result, poor mouth care.

Not listening to the carer

19.5 There was a consensus amongst carers that it was hard to get staff to listen to them; they reported to the Board that they had to be assertive to gather information about the person they care for.

19.6 There was a view from those who cared for children and adults with learning difficulties that nursing and medical staff are over politically correct in always referring to the patient, when very often the patient cannot speak or understand without the carer interpreting the situation.

Case Study 4

Mrs D

Mrs D's granddaughter had a lump removed on her eye at the Conquest in mid 2004. On admission she told the admitting nurse that her granddaughter couldn't speak or understand very much but could "talk" to the people she knew. The Staff Nurse came to the bedside and Mrs D began to explain again about her granddaughter but the staff nurse interrupted and said, "No, I must speak to the patient." Mrs D said, "be my guest;" after 5 minutes the Staff Nurse turned to Mrs D and apologised. Everything was fine after the initial rebuff from the staff nurse but Mrs D wished that people would listen to the carer first.

"In every circumstance when you can speak to the patient you should but when it says on the notes you can't and I've just explained that you can't, it's so stressful when they don't look at the notes and don't take any notice."

20. Hospital discharge

20.1 It was reported to the Board that the length of hospital stay is known for many surgical and medical elective conditions, and this information is given to the family and/or carer on admission. Each patient has a board at their bed, which includes the expected day of discharge. However, the decision to discharge remains with the consultant and can still be taken on the day and this can be a surprise for the family/carer. It was reported to the Board that at least half the daily discharges are decisions made on the day. Both senior nurses and the operations manager, cited above, would like to move away from 'same day discharge.'

Delayed transfers of care

20.2 A new referral form is in place, which builds on the ADAPPT system. Once a referral is made to Social Services, the team reviews the carer's situation and ensures that the patient's and carer's needs, wishes and priorities are being placed at the heart of the decisions. Between 01/7/04 and 5/11/04 there has been a reduction in social services assessment related delays (from 9 to 5) and slightly larger reduction in health assessment related delays (from 10 to 3) although it appears that total delays have on average increased slightly (from 25 to 27).

20.3 However patients are being discharged earlier and it is unclear what impact this is having on the carer, as there are no mechanisms to monitor this.

20.4 Carers reported a mainly negative view of hospital discharge. The Board heard of both children and older people being discharged late in the evening and at other inconvenient times.

Case Study 5

Mrs A (continued)

Mrs A, who cares for her husband, also looks after her three grandchildren when her daughter is ill. In 2004 her daughter was in hospital with abdominal pain. Some days later Mrs A was rung to collect her daughter, but Mrs A attempted to refuse this request as her daughter's pain was unresolved and she could not look after her children. Two hours later Mrs A was rung by ward staff to be told her daughter was in the discharge lounge and her bed already in use by another patient. Mrs A got a taxi and collected her daughter who was in the same state as before – Social Services visited 3 months later.

20.5 To improve the situation in hospital the overall consensus from carers was that

- professionals should listen to the carer in hospital and “*at every stage*”

Recommendation

- **In order to improve carers’ experience of hospitals, all hospital serving East Sussex patients must respond to findings identified in this report. These include:**
 - - **Carers being given time to arrange for the discharge of the person they care for.**
 - **Carer’s needs being taken into account on admission and on the discharge of the person they care for.**
 - **Carers being listened to by health care professionals.**
 - **Carers not being required to continually repeat the same information to staff.**
 - **Training being provided by health care staff for new carers.**

RESPIRE

21. Introduction

21.1 Because of the remit of the review the Board has not heard any direct evidence on respite (see 2.3). However, the Reference Group and other individuals and organisations drew the Board's attention to the lack of respite beds in East Sussex.

22. Findings

National research

22.1 While the 2001 Census cannot determine causal links between caring and ill-health there is much evidence around to show that there is a very strong link between caring without a break and ill-health. Carers are twice as likely to suffer from mental ill health if they do not get respite.

22.2 In the national study on the mental health of carers³⁵ 36% of those who provide substantial care and do not get a break suffered ill health compared to 17% of those who had access to a break.³⁶

Local research

22.3 Some recent research³⁷ commissioned by Care for the Carers has shown that out of 152 respondents only 36.8% had some form of respite care. This is similar to the 1990 research data commissioned by Care for the Carers³⁸ which showed that only one third of the respondents had access to respite.

22.4 By far the greatest reason for not taking up respite in the recent Care for the Carers research was availability of beds in East Sussex, much of this being due to the closure of respite care beds in favour of providing intermediate care.

22.5 The importance of respite is further highlighted in a survey conducted by the East Sussex Parents Forum in conjunction with Mencap. 58% of respondents had not had any short breaks in the past six months and 91% had felt close to breaking point.

22.6 Information from the Social Services department shows that the County Council supported Care for the Carers to commission the report, referred to earlier, on respite. Although the survey sample was quite small it revealed what Social Services already knew, that they needed to overhaul the strategy on respite including the completion of a mapping exercise across existing services.

22.7 Plans are in place to review the strategy in the context of developing a comprehensive commissioning strategy for carers' services in general this year (2005). A small sum has been allocated from the 2005/2006 carers' grant to commission a needs analysis to fill in the gaps in current knowledge. From this a commissioning strategy will be produced that incorporates respite but is

³⁵ Singleton et al (2002) *Mental Health of Carers*. London: The Stationery Office

³⁶ Quoted in Carers UK (2004) *In Poor Health. The impact of caring on health*. London: Carers UK

³⁷ Fyvie-Gauld, M (2004) *Respite Care: services for carers in East Sussex*. University of Brighton

³⁸ Frost, P. (1990) *Short Term Care in East Sussex: A study of the experience and needs of carers for the East Sussex Care for the Carers Council*. Eastbourne: Care for the Carers

comprehensive across the full range of carers' support services that need to be prioritised. The Board recognises this is an ambitious timetable but Social Services plan to do this work to inform allocation of the Carers Grant for 2006/2007.

Recommendation

- **Progress in mapping and monitoring of existing respite services leading to a review of the East Sussex Respite Care Strategy should be reported to HOSC in September 2005.**

WORKING CARERS

23. Introduction

23.1 One of the focus groups attended by the Board consisted exclusively of carers working for East Sussex County Council. The idea behind this was to widen the sample frame and contact as many different kinds of carers as possible within the timescale of the Review. The 2001 Census found that over 3 million people combine work with caring responsibilities; that is roughly one in eight workers in the UK, which meant there would certainly be working carers within the ESCC workforce. The workforce was contacted by email and a group of ten working carers met the Board.

24. Findings

24.1 Significantly approximately one third of the group had not realised they were carers until contacted by the Carer Review. Indeed, many carers do not recognise that they are carers; one Carers UK survey found that one in seven carers took ten years to realise that they were a carer, with nearly half (48%) taking two years or more to realise³⁹.

24.2 The consensus amongst the group was that the combination of work and caring could be exhausting but, for the majority, work was seen as a 'lifeline'. Positive comments about work and caring included:

- East Sussex County Council's (ESCC) flexible working system is helpful and appreciated by carers.
- ESCC Counselling services were useful.
- The majority found they received support from their team members and line managers.
- Some carers said that being at work is less stressful than their carer duties.
- Home working was viewed as having potential and it was noted that the working from home pilot is being evaluated.

24.3 Negative comments centred around:

- Health organisations in East Sussex have paid carers leave but ESCC does not.
- Some carers still have to return home at short notice to cope with emergencies
- The approach to carrying time over is inconsistent between managers.
- The majority found they give up leave to carry out their carer responsibilities e.g. taking people they look after to hospital appointments

³⁹ Carers National Association (1992) *Speak Up, Speak Out*. London: Carers UK in Carers UK (2004) *In Poor Health. The impact of caring on health*. London: Carers UK

- They do have to consider reducing working hours to cope with greater responsibilities as a carer
- A minority who worked in departments with long hours culture found their team colleagues less supportive and felt that their career prospects were damaged.

24.4 The general consensus was that working carers would like to be able to have choices over their work patterns and the same rights as those who have young children.

24.5 The Board also recognised and received anecdotal evidence that the situation within the County Council is likely to be similar within many other local businesses and therefore recognises that further work needs to be undertaken across the County by employers.

Recommendation

- **All major employers, including the County Council, should identify how many working carers they employ and address their needs.**

YOUNG CARERS

25.1 Because of the remit of the review (see 2.3) the Board has not heard any evidence on Young Carers.

Recommendation

- **It is recommended that HOSC sets up a separate review on Young Carers to be undertaken at a later date.**

RECOMMENDATIONS SUMMARY

26. Recognition and Support from GPs

- ❑ The excellent carers' protocol devised by Sussex Downs and Weald PCT is regarded as good practice.
- ❑ PCTs across East Sussex must continue to adapt and promote this protocol to ensure GPs provide a consistent and equitable approach to carers across the county.
- ❑ In order to address a lack of consistency in informing carers about support and assistance, all GP surgeries across the county must, as a minimum, provide information from Care for the Carers and Social Services on how to access carer services.
- ❑ PCTs, using their local knowledge and Health Improvement Programme work, must continue to develop the support and services carers need from primary care.
- ❑ The new GP contract, and the Locally Enhanced Services element, should be used to give further encouragement to GP practices to recognise and support carers.

27. Assessment

- ❑ East Sussex County Council needs to make urgent improvements to both the completion and recording of Carer Assessments.
- ❑ It is essential that when social care and the NHS work jointly in teams (e.g. the Community Mental Health Teams and the Single Assessment Process) joint computer systems are there to support the frontline staff struggling to meet the performance information needs of both the NHS and social care.
- ❑ The SAP project managers and the County Carers Strategy Group must liaise to establish the mechanisms needed to ensure automatic referral to Social Services once a carers has been assessed as part of the SAP overview assessment.
- ❑ The Social Services department must radically rethink the way in which the carers assessment process is administered in order to:
 - Ensure that carers know where to find information about the Carers Assessment and their rights to it.
 - Take account of good practice in assessing carers including a more sensitive approach to enquiries.
 - Always provide face-to-face assessment for carers.
 - Ensure the process is better understood by carers.

- Ensure the process is explicit.
- Ensure that carers are aware of follow-up processes and reviews.
- Improve the perception that the assessment does not result in any positive support or service.

28. Hospital Admission & Discharge

- All hospitals serving East Sussex patients should launch (or re-launch) the *Code of Practice for Involving Carers* to ensure it is implemented and put into daily practice at the ward level.
- Over time the Code must be monitored rigorously to address carers' concerns about hospital admission and discharge.
- All hospitals serving East Sussex patients, including those where the patient is referred on, must continue to use and promote the Care Passport when a patient is admitted to hospital.
- When carers need to stay in hospital (e.g. elective surgery) all hospitals serving East Sussex patients, the PCTs and East Sussex County Council Social Services Department must support carers' efforts to arrange alternative care including:
 - allowing sufficient time to make arrangements;
 - arranging appropriate care.
- In order to improve carers' experience of hospitals all hospitals serving East Sussex patients must respond to findings identified in this report. These include:
 - Carers must be given time to arrange for the discharge of the person they care for.
 - Carer's needs must be taken into account on admission and on discharge of the person they care for.
 - Carers must be listened to by health care professionals.
 - Carers must not be required to continually repeat the same information to staff.
 - Training must be provided by health care staff for new carers.

29. Respite

- Progress in mapping and monitoring of existing respite services leading to a review of the East Sussex Respite Care Strategy should be reported to HOSC in September 2005.

30. Working Carers

- All major employers, including the County Council should identify how many working carers they employ and address their needs.

31. Young Carers

- It is recommended that HOSC sets up a separate review on Young Carers to be done at a later date.

32. THE CARERS' REVIEW – final points

32.1 There appears to be inconsistent and inequitable support for carers across East Sussex; it seems to be a matter of luck as to how much recognition, support and services carers received. The QOF Management Indicator 9 is making some impact on GP management systems and should therefore make some difference to the way carers are supported and assessed by their GPs and social services. However, any work to improve numbers of carer assessments in East Sussex could be negated by an almost universal disenchantment with the assessment process.

32.2 While the review has taken place in the context of a great deal of work on delayed transfers of care, and systems are being put into place to reduce these delays, there are no mechanisms to measure the impact of this work on carers. The review was interested in hospital admission and discharge but some of the strongest views the Board heard centred around the experience of being in hospital; a dismal picture was received of neglectful and poor nursing care.

32.3 Above all the carers wanted professionals from both the NHS and social services to listen to them at every stage, and offer appropriate practical help.

Pak 1/3/05/Version 6/post Board meeting

Participants

Appendix 1

Evidence sessions to the Board

Clinical Matrons x 2
Single Assessment Process Managers x 2
Operations Manager, Joint post, Social Services & NHS
PCT Partnerships Manager
Adult Services Manager, Care for the Carers
Head of Primary Care

Telephone interviews/discussions

Directors/Head of Primary Care x 4
Senior GP
PALS, Conquest Hospital
MENCAP
Development officer, VOICES

Face to face interviews/discussions

Head of Policy & Strategy, Social Services
Policy Officer, Carers
East Sussex County Health Care NHS Trust PPI Forum
Care for the Carers
SAP project manager

Focus Groups and Reference Groups

Carers x 37

Carers additionally in contact x 10

**A complete list of evidence received is held at
East Sussex County Council, HOSC Support**

Contact:

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Scrutiny Support Officer
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Lewes
BN7 1SW

Telephone: 01273 481581
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9 November 2004

JB/gmc/SupportingCarers020804

All Practice Managers

Direct Line: 01273 403686

Direct Fax: 01273 403573

E-mail: jessica.britton@sussexdownsandwealdpct.nhs.uk

Dear Colleague

Identifying and Supporting Carers

The new GMS contract includes the following Management Indicator (9) to which many of you have indicated you are aspiring to achieve.

The practice has a protocol for the identification of carers and a mechanism for the referral of Carers for Social Services assessment.

There are three quality points attached to this indicator. The PCT, in conjunction with Care for the Carers, would like to offer some practical support in achieving this indicator in a simple way that best suits the practice.

As such, please find enclosed an information sheet outlining why we need to identify and support carers; the benefits to general practices in doing so; and how to access support for the carer in an easy way.

The Management Indicator requires that the practice should have a procedure for how carers are identified; Read codes can then be used to record this identification.

It also requires that practices have a referral protocol to Social Services for assessment of carers with specific needs.

As you may be aware, once a carer has been referred or has self-referred to the Care for the Carers outreach service, they will ensure that the carer is referred to Social Services for assessment where appropriate. In addition to this, Care for the Carers will provide, or ensure access to, a range of other services, and support to the carer.

In this way, practices need only to make a referral to Care for the Carers and they will ensure access to Social Services assessment. This should be simpler for both carers and practices and will help the carers be better supported in their caring role.

I enclose a draft protocol that meets the requirements of the Management Indicator. Practices are invited to make use of this if they would like to. In addition, may I encourage you to contact your local Care for the Carers outreach worker. They will be happy to offer training, advice, information, easy ways to agree how best to refer and will do this at a time that suits your practice. Contact details are at the end of the enclosed Information Sheet.

I hope this will be useful to practices and please do contact me if you have any further queries.

Yours sincerely

Jessica Britton
Partnerships Manager

Protocol for the Identification of Carers

1 Identification of Carers

- All new patients registering with the practice will be asked if they are a carer.

A carer is a person who looks after someone at home because of their relationship with that person. A carer may be a relative / friend or neighbour and does not always live with the person cared for. A carer is not paid for the care they provide.

- The status of a patient as a carer will be recorded using agreed Read codes. The practice will record this information under the code 'Is a Carer'.
- The practice will ensure that existing patients that are known to the practice as carer have this information recorded under the Read code 'Is a Carer'.
- The practice will ensure that patients whose caring status is unknown will be asked for the information where appropriate. The practice will record this information under the read code 'Is a Carer'.
- The practice will establish a register of carers using the information recorded under Read codes. This information will be collated annually to support an evaluation of how effectively the practice is identifying carers.

2 Mechanism for the referral of Carers for Social Services assessment

- Once a patient has been identified and recorded as a carer, the practice will gain agreement to refer the patient to Care for the Carers.
- Care for the Carers will, in all instances, provide advice and support to the patient in their caring role.
- Care for the Carers will arrange a Social Services assessment if this is appropriate and the patient consents to this action.
- The practice will ensure that identified cases are referred to Care for the Carers in order to meet the requirement for a social services assessment, where appropriate, together with additional advice, support and services.
- Following referral, the practice will record this under the Read code 'Carer Support'.

Table of Codes

	Version 2	Version 3
Is a Carer	918G	UaØVL
Carer Support	807	XaIOA

Ø = zero

O = Capital O

INFORMATION SHEET

Identifying and Supporting Carers

What is a Carer?

A carer is a person who looks after someone at home because of their relationship with that person. A carer may be a relative, friend or neighbour and does not always live with the person cared for. A carer is not paid for the care they provide.

How many people are carers?

In the Census (2001) over 50,000 people across East Sussex identified themselves as carers. However only 10% of these people are known to Statutory and voluntary sector agencies. The government believes that primary care has a key role to play in the identification of carers.

Why identify carers?

Carers provide a great deal of hidden support and care to a huge number of vulnerable, disabled or older people. In addition to this, it is worth noting that there is a growing number of young carers. These are generally children and young people who are caring for a relative at home. Without this care, the burden to the NHS and Social Services would increase enormously. In addition to this, in identifying carers, they can then be referred for the assessment and support they need, and this will help reduce:

- carers' stress and stress related illness;
- risk of back and upper limb injuries by enabling carers to access back care advice;
- the number of carers whose own health is neglected.

Benefits to General Practice

Practices that identify and record carers can refer them to Care for the Carers who will then provide advice, support and referral for assessment where appropriate. Care for the Carers have outreach workers across East Sussex that can provide a direct link to practices.

Practices that identify, record and refer carers will:

- Gain 3 QOF points;
- Gain recognition for the work they do;
- Reduce the incidence of carer related illness;
- Be valued by carers in providing a supportive service;

Carers can be simply recorded using Read codes. We recommend you need only record if the patient *is a carer* and (following referral to Care for the

Carers) **has carer support**. The relevant Read codes are detailed in the attached protocol.

Care for the Carers Outreach Service

Once referred, this service provides:

- Home visits when requested;
- Assessment of carer's needs with the carer;
- Information about local services;
- Referral to services as requested;
- Liaison with Social Services for assessments, OT etc;
- Referral for respite;
- Referral for Back Care Service and equipment loan;
- Referral for Carers' Skills Training Programme;
- Referral for Carers under 19 to Young Carers' Service;
- Help to access benefits for themselves without cared for person;
- Ongoing support for carers, including drop-ins and carers' groups.

To contact your local outreach worker call

01323 738390 (Sussex Downs and Weald and Eastbourne Downs PCTs)
01424 717931 (Hastings and St Leonards, and Bexhill & Rother PCTs)

Care for the Carers are happy to offer training, advice, information, easy ways to refer and will do this at a time that suits your practice.

Electronic copy not available

Please contact:

Sam White
Scrutiny Support Officer
Floor E, East
County Hall
St Anne's Crescent
Lewes
East Sussex
BN7 1SW

Tel: 01273 481581

Email: sam.white@eastsussex.gov.uk

CODE OF PRACTICE FOR INVOLVING CARERS

A carer is anybody who is helping to look after a partner, relative or friend who, because of illness, old age or disability is unable to manage at home without care – Public Health Report 2000.

1. This code of practice aims to operate within the needs of carers, patients and staff and will require ongoing review with staff, clients and all relevant agencies.
2. We recognise that we have much work to do in involving carers in the planning and delivery of services and in evaluating how well we are performing. We would like to see this code used as the basis for ongoing discussion rather than a definitive statement as to what is achievable.
3. Staff will aim to identify the main carer or carers during an initial assessment of the patient's needs. This may be for inpatient care or emergency or outpatient treatment.
4. In the case of inpatients there will be a meeting arranged between the carer and the designated nurse as soon as possible, preferably within 48 hours of assessment. This will be an opportunity to learn about the patient's home circumstances as well as to identify the carer's needs, insight and preferences and expertise in the care of the patient. If a face-to-face meeting cannot be achieved within 48 hours, then the designated nurse on duty will carry out a telephone interview as soon as possible. This will provide essential information for discharge planning.
5. The carer will be given the room to explore what they can or cannot contribute within nursing care. The carer's expectations and concerns should be noted; it is our aim that the carer is welcome to collaborate with staff and can negotiate their input into the care of the patient which will be incorporated into the care plan.
6. Information sharing between nurse, patient and carer will be our goal, which we will incorporate into each ward's philosophy of care with the

aim of involving the patient and carer in all decision making. As the carer will resume responsibility following discharge, it is in everyone's interest to ensure that the carer has the relevant information and skills to manage at home with the appropriate support. This will not only aid patients and carers, but also help to prevent some readmissions. It is important that the views and capacities of the carer be fully documented.

7. Explanation of probable treatment regimes and practices will be given to the carer enabling anxieties and fears to be acknowledged and explored. Treatment regimes seeking to promote independence can seem harsh to patients and carers and cause concern unless properly put in context.
8. All carers will have access to appropriate training in any relevant treatment practices, e.g. giving drinks, helping with correct positioning of specialist feeding techniques.
9. Carers can often have valuable experience of the impact of medication on the person they care for. The type, frequency and administration of medication, especially any form of sedation will be discussed and all appropriate information given by staff. Where medication is given against the judgement of the carer, they will have the right to register this viewpoint in the medical notes.
10. Care for the carer should be incorporated into any treatment of the patient in a holistic manner. The role of the carer should be explored sensitively to ensure that all available help is given to complement their role, both in hospital and in the community. It is the nurses' responsibility to ensure that all available channels of help are discussed with the carer; in the event that the carer wishes to relinquish their role then the final responsibility is with health and social services.