

“If it is not good enough for my mother, it is not good enough”

A Debenham Project, NHS Suffolk, & Suffolk County Council
Conference – Workshop
12th June 2015

Post-Conference Report and Conference Digest

Lynden Jackson - Chairman, The Debenham Project

The objectives of the conference were to:

- Increase awareness of what is going on, and what needs doing in Suffolk’s dementia and elderly care support
- Seek suggestions of how we can achieve quality and availability of services across the county
- Ask important questions, concerns, ideas and feedback from the “ground floor”
- Encourage communities, Health, Adult Care, charities, etc. to engage in a coordinated approach

A brief summary of the day:

This one-day conference and workshop presented some of Suffolk’s innovative projects for dementia and elderly care support services, and addressed the challenges facing the county’s health and social care sector. The event involved health and social care professionals, service users, service providers and community leaders. The aims were to question, to inspire, and to create a vision for the provision of quality services that meet the needs of our county’s ageing population.

It also asked for supplementary contributions describing many other initiatives in Suffolk which are supporting those who are trying to cope with the impact of dementia on their lives, and of tackling the problems presented by our county’s ageing population. These are definitely not an “Add-On”. They describe how more groups, communities, and ad hoc initiatives are coming together to make a difference. **I encourage you to explore (and thank them for) what they have already achieved with the enthusiasm of wanting to “get on and do something”.** [These contributions can be found here.](#)

The event was jointly organised by The Debenham Project, NHS Suffolk (IESCCG & WSCCG), and Suffolk County Council (ACS). Very special thanks are due to Isabel Cockayne and Carla Pinto for all their hard work in managing and coordinating the occasion – and for constantly reassuring me that it “will all be ok on the day” – which it was!

The programme:

- 9.00 **Registration**
- 9.25 **Welcome** – Lynden Jackson, The Debenham Project
- 9.30 **Opening remarks** – Alan Murray, Chairman, Suffolk Health and Wellbeing Board
- 9.40 **Session 1 – “Making a difference for those who are coping with dementia in Suffolk”** –
Chaired by Professor Alistair Burns, National Director for Dementia - NHS England
- 11.00 **Coffee**
- 11.20 **Session 2 – “Caring for those who are growing old in Suffolk”** - Chaired by Professor John Young, National Director for the Frail Elderly – NHS England
- 12.40 **Lunch**
- 13.40 **Session 3 - National perspectives** - Alistair Burns and John Young - NHS England
Panel discussion and question time
- 15.00 **Tea**
- 15.10 **Session 4 - Table-top discussion and response**
- 15.45 **Closing address** –

The format consisted of a morning of two sessions, each chaired by a National Director of NHS England, and comprising a total of six key presentations related to critical questions for the future of health and social care in Suffolk. The abstracts and presentations [can be found here](#).

The afternoon was devoted to our guests – “the senior wizards” of the NHS - talking about the national perspectives, and leading a question-time and discussion which brought together key people in Suffolk who can influence and make a difference. The video of the discussion [can be found here](#).

As is often the way of these things, running out of time, proceedings had to be drawn to a close without the final table-top discussion. We also had problems with the sound and lighting for the panel question-time which certainly detracted from the frank and valuable insights and comments from some of the key players in Suffolk’s health and social care scene. We have asked everyone to input their ideas, questions, concerns, and feedback so that we can ensure that all who attended will have an input to the critical debate of how we can achieve the aspirations of providing the highest quality care and support for our elderly and frail members of the population within an increasingly restricted financial environment. We have already received over 28 responses – everyone of which I have read with interest, and, certainly “taken on board”. All the responses [can be found here](#) and I hope that anyone who feels that they also have ideas, questions, and concerns will let me know. You will see that I have, in many cases, sought to provide my personal comments. Where there is a specific question, I have asked for a response from the relevant person.

My report:

This brief report is my personal assessment of the day. It is based upon comments made to me during the event and since, conversations with Alistair Burns, John Young and many (difficult to estimate numbers, but certainly more than 25) other participants, the contents of the feedback responses, Alistair and John’s blog, and my own personal impressions. I hope that it reflects your individual and organisational impressions of the day – please do not feel reluctant to add your

comments. I apologise in advance if I have missed a key point that was raised and must be included in the debate of how to respond to the increasing needs of Suffolk's ageing population.

It seeks to address the following questions:

Did the event meet its objectives as described above?

To increase awareness of what is going on, and what needs doing in Suffolk's dementia and elderly care support. There is little doubt that by lunchtime most of those who attended were saying that they had been, in some way, unaware of all that was going on and that they found the presentations not only informative but in many cases "inspiring". It also provided a significant opportunity for "networking". It was great that there was/were:

- A substantial participation by key senior people responsible for advising and making the decisions that will set the pattern for future funding and service provision across Suffolk.
- Representation from all the key stakeholders (NHS, Charities, Local Authorities, Care Providers, Communities, Support Workers, Family Carers, etc). We could do better to encourage more one-to-one discussion between family carers (and those who are directly supporting families and individuals) with the professionals and the senior people – a lesson for next time!
- So many delegates who work with and are routinely in contact with those who are living with dementia – again, we probably could do better to connect with family carers and those they care for, but we must not expect people in their late 70's, 80's and 90's, who are struggling to cope with the impact of dementia and other ailments to be able to respond to requests to participate in "engagements", focus groups and on-line surveys.

To seek suggestions of how we can achieve quality and availability of services across the county. It was very clear that "we actually know what has to be done" – the initiation and growth of locally-based services which concentrate upon implementing the preventative and palliative care models – to support those who need continuity of care for a range (and multiplicity) of illnesses that are limiting their quality of life – to develop a person-centred approach built upon the importance of long-term personal relationships - to pursue integration at the local level and to develop partnerships with the local communities – to transfer resources from the acute and crisis response sectors to primary care and community support.

To ask important questions, concerns, ideas and feedback from the "ground floor". The evidence gleaned from the questions put to the presenters, the discussions in the breaks, and in the feedback forms indicates that the event did raise many key questions and concerns which must be urgently addressed. As to ideas, there was a great enthusiasm for the visions which were presented but major concerns about how to release the resources to realise them. My personal view of the responses is that it is difficult for many in the professional sector to "think outside the box" whereas in the voluntary sector they are frustrated by the "limitations imposed by the box".

To encourage communities, Health, Adult Care, charities, etc. to engage in a coordinated approach. Certainly there seems to be a willingness to work together but, particularly in the area of post-diagnostic dementia support, it is not very clear how this can be translated into practice. On the other hand, the Integrated Network Team model seems to offer a significant step in the right

direction. The need for a common “Vision” and “Set of Aspirations” for us all to work towards was recognised. The conference brought together people from right across the health and social care sector who found the event very worthwhile and “inspirational”. Hopefully they will go on to stimulate local activities and support in their own communities.

What did this event show that Suffolk can be proud of?

Taken together, the presentations (6) and the supplementary contributions (10) detail excellent examples of initiatives and projects which are beginning to address the changes needed in the nature, quality, delivery and availability of the health and social care support for our ageing population and particularly those living with dementia. The conference highlighted:

- The NHS and ACS have been working together closely to engage with family carers, those they care for and service providers to specify and jointly commission future dementia support services. The urgency to redesign the services to be much more community- based reflects the importance of finding ways of avoiding or delaying crisis intervention, hospital admissions and transfer into specialist residential care.
- The major pilots, firstly in Sudbury and now in Ipswich, of the Integrated Neighbourhood Team approach. This is providing a framework for a much more effective way of delivering current services and responding to the needs of individuals and families. Furthermore, the project stresses the value of closely interfacing with “Neighbourhood Networks” (neighbours, community groups, relatives, etc) which provide individual support in the community. **(A personal note: I am concerned that the concept of “The Neighbourhood Network” needs to be made more concrete as a reliable support mechanism.)**
- Suffolk’s growing numbers of Synergy cafes, community-based support projects and support activities. These are the mainstay of the existing post-diagnosis support – not enough but critically important to their members. There is clear evidence that they are already cost effective.
- The development and expansion of the number of Dementia Friends, Dementia Friendly Communities, and Dementia Action Alliances.
- The achievements of Ipswich Hospital in responding to the needs those with dementia who are admitted following a crisis.
- An innovative proposal that offers a community- led integrated approach to health, social, housing and community care for our elderly and frail residents. It shows that it is possible more cost-effectively to deliver quality care and support within our own communities for all but the most critical conditions.

What were the important points, issues, facts, and concerns that were raised?

- Priority and investment must be given to post-diagnostic community-based services.
- There are approximately 11,000 families in Suffolk living with dementia – of the order of 20,000 individuals (family carers and those they care for) affected by the illness. The current availability of community-based post-diagnostic support across Suffolk is in the region of 1,000 person sessions per month!!!!
- There is a need for someone (a champion or expert group?) to take responsibility for the gap in the dementia pathway between diagnosis and crisis intervention.

- The Debenham Project costs about £85 per family per annum and provides approximately 200 person sessions per month.
- The withdrawal of the Dementia Advisor Service is seen as a retrograde step and a failure to listen to the support workers, service users, and those who are closest to their needs.
- The importance of personal relationships in the support of families who are living with dementia, and more generally of those who are becoming frail or have already become so, is central to providing both cost- effective and quality care.
- We must seek to engage all communities in some way. If the NHS and local authorities want to work with the voluntary sector they must be prepared to provide coherent medium and longer-term financial support. Volunteers sign up to “come alongside” those who need support and do what they can, as good neighbours and friends, to help. They do not want to spend half their time raising funds, or to have to cover their expenses from their own pockets when what they are doing is an integral element of health and social care.
- Overall funding of health and social care will continue to be severely limited. Hence increasing resources in the primary care sector can only come about by reducing resources in secondary care.
- The “demand” for Health and social care support will continue to rise almost exponentially but the funding is at best flattening out. Hence without a new and much more effective model for the care of those with dementia and the frail elderly, the NHS and Social Services face catastrophic collapse. The need is urgent.
- Continuing with the current “curative” model is not an appropriate option for our ageing population. What is needed is an approach which concentrates on avoiding and/or delaying hospitalisation and crisis intervention – to help to enable families coping with dementia, and elderly people achieve the best possible quality of life i.e the palliative care model.
- The importance of “doing things differently” proved to be a recurring theme. It was clear that innovative approaches must be piloted and implemented.

This list is by no means exhaustive, and there are a number of specific points from the feedback forms that I would like to take up on behalf of the respondents, but I hope, in a year’s time, we will be able to look at it and say **“yes, we have taken these on board and done something about them”**.

What did it say about what needs to be done?

There were some very clear threads:

- The need to work together – integration is important but I sensed that “it is more than that”.
- To successfully manage the future of health and social care in Suffolk requires doing things differently - more locally, more friendly, more about involving the community and more about responding to the individual needs of the family – the carer and the person they care for. If we can do this it will be a massive step forward.
- The importance of a common vision and set of aspirations to aim for.
- Increasing investment in reducing the demand for secondary care and crisis intervention, through rebalancing the existing funding towards prevention and community-based person centred care is essential.
- We need to increase the available resources by partnership with the voluntary sector.

How do we go forward and really “make a difference”?

I am very pleased to say that discussions have already started with a range of key people about how to practically build on the success of the conference. As a start we are exploring how to:

- Develop and implement a programme for stimulating community-based and led dementia support services across the county.
- Develop a common vision, a set of aspirations and a timeline for the future of the health and social care services (for those living with dementia and the elderly) that all stakeholders can buy into and work towards.
- Plan for another conference workshop in 2016 to hear about and discuss progress.

I believe that these are things that are practical and realisable in the coming year. I am sure that each and every one of us has had ideas that might be worth adding to this list. If you have any thoughts please let me know.

Conclusion

Finally, I just want to thank you for participating in the conference and for taking the time to tell us what you thought of it. I hope that you will have been inspired to look forward with optimism and take up the challenge of making Suffolk a county where:

“It is good enough”

More information

Please use the following links:

[Conference Digest](#)

[Programme & Presentations](#)

[Question Time](#)

[Feedback](#)

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