

AGENDA ITEM 4

CYP/09/10

Committee: Children and Young People Policy & Scrutiny Committee

Date: 4 March 2010

Review of Carers Support across the area of the South Essex Forum

Enquiries to: David Moses, Head of Member Support & Governance

1. Purpose of the item

The Committee is invited to note the final report (attached) of the review of Carers Support across the area of the South Essex Forum.



Review of Carers Support across the area of the South Essex Forum

November 2009



Essex County Council

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Preface

In December 2007 the Council adopted proposals for the modernisation of the Council's approach to Scrutiny, the aim of which was:

'to ensure the County Council's scrutiny committees are well-placed to adopt a challenging, outward looking approach which focuses on improving outcomes across public services in Essex; and ensuring consistency in approach and resourcing across a strategic scrutiny function, drawing on best practice both internally and externally.'



As the Chairman I have been keen for the South Area Forum to play a full role in this approach.

At its meeting on 6 July we had a very informative presentation about the findings of the refresh of the Joint Strategic Needs Assessment. One of the issues identified was the need for better support for carers across all three districts in the South Area. This is an issue I feel very strongly about and I was keen that the Forum take a closer look. I decided that we would devote the whole of our 2 September meeting to undertake a 'mini' scrutiny. We heard from Statutory Services, service providers and Carers themselves in what I believe was a very successful meeting.

As Chairman of the South Essex Area Forum, I am pleased to present the final report into the findings of the scrutiny. In doing so, I'd like to thank all those who gave their time to present to the meeting, in particular, colleagues from South East and South West Essex NHS, Basildon Crossroads, County Council Adult and Children's Social Care staff, Rayleigh and Rochford Association of Voluntary Services (Young and Adult Carers), Basildon District Young Carers and the two carers who gave their time to be interviewed, Mr Saxton and Mrs Avey, whose input to the meeting was particularly invaluable.

I commend this report to you and look forward to monitoring progress against the recommendations it contains at future meetings.

A handwritten signature in black ink, appearing to read 'R. Howard', with a horizontal line underneath.

Councillor R Howard
Chairman
South Essex Area Forum

Glossary of terminology

CAF	Common Assessment Framework
Crossroads	A charity providing support for carers and the people they care for
ECC	Essex County Council
GP	General Practitioner
JSNA	Joint Services Needs Assessment
NHS	National Health Service
PCT	Primary Care Trust
RRAVS	Rayleigh, Rochford Association for Voluntary Service
SEPT	South Essex Partnership Trust

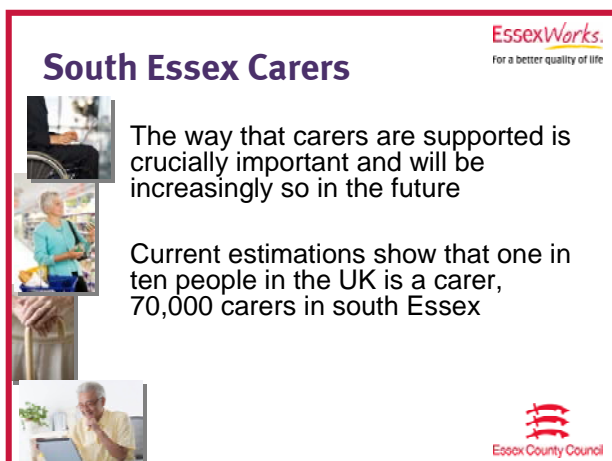
Findings	Recommendations
<p>Finding 1 Caring is a unique, emotional and draining experience requiring appropriate support.</p>	
<p>Finding 2 There are particular challenges and emotional conflicts amongst some residents of south east Essex who are trying to juggle caring responsibilities with commuting into London.</p>	
<p>Finding 3 There are concerns over the number of young carers on waiting lists to receive support.</p>	<p>Recommendation 1 Consideration should be given to the provision of support within schools for young carers who are not able to attend young carer groups. Owner: Executive Member for Education and the 2012 Games Implementation Review Date: April 2010 Impact Review Date: June 2011</p>
	<p>Recommendation 2 Elected Members should visit the Young Carer Clubs to support the young people and the staff, who were providing this vital service Owner: All County Councillors Implementation Review Date: June 2010 Impact Review Date: June 2011</p>
<p>Finding 4 Transport is a particular problem for young carers.</p>	<p>Recommendation 3 Consideration should be given to making the Link Bus available to young carers. Owner: Executive Member for Education and the 2012 Games Implementation Review Date: June 2010 Impact Review Date: June 2011</p>

Findings	Recommendations
<p>Finding 5 A major element of support is simply to provide carers with space to 'be themselves'.</p>	<p>Recommendation 4 The 24 hour Social Care Direct Service which carers use out of hours needs to be promoted more. Owner: Executive Member for Adults, Health and Community Wellbeing Implementation Review Date: April 2010 Impact Review Date: June 2011</p>
<p>Finding 6 Support to adult carers, particularly that given by the NHS could learn from the integrated approach adopted by children's services.</p>	<p>Recommendation 5 ECC Adult Care Services and the PCTs should work together to provide more integrated support to adult carers. Owners: Executive Member for Adults, Health and Community Wellbeing PCT Chairmen Implementation Review Date: June 2010 Impact Review Date: June 2011</p>
	<p>Recommendation 6 ECC and the Primary Care Trusts should give consideration of the need for a 'one stop shop' advice line for carers. Owners: Executive Member for Adults, Health and Community Wellbeing PCT Chairmen Implementation Review Date: June 2010 Impact Review Date: June 2011</p>
	<p>Recommendation 7 Primary Care Trusts should ensure that adequate arrangements are in place to follow up hospital discharges to ensure that adequate arrangements are in place. Owners: PCT Chairmen Implementation Review Date: June 2010 Impact Review Date: June 2011</p>

Introduction

At its meeting on 6th July 2009, Members of the Forum had received a presentation on the Joint Services Needs Assessment (JSNA). This identified the following issues as being shared across the whole of the South Area:

- Ageing population
- Reducing cancer related disease and deaths
- Ensuring good support for carers
- Ensuring all people have healthier lifestyles



South Essex Carers

EssexWorks.
For a better quality of life

The way that carers are supported is crucially important and will be increasingly so in the future

Current estimations show that one in ten people in the UK is a carer, 70,000 carers in south Essex

Essex County Council

In view of the number of carers within the Forum area, as indicated above, a decision was taken to drill further into the support provided for carers to identify whether there were any improvements that could be recommended by the Forum.

Invitations were issued to a number of organisations to provide either written or verbal evidence at the meeting on the 2nd September 2009. This aspect of the meeting took the form of a workshop and included:

- Short presentations from Adults Health and Community Wellbeing, Schools, Children and Families, and Health Services
- Evidence from Carer's support organisations
- Evidence from Carers
- Break out groups
- Plenary to define recommendations

The recommendations from the plenary session were then considered by the Forum on the 16th November 2009 and form the basis for this report.

Forum Members involved in the Review

Essex County Councillors:

- R C Howard (Chairman)
- Mrs I Pummell
- W J C Dick
- Mrs J M Reeves
- A M Hedley
- C G Riley
- S Hillier
- J M Schofield
- B Wood
- Mrs M J Webster
- D Abrahall

Partner Organisations:

Castle Point Borough Council:

- Pam Challis (Councillor)
- Ann Horgan (Councillor)

Basildon District Council:

- Michael Mowe (Councillor)

Rochford District Council:

- T Cutmore (Leader)
- James Cottis (Councillor)

Officer Support

- Sallyanne Thallon - Area Co-ordinator for South Essex (ECC)
- David Moses - Head of Member Support and Governance (ECC)
- Owen Bennett - Committee Officer (ECC)

Information presented at the Forum

Michael O'Brien

Service Development Manager, Essex County Council

The key points of the presentation were:

- Carers are people who spend a significant proportion of their life providing unpaid support to family or potentially friends.
- This could be caring for a relative, partner or friend who is ill, frail, disabled or has a mental health or substance misuse problem
- Current estimations show that one in ten people in the UK is a carer, 70,000 carers in south Essex
- Most carers are aged over 18 and the peak age for caring is 50 to 59 years
- In June 2008 central government released a new carers strategy; This aims to ensure that by 2018 carers will be:
 - ◇ respected as expert care partners
 - ◇ have access to integrated and personalised services
 - ◇ able to have a life of their own alongside their caring role
 - ◇ not forced into financial hardship by their caring role
 - ◇ supported to stay mentally and physically well and that children and young people will be protected from inappropriate caring roles.

A new Essex Multi-Agency Strategy is to be launched on 4th December 2009 as part of the Carers Rights Day. This will encompass all the main elements of the National Strategy.

Carers Strategy

EssexWorks.
For a better quality of life

In June 2008 central government released a new carers strategy;

'Carers at the heart of 21st century families and communities

A caring system on your side, a life of your own'

Essex County Council

The Vision

EssexWorks.
For a better quality of life

Carers will become universally recognised and valued as being fundamental to strong families and stable communities

Essex County Council

Support

EssexWorks.
For a better quality of life

Carers should receive personalised, tailored support to meet their caring role, sustain their own health and wellbeing and to minimise the negative impacts of caring on their lives

Essex County Council

Ashley King, Senior Commissioning Manager, NHS South East Essex.

Within the organisations Strategic Plan there are specific references to Carers and the move to seeing Carers as both key partners and a valuable asset in the delivery of NHS services. The strategy aims to ensure that their needs and wellbeing are recognised, ensuring that they are supported for their own health needs, and enabling them to continue in their caring role. It is considered important that carers are seen as key experts when it comes to providing services to the person for whom they care.

Within the recently published strategic plan a number of specific initiatives have been identified focusing on services to support carers and improve carer awareness.

These initiatives have started with the creation of a local enhanced service for GP practices, at present practices covering in excess of 75% of the population which the we serve have signed up to deliver this enhanced service. The key requirements of this are as follows:

- The creation of a practice based carers register, and the quarterly reporting of this to the PCT. At present this asks practices for the age breakdown of the carer, along with age break down of the cared for and whether it is a physical or mental disability
- A named carer leads within each practice signed up to deliver the enhanced service
- Have a designated up-to-date display area within the waiting area naming the practice carers liaison officer and promoting carers services available nationally and locally
- The aim being to ensure that carers are identified and supported by their general practice at the earliest possible stage, as well as recognition that carers are key partners and providers of care.



This is seen as the first step, and consideration is required as to how this enhanced service can be developed going forward, particularly around the remuneration

aspect and linking payment in some way to the identification of carers. At present it is paid on a capitation basis and lacks a means to incentivise carer identification.

Other initiatives identified within the strategic plan for the period until 2014 explicitly linked to carers are as follows: –

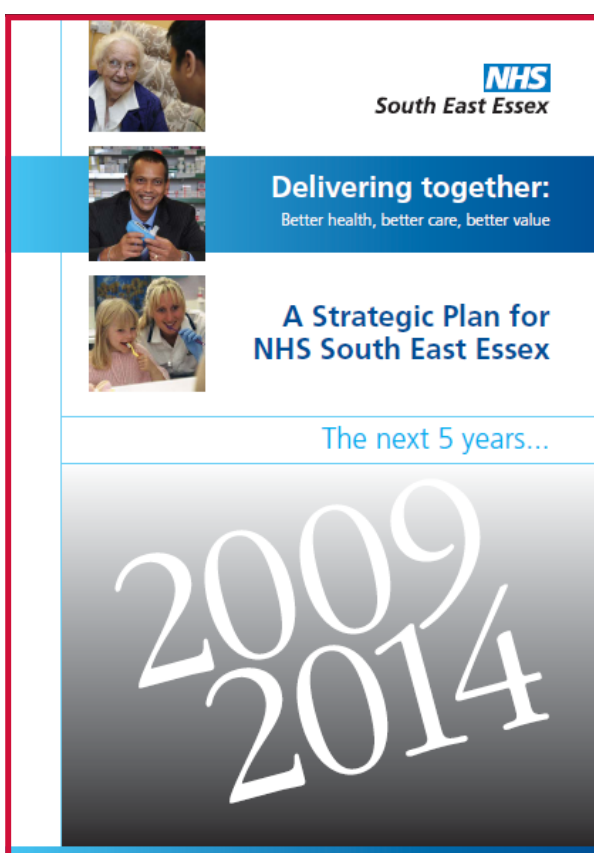
Building on from the practice registers it is envisaged that a further Enhanced Service be developed for GP practices to provide health checks to those carers caring most intensely. There are obvious difficulties in commissioning such a service and work will start soon on how we can best commission this getting best value for the investment identified, pilots are taking place nation wide and the PCT will look to use any learning from these if available.

The PCT also identified initiatives relating to the development or commissioning of expert carers programmes and the development of training programmes for carers leads in GP and hospital teams.

Since the writing of the strategy the local Mental Health Trust in South Essex has received funding from the Department of Health to roll out the new Expert Carers Programme which has been renamed as Caring with Confidence. This is a course with an introductory module, followed by six flexible modules that carers can choose which to attend. There are also requirements to provide online resources and self-study books. The PCT is in contact with the leads within SEPT to understand how the roll out of this programme is going across South East Essex, and whether there are gaps within service provision.

SEPT has also subsequently received funding from the Strategic Health Authority to develop and deliver carer awareness training programmes for staff. This covers their staff and PCT, Acute and GP staff and the aim is also local authority and voluntary sector staff. As such the PCT is currently developing its understanding of what is to be delivered and how this may contribute to delivering the PCT's aim of having training available for GP and Acute carer leads.

The PCT has identified funding for Carers short breaks from 2010/11, and increasing over the following 3 years. It is expected that the PCT will work with both councils operating across the organisations boundaries to plan how to use this resource. It is important that best value is obtained from it and that the services commissioned do not duplicate what is already available through council held carers grants.



In addition to these specific schemes the PCT is currently putting through its governance channels a proposal to develop End of Life Case Management & Co-ordination Services, with one aim being the provision of advice, emotional care and support for relatives and carers at every stage of the process, including support needed after death.

The PCT is committed to working with partner organisations around carers services such as Council bodies and the third sector. Within the unitary authority of Southend the PCT sits on a Carers Strategy Group that has membership from health and social care, and the voluntary sector. I have already discussed with Lynda Hampel the willingness to sit on such a group within the Essex area.


Linda Dowse Head of Integrated Governance and Helen Forster, Children, Young People, Maternity and Women's Services Commissioning at NHS South West Essex.

The presentation detailed current position in NHS South West Essex and in particular the:

- Scoping of current carers groups and contacts.
- Mapping of current contacts in local authorities, other PCTs, service providers.
- Internal Steering group to co-ordinate implementation to Carers Strategy.
- Carers support integral to strategic work streams and initiatives.


The next steps towards delivering the strategy are:

- Finalise scoping and mapping.
- Forge links to all networks/groups.
- Improve information and data on carers to support analysis and future planning.
- Increase number of carers registered.
- Plan and commission services based on carers feedback.
- Sustain work to ensure on going support is provided



South West Essex

- Children and Young People
 - 'Aiming High For Disabled Children'
 - Short Breaks
 - Expert Patient Programme 'Looking After me'
- End of Life Care
 - Linking to Hospices, supporting provision of holistic and therapeutic initiatives for carers .
- Mental Health and Learning Disability
 - Working closely with South Essex Partnership Trusts (SEPT) dedicated team.
 - Training DVDs for professionals to recognise carers and their needs.
 - Development of DVDs for young carers.
 - 'Better NHS Support for carers' - Joint bid with SEPT.



South West Essex

Strategic Plan 2009-2014

Summary



Health in South West Essex
A **Golden** Opportunity

Always putting patients first

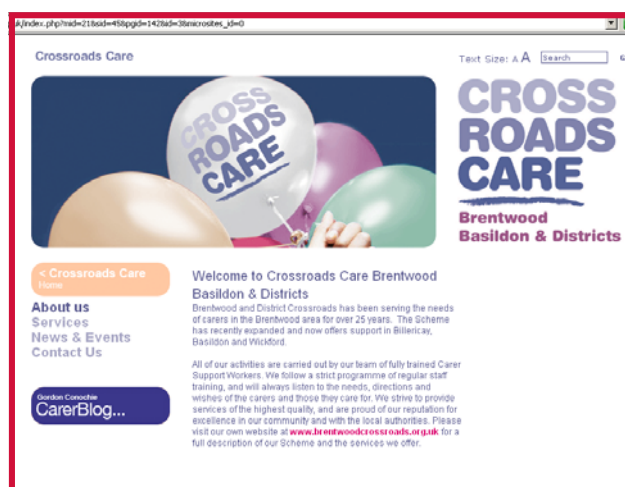
Evidence from Carer's support organisations

Valerie Long, Basildon Crossroads.

The aim of Crossroads is to support carers of all ages. The service provides carers with a much needed break from their demanding roles and helps to alleviate isolation, and reduce stress and depression.

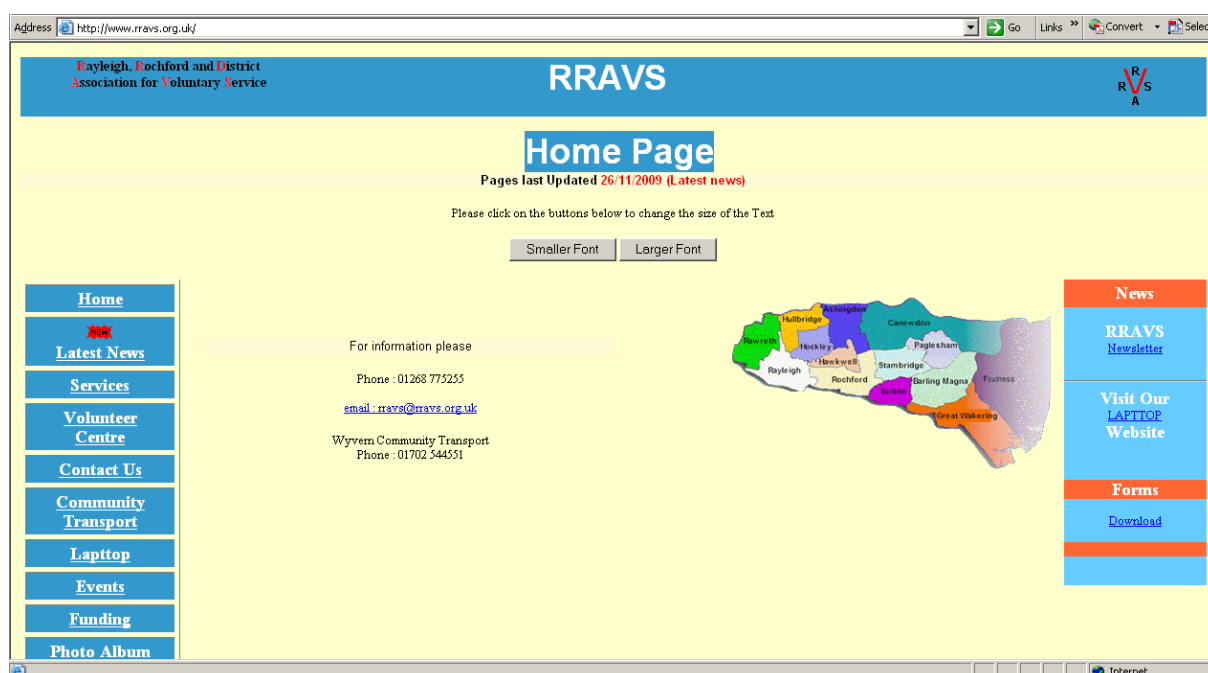
Support is given to carers by providing a sitting service and end of life care by trained carer support workers.

Support is given to carers with children who have a disability. This enables parents to provide some quality time with their other children who may experience feelings of resentment and being left out.



Marion Horsley of RRAVS (Young and Adult Carers)

As from the 1st September carers services across the Rochford District come under Supporting Carers and Families Together.



They run two young carers groups – one in Rayleigh and one in Rochford. At present about 80 children attend the group support. They run sessions and also provide educational activities.

They also take part in the Adventure Island trip run by Essex County Council. We are currently providing support in a secondary school and have just been successful in obtaining funding from the Children and Young Peoples Strategic

Partnership for £36,500 per year for the next two and a half years to provide support in six secondary schools across Rochford and Castle Point and to start up two support groups for families of children with a disability.

Good support is received from Essex County Council with regard to the running of the service.

Following the success of young carers they have now taken on adult carer support within the Rochford District. As with young carers they run two support groups one in Rayleigh and one in Rochford.

They provide trips out and, having consulted with the carers themselves, will be seeking to arrange moving and handling training and to bring in a pharmacist to talk to carers regarding medication.



Zoe Williams, Basildon District Young Carers.

Essex Young Carers was established to support children and young people between the ages of 8-18 years, who may take on a caring role at home. The project aims to provide respite and social development opportunities, as well as ongoing support via a multi disciplinary team.

Basildon Young Carers consists of 2 groups, that meet up on alternative weeks, one week primary (8 – 11) and one week senior (12 – 18).

To be part of Basildon Young Carers, you have to complete a CAF (Common Assessment Framework) form, or Young Carers Assessment form, these forms help the service to provide better support for people.

The service is open all through the year, except bank holidays and Christmas. During school holidays, they arrange trips and special activities, which include:-

- Bowling
- Stubbers Adventure Centre
- spymasters
- drama work shops
- local artist project
- pantomimes
- dance

Basildon Young Carers have the opportunity to gain a variety of qualifications and certificates. The Young Carer staff are professionally trained, and are a friendly and caring team. They can have access to Counselling, Connexions and Advocacy support, helping young people speak out about things that matter to them.

Evidence from Carers

The following recorded evidence was received from two carers who were unable to attend the Forum meeting:

- John Saxton who provided evidence by video - see Appendix 1 for the transcript of this interview
- Mrs Avey who provided evidence via an audio recording - see Appendix 2 for the transcript of this interview

Issues raised by Members of the Forum

- It was asked if Youth Centre runs could be changed to Tuesdays to avoid having to close on Bank Holiday Mondays. Michael O'Brien said that this would not be possible as often other people might be using the venue on the Tuesday.
- Valerie Long said that additional money is needed to get support in schools to get the children who do not come to the Young Carer's Groups. She also confirmed that transport is a huge issue for young carers. Councillor Terry Cutmore said that as the County Council funds the Link Bus, this should be made available to young carers.
- Micheal O'Brien confirmed that carers allowances are lost after retirement age.
- Terry Cutmore said that the number of carers in the region is a great deal more than what we have seen. He wanted to know what work is being done to let carers know that support is available? Michael O'Brien said that from the perspective of young carers, there is a Young Carers Council across Essex. There is also a Young Carers Strategy Group which will meet in the next few weeks. He also said that the Young Carers Council is very strong.
- Councillor Bill Dick expressed concern that there were too many silos with interests in this area. He said that a carers database is needed and that somebody needs to tie everything together. Michael O'Brien said the PCTs needs to engage with the County Council more.
- Councillor Iris Pummell asked if the training programme for carers which Ashley King referred to had been created following consultation with carers. Ashley King explained that the Department of Health has released a national

programme, and the PCT needs to understand if that meets the needs of carers in Essex.

- Councillor Mavis Webster said a Committee with power is needed to make changes to the situation. She also said that Dementia Care groups should also address this Forum. Michael O'Brien said that older carers are a complex group of people with complex needs.
- Pam Challis asked how the County Council's work links into voluntary organisations?
- Michael O'Brien said that Crossroads sit with the development groups. The voluntary sector deliver 60% of services.
- Councillor Brian Wood said that organisations need to get together to do training.
- Paul Warren said that volunteering shouldn't be an 'add-on' in this Scrutiny.

Group discussion

The Forum divided into three groups to consider the following questions:

1. What is it that makes Caring in South Essex a unique experience?
2. What particular support is appreciated by Carers?
3. What single thing would you like to see provided or done differently?

Is Caring in South East Essex a unique experience?

There was general acceptance that caring is a unique, emotional and draining experience, although one of the groups felt that there was nothing unique about south Essex. One group did however identify a problem associated with people who commute into London and give up work to provide care before finding out what services and support are available.

The support that is appreciated by Carers

From the following responses it is clear that Carers appreciate the ability to take time out from their caring responsibilities:

- Being allowed time to live – "Caring for Carers".
- Able to be a young person
- Emotional support to be a person and not a carer
- Time for a break; emotional support

The single thing that should be done differently

The common theme from the following responses was the need for better partnership working between local authority and health services:

- A single contact telephone number needed.
- 'Silo' thinking totally inappropriate.
- Integration of services. One-stop shop needed for advice and resources.
- Means of access to services and support groups

- Emergency plan.
- Single thing – joined up provision.
- Adult care services need to learn from what children's services have done.
- Multi-agency working.
- Assessments take too long.
- Equipment provided by the health services takes too long to provide; and there is no process to return and re-use equipment which is no longer required:

Findings and recommendations

Based on the feed-back from the break-out discussions, Members of the Forum came to a number of findings which resulted in them making the seven recommendations outlined in this section. They were endorsed at the next meeting which was held on 16 November 2009.

Finding 1

Caring is a unique, emotional and draining experience requiring appropriate support.

Finding 2

There are particular challenges and emotional conflicts amongst some residents of south east Essex who are trying to juggle caring responsibilities with commuting into London.

Finding 3

There are concerns over the number of young carers on waiting lists to receive support.

This finding led Members of the Forum to recommend that more support should be given within schools for young carers unable to attend young carer groups.

At the meeting on 16 November it was explained that the Young Carers Clubs provided by Essex County Council take place in the evenings and are split into two different age groups.

These clubs provide Young Carers with space to be themselves and to mix with other Young Carers. Staff provide counselling for the young people who often suffer from stress and access to other professionals who work with young people to support their individual needs.

Elected Members are urged to visit these clubs to demonstrate support for the staff and young carers.

Recommendation 1

Consideration should be given to the provision of support within schools for young carers who are not able to attend young carer groups.

Recommendation 2

Elected Members should visit the Young Carer Clubs to support the young people and the staff, who were providing this vital service

Finding 4

Transport is a particular problem for young carers.

Whilst transport is provided for the Young Carers Club run by the Essex County Council, young carers require transport to voluntary groups for example, scouts and guides.

Recommendation 3

Consideration should be given to making the Link Bus available to young carers.

Finding 5

A major element of support is simply to provide carers with space to 'be themselves'.

Members were concerned that the carers may not be fully aware of the range of support available to them and in particular considered that more could be done to publicise the 24 hour Social Care Direct Service.

Recommendation 4

The 24 hour Social Care Direct Service which carers use out of hours needs to be promoted more.

Finding 6

Support to adult carers, particularly that given by the NHS could learn from the integrated approach adopted by children's services.

Generally Members were more satisfied with the integrated arrangements for supporting young carers than for their elderly counterparts. There were particular concerns that:

- although strategies are in place in the agencies involved, there is a need for clearer individual carers assessments as they are crucial for the wellbeing of carers
- each agency is working with a degree of isolation which can mean duplication of services
- there is a need for more communication between agencies and joint working together including the voluntary sector
- whilst a care package is put in place before patients are discharged from hospital through a joint assessment by the NHS and Social Care, there is a need for better follow up assessments for both patients and carers

Recommendation 5

ECC Adult Care Services and the PCTs should work together to provide more integrated support to adult carers.

Recommendation 6

ECC and the Primary Care Trusts should give consideration of the need for a 'one stop shop' advice line for carers.

Recommendation 7

Primary Care Trusts should ensure that adequate arrangements are in place to follow up hospital discharges to ensure that adequate arrangements are in place.

Conclusion

A recurring theme throughout this scrutiny review is that outlined in finding 1; that Caring is a unique, emotional and draining experience requiring appropriate support. It is therefore important that both the social care and health services provide them with the best possible support that can be provided from the resources available to them.

This report identifies areas where improvements can be made and that some of this can be achieved by making better uses of existing resources through more effective partner arrangements.

Those attending this scrutiny review were impressed by the willingness of those involved to work together towards achieving this. Hopefully the recommendations in this report will be of assistance to them. The report will receive wide distribution and the implementation of the recommendations monitored at a future meeting of the South area Forum.

Appendix 1 - Transcript of the interview with John Saxton

Sallyanne Thallon: *“John could you tell me about your experiences of being a carer for your wife?”*

John Saxton: I have been looking after Chris to an ever increasing extent since the 1980's when Chris was diagnosed with multiple sclerosis. The current situation is that I am looking after doubling incontinent, feeding through a tube into the stomach. Chris can not communicate to me, she has lost the power of speech, and she is in danger all the time of choking. For two reasons the control her breathing is no longer very good and also she tends to drown in her own saliva, so I have a suction machine. Also I have to keep a very close eye on pressure sores actually avoiding any more pressure sores and making sure the dressings and so on are okay on the two existing pressure sores, which are pretty nasty.

Sallyanne Thallon: *“Thank you”*

John Saxton: The other thing is that I do try and go out of my way to keep up social contact with Chris and there is quite a lot of effort involved there in entertaining friends, family and actually in taking Chris out because you can understand with doubling incontinent that poses extra problems and also I have had to purchase an extra suction machine so Chris doesn't suddenly die of [asphyxiation](#) in the car.

Sallyanne Thallon: *“What things have worked well and what things haven't worked so well during the course of your increased burden of care?”*

John Saxton: The thing that has worked best is the Crossroad. They have supplied a wonderful lady always the same person and she is extremely capable. And as she walks through the door I am perfectly happy to just walk straight out. She looks after Chris fantastically well. When I compare that with the Social Services people who came as team after my wife was first sent home discharged from Broomfield Hospital. They were just appalling. Some of them were brilliant, others were awful.

For example she was lying on her back and one of them was trying to give her a drink through a straw so she could choke. I stopped her doing that. She came home with a catheter in and urine bag which is to make things easier for nurses is pretty awful for the patient. One woman was raising her in the bed; it's an electrically operated bed, without bothering to take the load of the full urine bag. It brings tears to your eyes to think about it doesn't it.

This is typical of not only them but also of the hospital ward nurses but I could speak for a couple of hours on the shortcoming of ward nurses. It was quite awful. They would leave her lying in urine and excrement's for hours. She came home with the most dreadful superficial bedsores as opposed to those ones that come through from bones from the inside. She looked like one of those poor folks who had been attacked by an ant farm in the Vietnam War, who will remember those horrible photographs.

She was not washed so she developed eye infections and so on. So I am talking about the hospital treatment, appalling as it was. Although I know you are really interested more on the social service side because I feel that from the patient's point of view and from the carer's point of view we just want a completed integrated

seamless service and what happens is the day you are taken into the hospital as a patient. The hospital call in Social Services and you can tell there is a tension between the two parties' and you are a little tennis ball being knocked between them and it's pretty undignified.

They both want to get you off their patch and off their accounts and as we have all paid in we don't really care where the money is going as long as it does the job properly. We're not really interested in one artificially separated body looking after its own account as oppose to the others.

It should be a general discipline on all spending. Anything else you want to know? I am being quite harsh against the hospitals. A lot of the staff there were wonderful and I feel very sorry for them as they are let down by the lack of discipline from the top on their shoddy colleagues. I think this is coming out in the recent patient association report, showed this.

Sallyanne Thallon: “If you could have one or two things done differently in the way which support is provided for carers, what would they be?”

At the moment I have given up a job that was probably 55 or 60 hours a week I am now doing 168 hours a week, now guess what I would like? I would like a night's sleep. I tried to engage the services of night carers so far they have considered it too daunting. I supposed they are worried about the suction side of things, I don't know, perhaps they are concerned they are not properly qualified to do that. Just having a night sleep is beyond my wildest dreams.

Continuing care, I think it is called continuing care courtesy of the NHS would be wonderful. My GP did try for that and in 2007 a couple of people did turn up from Social Services plus a psychiatric nurse who seem to want to know whether or not my wife was self harming. She could not self harm if you gave her an egg spoon to play with and they told me that I would hear within 3 weeks, I never heard and after 6 phone calls I did write a letter of complaint followed up with the recorded delivery letter of complaint as I have no response from that and I was told that the Social Services record all telephone calls and they had not log any call from me so you can guess I am pretty disappointed and disgusted.

That's where that one stands. I am just desperate for some extra care. If it gives me a day or two off a week just to be able to catch up with my own thoughts and things, my brain is turning to mush, and I am sure there are lots of other people out there saying here here.

Sallyanne Thallon: “Thank you very much.”

John Saxton: Is that all you want?

Sallyanne Thallon: “Unless there are other points you would like to make?”

Well I found equipment services to be pretty good on the whole. They come along and change equipment every now and again. The ripple bed and that sort of thing look after it, but I found there was no feedback system.

I am fairly critical in the best way possible I have use of equipment and I would like to provide feedback so that we can improve things. For example there is a ceiling hoist and it is all over the place and you press the button it goes the wrong way .

Now I think that could be dangerous and at the very least you end up with things all over the soft furnishings if it goes wrong at the wrong moment; so I am fairly disappointed at that and when I have spoken to people who should respond I find they just want to shut me up and tell me there is no problem there is no response at all. At the moment I am waiting for a replacement suction unit.

Now when Chris was last thrown out discharged from hospital. They did not send a suction unit. It was Friday, don't allow a discharge on a Friday, it's awful everything dies for the weekend. The District nurse, bless her, was distraught trying to get a suction machine my wife was chocking I was using an old syringe and a bit of plastic tube to clear her throat .District Nurse was getting distraught contacted Basildon and Queens, they both told us to get lost, she was almost in tears when she rang me and asked me to get back to Broomfield, to the original ward she had just come off, which I did and they said no sorry all have gone.

Any of those outfits should have recognised this was a serious health problem and have done their best to sort it out. To direct us in the right direction instead of just run away from it this is just not what health professionals should do. It doesn't matter what level you are at in an organisation you should do something even if just to it cart it up. The ethos is wrong. I got onto my MP Eric Pickles and the next morning I was being phoned and asked what I wanted and it came the next day. It was a clapped out old thing. I had a nurse come along and explain to me how to use it. I had to explain to her how to do the performance checking of the vacuum and so on she doesn't understand that side of it. So there's not much to it really. It was clapped out, it's been replaced, and it's got to be replaced again because this one has other faults. There is an entire overflow check value missing which I have managed to work around but again not too impressive.

Sallyanne Thallon: "Finally there was a point that when we talked before the interview you said you wanted to make about the wheel chair service."

John Saxton: Wheel chair service. I was offered, Chris was offered that services and I said yes please, 15 months went by and they suddenly turned up out of the blue and said sorry we seem to have lost your record. To be honest I wasn't particularly keen on getting a wheelchair out of the system I mean we had already bought one. I wanted a professional to tell us whether the right shape, size, geometry and so on.

Subsequently the wheelchair turned up and Chris' legs were sticking out miles from it and the young lady who had been the first time said that's funny your wife got very long legs hasn't she. I said it is the same legs as when you have measured her and so it went on they kept coming and going, coming and going, driving back to some remote depot instead of having a van full of tool, equipment and spares which any sensible business would do so they could do it all in one go. So very unprofessional.

I hear the same from other sufferers from around the county. It needs a lot more business. It should be integrated. It is just another part of the equipment service. There is no difference between that and say a speech synthesizer used by someone to hear. Not impressed. I have heard of young children being measured up for a wheelchair and by the time the wheelchair has arrived they have outgrown it. Not clever.

I do apologies this is all very adlib and very last minute because I have taken my wife away for a few days and came back to this request at the last minute. So I

haven't prepared this very well, I do apologies it's rambling but when I was asked could they come and do this I tossed it up in my mind and thought well yes perhaps we can always follow it up plus the fact that I got a repeat prescription I need to have delivered and a letter posted so they can do that for me on the way out please.

Sallyanne Thallon: "Absolutely. Thank you very much for your time."

John Saxton: You're welcome

Appendix 2: Transcript of the audio recording of the interview with Mrs Avey

Sallyanne Thallon: *“Mrs Avey thank you very much for agreeing to talk to us this morning we really appreciate it. Could you tell me a little bit about what your experiences of being a carer?”*

Mrs Avey: Well being a carer I had no idea that it was coming and therefore it was a great shock to me when I found that my husband was had it after a stroke that I would have to do quite a lot for him and as a result of that I sort of tried to sort of get in touch with people to support me.

The first sort of help was at the Lionsday Centre. Harry was placed with the Lionsday Centre for one day a week and as a result of that I used to go down there and meet people there, who were very supportive for both Harry and for myself but I did find in the course of a time, after about I think it was 18 months, I was so worn out with it that more or less finding myself getting quite ill myself which resulted in a near breakdown, but never the less.....

I found also at that time the people at the Lionsday Centre were very very supportive and also there was in fact a group I came to understand it was called a *group for carers* they started to meet once a month and they phoned me and would make arrangements for me to sort of be there if I couldn't get there by car and I found as a group I found that extremely supportive in so far as a learned what can happen in a stroke if it progresses to vascular dementia and also Alzheimer and it was meeting people that in a far worse situation than myself that gave me the support and background that I needed.

First of all, one needs emotional support, one needs physical support and needs to have someone at the end of the telephone that you can call as and when a situation arises when things become extremely difficult because they do as the time progresses things do happen that you don't recognise and you think “Oh my god” how am I going to deal with this and everyone feel slightly afraid in a situation like that.

I found the carers group did help me tremendously in so far as they were there, telephone numbers were exchanged and friendships were made and you didn't feel quite so alone. My family are distant and were unable to help me at that time in the actual care for Harry or for myself for that matter because it became a matter for me also that I needed support and at one time a person I found through the Lionsday Centre and connected to the group was able to help me in a situation in finding respite care for myself or respite for my husband and also allowed me that sort of fortnightly breather that I needed to get things back in kilter. The group itself I found not only made me feel able to continue but also to sort of let me see or understand what is happening and what is likely to happen and how to deal with it.

Without the support of the group and you don't I mean when you go to a groups like that. You are not necessarily indulging in miseries I mean there are things that are worse than you feel yourself but at the same time those people have learned through hard times and I found the whole thing very supportive in so far as we were able to exchange views, make light of something's, go to the nut of the problem by getting in touch with people that matter to help you both physically and emotionally. Emotional support people don't understand is vital, it really is, you can deal with the

physical things but it is the emotional support that the carers needs and the cared for needs and I can not stress that too heavily. People just don't realise, "oh she is dealing very well they say" but on the surface you may appear to be dealing very well but inside you are frighten and it is childish to pretend that your not.

Everybody goes through these periods of needing emotional support and when you become a carer to the point where things start to happen that you don't understand and it's not there for you like it wasn't there for me for quite a long time then I think one should see that groups are needed in the area that you are living in and know that you can reach any one of these people for support and they have been through hell themselves they know what you are about to go through or you are likely to go through and they have been there before so they can help you tremendously.

Sallyanne Thallon: *"Have you found that it's been difficult or easy to get a hold of the information you need around those sorts of services?"*

Mrs Avey: It was very very difficult and if it had not been for a friend of mine that was sort of in the matter of, who had been dealing with people of that kind. I found she was able to put me on to various things. To start with it seems if one has to go through Social Service and that in itself can be very very difficult. You can't always get a hold of the people that you want to deal with or talk too or you get passed off to something else or somewhere else. I think it is vital that there are people available that you can put a question to and they can answer it and not be fogged off by "oh they're too busy or whatever", they may not say they are too busy but you do get that impression that there is plenty of people like you and we have to deal with numbers of people. That's not for you. It's no good for you. You just can not afford to be fogged off at times when things become crucial emotionally and physically for the cared for and I did find that Social Services sometime took quite awhile to organise things.

Sallyanne Thallon: *"Okay and If there was one thing that you would like to see done or done differently what would that be Mrs Avey?"*

Mrs Avey: To make early contact with somebody who matters, who is going to be able to do something for you, be able to do something not only for you but for the cared for. I think if you get in touch with somebody that knows the difference between black and white and doesn't try to fog you off or that will take some time, sometimes it would take a day. I mean why does it take days or weeks in order to get transport say for people for the cared for to go to a day centre and also even to fix up for respite care?

That was something I found rather shocking that respite care can be outside your district and perhaps with people who that are far more along the line of Alzheimer's so that the cared for is placed in a situation where there is no help in so far as he or she is concerned to talk to people, to have their own kind of support and not to have conversation because people there are so far progressed. I think that is something the carer has to care about. Where the cared for is placed and how they are treated and to know that is how it is going to happen, what is going to happen and you need to know the progress of things like that. I mean I know my husband was in a situation where he had no conversation with people simply because they were so far along the line. He had no stimulation at a time when he badly needed it. He came

back from respite centre with less mobility and really worse state in his mind and his memory than he had been before. I mean from his stroke...

Perhaps we are deviating from the programme, are we not?

Sallyanne Thallon: "I think we have probably now covered the points we wanted to cover with yourself. Thank you very much indeed you have been very comprehensive and helpful."

Mrs Avey: I hope I have made it clear that emotional support is vital.

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