North East Lincolnshire Local Involvement Network (LINk)

A Report on

Dementia Services

Barriers & areas where problems may occur

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and
Dementia Sub Group

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Introduction:

Aims:

- To look for gaps in the dementia services that are offered in North East Lincolnshire.

- To identify examples of best practice across the area in both the public & private sectors, by liaising with service providers.

Objectives:

- To raise the standard of dementia care within North East Lincolnshire area by working with service providers and service users.

- Identify the successes made in dementia care and how they have been achieved.

- Look for pockets of excellence and understand how it works.

- To find any shortfalls or gaps in the services and recommend how and where improvements can be made.

Background

Working Group

A team was selected from the LINk Governing Body and the first Dementia sub group meeting was held at The Elms on 5th July 2012.
The Dementia sub group were: - Sylvia Leary (Lead), Maralyn Fox, Pat Schofield, Kay Houlder, Elaine Flower, and Bob Abbey.

It was agreed that two groups would be formed, with 3 members in each group who would visit service providers. The aim of each group would be to inspect service provision. A questionnaire was devised for each group to take into each provider, see Appendix 1. For a summary of the questionnaire responses see graphs below.

Group 1
Elaine Flower, Kay Houlder, and Maralyn Fox
Huntleigh Lodge, EMAS, and The Curzon Centre.

Group 2
Sylvia Leary, Pat Schofield and Bob Abbey, would visit Domiciliary Care providers ACE home Care, NAViGO, and The Bert Boyden Centre.

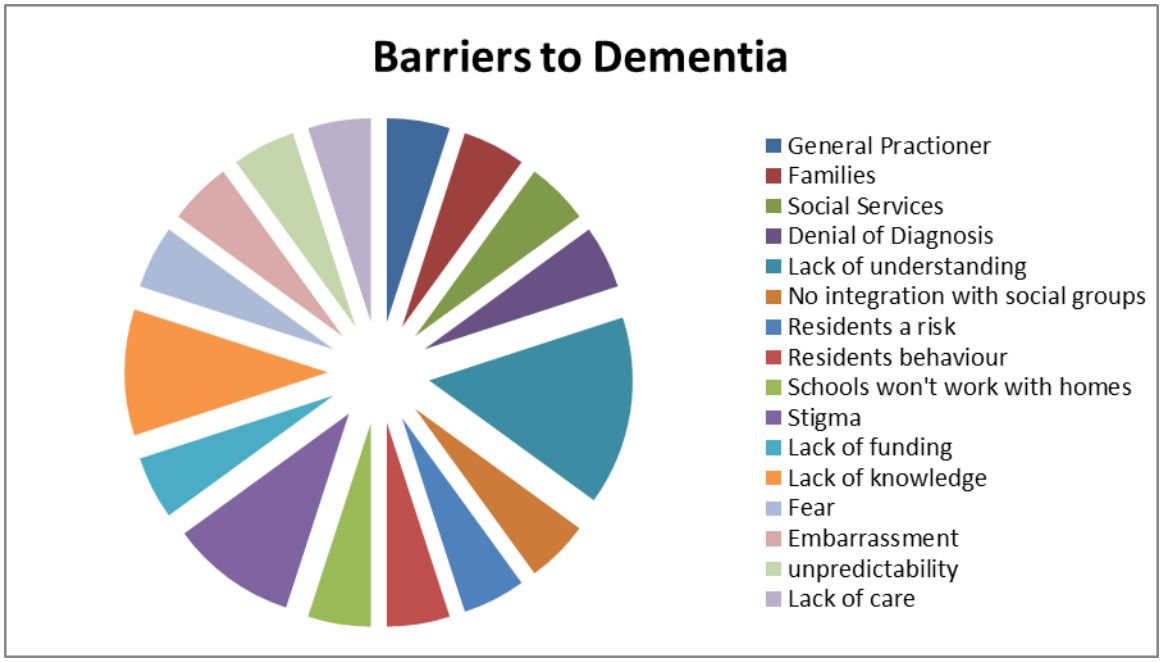
Both groups would visit the Diana Princess of Wales Hospital.

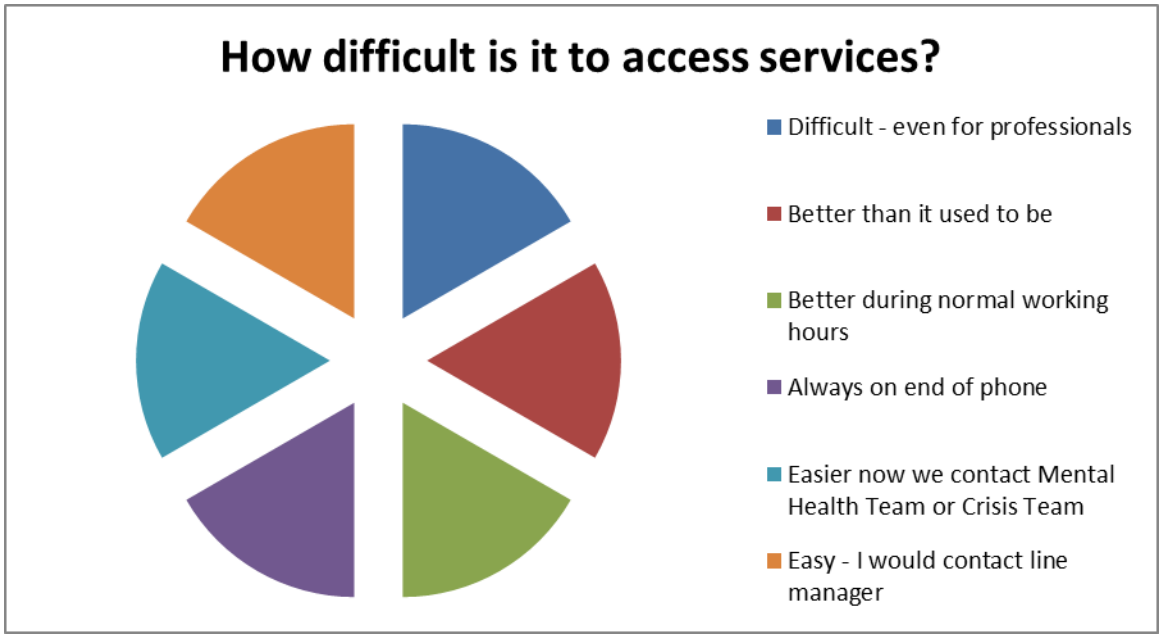
Jenny Smith worked with both groups

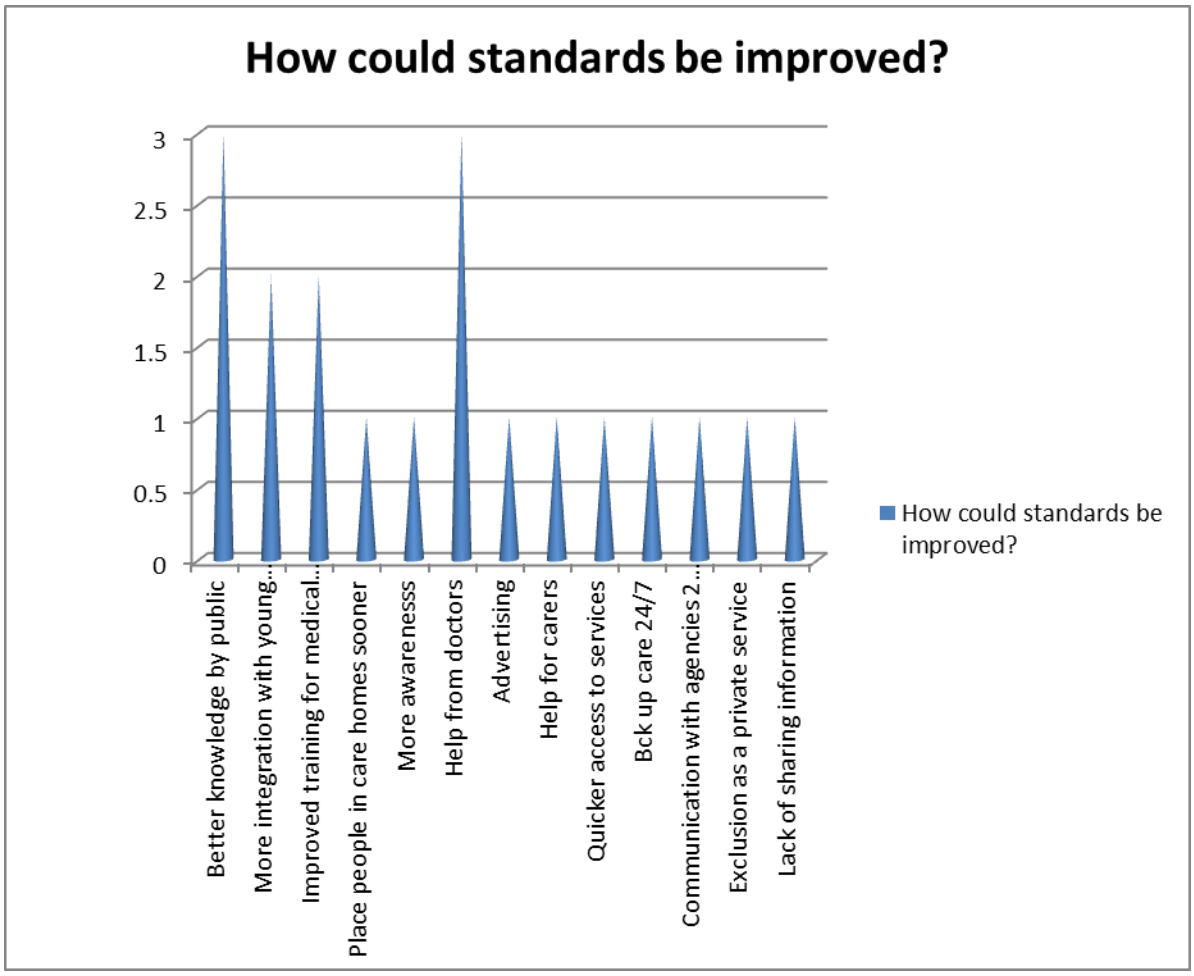
Collation of information and compilation of information in report format was supported by LINk Coordinator, LINk Administration Support and Development Work Lead, Voluntary Action North East Lincolnshire.

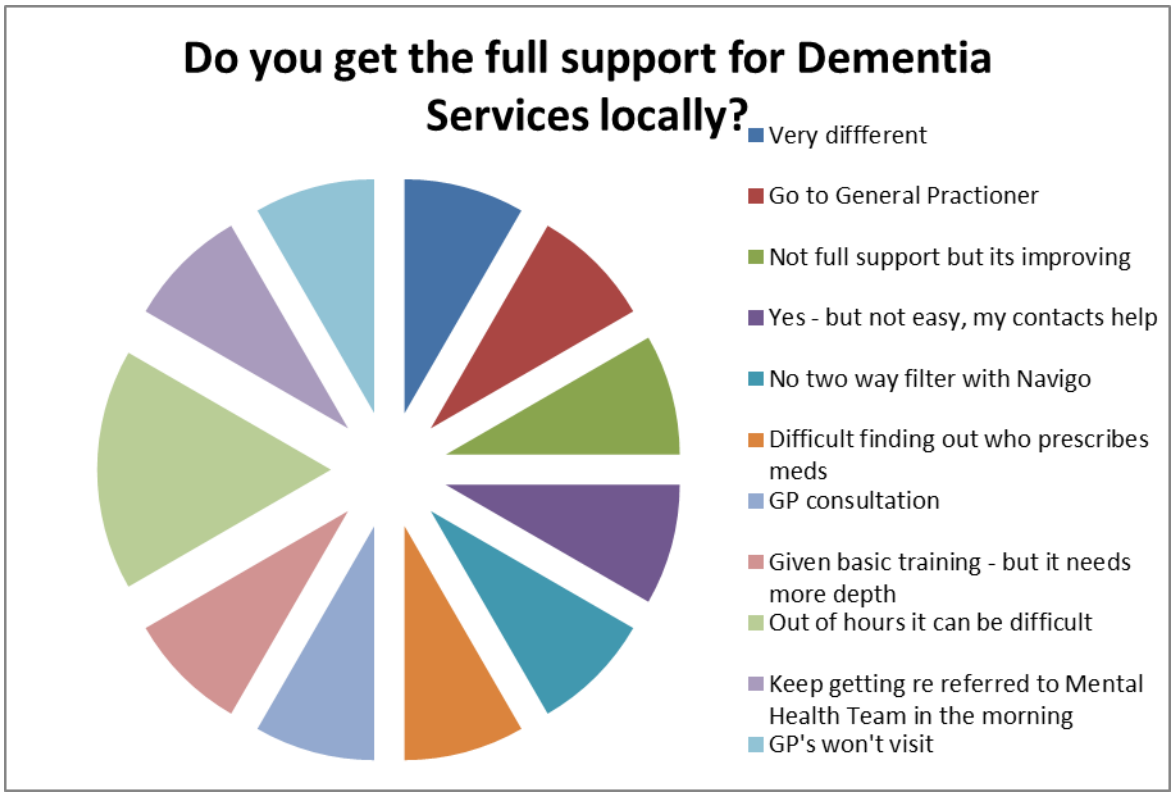
Summary: Questionnaire Findings:

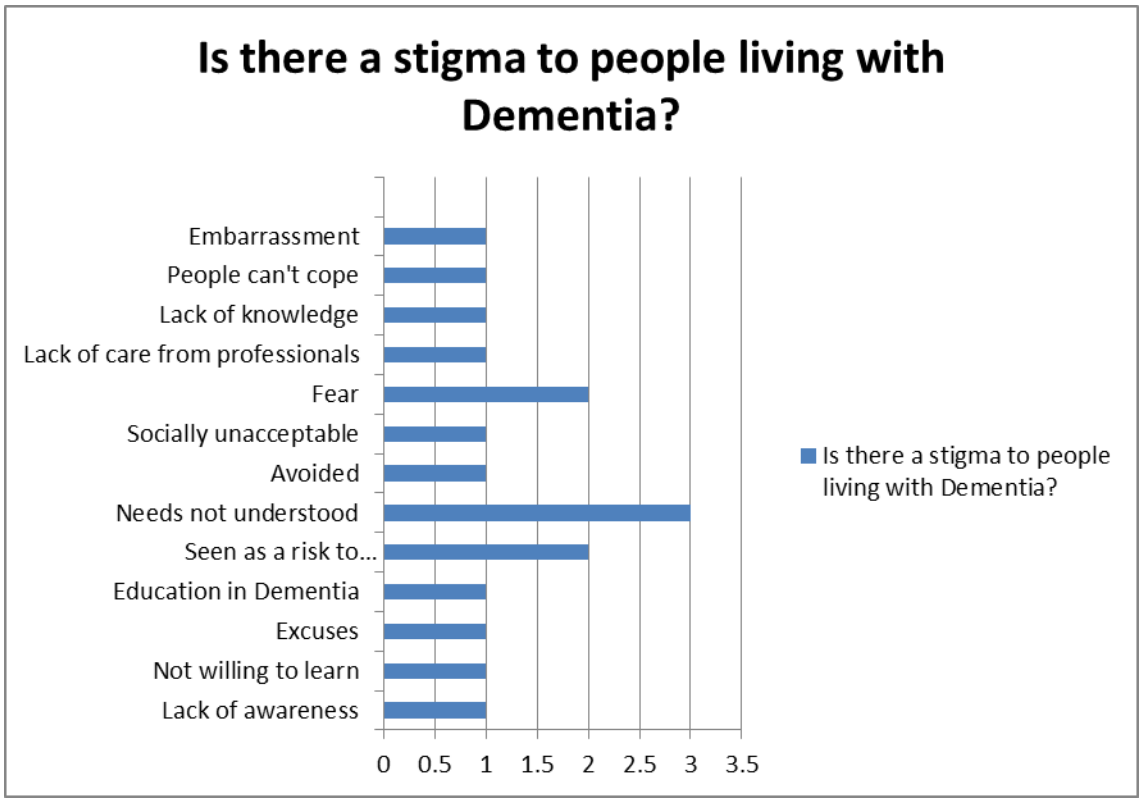
There seemed to be general agreement across our questionnaire sample, over services available, accessibility, their quality and without exception expressed similar views about the way forward. The overall feeling was that one of the improving services that still had issues is 'out of hours' accessibility. There is also frustration over the lack of knowledge and acceptance of the condition by the families of those who have been diagnosed, the willingness of people to 'write off' those with dementia and in some cases the lack of knowledge of medical staff.






How could standards be improved?
3
2.5
2
1.5
1
0.5
0
Better knowledge by public
More integration with young...
Improved training for medical...
Place people in care homes sooner
More awareness
Help from doctors
Advertising
Help for carers
Quicker access to services
Bck up care 24/7
Communication with agencies 2...
Exclusion as a private service
Lack of sharing information
How could standards be improved?


Do you get the full support for Dementia Services locally?
Very diffferent
Go to General Practioner
Not full support but its improving
Yes - but not easy, my contacts help
No two way filter with Navigo
Difficult finding out who prescribes meds
GP consultation
Given basic training - but it needs more depth
Out of hours it can be difficult
Keep getting re referred to Mental Health Team in the morning
GP's won't visit



Recommendations

- More education about Dementia for all, in order to ensure that sufferers are better integrated into society.

- The NHS move to join the 24/7 society that the rest of world live in, patients need proper care and attention as and when its needed, not put on hold until the 'next day' starts.

- An Advice Centre with fully trained staff to give support, day or night, to carers, care homes or medical staff involved in the Dementia sector.

- The 'My Life' Care Plan should be prioritized as soon as a diagnosis is given and the relatives/carers signposted to the appropriate services without delay.

- To encourage and support relatives to care for the person within their own home in order to maintain familiar surroundings and faces

Intermediate Care

Narrative

From April 2010 the Care Trust Plus launched a 24 hour 365 days per year single point of access known as the A3 team. All calls are received by an Integrated Advice Officer who will either:

- resolve your issue
- offer relevant advice and information
- divert you to the most appropriate person who will be able to help

They have direct access to a 24/7 crisis intervention team which are able to provide assistance and support for social and healthcare issues requiring a rapid response. Some of the support available includes:

- Emergency homecare support
- Access to a range of re-enablement services in the home or in a residential setting
- Access to rapid assessment and treatment Clients can also access the A3 Team via email on: NEL-CT.A3TeamPublic@nhs.net

Summary

The public's first point of contact is often with an A3 team member. There are some issues around raising staff awareness on the condition of dementia. There are also issues around the process of diagnosis and the effect that the diagnosis has on friends, family and the patient. These issues are compounded by the provision of only 1 Admiral Nurse, specialist Dementia Nurses, for the whole of North East Lincolnshire and the limited timeframe that A3 have to put a care package in place for those in need. To look into how some of these issues can be resolved a meeting was held between a LINk representative and Mental Health Team Leader, Intermediate Tier Services to discuss issues around the efficacy of the A3 team and intermediate care. From the discussions came a list of issues and recommendations laid out below.

Recommendations:

- Engage with local groups to work on reducing the isolation and social exclusion being suffered, as A3 services do not fully encompass social inclusion and integration with the community as a whole.

- Improved communication between services, in all sectors, and also to ensure that current information is available to ensure quality of care for each individual.

- Training is required for all staff within Intermediate Tier Services on dementia especially The Beacon as there are an increasing number of service users who all have cognitive impairment.

- Improved access to dementia services in general via a number of routes, such as improved referral process, access to information and improved training to medical centre staff who deal with the public at the point of diagnosis.

- Investigate the issues arising around the lack of capacity due to one Admiral Nurse in employment within the whole of North East Lincolnshire

- Improved 'out of hours' service provision, with additional support available to older adults already using the service; this needs to go beyond existing improvements and be monitored. These improvements should be made in conjunction with an expanded regular service provision i.e. not a Monday- Friday 9-5 service.

- Carers are not being assessed adequately and improved linkages need to be made between OPMHS and A3 Team in order that carers can be assessed in their own right upon diagnosis.

Bert Boyden Centre

Narrative

On the day of LINk representatives' visit the center was in the middle of refurbishment, extensive building work was being carried out along with re-decoration but work was still continuing despite the disruption. LINk representatives were invited to view the changes that had been made and the re-assignment of office and client space.

Consultation:

A minimum of consultation was reported having been carried out with the Centre staff over the positioning of the disabled toilet equipment and a major error was narrowly avoided by the intervention of the Centre's manager, prior to the work commencing.

LINk representatives also viewed the garden area and suggestions were made as to what may be available to be used there, however LINk representatives were told that Green Futures were coming the next day to sort the garden out, it was pointed out that the area was subject to flooding therefore putting anything of great value out there would turn out to be an inappropriate use of resources.

Clients expressed disappointment at the way that some of the regular service users have had their criteria changed by the staff member and it has resulted in some of them not attending the Centre as often as they had and in some cases did not attend at all.

There was a feeling that clients had been re-assessed unfairly resulting in insufficient attention and interaction within their group, which would be beneficial to dementia sufferers. Those carrying out the inspection were interested in viewing the guidelines used to make assessments that state a sufferer requires less care.

Summary:

It was clear to see that staff members had an enormous amount of experience and had passed down expertise to create a dedicated team that worked together well. Common sense was applied in putting their clients into suitable groups so that there are no personality issues, the fact that clients all knew each other so well created a friendly, stress free atmosphere despite the ongoing disruption from refurbishment. The staff have plans for a room decorated and laid out in the style of 'all our yesterdays' to stimulate the senses which would be good to see and get feedback from, so it may be a good idea to re-visit the Centre once it has settled down into a normal routine and go over what they have done.

Recommendations

- Improved co-ordination between those doing the referring and those doing the caring.

- Work on sustainability and resilience of the centre needs to be carried out so that it can continue to offer a service. Options include opening its doors to the wider community, offering integration with younger generations. Cost seemed to be the main issue not the level of care received.

- Internal report required on the nutrition of clients and support around their nutritional needs.

- Set up Carers Support Group to facilitate relations between staff and Carers.

- Work with A3 to reduce the delay in assessment times for service users.

- Day services too expensive for a lot of people £32 per day £3 for lunch

- For clients in receipt of direct payments there is no transport provision; this issue needs addressing.

Domiciliary Care Providers

Narrative

LINk representatives visited Ace Homecare on Alexandra Road to learn of their experiences and findings of dealing with dementia patients. LINk representatives found that it was a small but well organized provider, meeting minimum required standards across the board and beating them in a number of significant areas. Their client base is predominantly privately funded or service users that have NHS funding enabling them to find their own care provision. Ace Homecare claim to have a higher quality of care than the average provider but as that was not the nature of our visit we were not in a position to judge, however there was evidence of a comprehensive training regime in place and both the manager and her co-coordinator were knowledgeable and assured.

There were concerns over the way N.E.L.C provide domiciliary care and the tendering process is on a three year cycle. It was suggested that there was some discontent with service users in the relatively early days of the contract and the result of awarding all of the service to one provider has seen the demise of a number of smaller domiciliary care businesses thus producing a smaller number of potential bidders on the next cycle, the fear is that the long term effect will see zero choice, culminating in higher charges and falling standards. Issues had also arisen over communication problems with other service providers. E.g. when someone has been admitted into hospital overnight and the care staff arrive and cannot get an answer at the door or over the phone, the obvious dilemma for the carer is plain to see. An improvement in cross referencing and communications between the service providers would save both time and unnecessary worry.

Summary:

Overall LINk representatives felt that they were reasonably confident that they were providing a high quality service, trying to reduce the client's costs by lowering the minimum charging period and providing friendly well trained staff.

Recommendations:

- Improve assessment process for someone with dementia and families

- Improve access to training around Safeguarding issues as Ace are a private business and are not compelled to work in partnership.

- Improve integration and communications with other agencies and services
  E.g. if someone goes in to hospital they don't always let them know.

- Accessing people's houses with dementia

- Improved partnership working would possibly increase support from other services

EMAS (East Midlands Ambulance Service)

Issues:

1. Care pathway
2. Intermediate care
3. Out of hours

Narrative

They have great problems with referral to other agencies especially out of hours. This has a huge cost implication if they are held up with patients. If they could involve intermediate care this would often avoid a visit to A&E and a long wait for patients. EMAS are often called to care homes to lift residents who have fallen when there is a 'No lift policy'. Feedback from EMAS representatives' concerning the buddying scheme for dementia patients was that it would be a positive step forward, similar to the key ring scheme.

It was suggested by the LINk representatives that EMAS form a local volunteer community group to spread the word to get the buddy scheme up and running and give information to other groups connected to dementia and elderly patients. And also inform the general public about the categorisation of calls to the ambulance service.

Recommendations:
Encourage residential homes to address issue of having a 'No Lift Policy' impacting upon staff time at EMAS

Work with DPoW and Intermediate Tier to reduce going to A&E unnecessarily.

Work with local partners to devise a buddying scheme specifically to support those with dementia.

For further notes see Appendix 2

NAViGO

Narrative

NAViGO provides health and care services free at point of use to the people of North East Lincolnshire on behalf of the NHS, GPs and local authorities.

We also provide training consultancy locally, nationally and internationally to organisations working with people with mental health issues, learning disabilities and people with common life and work issues.

NAViGO response to work stream by Member of staff

Gaps in dementia care are considered to be:

- Inconsistency in primary care (GP) referrals, still postcode lottery in some cases. Importance of early detection – work still to be done.
- No direct access to specialist services, has to be agreed by GP
- Low level support, social interaction and meaningful engagement, effective befriending – services that would not be eligible for adult social care commission
- Integration of services – Care Plus, NLAG, Voluntary sector – lots of services involved creates duplication, causes confusion for service users and carers

NLaG (NORTHERN LINCOLNSHIRE AND GOOLE HOSPITALS NHS FOUNDATION TRUST) response to work stream by Member of staff

Firstly I think the working relationships we (NLaG) have with the girls from NAViGO is really good, and they are very good in coming to the wards and providing support regarding all aspects of care with relevant patients, I also feel this working relationship, is improving all the time.

We do have difficulty with referrals we make from the dementia screening tool, as in once the form identifies a patient requires referral, this can be quite time consuming, as it can take up to half an hour for each referral made. There are lots of issues around this screening tool, and I understand ongoing discussions are in place between NLaG and commissioners. Some of these issues are around the timing which the assessment is completed by NLaG staff, and again we are continuing with work around this.

Length of hospital stay is longer for those with dementia, but I am not sure what specifically this is due to.

We (NLaG) continue to highlight dementia to our staff, and all the work and actions which need to be achieved to improve the care of those patients with dementia and their families.

For further notes see Appendix 3

Recommendations

- Improvements need to be made to share ideas within the services. We expect to see some progress towards this urgently.
- Improve systems after form identifies person needs referral.
- Continue to work with patients and families for the best care for the patient.

Conclusion

There was awareness and usage of the Curzon Centre, Memory Café's, The Gardens, Falls Team, Bert Boyden Centre in Immingham plus therapy and advisory services however finding specialized services proved more problematic and was usually handled by a manager or a senior carer. The accessing of services seems to be a 'merry go round' where people are signposted on, repeatedly, only to find themselves back where they started. The A3 team was mentioned as part of this problem. It was found that some services could be accessed quite easily, although evenings and weekends were more problematic as GPs are unwilling to visit. Although access to services was seen to be part of an improving scene, access during the night and at weekends was still proving difficult and it was felt that an improvement in this area was needed. It was seen that access to the Mental Health Team had improved but once again not evenings and weekends The Crisis Team were criticised for their reluctance to come out after 8pm and over their referring back to the Mental Health Team the next day, claiming that they had been 'too busy' during the night.

There is an awareness of the Alzheimer's Society involvement across the sector and of the Memory Café's sites. There was a big issue with the barriers around dementia. These include emotional issues such as fear, embarrassment, and appropriate support for relatives of those diagnosed 'in denial' and relatives who don't know how to deal with the condition. Some social groups do not want to integrate with dementia sufferers and are passed from pillar to post by services. The lack of training and skills when dealing with unpredictability of sufferers compounded by a lack of knowledge particularly among medical staff and lack of 'care' does not facilitate the care process.

In addition to the above the stigmas around dementia sufferers who are seen as a risk, especially to children indicates that there is little or no understanding of their needs and their behaviour is seen to be socially unacceptable. Therefore, more education of the condition involving relatives, the general public and caring professionals is seen as essential with more integration with younger people, the need for 24/7 back up care with immediate help into the care system as soon as there is a diagnosis; people need help right from the start. The 'my life' care plan should be implemented without delay.

There are problems in accessing services plus a seeming reluctance of a number of G.P.'s to pass dementia sufferers on to specialist care providers in a timely manner. The worst examples include those who have waited for a year, despite the recognition that specialist care units give the best outcome for those diagnosed with dementia. Whilst not condemning these doctors and their expertise in any given area they are G.P.'s, 'general practitioners' and as such should be prepared to refer dementia sufferers to specialist services without delay as they would with any other serious illness.

It would appear that there is also a reluctance to share 'best practice' between service providers, a repeated theme in this report, despite shared knowledge only making things easier for all, especially the patient. It was noted that communication between services was not good, which, in the light of instant global accessibility of knowledge and communication, seems a little worrying. One would hope that an in depth inquiry would be set up into the general reluctance of health care professionals using the tools that will make the health service a more efficient and 'joined up' professional body.

Appendix 1
Questionnaire for Dementia Services
What services for older people are you aware of in NE Lincolnshire?

1. Have you used any services for older people during 2012?
If so which Services?

2. How easy was it to find the service you needed?

3. How easy was it to get access to the service you needed?

4. If you needed a service for older people in the future, how confident do you feel that you could get the help you wanted?

5. Do you feel you get the full support for Dementia services locally?

6. How difficult is it to access Mental Health services for you?

7. Do you know about the Alzheimer's Society have been commissioned to provide local services for dementia?

8. Are you aware there is memory café's in North East Lincolnshire provided by the Alzheimer's Society?

9. Do you think there are barriers around dementia? If so what are they?

10. Do you think there is a stigma attached to people living with dementia? If so why?

11. If you could change anything around dementia and improve the standards What would it be and why?

Are there any other comments you would like to add that would improve the services for older people and dementia care?

Appendix 2
Notes from Meeting

A3 tier care – 30 day beds (6 weeks) hospital discharge.

Safeguarding also plays a big part. EMAS : Karen and Blanch– Safeguard Adults – 1500 referrals per month.

Health & Social Care issues.

EMAS has a workbook and DVD – re patients with learning difficulties and they have had a huge amount of positive feedback from this. It explains when to call 999 and what to expect.

EMAS to send information to the group re DVD etc.

Dementia Services referrals – patients that have no clinical need but mental health needs.

Scunthorpe – out of hours mental needs. Everything ends 5pm on Friday evening. Patients cannot sort this out themselves. Ambulance needs to tap into this. "What is better for the patients"? When in drink the patients do not receive any treatment. Needs to be right pathway for the patient and costing's.

Crisis team not available. Assessment tool. A&E no good for people with dementia.

What is needed is out of hour's buddies – volunteers, "flags", warning signs.

EMAS – Care Home patients need someone with them but many times this does not happen due to cost and staff availability.

It was stated that this should come under "Duty of Care".

EMAS – volunteer buddies. Sylvia showed them our Message in a bottle system and said that a patient buddy system could be used in the same instance – either via bottle in fridge or on information via the key ring credit card system.

Pathway – immediate care.

EMAS were asked if their crews were trained in Dementia care for patients.
It was stated that "out of hours" EMAS do well looking after their patients.
Escorts – middle to end stages. They do struggle with a person when they are on their own.

FALLS – KPR's going to falls patients – nursing homes with no lifts – non-injury falls. 26,000 older people and 9,000 go to A&E. 1 in 3 comes from Care Homes.

Lots of falls people from East Coast (Mablethorpe, Skegness etc.) all came to Grimsby hospital.

EMAS stated they are running a Rapid Response Team – pilot in Northamptonshire and this is 2 specialised units just for falls patients. If this is a success it will be rolled out in other districts.

"Amplean Care" – 2 carers with patient – Dementia – no pain – none injured – all called 999 because of the "No Lift Policy".

Rural areas G4 clinicians – address triage call – identify despatch code.
8 Minutes is allowed for emergencies, 20/30 minutes for not so urgent.

Clinician calls back within control facilities within 1 hour.

It was stated that COPD – breathing have buddies and it works very well.

Ambulance service to work with us re buddies – go and "treat and leave".
Recognised "falls buddies" – falls outside are a different priority.

It was asked if EMAS could produce a leaflet with the do's and don'ts for calling 999.

Don't call 999 for the hospital unless the patient is in an immediate life-threatening situation. It would be rapid response for anything else.

Volunteers could give out this information. You could also have Ambulance Champions. Mystery patients for the ambulance services.

EMAS said that have inductions, clinical training etc. which could be given to volunteers.

EMAS to send Ops leaflet as to how they code a call.

Dementia Buddy – keying – patient – pilot scheme first. Intervention teams Falls.

Dementia – Pathways – Falls

QR Codes.

Bikers Buttons.

Appendix 3
Notes from Meeting

Explanation of LINk what it was and what we have accomplished and the reason of this meeting.

Obstacles regarding Dementia was, said felt that there are several areas which deal with dementia and it feels that no-one is pulling together over it.

Why dementia patients are not seen sooner. Replied that they see the patients within 12 working days of them being referred to them.
The problem seems to be that some of the G.P.s are not referring patients earlier. NAViGO is a service which is referred to by G.P.s. The ever present problem of funding creates problems as to what else can be done regarding dementia.

It was felt if people can get over their feelings over dementia and 'befriend and go round with the person with dementia to say golf, it would help.

Heard of the "Time Bank" and explained it was a government funded direct scheme where people volunteer to bank hours to help people.

Had not heard of this scheme.

Antipsychotic drugs are being used too much for dementia and there are other things that could be used in place. Feels that
the Media in general blows up too much regards dementia without knowing the proper story.

As from this February, the crisis team which deals with dementia problems will have longer hours and that the Night Nurse on the Concord Suite will be available to go out with the Crisis response team during night-time crisis's.

To summarise: A very good discussion too place and ideas pooled about dementia and we agreed the need to share ideas within the services are not there.

Special Thanks to:

All LINk members who have contributed to this report and who have been dedicated to the Dementia Sub Group work.

All those services who have allowed the LINk members to visit:

Huntleigh Lodge

Curzon Centre

A3 Team

EMAS

Domiciliary Care providers ACE home Care, NAViGO,
and The Bert Boyden Centre.