

Alzheimer's Society Early Diagnosis campaign: GP Evaluation Summary

Overview

- The Worried about your memory? awareness campaign materials are considered effective by GPs.
- Half of respondents are definitely displaying the materials they receive.
- The vast majority of GPs feel there is a benefit to receiving a diagnosis of dementia.
- Barriers to diagnosis include stigma, lack of patient presentation to General Practice and lack of support services following diagnosis.

Introduction

The Worried about your memory? campaign consists of information materials which aim to increase awareness of the early signs and symptoms of dementia, and encourage people to seek help if they have memory concerns. Leaflets and posters have been regularly mailed to GP practices in England, Wales and Northern Ireland since 2008. We wanted to evaluate the effectiveness of the Worried about your memory? campaign leaflet, and explore GPs' perspectives on dementia diagnosis.

Method

In January 2012 we emailed an online survey to GPs in England, Wales and Northern Ireland, receiving a total of 382 responses. The survey was designed by Alzheimer's Society and delivery was facilitated by working in partnership with a market research agency.

Results

Worried about your memory? Materials

GPs found the Worried about your memory? campaign materials to be effective, and half were definitely displaying leaflets in their surgeries.

Diagnosis

The vast majority felt there was a benefit to an early diagnosis of dementia, and most felt they had received sufficient basic training in assessment and management of the condition. Similarly, most felt at least fairly confident in their ability to diagnose dementia.

Barriers to diagnosis

Despite the majority of respondents reporting benefits to diagnosis, a range of barriers were identified.

Stigma and a lack of public awareness

Respondents reported that people do not present to General Practice with their symptoms because of the stigma attached to dementia, and also because memory problems are often seen as a natural part of ageing. Practical issues, including patients living alone or patients forgetting appointments, were also reported.

Professional confidence in dementia outcomes

Low confidence in the efficacy of treatments for Alzheimer's Disease was identified as a barrier to diagnosis by some respondents. Similarly, a lack of treatments for other forms of dementia reduced incentives for giving a diagnosis.

Diagnosis pathway

GPs commented on difficulties in the process of diagnosis, as they are unable to diagnose dementia themselves, and often lack the time or assessment tools needed to make an appropriate referral. Some GPs identified that the route into secondary care was also problematic, either due to poor integration or because of long memory clinic waiting times.

Access to support services

A lack of appropriate support services following diagnosis was a significant barrier. It was felt there needed to be more services available earlier on for patients with dementia. GPs also reported the need for a reliable source of information about local services.

Key figures

- 50 % of practices definitely displayed Worried about your memory? materials.
- 82 % of GPs thought that the leaflet would encourage people with memory concerns to visit their GP.
- 88 % of GPs agreed there are benefits to an early diagnosis of dementia.
- Key benefits included:
 - Time to plan for the future (84 %)
 - Access to treatments (78 %)
 - Helping to improve quality of life (74 %)
- 80 % of GPs feel confident (28 %) or fairly confident (52 %) in diagnosing dementia.
- The main barriers to diagnosis were identified as:
 - Stigma (66 %)
 - Lack of patient presentation (65 %)
 - Lack of support services following diagnosis (53 %)
 - Lack of training for GPs (35 %)
 - Lack of suitable drug treatments (33 %)
 - No local memory clinic/ long waits (23 %)

Conclusions

GPs see great value in the Worried about your memory? awareness campaign, and in dementia diagnosis more generally. This is an increasing trend, mirroring the growing public profile of dementia in recent years.

Despite positivity about the value of diagnosis, respondents identified that there are still significant barriers to diagnosing dementia. These barriers largely related to external factors, such as stigma, low public awareness of dementia, and a dearth of support services post-diagnosis. Some barriers were identified relating to GPs themselves, such as a lack of time to make a diagnosis, lack of practical assessment tools and low clinical confidence in the efficacy of available treatments.

These findings will inform both our public awareness raising and the development of resources to support health professionals in dementia diagnosis and management.

For further information about the survey and results, or to find out more about the Early Diagnosis campaign, contact waym@alzheimers.org.uk.

Appendix A: Full survey results

1. *Your practice may receive mailings of Worried about your memory? materials. Does your practice display these materials?*

Yes	50 %
No	7 %
Don't know	32 %
My practice does not receive the mailing	11 %

2. *Do you think that the campaign leaflet would encourage people to visit their GP if they had memory concerns?*

Yes	82 %
No	4 %
Don't know	14 %

3. *Do you think the information in the materials strikes a responsible balance between informing people to action where necessary, without making them overly concerned where no real symptoms exist?*

Yes	73 %
No	7 %
Don't know	20 %

4. *If we were to further develop our dementia resources for GPs, how would you like to access that information (select multiple options)?*

Online	71 %
Publications	4 %
Print materials	41 %
Media	11 %
Face-to-face learning	38 %
Other	2 %

5. *Do you feel you were given sufficient basic training in diagnosis and management of dementia?*

Yes	37 %
To some extent	28 %
No	28 %
Don't know	7 %

6. *Do you feel you were given sufficient post-qualification training in diagnosis and management of dementia?*

Yes	23 %
To some extent	43 %
No	28 %
Don't know	6 %

7. *Are there any specific areas you would further information on (select multiple options)?*

Initial assessment and referral	41 %
The dementia pathway and my role in it	39 %
Information and support for people with dementia	51 %

Management of behavioural symptoms of dementia	75 %
Available drug treatments and their effectiveness	47 %
Support for carers	54 %
Other	6 %

8. *What in your opinion are the barriers to diagnosis (select multiple options)?*

Dementia is not important	1 %
Many people do not present to GPs	65 %
No local memory clinic/long waits	23 %
Lack of training for GPs	35 %
A lack of support services following diagnosis	53 %
A lack of suitable drug treatments	33 %
Stigma attached to dementia	66 %
Other	14 %

9. *Do you think there are benefits to an early diagnosis of dementia?*

Yes	88 %
No	12 %

10. *If yes, what are they (select multiple options)?*

Access to treatments	78 %
Access to care pathways	69 %
Time to plan for the future	84 %
Helping to improve quality of life	74 %
No benefit	1 %
Other	9 %

11. *How confident are you about diagnosing someone with dementia or Alzheimer's disease?*

Confident	22 %
Fairly confident	58 %
Not confident	15 %
Don't know	5 %

12. *Do you tell your patients about the support they can receive from Alzheimer's Society?*

All the time	13 %
Often	33 %
Sometimes	28 %
Rarely	20 %
Never	6 %

Appendix B: Comments

Need to ensure that campaigns targeted at GP's strike the correct balance between encouraging thoughts about dementia without seeking GP diagnosis as this is beyond the remit and should be done in specialist clinics.
I think that it would be helpful to learn about techniques used to persuade a dementia patient to accept a referral and help in the home. There seems little that is offered to patients in the early stages to stimulate them in terms of befriending services and activities. This group of patients go through intense isolation from friends that have given up on them for many years before they require day centre care. By introducing them early to a day centre before they become paranoid and distrusting of others, it would ensure that they are happy in that environment. This could take the form of art clubs or cookery etc. To introduce members of staff from the day centres early on in the disease process would ease the way to starting full day centre based care. In the early stages, psychiatrists seem obsessed with testing these patients and offering medication rather than concentrating on preserving those activities that they enjoy.
In our PCT we have added Dementia screening to our Commissioning Incentive Scheme this year and have asked each practice to screen at least 20% of their over 65 years old patients using the MMSE.
I have a family member with dementia so probably more aware of things than others. I find a problem with support from specialist if not on any px meds i.e vascular dementia no one really follows up as speciality mainly GP.
It will remain a Cinderella illness until some real effective treatment is available, there feels little point sometimes clarifying a diagnosis only to be unable to alter the prognosis of the pathology.
GPs may be capable of diagnosing dementia but currently the patient needs to see a specialist in order to get a diagnosis.
Reticence of local memory clinic to diagnose early dementia - discharged with ""mild memory deficit"" diagnosis back to GP = hopeless!!
Media campaign also important, encouragement from clinician and availability of support to both patient and family are important in care of people with dementia.
It is helpful to identify, diagnose and support people with Dementia. However in time scale limitations at GP practice backup support is vital to GPs
Great that you are trying to improve services
Tend to not see patients after referral to local memory clinic as much as other conditions if prescribed medication tend to get it from the clinics. Main issue is lack of comprehensive local information for sources of help locally from voluntary and other organisations and any benefits available. A web source of local services would be an enormous advance in effective communication with this vulnerable group of patients AND vulnerable group of carers. Support and training for carers in old people's homes too essential re behavioural issues.
Would not have thought of recommending society but aware of many patients receiving their support. More likely to think of recommending now rather than rely on others.
Work part of my time in Nursing Homes as well as in practice and can see the great possibilities for advancing care.
Formal testing in common usage, e.g. mini-mental, seems to under diagnose a problem even when it is relatively apparent there is an early problem.

An email link on my desktop with mental testing sheet would help me
On the leaflet it says to make an appt without delay; this advice is appropriate for patients with chest pains or immediately life-threatening conditions, less so with chronic diseases such as Alzheimer's.
Not always relevant to all patients with dementia as not all have diagnosis of Alzheimer's. However I do sometimes forget to mention the role of the society to those who do have Alzheimer's.
Patients do not want a diagnosis. GPs often wait patiently for 18m - 2 yrs in order to be able to work with people they have long recognised have dementia.
Direct access for CT scan of brain would be helpful.
Many patients are diagnosed with mild cognitive impairment when in the early stages of dementia. More of these patients would be carefully followed up and diagnosed with dementia if there was a belief that the treatments available are likely to have a meaningful impact. I believe that clinician confidence in the effectiveness of acetylcholinesterase inhibitors, and memantine, is lacking.
It's really emerging with media coverage that patients are coming forward. We need info in practice & support for GP training & resources (time being a big-one) to make the right diagnosis.
Patients think it's part of NORMAL ageing
Local support is very patchy, specialist medical OK but little community support actually available
This will be unpopular with you but my opinion as an experienced GP very much at the heart of my local community is that ""awareness raising"" of individual illnesses by special interest groups is counter-productive. This approach simply produces yet more ""worried well"" that clogs up an already overburdened NHS and in fact delays timely treatment for the truly unwell. The same applies to recent government inspired advertisements with regard to loose motions/bowel cancer, it simply worries the vulnerable and the ""just chat to your GP about it"" implies we all have time for constant reassurance. We do not. All the GPs i know work excessively long hours dealing with highly complex and multiple medical issues, please remember that the patient with dementia may also have diabetes, arthritis, heart disease, depression etc etc and be on multiple complex drug regimes. My other moan is the constant refrain ""GPs should know more about ""X"" or need training about a specific disease or illness. Please remember GPs have a breadth of medical knowledge about 50 times that of single-issue consultants and are very highly knowledgeable. Of course further information is always helpful but i do, in fact, know a lot about dementia, the same as I know a lot about dermatology, neurology, depression, asthma, hypertension, trauma, management etc etc etc! What is needed is hands-on care for people with dementia in the way of home-visitors, clubs etc especially in rural areas such as mine where the nearest facilities can be 10 miles away and public-transport is non-existent. May I suggest you spend your funds and time on organising local volunteers. Please take these comments as they
NICE feels dementia drugs of very limited value. local services already hugely over stretched with more severely affected people and adding to that the bottom of the pyramid needs to be balanced with what is affordable and available and raising unmeetable expectations leads to yet more frustration
I am yet to be convinced that an early diagnosis does more than increase anxiety and depression and it is not possible at an early stage to differentiate between normal memory loss and more aggressive forms of dementia.
We do have an in practice Dementia cafe run by the Alzheimers society, which is very helpful.
Early diagnosis without effective treatment potentially causes more harm than good. Drug treatments are

disappointingly very poorly effective and support should be able to be accessed in the community without the unnecessary delay of having to attend a memory clinic.
All people over 65 should have annual checks for dementia. They do not always come in routinely to see GP's and not always picked up. Once a person is diagnosed they should automatically be referred to day care unit for themselves and their carers
Our local memory clinic is fantastic but recently changes to pathways made without involving the lead psychiatrist or GPs with all referrals via triage of Wellbeing service, not good! Other point is relative's history needs more weight than assessment tests, high IQ patients sometimes fool us and delay diagnosis...
Not confident about diagnosis as local social services have never accepted GP diagnosis and will only accept diagnosis if patient seen in secondary care
I have a close family member with vascular dementia. I work as a GP and have reasonably frequent contact with persons with dementia and their carers. I have learnt more about the 'coal face' needs for caring for someone with dementia since being involved in this way myself with a close family member. I have found the Alzheimer's Disease website information leaflets invaluable. I was unaware of the importance of eg the eating problems management, tips on improving mobility, continence problems and the importance of maintaining socializing in the person's known local environment ,family and friendship circles as much as possible + the benefits of eg singing, reminiscence therapy. I have much more insight into the challenges and hard work of caring for someone with dementia, but also the rewards when 'you get it right' ! I feel very strongly that there is a big gap in knowledge between medical and social care. I have seen dedicated social service staff who look after people still able to live in their own homes and get to know their clients very well.
Question 11 about benefits of early diagnosis, depends on the individual. Unless drug treatment is available it may not be helpful
There is great variability in practice both in primary and secondary care. Our own waiting times for specialist care are prohibitively long, not 6 months into recommissioning a 'superior' system. My concerns expressed bluntly about your written materials are that they are directed appropriately at the right stage of disease i.e. I believe only 1/20 patients with self defined memory concerns are subsequently diagnosed with dementia (according to a RCGP update course) but those presenting through loved ones are far more likely to have a significant cognitive deficit. Written materials might be directed more specifically according to the pattern of presentation
I would like to see the initial memory loss campaign adverts NOT to be heavily labelled with Alzheimer's disease - I believe there is a stigma attached to the word Alzheimer's , people associate with the end stage of the disease and fear the label. There are many differentials for memory loss and patients need generic encouragement to attend their primary care team.
Patients don't think there is any treatment, it's just natural ageing, not a problem yet, just make more lists, don't want a diagnosis.
It is not always right for the patient to be diagnosed with early dementia as they may not be ready for it. Early diagnosis in these patients is cruel. One size does not fit all, but unfortunately all our pathways are set up for this.
Dementia is a Cinderella condition often hidden by fear and shame
It may be helpful to have leaflets aim at family/carers of patients with memory problems - usually person that

brings them to the gp surgery.
Keep up the good work. People should be encouraged to report symptoms of dementia as soon as they are noticed, and access services at an early stage.
Dementia is becoming the main problem in old age that we deal with. Patient's family are key.
There is a massive stigma attached to dementia and people see it as a life sentence. Press reports about voluntary euthanasia get a higher profile than treatments for dementia, and how most people actually live a good quality of life until the end, as with all chronic diseases such as lung disease and heart disease. I think there needs to be more positive media coverage of how people cope with dementia and the tricks they can use to get by and the pleasure they still get out of life along with the drug treatment that slows it down. I also think people need to be aware that all dementia is not Alzheimer's and that good cholesterol, BP and sugar control is vital to keeping your brain healthy.
Diagnosis locally is made after a quick screening consultation with a GP and then referral for assessment by a psychiatrist.
Hesitant to give a diagnosis unless it is beneficial and when support services and treatments are poor not sure it is a good idea to raise possibility.
I think the public has been misled to an extent into believing that early diagnosis will result in successful treatment. Of course there is benefit in confirming a treatable medical cause but this is very rare. The other rather ironic feature of dementia is it's about the only disease I, as a GP, am not deemed capable of diagnosing! Only a specialist service can do this and only then will Social Services accept the diagnosis.
The local pathway is fragmented. the assessment of dementia (the memory clinic) seems to have a long waiting list, they also don't start any treatment- that means another referral to someone else for treatment
Dementia is seen as an older persons' disease and we do not value older people in this country. It is also not seen as exciting as some other forms of health care and so is side-lined, along with the older person
Incidents are high due to increase in aging population the service level remains the same
This questionnaire has raised my level of awareness regarding the Society.
I feel confident re the diagnosis and referral of patients. I feel less confident managing the behavioural symptoms of patients and getting support for carers. I feel more confident dealing with the End of life issues as I lead for the practice in this. There are however gaps in provision in care in end of life issues for dementia patients.
Local Alzheimer's soc does a fantastic job
There is a philosophical consideration. Given large numbers of patients have vascular dementia which has no available treatments to alter prognosis there needs to be clarification on the benefits of early diagnosis of these patients (from the patient perspective)
Stigma in different cultures
Fatalism re Rx
People see it as part of normal aging
Lack of effective treatment - rather than currently available delaying medication that often doesn't seem to work very well (in my limited experience!). Acceptance of failing memory as part of getting old.
Lack of time/demographic changes - burgeoning elderly population

Ineffective memory clinic
Feeling unclear whether there is really any benefit to having a diagnosis
Lack of national guidelines on screening
Sometimes it takes families time to recognise that there is a problem. People living alone.
Patients refusing referral
No diagnosis made when referred early. Patients unwilling to cooperate.
The patient forgets that anything is wrong.
Workload in general practice.
Just not recognised by family/health professionals and assumed normal ageing
High alcohol intake confounding assessment
Lack of family support as pts forget appts etc
Late presentation and lack of insight by patient
Lack of Public Awareness
Ethnic minorities/language/culture
Not aware of benefits of early diagnosis
Fear of diagnosis
Patients think memory is just due to getting older
Delay in making diagnosis/referral
A feeling that the diagnosis doesn't help
Difficulty in encouraging people to come back. forget appts etc
Patients viewing it as normal part of getting old and not seeking help
Patient denial
It has limited therapeutic impact to make the diagnosis in my area