



SUPPORT FOR CARERS

A review by the Health & Adults Services
Scrutiny Committee



September 2010

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Foreword from the Chairman

On behalf of Devon County Council's Health & Adults' Services Scrutiny Committee I am delighted to publish this report. It follows a detailed investigation into support services for carers across Devon carried out by the support for carers task group previously set up by the committee. I would like to thank all those who participated in the process, for their time and effort and continued commitment to helping to shape this review and recommendations for improvement. I would also particularly like to thank our contributors for the detailed evidence they gave to the task group.



A carer is someone who, without payment, provides help and support to a partner, child, relative, friend or neighbour who could not manage without their help. This could be due to age, physical or mental illness, addiction or disability. The carer may be a child, a young person or an adult. Approximately one in ten people in Devon is a carer and approximately two million people move in and out of caring roles every year in the UK. Research carried out before the start of the national Carers Week in 2009 suggested that three out of four carers are exposed to extreme levels of stress and depression as a direct result of caring and that they had been stretched to their limits. Frustration with the bureaucracy of accessing care and benefits and the burden of the role were the most common reasons cited as forcing carers to breaking point.

Being a carer can be an immensely awarding experience but carers need support because taking on a caring role can mean facing a life of poverty, isolation, frustration, ill health and depression. Many carers give up an income, work prospects and pension rights to become a carer or they are trying to juggle jobs with their responsibilities as carers. The majority of carers struggle alone and do not know what help is available to them. Carers say that access to information, financial support and, particularly, respite breaks from caring are vital in helping them manage their roles. The task group is also aware of the changes facing the public sector over the coming years and hopes that the recommendations suggested in this report will be incorporated in any service redesigns.

Conducting this piece of work has been very worthwhile and has engaged a large number of people. We have been able to look at the issues involved in depth and it has been wonderful to see such a high level of dedication and enthusiasm from everyone involved. If we continue to work together and develop even stronger partnerships, we will be able to make significant improvements to support services for carers in Devon.

A handwritten signature in black ink, appearing to be 'A. Boyd', with a large, stylized flourish at the end.

County Councillor Andy Boyd
Chairman, Support for Carers Task Group

Introduction

The government's national carers strategy, *Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own*, was published in June 2008 as guidance. This strategy was underpinned by £255m to implement some immediate steps alongside medium and long-term plans. Commitments in the strategy also included £150m towards planned short breaks for carers, £38m towards supporting carers to enter or re-enter the job market and £6m towards improving support for young carers. Other schemes included the piloting of annual health checks for carers to help them stay well and training for GPs in identifying and supporting them. The strategy also envisaged a more integrated and personalised support service for carers through easily accessible information, targeted training for key professionals to support them and pilots to examine how the NHS can give better support.

The committee undertook some preparatory work on carers support. For example, a task group on mental health services for older people (March 2010) recognised that carers needed to be able physically and mentally to carry out their roles and that they needed support and training. Adequate provision of respite care, stimulation of the cared for person and access to professional medical care also had to be ensured. The task group found a high and unmet demand on respite care as well as advice and guidance on entitlement, help and affordability of individual care solutions. In its final report the group recommended the following:

To emphasise the importance of good communication and supportive relationships with families and to encourage joint decision making between health professionals and carers wherever appropriate.

To increase and secure carer support arrangements and keeping carer support separate from patient support.

The County Council and NHS Devon adopted a ten year carers strategy in November 2009, entitled *Carers at the heart of 21st century families and communities in Devon*. The strategy focuses on the

- a) assessment of carers and review
- b) partnership working
- c) information, advice and support
- d) benefit entitlement advice
- e) finance
- f) access to work and education
- g) access to breaks and leisure

A national demonstrator site for health and wellbeing checks for carers is being developed in which 35 GP practices and ten pharmacies have been taking part from 1 April 2010 alongside other partners such as St Johns Ambulance (see page 8).

Estimates suggest that carers save the UK economy around £87bn annually by relieving pressure on health and social services.

Review approach

Devon County Council's Health & Adults Services Scrutiny Committee established a task group on support services for carers in July 2009 which started its work in February 2010. Members of the group were county councillors Andy Boyd (Chairman), Caroline Chugg, Polly Colthorpe, Debo Sellis as well as South Hams district councillor John Squire and representative of the Devon Association of Local Councils Jenny Roach.

The review of services for carers combined an analysis of available data with hearing a wide range of contributors and carrying out visits. At the first meeting the group agreed to conduct work under the following headings:

- i. respite care
- ii. financial help
- iii. cooperation with professionals, including the role of GPs
- iv. Care Direct
- v. assessment processes and paperwork
- vi. duplication and overlap of services

The task group first reviewed plans and proposals from statutory bodies in Devon in order to establish how they envisaged implementing the objectives set out in the national carers strategy in Devon and how they generally supported carers in their roles. These were:

- Devon County Council's Adult & Community Services directorate
- NHS Devon
- Devon Partnership NHS Trust
- Northern Devon Healthcare NHS Trust
- Royal Devon & Exeter NHS Foundation Trust

During the investigation, the task group collected evidence from the following organisations, groups and individuals:

- Alzheimers Society Plymouth and Kingsbridge Memory Café
- Barnhaven Community Care
- Carers UK
- Carers for people with a learning disability, multiple sclerosis, dementia, mental health problems and addictions
- Cool Recovery
- Crediton Hospital Campaign Group
- Crossroads Care South West
- Cruse Bereavement Care
- Dartmouth Caring
- Devon Carers Link (East Devon VCS, Exeter CVS, Westbank)
- Devon Local Involvement Network (LINK)
- Devon Local Medical Committee
- Hospiscare
- Newton and Noss Carers Support Group
- Princess Royal Trust for Carers
- Saltstone Caring

- Senior Council for Devon
- South Hams CVS
- Taw and Torridge Caring (TTS)
- Totnes Caring
- Unite Carers in Mid Devon
- West Devon Community and Voluntary Services

The task group also considered the following written material:

- Department of Health, *Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own*, 2008
- NHS Devon, Adult & Community Services, *Carers at the heart of 21st century families and communities in Devon*, 2009
- NHS Devon, Adult & Community Services, *Carers at the heart of 21st century families and communities in Devon Action Plan*, 2009
- NHS Devon, Adult & Community Services, *Carers at the heart of 21st century families and communities in Devon*, health and wellbeing check booklet (demonstrator site)
- NHS Devon, Adult & Community Services, *Carers at the heart of 21st century families and communities in Devon*, health and wellbeing check process (demonstrator site)

Findings

In the recent Devon survey of carers, approximately 75% of respondents reported being “satisfied” with the support they received from social services. Within this figure, approximately 32% were “very satisfied”; 6% of respondents were “dissatisfied” and 7% were neither.

CARERS STRATEGY

Carers need individual support and resources in order to carry out their roles successfully. The strategy *Carers at the heart of 21st century families and communities in Devon* was launched in November 2009. Carers emphasised that this document provided a structure and process for influencing decision-making for service planning and changes. The task group highlighted the importance of using plain English and raised concerns over the direct impact of the amount of strategic work on carers. Carers stressed that they required emotional and practical support when they needed it and breaks both long and short term. Carers need to know what services are available, where, when and how to get them.

One contributor highlighted that condition-specific information from the point of view of the carers is not available, i.e. material which would set out typical caring requirements for individual conditions and which could be given to carers at the point of diagnosis of the cared for person. A significant proportion of carers do not recognise themselves as such and the number of carers receiving services was low compared to the overall estimated total in Devon. However, the task group recognised that services cannot be provided for every individual within the current financial framework.

<p>Recommendation 1: That the Public Information Strategy considers how it can respond to the request to produce condition-specific information which describe conditions and typical caring requirements from the point of view of carers.</p>
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Evidence also suggested that resources and services are distributed unevenly across Devon affects carers (e.g. accommodation and support joint strategic needs assessment for adults with a learning disability, 2010). Furthermore, allocating resources needed to take into account sparsity, health inequalities and deprivation as well as population in order to recognise the time and financial pressures on service delivery in rural areas. A long-term vision for service development and maintenance as well as continuity in service provision is crucial in enabling carers to carry out their roles. For example, contributors expressed their lack of understanding as to why office hours of crisis teams vary across the county. Shorter term contracts for provider organisations and staff also result in uncertainty, discontinuity and the loss of knowledge and skills.

The strategic focus should be on building a sustainable infrastructure by e.g. contributing to small local organisations’ administrative costs as well as granting money to individuals and establishing carer involvement on the panels responsible for the distribution of funds. Emphasis should also be laid on early intervention by e.g. establishing counselling and

befriending services for carers to pre-empt crises which carers can access without having to be assessed, referred or signposted.

Recommendation 2: To develop a carers impact assessment for all needs assessments and business plans across statutory bodies, to involve carers in the planning and decision-making processes where appropriate and to strengthen current practice.

Recommendation 3: To encourage partner organisations in the Devon Local Strategic Partnership to develop approaches of assessing impact on carers.

Recommendation 4: To develop early intervention measures and consider how current arrangements for carer involvement and support could best be offered in the future.

National funding

The Princess Royal Trust for Carers found that NHS Devon received allocations from the Department of Health for carers breaks of £679,752 in 2009-10 against zero spent on breaks and £215,000 on carers services. This included support for the Devon Carers Link and GP practices' League of Friends in Exeter as inherited from the former PCT in this area but strict guidelines exist for some Leagues as to how they can use come funds. Consideration should be given to the more flexible use of funding.

The current commissioning aim is to achieve equity across the county with regard to funding and ensuring the right mix of universal, targeted and "fair access to care services" (FACS) for all carers. According to the Princess Royal Trust for Carers, the Department of Health allocated £1,364,910 for carers breaks to NHS Devon in 2010-11. NHS Devon emphasised that these figures might be misleading since the allocations were not ring-fenced and attributing the amount of discrete spend on carers would be more problematic in the future due to personalisation and the move towards outcome-focused contracts. The task group remains concerned that the auditing and funding for carer services by NHS Devon is not transparent. The group also noted similarities in the local distribution of allocations from the Department of Health in relation to the National Carers Strategy, the End of Life Strategy and the National Dementia Strategy.

One provider, Cruse Bereavement Care, emphasised that the Department of Health had ceased national funding for that organisation in 2008-09 and that local authorities and primary care trusts were now administering the non-ring-fenced funding. The charity received no statutory funding in Devon except a training grant from NHS Devon.

Recommendation 5: To allocate funding for their intended purpose locally and to establish an audit trail for all funding which has not been allocated for the intended purpose.

Recommendation 6: To recommend to the Health & Adults Services Scrutiny Committee that a separate task group be convened to review in general the

- a) criteria, choice and priorities in the distribution of funding and resources
- b) impact on services, including voluntary services
- c) impact of the decrease in public spending

Over the lifetime of the Devon carer strategy, the number of carers in different service areas will be projected and aligned with finances and demographics. Members suggested that more work might need to be undertaken to better understand current spending patterns and to inform future projections, especially in the light of the future of public expenditure. The 2010-11 resource allocation process was due to be finalised in May and would inform spending intentions for the current financial year. All new proposals were joint plans between NHS Devon and the adult & community services directorate.

Recommendation 7: To undertake research to establish current spending patterns to inform future projections, especially in the light of the future of public expenditure.

Currently there are no measures for contract monitoring health & social care providers on the implementation and achievement against the Devon carer strategy. There were also no financial allocations from the commissioner and therefore carer services were not reported separately in financial terms.

Recommendation 8: To establish means of contract monitoring on the implementation and achievement against the Devon carer strategy and to support health & social care providers in the implementation of the carers strategy.

Demonstrator site

NHS Devon hosts a demonstrator site for health and wellbeing checks in conjunction with the national carer strategy. 241 checks were made between November 2009 and April 2010 and approximately 500 by the end of June. 35 GP practices are participating in the pilot which also supports research at the University of Plymouth as well as ten pharmacies, St Johns Ambulance and social care providers. All GP practices in Devon have signed up to the quality outcomes framework indicators for carers which provides a process for identifying carers.

DEVON CARERS LINK

Devon Carers Link, a Devon County Council funded service managed by Carers+, a consortium of Exeter Council for Voluntary Service, East Devon Council for Voluntary Service and Westbank, was set up to provide support, information and involvement for carers. Membership of the Link is free and members can get flexible breaks grants as well as a “take a break” sitting service for a maximum of three hours per week which could be spent flexibly over a three-month period for £2.50 per hour (see section on respite care). Carers for people under the age of 18 or carers for an adult aged 18 to 64 with a learning disability or mental health difficulty are not currently able to use take a break.

The Carers Link cooperated with numerous agencies, including GPs, the Parkinson’s Disease Society, the Senior Council for Devon and Care Direct. Work had also started with the Adult & Community Services directorate to review the eligibility of carers to use direct payments for respite care in order to prevent duplication. The Carers Link recognised the importance of providing respite care and was working with commissioners and voluntary sector providers to enhance the provision and use all the involved agencies’ skills and strengths.

Carers emphasised that the Devon Carers Link has been making a very valuable overall contribution to carers' support e.g. in the provision of information, improvement in the access to short breaks and the set up of an emergency alert card scheme.

RESPITE CARE

The quality of life of carers is highly dependent on the quality of life of and the quality of services for the cared for person. The idea of taking time off from caring is often hard for carers. Even though it is essential for their wellbeing, they often feel guilty about leaving their loved ones. Any complication in the process of accessing respite care is therefore doubly painful.

The task group found evidence that access to respite care varied across the county and was generally better in urban areas. The "take a break" voucher scheme which entitled carers to three hours respite per week was viewed as a major improvement but was not sufficient either in rural areas due to the distances and travel times involved or for carers whose level of care was particularly high or stressful. Additional vouchers could be provided at the discretion of a named care professional. The scheme has almost reached capacity, however. Both provision and funding from both the County Council and NHS Devon have grown significantly year on year but cannot keep pace with the growing demand. Therefore, a waiting list will be in operation from the end of September 2010.

Providers of respite care are virtually non-existent in some rural areas as providing services outside the urban centres is seldom profitable. Additional travel costs in rural areas are currently not recognised in the provision of respite care. Voluntary providers currently subsidise schemes in many rural locations where domiciliary care providers do not deliver. The Devon Carers Link does provide, however, provides assistance if carers are experiencing problems choosing a provider.

Some domiciliary care agencies also highlighted that the "take a break" hourly rate is insufficient as it is lower than providers' domiciliary care rate and the administrative overheads are greater. This is even more the case for other, especially voluntary, providers as they do not have a core domiciliary care business to cover the administrative costs for staff recruitment, training, CRB checks etc in order to provide the "take a break" service. Voluntary providers receive a high number of referrals for carer support from the Complex Care Teams, 40% of which will generate no income.

Recommendation 9: To ensure that professional provider organisations do not evade non-profitable duties by passing some domiciliary and respite care to the voluntary sector, especially in rural areas and to review the hourly rate to ensure that it recognises the full cost of delivering the service in rural areas.

The provision of respite care across the county is problematic. For example, contributors emphasised that residential respite accommodation is difficult but necessary for long term carers of people with complex needs and in need of intensive care and supervision, especially if they have behaviour or communication difficulties or suffer from complex conditions. Care in the community is likely to help more people who use services and their carers with less difficult problems but not the more complex cases. Currently there is no respite unit for individuals with complex needs in Northern Devon who must instead

use units in Exeter or the local mental health unit. There is also a shortage of respite beds for people with dementia in the west of the South Hams. Carers also found it difficult to find respite care for their cared for persons aged 40-60 with medical needs – often the only options were hospitals or residential homes for the elderly. Especially due to the shortage in rural areas, accessing respite care is virtually impossible for some carers. Pressure was added as some respite providers do not cater for people with certain conditions and both the carer and the cared for have to feel comfortable choosing a provider. If carers are unable to find personal care for their cared for person, they will not be able to get respite care.

The availability of accurate and local information is also important. Carers reported that some providers suggested to them by statutory bodies did not operate in their area, would not travel a certain distance, did not operate under a certain scheme or could not provide personal care. These problems were exacerbated for residential respite care. Information was also necessary on the impact of unforeseen events. For example, in one case highlighted to the group, a carer on a budget had to pay for emergency respite care after an unexpected hospital stay and this did not help the carer's health and wellbeing.

Respite care should also be bookable in advance to provide security for carers and enable planning, e.g. for holidays. This might mean that additional respite beds needed to be commissioned at peak times. One contributor suggested working in partnership with voluntary agencies or hotels and holiday camps to increase provision.

Recommendation 10: To ensure that the booking system for respite beds suits the needs of carers, e.g. in the longer-term booking of beds.

Domiciliary care

Accessing domiciliary care for the cared for person often stands in a direct relationship to accessing respite care. A number of challenges regarding domiciliary care was highlighted to the task group, including:

- limited choice of providers in rural areas
- low pay, minimal training, lack of career structure, resulting in problems retaining staff and changing carers for individuals
- poor time keeping
- care agencies often run on minimal administration staff, resulting in limited contact, booking and billing options

Recommendation 11: To ensure easy contact with providers and the general satisfaction of people who use services with regard to time-keeping and continuity of individuals' professional carers.

Recommendation 12: To encourage providers to train and manage staff adequately and to agree a training standard for staff with providers.

FINANCIAL HELP

Securing financial stability can be very hard for carers as many give up an income, employment prospects and pension rights to become a carer or are trying to juggle jobs with their caring responsibilities. Financial help is available both for the cared for person and for the carer. The task group found that the granted finances were generally sufficient but response times could be improved. Though the grants may be backdated, delays cause carers undue stress and hardship during the assessment period. Employers need to become more flexible and supportive.

Recommendation 13: To explore how best the County Council and NHS trusts can support staff with caring responsibilities in the workplace and issue information and advice to line managers.

It was highlighted to the task group that cared for persons and carers currently have access to a maximum of four incontinence pads in two different varieties per day which resulted in private purchases of alternative and/or additional pads as the contracted pads do not always provide a suitable replacement; nor is four per day enough. Commissioning needs to be more flexible in order to provide individual solutions.

COOPERATION WITH PROFESSIONALS

Carers reported that their involvement is improving at strategic level but with regard to their involvement with their cared for persons' professional care was still rare. Carers' views and advice should be taken seriously and they should be involved in multidisciplinary team meetings, case conferences, discharge planning, consultation, correspondence etc in relation to their cared for person, subject to the cared for person's informed consent. Achieving improvements for carers as well as the cared for means listening to carers and ensuring that voices are heard across care decisions as well as strategic service design. This is a challenge for commissioners and providers in areas including social care, health, housing and leisure.

One contributor reported that some professionals can by-pass carers when the cared for person is of adult age but does not have the capacity to make their own decisions. A recent assessment was highlighted to the group where the cared-for "chose not to take part in the review" although the person was unable to understand what the assessment was for, communicate any view or understand consequences.

Recommendation 14: To seek an informed consent with every person who uses a service who has a carer so carers can be fully involved in any decision-making process about the cared for person.

Recommendation 15: To highlight carer information in the electronic discharge summaries to GPs.

Partner agencies should consider revising existing information by sharing protocols or developing new ones to facilitate support for carers e.g. the establishment of a database of contacts.

The acute trusts in the Devon local authority area have developed various measures to support carers and recognise that they play a significant role in identifying them. The uptake of support in acute settings was often low, however, because carers were usually preoccupied with organising support for their cared for person rather than themselves. Carers' assessments do not automatically lead to eligibility for services.

Staff were working to improve staff awareness and capacity to engage sensitively with carers and ensure that they were able to offer advice and signposting to relevant information and services if appropriate. For example, "real life" training sessions had been offered in which carers jointly deliver the training. Different Patient Advice and Liaison Services (PALS) also act as the first point of contact for enquiries, raising concerns or making a complaint. PALS staff work with carers to ensure carers' needs are identified, addressed and carers signposted to appropriate support services.

The Royal Devon & Exeter NHS Foundation Trust (RD&E) established a carers issue group in 2009-10 of carers and staff who met every six weeks and set the Trust's agenda in relation to carer support with a direct reporting avenue to the Trust's Board. Issues included the identification of carers by an acute provider and the negotiation of benefits for carers, e.g. reduced cost meals and offers from local traders. The group had also designed a questionnaire to establish if carers and staff shared expectations and assumptions in order to inform policy-making.

<p>Recommendation 16: To establish a group representing carers issues at the Northern Devon Healthcare NHS Trust.</p>
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The RD&E has also included carer and cared for categories in admission documents. Staff engaged with identified carers and referred them to support services if appropriate after having sought the person's informed consent. Carers issues were also included in the handover safety briefings between shifts, together with information about patients' medication and safety risks such as falls. The Trust's 2010-11 priorities for carer support are staff training and discharge planning, including dispensing medicines at the same time as the discharge and timing the discharge better with respect to carers' needs. The Trust already trains all staff with patient contact, including support staff such as porters, and uses techniques such as podcasts and training booths. Work was also continuing to improve carer support prior to admissions.

Despite these examples of best practice, the task group remains concerned about carer involvement in patient care where staff shortages occurred on wards as well as the need to improve information for carers when patients are moved in and between wards. Carers pointed out that fixed dates should be given for any elective surgery they may themselves have so that suitable arrangements can be made for the cared for.

Contributors reported a fragmentation between complex care teams, mental health teams, district nurses, community psychiatric nurses and GPs as well as gaps in the review of care plans, out-of-hours services and the prescriptions of medication. The situation is more problematic in rural areas where staff work in isolation in large areas with limited resources. Hence, a transfer between statutory providers can result in a loss of continuity and sometimes support services. One contributor even reported inconsistencies of statutory service delivery depending on which officer was working on a particular case. It is essential that carers experience a smooth transition from one part of the system to another and achieving this will require joint commissioning across

life transitions, e.g. from childhood to adulthood for young carers and for children with disabilities, hospital admission and discharge as well as at the end of the caring role.

Carers often need to repeat basic information to or within statutory agencies and they reported a lack of pro-activity in both health trusts and adult services. For example, some carers are not told about different allowances to which they may be entitled and some health professionals are not aware of voluntary support services or make inappropriate referrals, e.g. to individual voluntary organisations instead of the Devon Carers Link. More coordination of and communication between service commissioners and providers is therefore crucial.

Although all GP practices in Devon had signed up to the quality outcomes framework indicators for carers which provided a process for identifying carers, contributors highlighted that GPs should act as the first point of contact and the primary source of information. Nevertheless, some GPs were reluctant to develop and improve their services for carers. Carers reported inconsistencies of the provision of carers assessments and the quality of liaison with GPs regarding the cared for person. Best practice guidance, such as the *Supporting Carers: An action guide for general practitioners and their teams* (Princess Royal Trust for Carers, College of General Practitioners) or the Devon Partnership Trust's *Confidentiality and carers guidelines* would provide valuable sources for the improvement of carer support.

Example of best practice: Clyst Caring Friends

Clyst Caring Friends is a registered charity based at Pinhoe Surgery in Exeter offering a befriending service, a day centre at the surgery's second site in Broadclyst, a carer support group, social lunches and drop-in sessions at the Pinhoe site.

The six GPs based at the surgery refer carers to Clyst Caring Friends after seeking the carer's informed consent. Clyst Caring Friends in turn undertook to keep patients' details confidential. GPs at Pinhoe Surgery showed initiative, e.g. carers were specifically marked on the surgery's IT system and were given priority for appointments.

Clyst Caring Friends was also involved in core group meetings once a month which involved GPs, social workers, occupational therapists, district nurses etc to discuss individual patients and their carers using a coordinated approach. A significant number of carers did not readily recognise themselves as such and many were isolated, unmotivated or depressed. Clyst Caring Friends could then access these individuals and their contact details via the GP or the core team. Alternatively, the charity could also raise points about individuals with the health professionals.

Recommendation 17: To suggest to the Local Medical Committee that it raise its members' awareness of how to improve carer support and to highlight Clyst Caring Friends as an example of best practice.

Example of best practice: Hospiscare

Hospiscare provide services for approximately 700 patients at any one time. NHS Devon contributed £1.2m to the organisation's budget of £4.7m. The organisation uses approximately 1,000 volunteers of all age groups whose roles vary from running groups and driving to providing sitting services. Hospiscare coordinates its services with other agencies, e.g. the Peninsula Cancer Network, Macmillan Cancer Support and Dream-

A-Way. The wealth of information and the number of agencies involved confused carers. Hospiscare provided carers with a comprehensive information pack which was being reviewed as carers preferred information on points of contact. The task group commends the organisation's ability to evolve their services in response to carers' needs in a timely manner.

The Devon Partnership NHS Trust established *Confidentiality and carers guidelines* two years ago and the task group recognised the best practice. Contributors have highlighted, however, that mental health professionals should be further trained in applying the guidelines. The Trust endeavoured to involve carers at every stage of patients' pathways but communication gaps occurred in certain areas. A dedicated mental health out-of-hours service would also benefit mental health carers as NHS Direct and Devon Doctors focussed on physical problems and not psychological crises. Carers indicated that they would prefer one coordinator for their own and their cared for person's needs. One voluntary organisation suggested that the coordinating role could be fulfilled by the community matron who would be able to assist with issues such as transport, benefits etc. for both carers and the cared for person. Specialist nurses for specific diseases are also regarded as providing a valuable one-to-one service but they cover large areas, even when available. Services could also be delivered through a "community hub" at the level of a cluster of parishes, such as GP surgeries, supported accommodation or nursing homes. The hubs would be manned by community care workers, supported by volunteers and would have the resources to organise both domiciliary care and respite care locally.

Recommendation 18: To provide coordinated support for carers by named and contactable staff with capacity for visits.

The current strategic commissioning direction of providing more care in the community is not without its drawbacks. Carers felt channelled into specific modes of caring depending on available services or the current strategic direction, e.g. providing more care in the home. Carers highlighted that the redeployment of staff, e.g. from closed residential units or day services as community intervention workers during office hours, meant that they might not be sufficiently equipped with the knowledge and skills needed in the area they are redeployed to.

ASSESSMENT PROCESSES AND PAPERWORK

The task group received evidence that the provision and the quality of information provided at hospitals as well as in primary and social care settings is inconsistent and sometimes irrelevant to the geographical area. The amount of information which needs to be captured on assessment and membership forms can burden carers and, consequently, lead some to disregard paperwork and not use services.

Contributors also reported that the majority of carers describe initial information about services as confusing. However, they stressed that this does not relate to the quality of the information but to the ability of carers to process and understand it, demonstrating the need for face-to-face support, especially for older carers. More clarity is needed on eligibility for assessment and services; the distinction between the assessment of carers and the person cared for; what assessment involves; and its potential benefits.

Recommendation 19: To introduce one-to-one or call-back services to assist carers with paperwork, self-assessments and membership forms if needed.

Care Direct

Care Direct, the “one-stop shop” telephone service provided by the County Council, offers information, advice, signposting and benefit check referrals. A new Care Direct performance regime is being developed which will measure outcomes and how cases are dealt with over time as individuals traverse the care pathway.

The centralised nature of Care Direct creates difficulties for frontline staff in providing more coordinated, creative, tailor-made, local and needs-led support. For example, an agency might not cover a particular village in the area where the organisation operates. Contributors emphasised that providing parish-specific information would save carers as well as agencies time and frustration and the task group noted that as part of the overall Public Information Strategy a community directory is being developed. Parish councils could also be involved in collating relevant information. As an example of best practice, South Hams CVS is currently working with five local voluntary organisations in a joint effort with the Ivybridge and Yealm Complex Care Team to produce a local directory to inform patients, carers and professionals in the area.

Recommendation 20: To develop a locally accurate service directory which provides relevant parish- or postcode-specific information on all statutory and voluntary services across Devon and which can be used by all involved agencies to identify more coordinated, creative, tailor-made, local and needs-led solutions.

Concern was also expressed about people who self-funded care. Individuals who are eligible for adult services received information and help in setting up services while self-funding service users often had to locate information and advice themselves.

Brokerage

Staff involved with the brokerage process need to be sufficiently trained to assess an individual’s needs correctly and in great detail as well as to advise providers of a bid appropriately. The task group noted that work is ongoing to ensure outcome statements are clearer and more focused. Carers reported that the information about clients is often based on inadequate assessments and hence inappropriate outcomes affect clients and families, both in respect of finances and delivered services. One contributor pointed out that telephone assessments could lead to inaccurate results, especially with the elderly, those with hearing difficulties or less articulate people. Assessments are sometimes undertaken without the involvement of carers or families. Contributors also reported that carers’ needs are insufficiently recognised when assessing clients.

Recommendation 21: To involve all carers in all brokerage assessments early on.

The assessment process for services was described to the task group as “long winded and painful” and difficult for a carer to carry out when he or she may already be at breaking point. Contributors felt that it was unnecessarily stressful for carers to have to deal with several operators and multiple stages of the process. The response times could also be improved (see page 10) in order to ensure a timely provision of financial aid, home adaptations and other practical support, especially in end of life care.

Example of best practice: Local Consortia

A local consortium has been planning to restructure Barnhaven Care Home in Bampton near Tiverton. Their model includes voluntary services, e.g. dog walking, shopping etc, for people who needed support in their homes to professional care from local staff as well as residential and respite care in the 15 beds at Barnhaven which could be used flexibly. The establishment of community facilities was also envisaged, e.g. carer support groups and self-contained flats. The consortium believed that generic social care which included children and young people, people of working age and older people applied a more holistic approach to the individual. The Barnhaven model was broad, integrated and diverse and would provide flexible solutions responding to individuals' needs.

The consortium planned ultimately to take the enterprise over and manage it locally but an initial capital investment would have been necessary. Department of Health enterprise funding was not available as the main house was owned and managed by the County Council and the surrounding bungalows by Mid Devon District Council and to pursue a coordinated approach had proved difficult.

Adult & Community Services would not support this model for reasons of viability although a previous similar pilot had been successfully delivered in another area and research demonstrated that the new service model would be more cost-effective. Also, small, local solutions did not match the required economy of scale. For example, the minimum extra care housing Adult & Community Services would support was 50 units.

Recommendation 22: To support local, innovative solutions for service delivery.

DUPLICATION AND OVERLAP OF SERVICES

The wealth of information and the number of involved agencies, voluntary organisations, support groups etc cause confusion, particularly among new carers. Contributors reported, however, that this situation had improved since the establishment of the Devon Carers Link. Contributors also stressed the importance of relevant and local information, particularly in the rural areas. Carers emphasised the importance of establishing more outreach services, including acute services, in the community hospitals.

As well as establishing a directory with locally accurate information, all organisations involved in carer support should be captured with their unique qualities and services in order to establish how they fit together and how resources can be combined or released.

Recommendation 23: To establish how providers can work together and how resources can be combined or released on the basis of the locally accurate service directory (recommendation 20).

One contributor pointed out that independent service providers were not always aware of services offered by fellow organisations and suggested that joint training for all carer support workers across organisations could help to resolve this issue. The Devon Carers Link functioned as a single point of contact but carer support workers often needed to be made aware of this too. It was also hard to maintain up-to-date information about different services and matching appropriate services with individuals.

Conclusion

Through the course of this review, many cases were brought to the task group's attention demonstrating why services need to listen to the family, work together, have a lead person, someone who takes responsibility and who is a *care coordinator*, especially in complex cases. Prompt responses can decrease the distress of families and lead to a better use of time and money for families, providers and commissioners. Contributors also repeatedly expressed the concern that adequate service provision could sometimes only be achieved by articulate and persistent individuals. Carers also need to be equipped with the basic resources, e.g. support by professional staff or sufficient incontinence pads, to enable them to carry out their caring roles.

The task group hopes that by presenting this report and its recommendations to contribute constructively to the improvement of support services for carers in Devon.

Recommendation 24: To recommend to the Health & Adults' Services Scrutiny Committee to request a report on the implementation of the recommendations of the support for carers task group in March 2011 and in regular intervals thereafter.

Recommendation 25: To recommend to the Children & Young People Services Scrutiny Committee to review support arrangements for young carers.

Summary of Recommendations

1	That the Public Information Strategy considers how it can respond to the request to produce condition-specific information which describe conditions and typical caring requirements from the point of view of carers.
2	To develop a carers impact assessment for all needs assessments and business plans across statutory bodies, to involve carers in the planning and decision-making processes where appropriate and to strengthen current practice.
3	To encourage partner organisations in the Devon Local Strategic Partnership to develop approaches of assessing impact on carers.
4	To develop early intervention measures and consider how current arrangements for carer involvement and support could best be offered in the future.
5	To allocate funding for their intended purpose locally and to establish an audit trail for all funding which has not been allocated for the intended purpose.
6	To recommend to the Health & Adults Services Scrutiny Committee that a separate task group be convened to review in general the a) criteria, choice and priorities in the distribution of funding and resources b) impact on services, including voluntary services c) impact of the decrease in public spending
7	To undertake research to establish current spending patterns to inform future projections, especially in the light of the future of public expenditure.

8	To establish means of contract monitoring on the implementation and achievement against the Devon carer strategy and to support health & social care providers in the implementation of the carers strategy.
9	To ensure that professional provider organisations do not evade non-profitable duties by passing some domiciliary and respite care to the voluntary sector, especially in rural areas and to review the hourly rate to ensure that it recognises the full cost of delivering the service in rural areas.
10	To ensure that the booking system for respite beds suits the needs of carers, e.g. in the longer-term booking of beds.
11	To ensure easy contact with providers and the general satisfaction of people who use services with regard to time-keeping and continuity of individuals' professional carers.
12	To ensure that providers train and manage staff adequately.
13	To explore how best the County Council and NHS trusts can support staff with caring responsibilities in the workplace and issue information and advice to line managers.
14	To seek an informed consent with every person who uses a service who has a carer so carers can be fully engaged in any decision-making process about the cared for person.
15	To highlight carer information in the electronic discharge summaries to GPs.
16	To establish a group representing carers issues at the Northern Devon Healthcare NHS Trust.
17	To suggest to the Local Medical Committee that it raise awareness with its members on how to improve carer support and to highlight Clyst Caring Friends as an example of best practice.
18	To provide coordinated support for carers by named and contactable staff with capacity for visits.
19	To introduce one-to-one or call-back services to assist carers with paperwork, self-assessments and membership forms if needed.
20	To develop a locally accurate service directory which provides relevant parish or postcode specific information on all statutory and voluntary services across Devon and which can be used by all involved agencies to identify more coordinated, creative, tailor-made, local and need-led solutions.
21	To involve all carers in all brokerage assessments early on.
22	To support local, innovative solutions for service delivery.
23	To establish how providers can work together and how resources can be combined or released on the basis of the locally accurate service directory (recommendation 20).
24	To recommend to the Health & Adults' Services Scrutiny Committee to request a report on the implementation of the recommendations of the support for carers task group in March 2011 and in regular intervals thereafter.
25	To recommend to the Children & Young People Services Scrutiny Committee to review support arrangements for young carers.

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