

Oldham

LINK

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HAPPEN!**

Local Involvement Network

**Report of the Oldham
Standing Conference
Dementia Action Plan**

“12 Months On”

Workshop

May 2011





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1.1 Background

1.1.1 Why the Standing Conference?

Oldham's mental health commissioners wanted to improve engagement practices within mental health. A bottom-up model was devised to enable local people to have their say about local mental health services and to enable their views to be communicated to service commissioners. The result was the Oldham Standing Conference.

1.1.2 What does the Standing Conference do?

The Standing Conference has been designed to provide the space for users, carers and members of the public to look at issues of mental health service performance and development in the borough. Its intention is to capture the perspectives of service users, carers and the public to ensure change is influenced by real lives, experience and knowledge.

The Standing Conference is also a means to provide information and relevant policy updates to users, carers and the public so that, as an informed community, Oldham can have its voice heard and set its own agenda.

1.1.3 Who organises the Standing Conference?

The conference is hosted by the Oldham Local Involvement Network (LINK). The LINK's impartiality as an engagement body for health and social care places it in a good position to be able to gather information and communicate it to commissioners.

1.1.4 How does the Standing Conference inform service development?

As new arrangements for the commissioning of services develop with the introduction of Clinical Commissioning Groups that will replace the role of primary care trusts, we are exploring with the GPs leading this process in Oldham how best to incorporate information gathered from the Conference into their commissioning practices and plans for local services. The aim is always to enable a direct route for communication from service users, carers and members of the public to service commissioners.

1.2 The “12-Months On” Dementia Action Plan Review

- 1.2.1** A comprehensive action planning process for dementia was undertaken at the May 2010 Oldham Standing Conference. This provided a very comprehensive set of recommendations to inform mental health commissioning practices over a 12 month period. Full details are at Appendix 2.
- 1.2.2** Oldham LINK and members of the Standing Conference have been keen to monitor the primary care trust’s (NHS Oldham) progress against this work and make further contributions. Interim reporting from NHS Oldham has been built into the Standing Conferences (as at Appendix 3), although feedback from Conference participants indicated that it would be appropriate to conduct a full annual review.



- 1.1.3** Participants of the May 2010 Conference – and others – were invited to attend a half-day event facilitated by Oldham LINK to consider the breadth of travel made against the original action plan, and for the LINK to support a dialogue about the experience of dementia-related services 12 months on from the initial conversations.
- 1.1.4** The original key recommendations can be found at Appendix 1. The findings from this work show that these should still be considered as ‘active’, and supplemented by the recommendations of this report.

2. Reflections and Recommendations

2.1 Reflections

- 2.1.1** A lot of the issues raised were similar if not the same as those that informed the recommendations from the initial dementia-themed Standing Conference in May 2010.
- 2.1.2** Problematic issues highlighted by this review predominantly concerned: initial presentation to one's General Practitioner (GP) and the often lacking specialist knowledge base regarding dementia; limited available services; and the lack of information available to staff, dementia sufferers and their carers who have a role to manage the condition.
- 2.1.3** A need to strengthen the provision of access to information and signposting is highlighted across all service user/patient groups the LINK has engaged with. This can be seen therefore as a definite trend in need of addressing within most service areas.
- 2.1.4** Additionally, the importance of including carers in treatment was again highlighted. This is consistent with the LINK's findings from other areas of work, particularly the April 2011 Standing Conference, in which the needs of carers supporting people with mental health diagnoses were assessed (see http://www.oldhamlink.org.uk/assets/documents/StandingConferenceReportApril2011-CARERS_000.pdf).
- 2.1.5** In short, therefore, key issues from this work to be highlighted concern:
- GP awareness of dementia (and mental health issues more broadly)
 - Availability of relevant information regarding mental health issues, illnesses, services & support; and
 - Carer involvement in the process of managing the patient/service users' condition.

2.2 Recommendations “12-Months On”

The following recommendations have been categorised under the themes that the May 2010 dementia action planning exercise was organised into.

2.2.1 Access & Awareness

Original recommendations 7.1, 7.3 and 7.9 (as at Appendix 1) are reasserted by the following:

- 2.2.1.1 The Centre for Independent (CIL) should be promoted (as most people are not aware of this facility) so that the uptake of the facility by dementia sufferers and their carers can be enhanced.
- 2.2.1.2 Social care services should be more heavily involved in the ongoing evaluation and decisions regarding treatment and management, rather than this being solely determined by clinicians. This is with a view to enabling a more rounded view of the patient to be ascertained, from which to base and contribute to clinical assessment.
- 2.2.1.3 Provision is needed to enable carers to access information in a timely fashion so that they are able to competently and confidently deal with issues that arise. Feedback shows that information for carers (and users) is not made readily available and is only usually accessed when a person proactively searches for it. This is reported to disadvantage carers/users who are not confident enough to do this or do not have the skills to do so.
- 2.2.1.4 An information publication from Stirling University is considered to be a very good practice example of information about dementia. It is suggested that this should be available from the NHS and to people in Oldham.
- 2.2.1.5 Information about the rights of people with dementia and their carers is not considered to be readily available enough. Information and/or support to understand what can be expected from services is needed and current provision needs to be strengthened.

- 2.2.1.6 Better information and support to understand the condition from the GP/health professional at the time of diagnosis or leading up to diagnosis would be helpful for a lot of people and their carers.
- 2.2.1.7 Training for **all** GPs in Oldham, across all practices is needed to enhance a GP's ability to properly support the early diagnosis of dementia, which has been shown to make a big difference to the success of managing the condition in the longer term.
- 2.2.1.8 An understanding by GPs that people may be frightened to admit to symptoms they are experience is needed. This is with a view to getting the right support for an accurate and timely diagnosis. A common view that dementia is inevitable and that it cannot be managed must be challenged, particularly by GPs, as the health professional that is most likely to have the opportunity to do so.
- 2.2.1.9 A four-day training course that is available to understand the condition is considered as crucial to help people to identify and manage a dementia sufferer's condition. As such, this should be provided to all front line workers and clinicians and offered to carers as standard.
- 2.2.1.10 Point 2.2.1.9 has particular resonance for workers within residential care settings. Many people explained that they have bad experiences with residential care home staff having misinterpreted symptoms of the onset dementia as aggressive behaviour, or simply just as part of growing old. As such, the appropriateness of residential care services should be reviewed and this care model reconsidered within the frame of developing specialist care provision for people with dementia.

2.2.2 Diagnosis & Early Intervention/Support

Original recommendations 7.5, 7.6 and 7.7 (as at Appendix 1) are reasserted by the following:

- 2.2.2.1 Dementia 'Champions' are needed in each GP surgery.
- 2.2.2.2 The NHS should re-evaluate its procedures and referral time scales if the early onset of dementia is to be identified and treated in a timely fashion, each and every time.

- 2.2.2.3 User/carer feedback indicates that greater coordination between GPs and the memory clinic is needed to prevent a person from being referred too late or unnecessarily.
- 2.2.2.4 Admiral Nurses are required in Oldham to provide adequate support for carers (and the cared for as a consequence).
- 2.2.2.5 The life story project is very helpful and therapeutic. This should be sustained.
- 2.2.2.6 The Dementia Café run by a third sector organisation provides a good service and is a source of helpful information. It is therefore strongly recommended by delegates that this should be supported to be sustained.
- 2.2.2.7 The Memory Clinic (commissioned by NHS Oldham from Pennine Carew NHS Foundation Trust) needs to operate at an enhanced capacity level to be able to meet current demand for the service.

2.2.3 Carers' Issues

Original recommendations 7.2 and 7.8 (as at Appendix 1) are reasserted by the following:

- 2.2.3.1 Carers should be heavily involved in the process of diagnosis and treatment to ensure that all relevant information is taken into account, especially where the patient's memory is particularly affected.
- 2.2.3.2 Carers should be privately consulted to discuss issues they face, so as to support them to safely and effectively undertake their caring role.

2.2.4 Long-term Management

Issues for long-term management fall within the above themes, particularly with regard to the specific needs of informal carers and care/clinical staff to help dementia sufferers manage their condition.

3.1 Future Monitoring Arrangements

- 3.1.1 Discussions with members of the Alzheimer's Society Carers Dementia Support Group present at the event indicated a willingness from them to monitor the work of NHS Oldham against the action plan and subsequent recommendations. Sian Wimbury, Mental Health Commissioning, NHS Oldham offered her time to regularly attend the group as means of reporting back to and responding to carers' (and subsequently the people they care for) issues and concerns.
- 3.1.2 Whilst the LINK could continue with annual monitoring, discussion with the Conference participants as a whole showed this to be a preferable approach. This would enable a more regular and ongoing dialogue with mental health commissioners than the LINK could facilitate at this time, to provide ongoing scrutiny and feedback about the impact of actions by NHS Oldham on the experience of services, solely from people who directly use them.
- 3.1.3 Discussions are underway with the Alzheimer's Society to consider whether this arrangement can be formalised.

4.1 NHS Oldham Update

4.1.1 Sian Wimbury, Senior Project Manager for Mental Health, NHS Oldham, delivered a presentation to update delegates on progress against the action plan, since the interim update was provided in October 2010 (see Appendix 3).

Figure 1 details the progress made by NHS Oldham up until the end of April 2011.



Sian Wimbury, NHS Oldham

You said	We did/ plan to do	Current position
GP training	1 ½ day session run for GP's	COMPLETE
	2 ½ day sessions planned for 2010/2011	COMPLETE
	E learning for GP's promoted and advertised	ONGOING
	Ongoing training is being developed Awareness training 4 day Alzheimer's society course	COMPLETE ONGOING
GP contracts	Identified key performance indicators for newly commissioned	COMPLETE
	Continue to work with primary care colleagues to develop services for people with dementia and their carers	ONGOING
	Primary care pilot project	ONGOING

Figure 1: Progress made by NHS Oldham against May 2010 Oldham Standing Conference Dementia Action Plan

4.1.2 Notes of Question and Answer Session

Q. What are appropriate medications, and what are not appropriate?

A. Inappropriately prescribing anti-psychotic medication (early on)
Don't attempt to put other things in place.

Pennine Care doing audit

Stimulate, keep occupied

Q. Aricept; is it specific to dementia?

A. Yes.

Q. GP training – how many attended?

A. Don't know, but can find out.

Q. This ward that has been used for the initial training; how do they cope with new starters?

A. Not just new, includes night care etc. Adele will act as a cascade trainer.

Q. Where is money for training coming from?

A. Pennine Care do it through their 'protected training time'. Pennine Care will provide training to Pennine Acute and vice versa.

Q. Is it mostly in-house?

A. Yes.

Q. What about outside agencies?

A. The council provide training.

Q. Staff need to do the 4 day course rather than the 1/2 day.

A. Yes, but it is difficult to make the time available.



Q. With Vascular dementia, Aricept is no good. It requires control of the blood. New medication is out but not tested.

A. There are more complexities. Polly Kaiser focuses on this. There are generic services in Oldham but not specialist services.

Q. In respect of the money situation; how much has been allocated as a percentage compared to last year?

A. There have been no cuts to mental health. Actually there has been a 1.5% uplift. Mental health is still the biggest area of spend. We are looking at spending it effectively. Not enough is spent on the majority in terms of prevention. A lot of money is spent on just a few people with high needs, making it quite expensive care.

Q. Training; is it now policy for dementia nurses/staff to have dementia training?

A. Will check it out and get back to you.



Q. What provision is made for the carer where the patient is getting worse, bed bound, and something happens? We need to go through GP. Things started in February are still awaiting conclusion.

A. This is a really good point. There are lots of different people and agencies involved. The memory clinic has had more referrals and the 'bottle is full'.

(Sian offered to assist the delegate asking the question.)

Alison: There is a care line available.

Q. There is training run by the council. New members may not be aware of it.

A. If anyone wants to know please give their details to Ursula.

Q. There has been an increase in monies, but looking to close places, with money being invested in the Centre for Independent Living (CIL). The CIL (Link Centre) needs to be used more or it will be closed.

A. It's about effective use of resources.

Q. The GP training was not mandatory. Was each surgery represented? Can we have champions in each one?

A. Looking at priorities for GPs. There will be work with LINK. GPs listen to GPs. It's difficult to make it mandatory because of contracting. There was probably not one from each surgery.

Q. Any provisions made with early onset dementia?

A. Nothing specific, but looking to put it into the planning.

Q. What about training for people to recognise signs? Many people do not want to accept it.



A. There has been a TV advert for Alzheimer's. An information kiosk has been made available by Pennine Acute Trust. Some people may misdiagnose self. Cost is an issue.

Q. The CIL; trouble is that people have never heard of it.

Gary: It's the Link Centre. There is a management board, made up of users, disabled people and council members. There is a written agreement from the council. Mental health comes under the disability act so is included in the CIL. We need to 'open the doors' widely.

Quality Issue:

All patients admitted will complete a life story.

Q. Nothing's changed. Still have the same carers. Confusion over whether person in mental health team is a social worker or not.

A. ADIS – have you had contact with them? Oldham Council's front door for anything social care wise. 0161 770 5145.

Q. ADIS can point you in the right direction.

A. Nobody gets in touch with you.

Q. Gets reviewed once a year. Mental health team does this. I'm dissatisfied with the mental health team. Who can get mother in the bath? She will not go in, or wash her clothes.

Q. Same nurse takes blood pressure – Asks him questions, how much does he drink etc. But, he lies when he answers. Carers should be able to be interviewed alone (this just a normal practice nurse). What do I class her as?

A. General Practice Nurse.

Q. Saw Dr Day and my husband had a scan; he was diagnosed with vascular dementia. Lyn Ward said "If you need us, ring us". Rang her to get a follow-up with Dr Day. Answered – don't think he will be getting a follow-up. Don't know how to answer when you will have a review.

A. There is a dispute between GPs and the Memory Clinic. You have a process of patients going from GPs to the Memory Clinic and then back to the GPs. Memory Clinic says GPs have to take some people back from the Memory Clinic so that new people can come in to the Memory Clinic. GPs then retort that they are not specialists and can't do it. All this has happened in the last two weeks. GPs refuse Dr Day's request. There is a meeting with GPs and Pennine Care next week. There are huge issues with patient responsibility

4.1.3 Notes of General Discussion

My mum has Alzheimer's and vascular dementia. Should have had a care plan/assessment. Who is responsible? And when does it come into place?

My mum diagnosed 2 years ago (didn't attend Standing Conference last may). At first GP wasn't bothered. GP view was no medication. Had to act as an advocate. Changed GP. We have effectively 'fallen at the first fence'. Need to catch it early and treat it.

Could have helped to know who had had training.

Why have we got no specialist nurses? (Admiral nurses).

Issue that step-father is obstructive and wants to keep caring.

Difficult personal/family situation

What would help?

Very tenacious, lots of digging. Joined Alzheimer's Carers Group.

Nothing to support you, have to find own information. Set up post diagnostic drop-in. Go through practical things. Power of attorney, health and safety. Tend to be left to it.

Hard to live with person. Most of time spent on caring, and not these other issues. Group have produced leaflet. (Stirling University have done lots of work.)

Dad had accident. Not going to do anything. But did memory test, but did well. Walked to GPs so they said you're ok. Doctors going off what they can see. But referred to memory clinic after spoken to doctor. Person knows something is wrong but is frightened by it.

We all know situation – but step-father is frightened.

Ageing population – so is only going to get worse.

What if people are on their own?

Mother shut herself away.

Difficulty of family relationships.

Is a 4 year plan quick enough?

National guidelines are being implemented – alongside local priorities.

Being able to attend council courses for free has been helpful (Professionals training). Alzheimer's Society do 4 day course. But got to find out about it all rather than handed to you. Needs to come from your GP etc.

What about day centre?

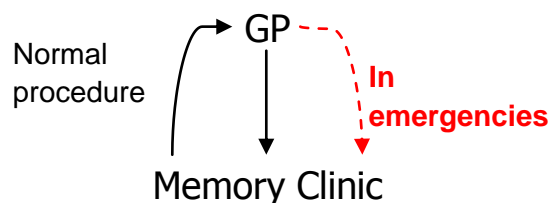
Not always easy to access day centres. Some may have been closed down. Was social worker pulling their weight? Council only step in when it's high need. Get tired and fed up of pushing people. Get support from family.



Got involved with life story project. Very useful. Need two life stories; one précis for carers and longer one for others. Life story is therapeutic.

They said Limecroft was not being used – but was actually full

What the patient pathway could be



There is inconsistency with GPs. Some GPs are happy to help. Prescribe Warfarin.

Some homes had interest in dementia.

Some delegates have had problems/bad experiences of residential care homes in Oldham

People highlighted they need good social workers to guide them into make right decision regarding residential care.

There is good information received from voluntary organisations e.g. being informed of the Dementia cafe.

Progress is going along the right lines.

Modern Matrons on wards may be the answer to improved dementia care whilst a person with dementia is admitted to hospital.

Have a liaison team for physical and mental health.

Ensure GP surgeries have literature available that can be taken away (this is currently part of the dementia strategy).

Dementia services vary in level of expertise & service throughout the borough of Oldham. This is predominantly related to where you present, how well a service you receive.

Pharmacists have a lot of leaflets.

Help & support is not always timely.

It is unfair on both dementia sufferers & care workers if they have not been trained properly to care for dementia sufferers. Behaviour may be misinterpreted as aggressive, if a person struggles to express themselves. Professionals also need patient personality and correct approach, with tighter supervision for staff to flag problems & draw solutions promptly.

There are difficulties for families to identify signs of early onset dementia. People want to act soon enough to get treatment, but not push the sufferer too much for fear of isolating them if they are in denial about the possible diagnosis.

Families, carers and sufferers need support to deal with it.

Need more info and guidance at early stages and help for relatives.

4 days training is crucial to enabling people to identify & deal with dementia sufferers.

5.1 Summary

Eighteen evaluation forms were handed in at the end of the conference. There were 26 people who were recorded as attending the conference. This equated to a 69% return of forms.

5.2 Evaluation Comments and Scores

5.2.1 What was your main reason/s for attending the conference?

To find out what has happened in the last 12 months in dementia services – as nothing has changed as far as my mother is concerned.

To learn more about dementia care in the borough and get feedback from the professionals and carers.

To find out more info on dementia.

Keen interest in dementia as mother suffers from it.

I am interested in all health services.

Interest in dementia.

Come along as see what was going on, see what ideas people bring in their own words.

Carer

Both my parents and auntie have dementia. I feel I need to share their lives, so services will/need to improve.

Carer for parent with Alzheimer's and vascular dementia.

To gain information for dissertation on dementia/carers

As a manager of a mental health team I am always interested in the developments between the partnership organisations.

To discover if any improvements had been made over the last year and

what are the plans for the future.

To find out the improvements in dementia services in the last 12 months. Although some issues had improved, it identified other issues such as lack of info from GPs and help for carers to cope with the ongoing memory decline of their relative.

My wife has developed vascular dementia. Need to know more about consequences and any timescale for ongoing changes in memory. Some initial problems have increased in memory loss.

To find out about what services are available in Oldham.

5.2.2 Was there anything else you would have liked to have been included?

GPs to attend

Attendance by people living with dementia themselves – we should be making sure they can participate.

A care home manager invited.

No

Should the change in the facilities provided by people with mental health problems by the local authority be reviewed?

No

Wanted to get more involved with the group discussion – felt I couldn't do that.

Smaller groups

New to this so gaining info.

Need to find out how carers can gain training to deal with difficult situations.

Surgeries (Market Place) leaflets etc could have been made available for the participants.

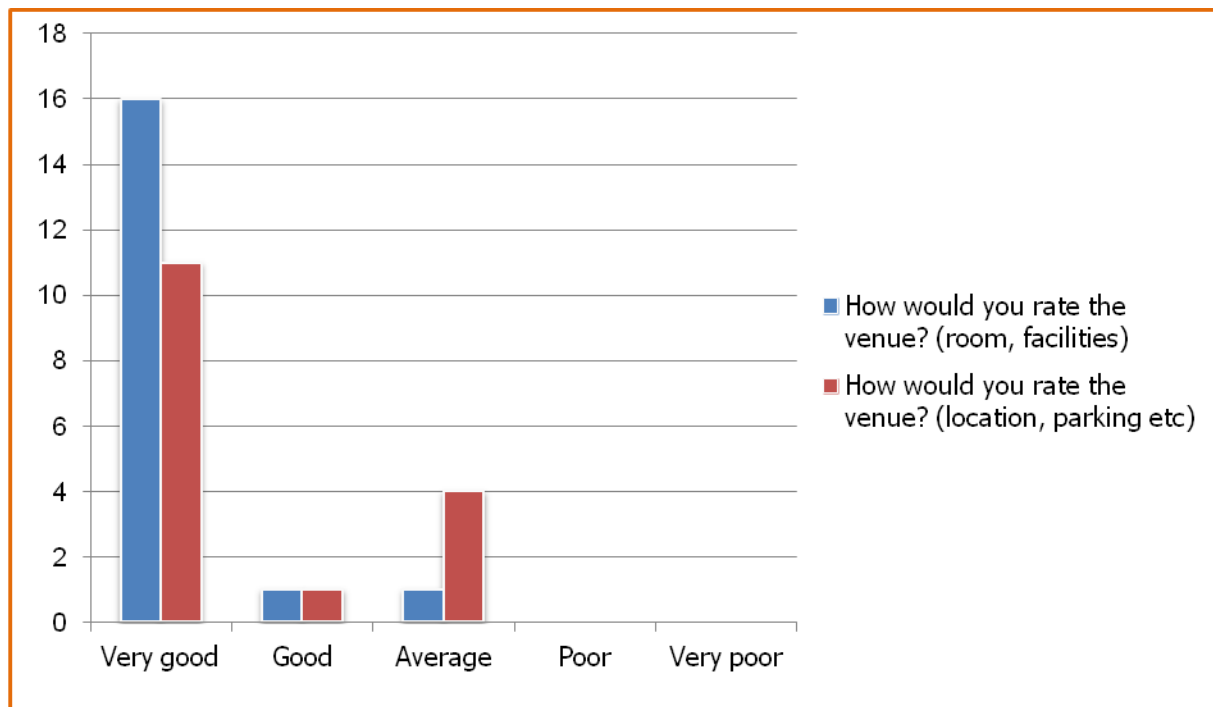
The meeting was too short. More time is required to discuss issues being raised.

The concerns from GPs – it was obvious from Sian's presentation.

No, thought it was well prepared and executed. Look forward to next meeting. Picked some good contacts, professionals and friends with same difficulties.

It was a lot to take in. I found it very useful.

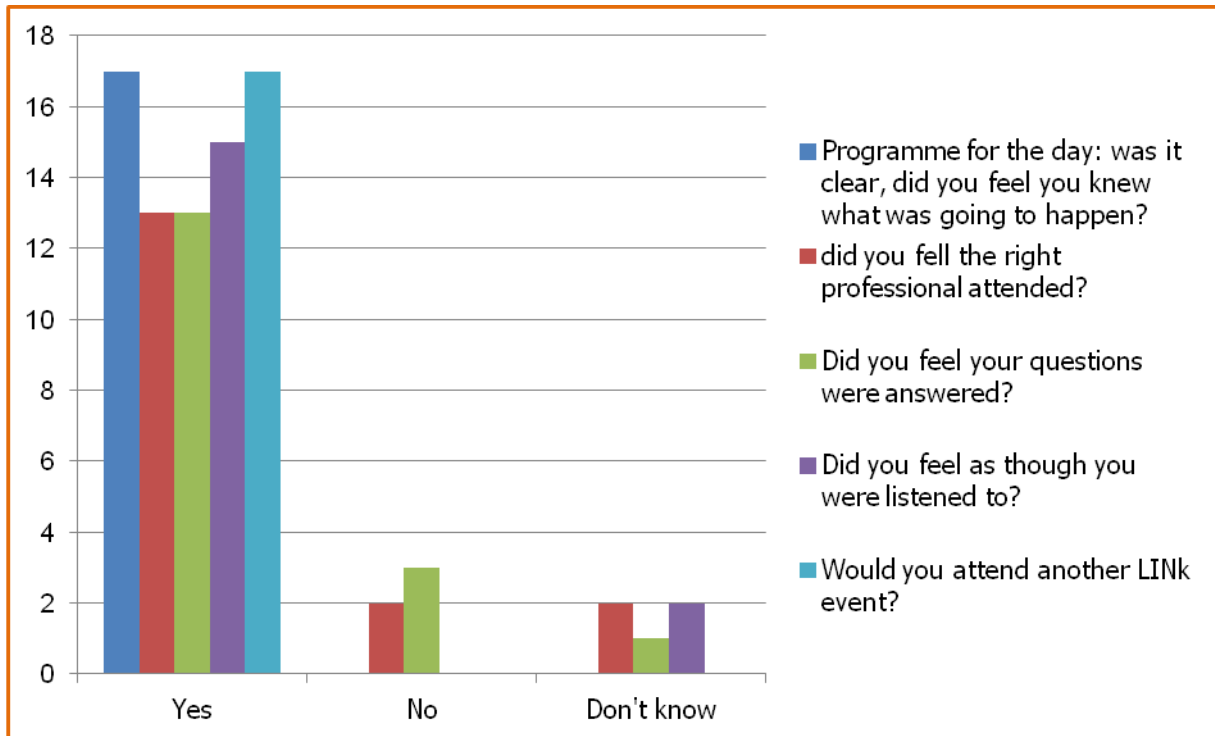
5.2.3 Venue



The scores for the venue are generally very good and are actually higher than for an event held the previous month. This may reflect that most of the delegates were quite familiar with the Phoenix Centre (Carers Centre), although as the previous event had also been aimed at carers we might have expected the scoring to be quite similar.

The lower scores around the 'location and parking' are most likely related to parking as this is an issue at the centre.

5.2.4 The event



5.2.5 Additional Comments

Did you feel the right professionals attended?

"Where was the champion from the council, Jonathan Sutton?"

"More?"

"The event could have included practitioners, GPs etc."

Did you feel your questions were answered?

"Some, but it raised more."

"We need more time, these events are very good and lots of people attend, but this time I feel things have been rushed. But very good event. (Still long way to go.)"

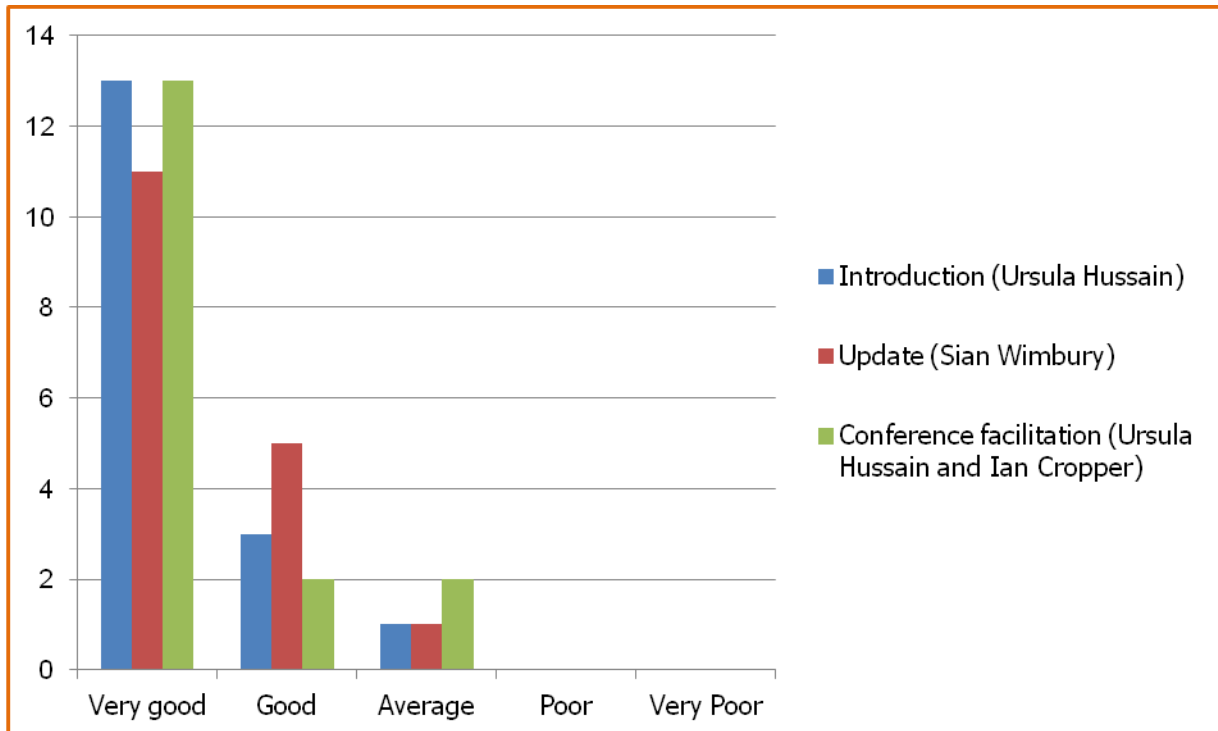
Did you feel as though you were listened to?

"To be fair I was quiet because I am here as a student doing an MSc in Dementia Care."

Would you attend another LINK event?

"Definitely very informative and hope I can contribute more in the future."

5.2.6 Presentations



5.2.7 Additional Comments

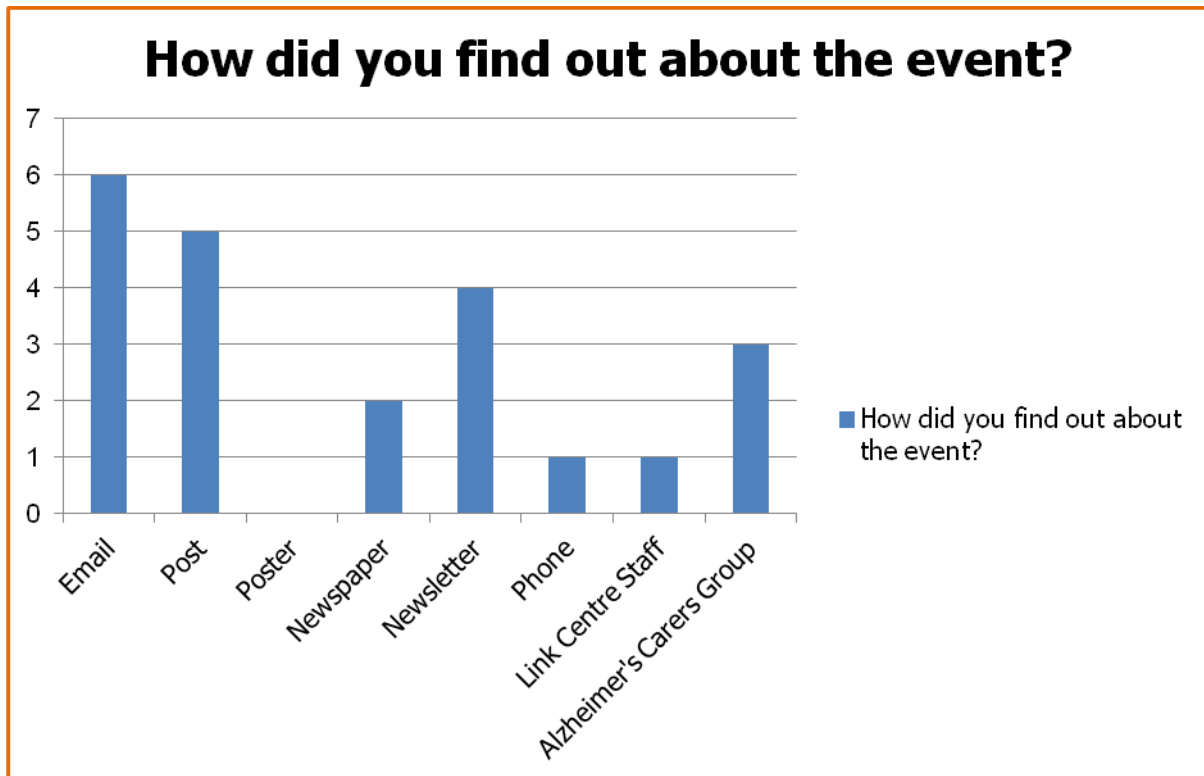
Introduction

“Very positive and good speaker.”

Update

“Good speaker but not enough hard data and handouts. E.g. size of cuts (on website) and number of GPs attending training.”

5.2.8 Publicity



5.2.9 Additional Comments

“From Alzheimer’s society contact.”

“These meetings have followed on.”

Email again scored the highest but again there was a wide range of sources for people finding out about the event. The Alzheimer’s Carers Group brought in a few people and this demonstrates the value of making contact with key groups. It’s not clear whether someone really was informed by the Link Centre staff or whether this is another example of the confusion we have become used to, between the LINK and the Link Centre.

5.3 Conclusion

The feeling of the team post event was that the event had been quite successful and this appeared to be supported by the scores and comments. A concern that the event might have been a little too short was also reflected in a comment from a delegate.

One really positive note was that delegates were happy with the event even when they still had issues which they felt had not been resolved.

It was also clear from comments that people had made and from things that were said in the group discussions, that people were coming from widely varying levels of experience, and a search for information was a major reason for attending the event.

**Appendix 1: Key recommendations of the
May 2010 Oldham Standing
Conference (Dementia)**

**Appendix 2: May 2010 Oldham Standing
Conference Dementia Action
Plan**

**Appendix 3: NHS Oldham Interim Progress
Report**

Appendix 1: Key recommendations of the May 2010 Oldham Standing Conference (Dementia)

- (7.1) The development of GP services to become more specialised around dementia and mental health generally must be undertaken if appropriate and timely diagnoses are to be made. It is recognised that this would be a long term process of change, although this should not negate the impetus for it to begin. Long term and proactive commitment, co-ordination and initiative for this are required from service commissioners.**
- (7.2) Ensuring a means by which appropriate support - as based upon issues raised in this report - can be identified and provided for carers when presenting to GPs must be addressed by commissioners and within GP contracts.
- (7.3) The need for mandatory dementia awareness training for key frontline personnel to include all domiciliary care agency staff and staff within nursing homes as a priority, as well as nursing staff and clinicians within hospital and community settings must be acknowledged and actioned. The role of the Care Quality Commission in standardising such practice should also be explored.**
- (7.4) Monitoring of practice within these disciplines in line with better monitoring of how care planning principles are practically applied must also be tightened if dementia patients are to receive a quality service that meets their needs. This is also necessary if the personalisation agenda is to be realised.
- (7.5) Interagency awareness training within frontline services (such as housing and police for example) is also necessary for the holistic treatment of a person with dementia, and as a means of supporting the long term management of the condition via more appropriate interventions.**

- (7.6) The pursuit of providing an admiral nursing service within Oldham is shown to be a priority issue and a consistent theme from this work.
- (7.7) Infrastructure support and financial investment is needed for voluntary organisations in order for vital self-help to be available to carers. A commitment from service commissioners to develop this in a suitable manner is needed if this already vulnerable group is not to be exploited.**
- (7.8) Formalising support for carers by offering awareness training as standard would also be helpful as a means of supporting them in their role to understand and manage the condition. As such, this could be made available along the same lines as it could be to frontline workers.
- (7.9) The existing shortcomings of current home care services for people with dementia must be acknowledged and addressed. This is with a view to meeting service user needs, supporting the long term management of the condition and to realise the values of the personalisation agenda.**
- (7.10) OMBC's current policy position regarding the funding for transport to and from day care provision and the usage of individual budgets must be re-evaluated. This is with a view to enabling a fairer access to day care services and to account for the respite needs of carers.

Appendix 2: Dementia Action Plan

Taken from the Report of the May 2010 Oldham Standing Conference

Access & Awareness			
Initial Issues/Gaps Raised	Now (0-6 months)	Soon (6-12 months)	Later (12 months+)
<p>General Practitioners (GP): <i>GPs are gatekeepers to diagnosis and service as they are the first point of contact</i></p> <p>Poor Training, knowledge of mental health conditions and lack of cooperation.</p> <p>GMC do not embrace legislative change</p>	<p>Begin the process of contractual change, to increase the demands on GPs to train & provide services specifically in relation to mental health.</p>	<p>Contractual change</p> <p>Training should be offered and supplied to GPs Larger practices with 8-9 GPs should also have a specialist (mental health) clinician/practitioner</p>	<p>Contractual change</p> <p>GP training for smaller practices (inc. Incentives to take on extra work) No bias opinions when reforming statute</p>
<p>Lack of liaison between GPs and psychiatrists.</p> <p>Lack of agreement regarding medication</p> <p>No ruling for GPs to train. This would be in addition to their current role</p>			<p>GP training for smaller practices (inc. Incentives to take on extra work)</p>

Initial Issues/Gaps Raised	Now (0-6 months)	Soon (6-12 months)	Later (12 months+)
The introduction of personal health budgets although good for increasing competition and good practice could lead to oversubscribed services.	Training to encourage services that the public want and encourage healthy competition.		Market forces to encourage service improvement. Implementation of personalisation health/social care budgets in the manner outlined by Darzi
Lack of knowledge regarding Dementia (Both professional and by the public, some people just think it is a part of getting older)	Early treatment and diagnosis (medical acceptance)	Lack of knowledge regarding Dementia (Both professional and by the public, some people just think it is a part of getting older)	
Lack of Information Available to both professionals and the public	There should be a single access point for patients to obtain all information – e.g. via a dedicated worker, Admiral Nurses, One Stop Shop	Lack of Information Available to both professionals and the public	
There are no high profile people that are involved in promoting the disease, as there are in other mental health problems There is little interest in dementia issues in comparison to other	Create interest on dementia issues Getting the health minister on board. Multi-disciplinary campaigning	High profile campaign (effective like the FAST advertisement for stroke awareness) High profile campaign (effective like the FAST advertisement for stroke	

diseases e.g. Cancer. Make dementia 'interesting' to increase awareness and funding	Word of mouth & Networking Leaflets Learning from best practice of successful PR campaigns in health (E.g. cancer promotion).	awareness)	
Funding Gap			

Diagnosis, Early Intervention and Support

Initial Issues/Gaps Raised	Now (0-6 months)	Soon (6-12 months)	Later (12 months+)
Ensuring there is a community care assessment	Care coordinators to organise multi disciplinary meeting, including housing		Develop information packs to enable people to find the right services
Not enough day care provision for those with dementia (exclusion)	Increase day care places	Increase day care places	
Attitudes and arrogance of professionals should be addressed.	Website to be updated regarding services for sufferers and carers	Training events to address negative attitudes of staff re: dementia & mental health issues to include experts through experience as facilitators	Specialist psychological talking treatments for clients and carers
Carers' and sufferers' confusion regarding the illness and services	Forum 4 Age leaflets to be given out to carers and clients?	Advocacy for carers aligned to memory Could be clinic?	
Housing does not seem to be involved in the care plan and it's hard to get one in the first place Carers' support that can be involved socially and not just in personal care (Individual budgets and In Control)	IBs to be processed within 6 months to included carers needs, respite etc.	Admiral nurses to support carers	

Initial Issues/Gaps Raised	Now (0-6 months)	Soon (6-12 months)	Later (12 months+)
Lack of awareness - for example the Failsworth support group.	Information packs to be made available Support for smaller support groups to promote themselves		
Need for more psychological support in the form of dementia support workers and not just psychologists	Vision for the future amongst leadership; recognition of experts through experience.	Appointment of Admiral Nurses	
Lack of feedback regarding recommendations and follow ups. A need for more interagency communication	These action plans to be responded to Agencies to use public arenas to provide verbal/face-to-face feedback		
Carers not heard/listened to before diagnosis and not informed even when a diagnosis has been made	Carers views and opinions listened to and pre and post diagnosis Post diagnosis -support groups would be useful. (one exists in Failsworth)		
Advocacy workers need to get carers voices heard		A need for more advocacy workers	
A lack of focus on physiological needs once diagnosed with a mental health illness.	Physical assessment alongside neurological.		

Initial Issues/Gaps Raised	Now (0-6 months)	Soon (6-12 months)	Later (12 months+)
<p>Rehabilitation for intermediary care: in Oldham people with dementia are not offered intermediary care. Does the intermediary care strategy include dementia?</p>	<p>Find out if dementia features in intermediate care strategy</p> <p>Relevant agency to provide update</p>		
<p>Lack of access to day care, specifically Dementia day care, or oversubscribed.</p> <p>Lack of transport to day care services: this deters people from attending these available services. That may cease to exist if people do not attend.</p>	<p>Transport to day care services made more available.</p>		
	<p>Life story; work with each service user to go with client as they progress through service.</p>		

Carers

Initial Issues/Gaps Raised	Now (0-6 months)	Soon (6-12 months)	Later (12 months+)
Lack of specialist support groups	Specialist support group/s either developed or existing (voluntary) provision supported and promoted.	Raise awareness about carers issues locally and nationally. Campaigning/ publicity web press etc.	
Lack of collaborative work between people and services & lack of knowledge of processes	More collaborative work	Flowchart of services	
No accountability for those that provide unacceptable services	Map services that already out Feedback mechanism (complaints/compliments)	Greater accountability of statutory services	
No real support on diagnosis	Counselling/emotional support available at diagnosis	More support via talking therapies & information about long term support for carers	Admiral Nurses 'One Stop' for dementia carers
No peer groups to improve wellbeing and encourage moral support	Peer support groups		

Initial Issues/Gaps Raised	Now (0-6 months)	Soon (6-12 months)	Later (12 months+)
Stigma- non person	Increased public awareness general via education Mandatory staff training	Increased public awareness general via education Mandatory staff training	Increased public awareness general via education Mandatory staff training
Nurses on general wards not understanding dementia issues	Mandatory staff training	Mandatory staff training	Mandatory staff training
Negative attitudes of consultants are endemic	Mandatory staff training	Mandatory staff training	Mandatory staff training
Dominance of medical model		Funding/research into alternative therapies & approaches(open minded)	
Fear of dementia for carers	Reduce fear via education	Reduce fear via education	Reduce fear via education

Initial Issues/Gaps Raised	Now (0-6 months)	Soon (6-12 months)	Later (12 months+)
Lack of support lead to crisis	Information and support for carer and client before crisis point, including carers to understand the effect on them.	Admiral Nurses to support & provide recognisable person to talk to	
Employment opportunities: fear/lack understanding.			
Lack of early treatment can lead to decline	Intercept Alzheimer's drug – delaying decline for all required		
Isolation and deterioration of cared for when living in residential homes	Review of residential care services. Training & support for residential care homes, including private sector.	One to one, personalised support for individuals. Socially included when living in a home.	
Care Plans not being adhered to and no one to monitor this/follow it up.	Closer monitoring of care packages in accordance with care planning objectives with penalties for care providers not so doing	Closer monitoring of care packages in accordance with care planning objectives with penalties for care providers not so doing	Closer monitoring of care packages in accordance with care planning objectives with penalties for care providers not so doing

Long-Term Management			
Initial Issues Raised	Now (0-6 months)	Soon (6-12 months)	Later (12 months+)
No information	Improvement in the lack of information	Age Concern more advocates Admiral Nurses	
Support from someone who understands the progression and can support with stimulus to keep someone independent		Admiral Nurses	
Inconsistency of carer/s leads to problems for person and carers	Support for people Consistency of carer (see Home Instead model; it works) stimulus knowing the person, stages of dementia, having the tools/knowledge	Consistency of carer (see home instead model it works) stimulus knowing the person, stages of dementia, having the tools/knowledge	Consistency of carer (see home instead model it works) stimulus knowing the person, stages of dementia, having the tools/knowledge
Irregular reviews of care	Care plan reviews, resources and training Budget reviews	Care plan reviews, resources and training Budget reviews	Care plan reviews, resources and training Budget reviews
Lack of understanding for the person in the community and not just in residential settings	Life story worker within the community		

Initial Issues/Gaps Raised	Now (0-6 months)	Soon (6-12 months)	Later (12 months+)
Not enough Day care and transport has been stopped	Day care service transport to be provided as taxis are not safe for people with dementia	Day care service transport to be provided as taxis are not safe for people with dementia	Day care service transport to be provided as taxis are not safe for people with dementia
Lack of training & understanding for lower level staff in housing	Training for housing staff on dementia	Training for housing staff on dementia	Training for housing staff on dementia
Lack of training needs to be addressed as well as the lack of regular reviews with the carer and client	Training for anyone who comes into contact with people with dementia	Training for anyone who comes into contact with people with dementia	Training for anyone who comes into contact with people with dementia
Lack of information	Increased awareness via marketing	Increased awareness via marketing	Increased awareness via marketing
Lack of knowledge/understanding from people about how the brain works and how to stimulate a person with dementia, as well as the importance of providing stimulation and effective communication.	Care home stimulus 1-2-1 activity Personalisation Mandatory care home consistent & joined up dementia training		
Non-specialist services can be insensitive to needs of a person with dementia – e.g. i.e. housing staff moving someone, made things worse and ended up in day care	Inter-agency training for non specialist front-line staff	Inter-agency training for non specialist front-line staff	Inter-agency training for non specialist front-line staff

Initial Issues/Gaps Raised	Now (0-6 months)	Soon (6-12 months)	Later (12 months+)
Inappropriate ways of communicating with a dementia patient	Mandatory dementia training for all staff in care homes, home care and health care.	Mandatory dementia training for all staff in care homes, home care and health care.	Mandatory dementia training for all staff in care homes, home care and health care.
Stigma can lead to further denial of symptoms, or from family.	Better awareness, education and information	Appointment of Admiral Nurses	
Not getting the right information and support about what can be accessed	Support of skills and knowing the right assisted technology that the "individual person" can use.		

Appendix 3: NHS Oldham Interim Update

You said	We did / plan to do
GP training	<p>1 half day session run for GPs</p> <p>2 half day sessions planned for 2010/11</p> <p>E-learning for GPs promoted and advertised</p> <p>Ongoing training is being developed</p> <p>Awareness training</p> <p>4 day Alzheimer's Society course</p>
GP contracts	<p>Identified key performance indicators for newly commissioned</p> <p>Continue to work with primary care colleagues to develop services for people with dementia and their carers</p> <p>Primary care pilot project</p>
Public and professional awareness	<p>July 2010 public awareness campaign was held</p> <p>Dementia drop in session held for information and support</p> <p>CDWs have a distinct focus on dementia: KPIs and outcomes</p>
Early diagnosis	<p>Reviewed access to specialist memory assessment service</p> <p>Pilot project to maintain good access</p>
Improve standard of care for people with dementia in acute hospital	<p>Liaison service</p> <p>Pathway work</p> <p>Intermediate Care</p>

Oldham



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