



**By:** Rebecca Barraclough, Healthwatch Development Worker,  
Kent LINK

**To:** Health and Wellbeing Board (Shadow)

**Subject:** LINK's view of Dementia services in Kent May 2012

**Classification:** Unrestricted

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### **Recommendations**

- 1.** Health and Wellbeing Board is asked to receive this report for information.
- 2.** To consider looking into further services for people with dementia, with a particular emphasis on how integration of health and social care services could help patients and carers.
- 3.** To consider leading on and working with others to raise public awareness and education in relation to dementia services.

### **Introduction**

As this is the first formal report that Kent LINK is submitting to the Health and Wellbeing Board (Shadow), we have taken the opportunity to outline the role of the LINK and how it fulfils that role through its volunteers and internal structures, before we comment on dementia services.

#### **1. Introduction to the Kent LINK**

The Kent LINK is a network of individual people and organisations who want to help improve health and social care services for the community of Kent. They join the LINK as volunteers. LINK participants play an important role in raising issues about health and social care, identifying which services provide good services, those that need improving and then taking action to make changes. There are a variety of ways people can get involved in the LINK. Participants can get involved as much or as little as they wish; by receiving information on current consultations, taking part in projects or becoming a core group member:

*The Governor's Group* - ensures that the LINK operates within the law and within its budget. The LINK Governance is set by participants and reviewed at the LINK's Annual Meeting. Governors also ensure that as many people as possible have their voices heard, when and where it counts. Each Governor takes the lead on specific areas such as equality and diversity, projects and finance.

*The Priorities Panel* - assesses, against a set of criteria, issues about health and social care services brought to the LINK and recommends how they are taken forward. They do not look at individual complaints but can signpost individuals to the appropriate service.

*Authorised Visitors* use the LINK's right to enter and view NHS and Social Care settings. To become authorised, the volunteer has to go through a rigorous process of recruitment, selection, references, training and CRB checking. They also undertake project-specific training.

*External Representatives* ensure the LINK is represented at the decision-making level on organisations across Kent. They use the LINK's (and their own) networks to seek information and views from the public and users of the services. They feed this into the organisations – providers or commissioners - they attend meetings and they feed back to the public via the LINK.

*Mystery Shoppers* carry out research for the LINK through questionnaires, visits and telephone calls, collecting information about health and social care services as part of LINK projects.

The LINK and its participants are supported by its Host organisation, Kent & Medway Networks Ltd (KMN), which handles administration, community engagement, project development, information and financial management, event organisation, secretariat, and the contact point for the LINK.

The ethos of the Kent LINK is to be a network of networks, expanding the opportunities for people to be involved in improving health and social care. This year the LINK has enhanced its network through setting up further LINK groups and developing partnerships with community / voluntary and public sector stakeholders. These groups and partnerships are forged by LINK participants, supported by Host organisation staff, and enable the LINK to be involved in decision-making within health and social care.

The LINK undertakes a full work programme each year. It consists of a mixture of activities to fulfil the LINK's statutory duties, community engagement, LINK projects (that is major pieces of work where the LINK needs to invest resources, time and effort) and issues that have come to the LINK throughout the year.

Ideas for the Work Programme come from individual LINK participants, LINK participant organisations and projects which stem from the LINK's statutory duties. An example of the latter is providing a community response to NHS Trusts' Quality Accounts. The LINK's Annual Work Programme is reviewed and agreed by LINK participants at the LINK's annual meeting.

In addition to the planned programme of work, the LINK receives throughout the year, other items or issues from the public, LINK participants (individuals or

organisations) or LINK stakeholder groups, i.e. the NHS or social care agencies in the county. For an issue to be added to the LINK Annual Work Programme it is considered first by the LINK's Priorities Panel, which takes into account a number of factors. Any issue that appears not to be within the remit of the LINK will be referred to the Governors' Group for decision. In addition, if an issue is to be followed up but will incur LINK resources, the Panel refers it to the LINK's Governors' Group to assess the impact on its budget and other priorities.

The LINK's monthly Bulletin and quarterly newsletter – Kent LINK News – are used to provide and gather information for current issues being investigated by the LINK, promote any events or workshops, provide an opportunity to respond to consultations and update on work being undertaken by the LINK's participants.

The Bulletin and quarterly newsletter are sent to over 200 groups and organisations, providing information and opportunities for involvement. Copies of the Kent LINK newsletter are sent to every Doctors Surgery, Optician, Dentist and Pharmacy across the County, as well as libraries and other public outlets.

## **2. LINK Participants**

The Kent LINK has 1249 participants listed on its database. Of these 1044 are individual people and 205 are organisations. The organisations include voluntary/community groups who bring with them their own membership and networks, meaning the LINK can readily engage with upwards of 6,000 residents in Kent.

The Kent LINK is committed to working with local community organisations and groups through its project work, consultations, community based engagement and information sharing including its Bulletin, website, Facebook and Twitter. The LINK continues to develop links with other groups on any relevant project work and the LINK Development Workers work with others in their communities.

When registering, LINK participants list their areas of interest in NHS and social care and also give the LINK permission to share their contact details, where appropriate, with those within the LINK with similar interests. Those could be around a locality, or a health condition, or other topics such as transport or social care support in people's homes.

For the purpose of this report it is useful to note that, when registering with the LINK, 86 participants have identified Dementia as an area of interest. Given more time it would have been possible to seek their views on Kent dementia services direct.

## **Dementia Services – Kent LINK comment**

## **3. Kent LINK Projects**

The LINK has undertaken several projects in which dementia services have featured, several are due for completion this year:

- 3.1. *West Kent Enhanced Dementia Crisis (2009)* - The Kent LINK was invited by NHS West Kent and Kent Adult Social Services to contribute to their contract tendering process for the new West Kent Enhanced Dementia Crisis Service (Emergency Support Service). There were two stages where LINK participants were involved: reviewing the written applications, then sitting on the panel for the short listed presentations. LINK Participants that took part had personal experience of caring for someone with dementia. Participants were particularly pleased that someone had given them the opportunity of not only being heard, but being listened to, and thinking that they had something worthwhile to say. The LINK believes this highlights the importance of public/patient involvement when considering commissioning a service and congratulated the commissioners for their approach.
- 3.2. *A Users Perspective Of Day Centres In East/West Kent (2009-2010)* - In 2009 the Kent Local Involvement Network (LINK) was approached by Kent Adult Social Services (West Kent) with a request to assist them in gathering the views of individuals who use day care services run by Age Concern in the west of the County. This work was then replicated in 2010 in the East of the County. LINK Authorised Visitors were used to visit centres across Kent, hold focus groups with users of centres, and further in-depth interviews. The final report highlighted the use of day centres by people suffering from dementia, which provide not only a lifeline for those users but a welcome respite for families/carers. Service users drew attention to the increasing number of their fellow users suffering from dementia to varying degrees. It was apparent that users also form part of the caring regime for this vulnerable group and tend to “watch out” for them. The extent to which users felt they missed out because of this was not easy to gauge. However, it was apparent that some users are concerned about staffing levels, including the level of volunteers, and about perceived funding problems.
- 3.3. *Monitoring Quality of Residential Homes in East Kent (2011)* - The Kent LINK was approached by Kent County Council (KCC) and asked to assist with a project being run in conjunction with Older Peoples’ Forums to monitor the quality of care in residential homes across East Kent. All care homes across East Kent received information about the LINK, its right to enter and view, the project being undertaken on behalf of KCC and informing them of unannounced visits taking place at a selection of homes in the area. Three homes were nursing homes for older people, eight were nursing homes for people with dementia, sixteen were care homes for older people and nine were care homes for people with dementia. All homes were privately owned but hold contracts with KCC. The LINK was pleased to note that the nursing homes for people with dementia all received positive comments, especially in relation to safety.
- 3.4. *Monitoring Quality of Residential Homes across Kent (2012)* - Following on from the East Kent project, the Kent LINK has decided to expand its remit to look at homes across Kent using the lessons learnt previously.

Once again, the work will be focused on residential homes for older people specifically and nursing homes and homes catering for people with dementia are included. The information received will be used to make recommendations to Kent County Council and the individual homes visited. The LINK will be happy to share this report with the Health and Wellbeing Board when it is due to be completed in July 2012. In the meantime if any significant issues are raised (such as safeguarding), then the LINK will immediately notify the home owner and Kent County Council.

3.5. *Care of Older People in Hospitals (2012)* - Following several issues raised by members of the public, the aim of this project is to establish local and national best practice with regards to the care of older people in hospitals and establish if patient experience suggests that best practice is being followed in Kent. As part of the project, LINK Authorised Visitors are talking to patients with dementia or their carers. The initial research is being collated now, and a full report will be available in September 2012. Recommendations will be shared with all relevant parties.

Projects included on the 2012/2013 work programme (subject to agreement at the LINK Annual Meeting on 16 May 2012) which may involve dementia as a subject include:

- Health and Social Care Integration
- Discharge from Hospital procedures
- Follow-up to Monitoring Quality of Residential Homes project
- Follow-up to training and supervision of care staff project

#### **4. Kent LINK Monthly Bulletin**

Articles on dementia have featured in 18 of the 48 bulletins that have been produced since 2008. This includes:

- National Information regarding dementia
- Advertising Events that relate to dementia services
- Promoting external volunteering opportunities
- Requests for information from LINK participants
- Opportunities to get involved in LINK projects that include looking at dementia services
- Reports from meetings where dementia has been discussed

#### **5. External Representatives**

The LINK currently has two participants who sit on the Maidstone and Tunbridge Wells NHS Trust Dementia Strategy Group. To help the LINK External Representatives contribute and take part in the discussion, KMN invites anyone with an interest in the subject to provide views, which can be raised at the meetings. As part of the information sharing and feedback, reports from the

meetings are advertised in the LINK bulletin and on the LINK website. Any recommendations for LINK action are considered by the Governor's Group.

Recently some concern was expressed regarding the reality of availability and extent of supplementary dementia support services. The LINK would support the Health and Wellbeing Board looking into further services, with a particular emphasis on how Health and Social Care Integration can help patients and carers. **[Recommendation Two]**

The LINK also has representation on the Health Overview and Scrutiny Committee. Following the report received from the March 2012 meeting, the LINK has agreed to monitor the recommendation made in the Kent County Council Dementia Select Committee Report.

## **6. Consultations**

LINK participants are kept up to date on consultations that are happening locally, regionally and nationally and are given opportunities to get involved and have their say on the services they use. The consultations are advertised online via the LINK's website or in the LINK's monthly Bulletin.

The LINK has provided the opportunity to get involved in the following consultations related to dementia:

- Nursing Care at Home - Queens Nursing Institute
- Proposed Regulations to Care Quality Commission registrations - Care Quality Commission
- Implementing a 'Duty of Candour'; a new contractual requirement on providers - Department of Health
- Development of the Social Care White Paper - Department of Health
- Preventative Services - Strategic Commissioning Families and Social Care, Kent County Council.

## **7. Issues raised with Kent LINK**

Several issues involving the subject of dementia have been raised with the LINK and considered by the LINKs Priorities Panel:

- ID 078 – Tunbridge Wells Hospital issues
- ID 059 - LINK visits to care / nursing homes in West Kent
- ID 057 - Ombudsman Report – Care of Elderly people
- ID 053 - Transport to Pembury Hospital
- ID 048 - Withdrawal of minibuses for the elderly
- ID 045 - Lack of joined up services for vulnerable adults
- ID 034 - Medication Errors in Care Homes for Older People
- ID 032 - User Perspective of Age Concern Day Centres in East Kent
- ID 025 - Input into tender for West Kent Enhanced Dementia Crisis Service
- ID 021 - Eligibility for Continuing Care and Concerns over Neglect

- ID 020 - Failure of NHS West Kent to allocate the funding it has been given to provide carers with short breaks
- ID 009 - Financial abuse of self funders and other vulnerable adults

Further details of the issues and outcomes are outlined within the attached appendix. All such issues are considered by the LINK's Priorities Panel against a set of criteria, and they decide what action is the most appropriate for the LINK. Actions range from seeking further information, enquiries or fact-finding from the providers or commissioners to full-scale project work. Where the LINK feels it is unable to offer assistance, the originator is signposted to the most appropriate source.

The LINK has noticed, through issues raised with the Priorities Panel, that there is an increased interest in the care of the elderly. The subject is often reported both nationally and locally, usually in a negative light. The LINK projects that have arisen as a result of these concerns, give opportunities to highlight cases of best practice as well as areas for improvement. The LINK would welcome anyone else to do the same to help increase public awareness and education. **[Recommendation Three]**

## **8. Conclusion**

As highlighted, the LINK has a wide range of mechanisms for involving the patients and public. The way in which the LINK operates will be useful to the Health and Wellbeing Board as a whole, but also to the individual members.

The LINK is able to gain the lay perspective, as required for the Health and Wellbeing Board. This will continue to be an intrinsic and valuable part of Local Healthwatch. The LINK wishes to establish a process for working with the Health and Wellbeing Board, which can then be passed onto Healthwatch as part of its legacy.

As evident above, the LINK has a variety of methods it can employ to gather the intelligence needed, however it should be noted that the LINK does require time in order to be able to fulfil its functions to the best of its ability. The LINK welcomes the opportunity to sit on the Health and Wellbeing Board, with this in mind it might be helpful to give earlier indication for possible future subjects and a time line for submissions as is done by the HOSC, to ensure it can achieve the best value and impact for the committee and , of course, the residents of Kent.

### Appendix: Priorities Panel Issue Log

Item No.	ISSUE TITLE (PDW)	Status
<b>ID078</b>	Complaints against Tunbridge Wells Hospital	External Representative to attend MTW Trust meeting and raise concerns
<b>ID 059</b>	LINK visits to care / nursing homes in West Kent	Visits are being scheduled in to the LINK work programme where visits to West Kent will be included in a county wide project.
<b>ID 057</b>	Ombudsman Report – Care of Elderly people	Ombudsman Report on Care of Older People while in the care of the NHS noted. LINK project initiated.
<b>ID 053</b>	Transport to Pembury Hospital	Letter received from Tunbridge Wells Borough Council on 8 September 2011 advising that the NHS and KCC are working together to come to an acceptable resolution and that they do intend to make provisions but these are still under discussion.
<b>ID 048</b>	Withdrawal of minibuses for the elderly, Age Concern	Sent letter of concern about the effects on older people to Sevenoaks District Council. They, are now investigating whether better co-ordination of existing transport services might be possible.
<b>ID 045</b>	Lack of joined up services for vulnerable adults	Sent case study to Director of Social Services and Chief Constable but no response. Have requested this issue be addressed by the Policy Overview and Scrutiny Committee for Adult Social Services.

Item No.	ISSUE TITLE (PDW)	Status
<b>ID 034</b>	Medication Errors in Care Homes for Older People	Guidelines have been issued. No action to be taken immediately, but decision to write to PCTs after deadline for recommendations to establish how recommendations have been implemented.
<b>ID 032</b>	User Perspective of Age Concern Day Centres in East Kent	Approved by Kent LINK Governors as a project.
<b>ID 025</b>	Input into tender for West Kent Enhanced Dementia Crisis Service (or Emergency Support Service)	LINK participants involved in process.
<b>ID 021</b>	Eligibility for Continuing Care and Concerns over Neglect	No further action as constitutes complaint; advice to referrer.
<b>ID 020</b>	Failure of NHS West Kent to allocate the funding it has been given to provide carers with short breaks	Response to West Kent for further clarification as to how this funding is to be used.
<b>ID 009</b>	Financial abuse of self funders and other vulnerable adults	Referred to Governors' Group; issue was raised with Adult Protection Committee, KCC.