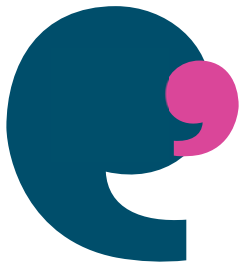




**East Riding of Yorkshire
Community Based Dementia Services**
September 2014



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Executive Summary

The Role of Healthwatch

The role of Healthwatch East Riding of Yorkshire is to work with local communities, talking and listening to people to enable them to share their views about their local health and social care services, helping to build a picture of where services are doing well and where they can be improved.

Purpose of Project

Following a recommendation of the East Riding of Yorkshire LINK Inpatient Dementia Report, Healthwatch East Riding of Yorkshire reviewed the provision of services in the community for people diagnosed with dementia and for their carers. The report identifies services available and how they are accessed, as well as identifying areas for improvement and offering recommendations.

Views of carers and patients were sought at the Memory Cafes held by the Alzheimer's Society.

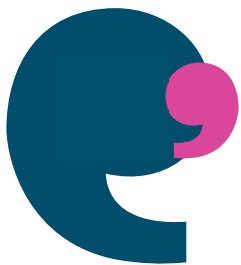
37 GP practices in the East Riding were sent surveys.

We present an account given by the husband of a patient suffering with dementia which illustrates the concerns and experiences of a carer including the comment that "Dementia sufferers are cared for, their carers have heart attacks".

Recommendations

At diagnosis carers should receive information about carers' assessments and local support agencies. Healthwatch can play a key role through its signposting service and would be keen to work with commissioners and providers to determine the best way forward.

- Increased support for carers both whilst they are caring and when their caring role has come to an end.
- Improved co-ordination between agencies to improve access to support.
- The creation of a "Dementia Hub" as a central point for all information.
- The Dementia Academy to operate in the East Riding.
- Training made available for carers and residential staff, to include emotional issues.
- Improved information and access to appropriate benefits.
- Letters and forms issued by health and social care providers should not use insensitive terminology.
- Wider delivery of dementia awareness training e.g. via Dementia Championship scheme.
- When assessments are made regarding modifications to the homes of patients, thought should be given to suitable adaptations to make it more "Dementia Friendly".



Introduction



Working with local communities, talking and listening to people to enable them to share their views about their local health and social care services

Role of Healthwatch

The role of Healthwatch East Riding of Yorkshire is to work with local communities, talking and listening to people to enable them to share their views about their local health and social care services, helping to build a picture of where services are doing well and where they can be improved.

Healthwatch East Riding of Yorkshire, along with all other local Healthwatch organisations has been developed under the Health and Social Care Act 2012, and has legal powers to:

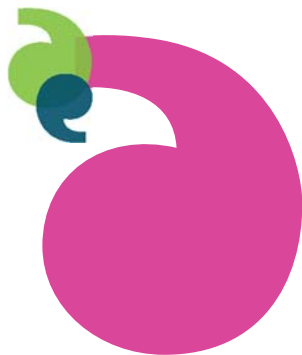
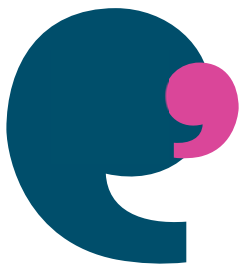
- Gather people's views and experiences of the health and social care system.

- Send trained representatives to enter and view local services in order to speak to patients and service users, as well as to observe services being delivered.
- Make reports and recommendations and to get a response from commissioners and service providers.
- Influence local commissioning decisions through membership of the statutory Health and Wellbeing Board and involvement in preparing joint health and wellbeing strategies.
- Alert Healthwatch England, the Care Quality Commission, MONITOR and local commissioners as appropriate, to concerns about specific care providers, health or social care matters.

Purpose of Project

Following a recommendation of the East Riding of Yorkshire LINK Inpatient Dementia Report, Healthwatch East Riding of Yorkshire reviewed the provision of services in the community for people diagnosed with dementia and for their carers.

The report identifies services available and how they are accessed, as well as identifying areas for improvement and offering recommendations.



Limitations of the Project

Views of carers and patients were sought at the Memory Cafes held by the Alzheimer's Society. The limitations of this process are that only a few patients with dementia and their carers attend these events. There are various reasons for this limited attendance such as: being uncomfortable meeting people who they already know, difficulty in getting to venues and the fact some people do not enjoy group settings.

The 37 GP practices in the East Riding were sent surveys of which there was a 59% response rate.



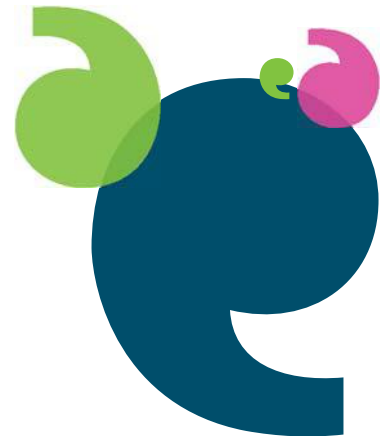
Structure of the Report

The first section of this report examines the services that are in place in the East Riding for dementia patients and their carers. It also provides information on the services available in the surrounding areas of Hull, North Yorkshire and North & North East Lincolnshire in order to identify any gaps in East Riding provision.

The second section examines feedback from service users including those who attend the memory cafes across the region that are provided by the Alzheimer's Society. This section contains feedback on the services currently available to service users in the East Riding and what (if anything) they feel is missing from service provision.

The third section includes information which has been gathered from providers and GP practices across the East Riding. It includes a survey to identify the level of knowledge GPs have around services and support for people with dementia, and how they support their patients once they have received a diagnosis.

This enables us to draw together recommendations for improvement and identify areas of good practice in existing community dementia care services.



Prevalence of Dementia

There are 800,000 people living in the UK with dementia and it is estimated that this will rise to 1 million by 2021. The risk of dementia increases with age. The rate of dementia rises from one in fourteen people over 65 years of age having dementia, to one in eight people over 80 years of age. Over 17,000 younger people (under the age of 65) have dementia. This is often known as early onset dementia.¹

In the East Riding the percentage of adults (18+) with dementia is slightly higher than the national average at 0.54% rather than 0.53%.² The total number of reported patients with dementia in the East Riding is 1828. This is unsurprising as according to the 2011 census the East Riding has a higher percentage of residents over the age of 65 accounting for 21.4% of the population compared to the national average of 16.3%.³ Within the younger age group, i.e. under 65 years of age, the number of reported cases is 97.⁴ This figure is from 2007 so is likely to have increased. Neither the National Dementia

Prevalence figures nor the Dementia Registers distinguish between the under or over 65s so a more up to date figure could not be found. Alzheimer's Society estimates that half of the people living with dementia in the UK do not have a diagnosis.⁵

Although this report is not about the diagnosis of dementia, information regarding the symptoms, diagnosis and treatment is available in Appendix C.



¹ Alzheimer's Society. *The Dementia Guide: About Dementia*, Alzheimer's Society, August 2013 http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2227

² East Riding Community Mental Health Profile 2013, NEPHO 2013 at <http://dataobs.eastriding.gov.uk/>

³ 2011 Census data for the East Riding at <http://dataobs.eastriding.gov.uk/>

⁴ Alzheimer's Society Dementia UK 2007 http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=4

⁵ Alzheimer's Society http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2165

Section 1:

Services and Support Available

Identification and Diagnosis

Hospital Screening

Hull and East Yorkshire Hospital Trust have implemented routine dementia screening of patients over the age of 75, who have entered the Trust through a non-elective referral. According to the report from the Dementia Programme Board there has been a marked increase in this area of hospital screening and has led to an improvement in the level of diagnosis of the condition.

Directed Enhanced Service for Dementia

Local GPs have been invited to offer the Directed Enhanced Service (DES) for Dementia which is a national service to support improved diagnosis. The aim is to identify those people who may be at risk of dementia and who may benefit from assessment using a screening tool. 87% of GP practices have so far signed up.

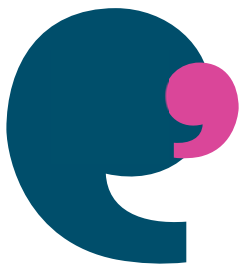
Mild Cognitive Impairment Assessment Service

In conjunction with the DES, the East Riding of Yorkshire CCG has introduced a primary care based service to identify people who may have mild cognitive impairment, but may not at this stage need a full dementia assessment.

This service will enable people with mild cognitive impairment to be managed effectively in primary care, including care planning, assessment and signposting to support including carers support.

Memory Assessment Service

Humber NHS Foundation Trust is the primary service provider for mental health services in Hull and the East Riding. East Riding of Yorkshire CCG has agreed a new model of services and specification with the Trust. This model will provide enhanced assessment capacity for diagnosis of people who may have dementia, a reduction in waiting times and enhanced support to care planning, treatment and advice. This service forms part of the service offered by the Hull Memory Clinic.



Section 1: Services and Support Available



Hull Memory Clinic - Early Memory Service

Hull Memory Clinic provides a specialist service which responds to increasing health demands due to the ageing population, for people of all ages, aiming to meet the needs of people who are concerned that they may have a memory problem. The team also work with the person's supporter to ensure a quality assessment and treatment process that takes everyone's needs into account. This is available at their clinic in Coltman Street in Hull but is also offered by its community team for those in the East Riding in the form of an Outreach Service. This Outreach Service operates a clinic in every locality in the East Riding.

A multi-disciplinary team, qualified in diagnosing and treating memory problems, will comprehensively assess and diagnose the nature of a person's memory difficulties. The team includes: nurses, support staff, time & recovery workers, psychologists, psychology assistants, occupational therapists and psychiatrists. Findings from assessments and any diagnosis are usually reported to the patient's registered General Practitioner (GP). Referrals for this service usually come from patients GPs but patients and carers can self-refer themselves as well.

Following diagnosis, a range of treatment interventions can be offered to both individuals and groups, and can include medication if necessary. All of this is provided with additional input from a range of support workers and robust links with other agencies.⁶

After examining the services available in North Yorkshire and North and North East Lincolnshire the memory service that is provided in East Yorkshire seems on a par with that provided elsewhere.



⁶ <http://www.humber.nhs.uk/services/dementia-services-and-hull-memory-clinic.htm>



Section 1: Services and Support Available



Support After Diagnosis

Single Point of Access - Ongoing Support

The Single Point of Access (SPA) service provides a first point of contact for people aged 18 and over who have been referred to adult mental health services in Hull and the East Riding.

This service is provided by Humber NHS Foundation Trust and offers mental health triage and assessment to enable people to be directed to the most appropriate service to meet their needs. If a psychological need is identified by the SPA team, patients are referred to the most appropriate service.

In cases of a mental health crisis, this service works closely with the intensive home treatment and early discharge team.

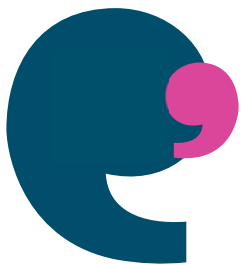
The SPA service has an open referral system and people can refer themselves via a dedicated telephone answer phone line. People contact the service seeking help and depending on their needs are referred on to an appropriate care team. In the case of dementia the referral is to the Memory Clinic in Hull, (which is now available for East Riding

residents). If an East Riding resident is registered with a Hull GP they may also be referred to an Admiral Nurse (please see p14). When the person suffering with dementia is in crisis they would be referred to the Crisis Management Team.⁷

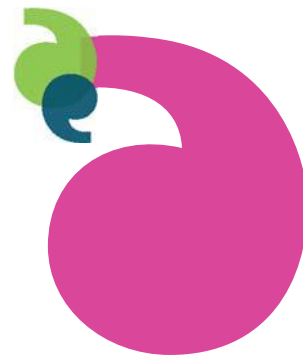
Older People's Community Mental Health Teams

The Older People's Community Mental Health teams provide assessment, treatment and therapeutic interventions for clients over 65 years old who have a mental health problem of a functional (such as depression or anxiety) or organic nature (such as dementia). Therapeutic interventions include cognitive stimulation which involves taking part in activities and exercises designed to improve your memory, problem-solving skills and language ability; and behavioural therapy tries to find reasons for difficult behaviour and applies different strategies to try to change that behaviour. Clients are seen in their own homes, residential or other care settings by community mental health nurses and support workers. The teams also provide carer assessment support and advice to family members and carers. Treatments can include medicines management, evidence-based therapies, behaviour management advice and support for carers, such as education about diagnosis and prognosis.

⁷ <http://www.humber.nhs.uk/services/single-point-of-access.htm>



Section 1: Services and Support Available



The Older People's Community Mental Health Teams are located at:

- Beverley
- Bridlington and Drifffield
- Goole and Pocklington
- Haltemprice and North Bank villages
- Holderness

This again is a very similar service to those provided in the surrounding areas of Hull, North and North East Lincolnshire, York and North Yorkshire with all of them providing Older Peoples Community Mental Health teams and delivering similar services.



Older People's Intensive Home Care Treatment Team (East Riding)

The intensive home treatment team provides an alternative treatment option to inpatient admission when someone has an increased mental health need. If the person requires inpatient admission, the team work closely with the hospital ward team along with colleagues from other statutory and voluntary agencies to help the individual to return home as soon as possible.

Patients are referred by Community Mental Health Teams. Outside of normal working hours, (Monday to Friday, 9 to 5), the team can respond to an urgent referral for older people's mental health services within the East Riding. These referrals usually come through the Crisis Resolution Service. The Crisis Resolution Service is available 24/7 to individuals and their families who are experiencing severe mental health issues.



Section 1: Services and Support Available



Specialist Inpatient Units

Humber NHS Foundation Trust provides two specialist inpatient units that are primarily for patients over 65 with acute mental health problems. An acute mental health problem is one in which urgent help is needed. This can be a worsening episode of an already diagnosed mental health condition e.g. dementia, or it can be the first episode of a mental health issue. Examples include suicidal thoughts, extreme anxiety attacks and psychotic episodes, (loss of sense of reality, hallucinations and hearing voices).

- Maister Lodge located in Hull but available to East Riding residents Is a 16 bed unit which deals primarily with organic mental health problems (e.g. dementia). It offers hospital based care in a therapeutic environment and aims to get patients back to their home environment as soon as possible. The unit utilises an activities co-ordinator to provide activities aimed to help patients develop skills needed for daily life.
- Mill View, Castle Hill hospital Is a 9 bed unit for people who are experiencing functional mental health problems, (e.g. anxiety or depression), and memory impairment. Again the unit utilises an activities co-

ordinator who ensures activities incorporate daily living skills, but activities are tailored to patient's individual needs.

Neighbouring areas also provide specialist inpatient units. Tees, Esk and Wear Valley NHS Trust have recently opened the Springwood Unit in Malton which offers 14 beds for those with complex organic illnesses with associated frailty or vulnerability.⁸ A key feature in this new unit is that they have created indoor and outdoor wander pathways which allow dementia patients to be able to wander safely. Leeds and York Partnership NHS Foundation Trust offer a male only inpatient service at Bootham Park Hospital for York based males.⁹ The Retreat in York is a specialist mental health provider, working with the NHS to provide care for people with complex and challenging needs. Ninety percent of their patients are NHS funded and over 45 CCGs regularly refer to them. The Retreat offers a Dementia Care Pathway for those patients with dementia who require specialist hospital care and emphasis is placed on helping the patient remain as independent as possible.¹⁰

⁸ Tees Esk and Wear Valley NHS Trust
<http://www.tevv.nhs.uk/Our-services1/Harrogate-and-Craven>

http://www.leedspft.nhs.uk/our_services/Olderpeople

⁹ Leeds and York Partnership NHS Foundation Trust

¹⁰ <http://www.theretreatyork.org.uk/services/older-adult-services/dementia-care-pathway.html>



Section 1: Services and Support Available

The Retreat is also a member of the Dementia Action Alliance which brings together organisations who are committed to improving the lives of dementia patients and their carers.

East Riding of Yorkshire Council Social Care

The council offers a range of services for older people who are experiencing a mental health issue, including dementia. These include:

- Specialist Social Workers who can be accessed through the care management teams.
- The Safeguarding Adults team who can be contacted if there are concerns that an older person with a mental health issue is being abused or is at risk of abuse, or if there is a concern about a specific incident relating to abuse.
- A Short Term Assessment and Re-enablement Service (STARS). The STARS team provide support to people in their own homes, usually for up to six weeks, and support people of all ages. During this time the team also assess people to see what future support they might need, provide a free home safety check and give free advice on a range of areas including falls prevention and fire safety.

To access the support of East Riding of Yorkshire Social Care, the Council's customers service team must first be contacted who will then forward the individual to the relevant department. A decision will then be made as to whether an assessment is needed, and a member of an adult care management team will discuss the process with the patient and carer.

The Help at Home service includes the Lifeline service, which offers a range of alarms and sensors to help support people to live safely and independently within their own home. These include: personal alarm pendants/buttons, smoke alarms, fall sensors, bogus caller buttons, high/low temperature monitors, and flood sensors.

East Riding of Yorkshire Council also commissions:

- Respite care in approved care homes
- Home Care providers who specialise in dementia care



Section 1: Services and Support Available



Information, Activities and Carers Support

The Alzheimer's Society East Riding

Alzheimer's Society is commissioned by East Riding Council to provide a range of support services in the East Riding for people with dementia, their families and carers. Referrals can come from GP's, other health professionals or individuals with dementia, their carers or family members including:

- **Dementia Adviser Service** providing information and advice on dementia, services available locally and how to access them.
- **Carer Information and Support Programs (CRISP).** A 4 week programme held at venues across the East Riding that consists of a series of workshops for people caring for a family member or friend with dementia.
- **Memory Cafés.** For people with dementia, their carers and families to meet and socialise with others affected by dementia. The Cafés are facilitated by a member of staff who is available to give support and provide information, and are held at venues across the East Riding.

- **Singing for the Brain Groups.** These are held fortnightly at Willerby, and provide a way for people with dementia, along with their carers, to express themselves and socialise with others in a fun and supportive group.
- **Befriending Service.** For people in the early to moderate stages of dementia. The service provides activity and support and enables the person with dementia to get out and about (if they wish to) and enjoy a hobby or interest of their choice.

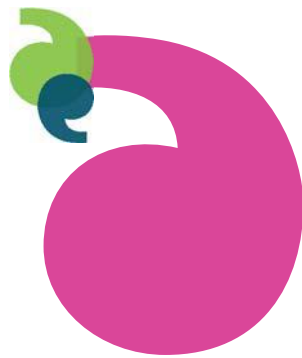
The Alzheimer's Society provides different services in other areas; in Hull they provide an arts and crafts group, tea dance and 1-1 dementia support; in North and North East Lincolnshire they offer one off Dementia Awareness events and in York they offer activity groups such as reading aloud, walking, arts and crafts, dancing and sports.

Dementia Friends/Champions

This is a Government sponsored initiative run by the Alzheimer's Society to enable people to better understand dementia, and the small things that they can do in their day to day lives to assist people with the condition. Dementia Friends/Champions then pass this knowledge onto others via training and information sessions and help to raise awareness of the difficulties faced by those living with dementia.



Section 1: Services and Support Available



Age UK East Riding

Provides services to support all older people, including:

- Information and advice
- Good Neighbour Scheme. This is a Befriending Service provided in the home or over the phone.

East Yorkshire Carers Support Service

East Riding of Yorkshire council provides a Carer Support Service that offers information and advice, drop in sessions, newsletters, training, relaxation and stress reducing techniques.¹¹ Other councils' carers support services follow a similar pattern to that of the East Riding, offering advice, support and training either in the form of telephone contact or support meetings.



East Riding of Yorkshire Council Public Health Initiatives

Digital Reminiscence Therapy Units

Funded by East Riding CCG, this initiative comprises 17 units located in 7 different settings across East Riding that provide therapeutic tools for people with dementia, their carers and family. These are currently being tested to determine their impact on people at different stages of their dementia. They are currently located in the community aimed at newly diagnosed dementia patients, and within specialist assessment centres for people at an advanced stage. Units can be found in libraries, the Carers Support Service, The Alzheimer's Society, care homes, day centres, hospitals and FIND 3. Archived photos and footage has been uploaded by Hull FC on to the machines and Libraries have agreed to upload local archived photos of East Riding.

¹¹ A guide for carers in the East Riding
www.eastriding.gov.uk



Section 1: Services and Support Available



Other services identified regionally but not present in the East Riding

Dementia Forward

Dementia Forward is a dementia charity that is based in Harrogate and Richmond and has a team of experienced dementia support advisors. In its first two years of operation, Dementia Forward was completely self-funded but have recently tendered for the Dementia Navigator role for York and North Yorkshire Clinical Commissioning Groups (CCGs). Dementia Forward works alongside families from the point of diagnosis to those needing full time care, and will work with people for as long as they want the support. The service offers information, a helpline, and support workers who can help sign post to available services. In addition, they provide the only Admiral Nurse in North Yorkshire, and provide various activities including befriending as well as specific services for younger sufferers.

Dementia Academy

The Dementia Academy is based in Hull and is an initiative to improve the standard of care across the city for those suffering with dementia and their carers. It offers Dementia Care Mapping which is the method used to assess care from the patient perspective, and is also used in formal care settings e.g. care homes. The Dementia Academy is also working alongside key partners to promote person centred care and to develop programmes to improve care. Training is offered to anyone living or working in Hull that aims to help ensure a consistent approach towards dementia across the city.¹²

Admiral Nurses

Humber NHS Foundation Trust provides two Admiral Nurses for patients with dementia and their carers in Hull. The service is there to help prevent carer breakdown and to keep people out of hospital and long term care. Referrals come from both professional and voluntary organisations and can come from carers and patients themselves. In Hull the Admiral Nurses also provide a circle dancing group for patients, carers and carers support groups.¹³

¹² www.dementiaacademy.co.uk

¹³ <http://www.humber.nhs.uk/services/admiral-nurses.htm>



Section 2: Engagement with service users



Volunteers for Healthwatch East Riding of Yorkshire attended 10 memory cafes across the county, engaging with service users around their current experiences of the service provision in the community. A survey was available, however only 14 were completed as it was realised that many of the carers and patients preferred having a conversation with the volunteer rather than filling in a questionnaire. From in excess of 30 conversations we managed to gain very useful qualitative information which is outlined in this section. There have been other engagement activities at various Healthwatch East Riding of Yorkshire events with particular concerns being raised regarding community transport for the elderly, including those with dementia.

Further engagement activity included attendance at the Dementia Champions meetings, where volunteers were able to speak to the Dementia Champions and other attendees. Attendance at this meeting enabled engagement with a broader section of individuals that either work with or come in to contact with individuals touched by dementia, including district nurses, voluntary sector representatives and retail staff or organisations, of which included Boots.

Qualitative Responses

This section examines the information that the volunteers gathered from speaking to those attending the Memory Cafes, identifying what they felt worked well and what not so well in terms of support for dementia in the East Riding. The comments we received can be grouped in to a number of themes as follows:

Diagnosis and follow up

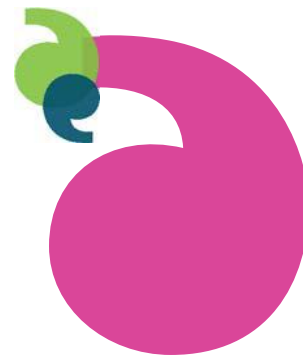
- Long waiting times for diagnosis and no support whilst waiting for diagnosis.
- It would be useful at diagnosis to have a tick box for your address and what is available and what you may require.
- After diagnosis, we were pointed at Alzheimer's Society and then just left.

Communication

- Needs to be better cross boundary working between Hull and East Riding.
- Duplication of services repeating the same information to every service- including repeating information to different staff members in the same service.
- Poor communication causing more work for the carer.
- Social Services difficult to contact.



Section 2: Engagement with service users



Concerns regarding support available

- Admiral Nurses not available in East Riding
- Lack of support from mental health services
- Respite is only offered every 5 weeks for a few hours
- Need more drop-ins/one-stop shops
- 2 hours sitting service a month is the only respite. Sometimes this is cancelled and there is no back up
- Various activities often clash if run by different organisations, means there are days when there are no activities.
- Have to fight for support nothing is upfront-should be able to access clear information. No central point for information on what is available
- GPs don't look at physical problems of the patient
- Issues with respite care not being good and so leading to being nervous to arrange again
- Some GPs are not very supportive and do not understand dementia and the support that is available
- Would like evening/twilight carers support in addition to weekend help

Transport

- The Sitting Service from the East Riding can no longer transport people.

Areas of other positive support

- Alzheimer's Society have been brilliant-offers peer to peer support
- Hedon Library offers a reminiscing group-computer programme and life story
- The Carers Information and Support Programmes (CRISP) are very good information sessions
- Dementia Champion training very good in the East Riding
- Some memory cafes are closing due to low level support, they are a very useful area of support
- The Dementia Academy in Hull was judged to be very important and effective
- Elizabeth House was praised for its high quality provision, this is a care home which also provides on outreach service.



Section 2: Engagement with service users



Other Issues

- Physical activities for carers would be beneficial
- Male carers need more specific support.

This feedback shows the key themes that have emerged from both the survey and the conversations had by the volunteers. In particular the lack of co-ordination between services; lack of respite care, both domiciliary and residential; insufficient community transport and no physical activities being offered to carers, were key emerging themes.

Healthwatch East Riding of Yorkshire was also able to gain a case study from the husband of a patient with dementia. The full case study is included in Section 4. The key points that are raised link into the comments from the Memory Cafes especially with regards to the issues that carers face and the lack of support available.





Section 2: Engagement with service users



Survey Results

Question 1:

Please select the option that applies to your situation

- ☐ I have dementia
- ☐ I care for someone with dementia

Of the 14 questionnaires completed only 1 was completed by someone with dementia the rest were completed by carers. There may be many reasons for this for example, many of those with dementia at the cafes were in quite advanced stage, so would struggle to answer the questions. At the memory cafes a lot of activities are laid on for the patients, so they are often caught up with these activities. It was the carers who had a lot more to say on the subject, as they are the ones who have to cope with caring on a daily basis.

Question 2:

Please rate the support services that you currently use.

The results for each service are illustrated in the charts below. It is important to note again the small sample size of 14 when examining the percentages shown in the graphs.

Chart 1: GP Practices

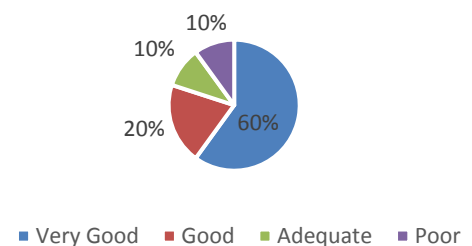


Chart 1 shows that of those people who rated their GP practice, 80% of them rated it as either Very Good or Good.

Chart 2: Alzheimers Society

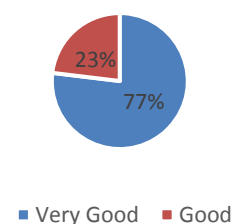


Chart 2 shows that respondents rated the Alzheimer's Society as Good or Very Good. It is important to note that all the surveys were completed at memory cafes which are held by the Alzheimer's Society, so that may have created a bias with regards to the answers provided.



Section 2: Engagement with service users

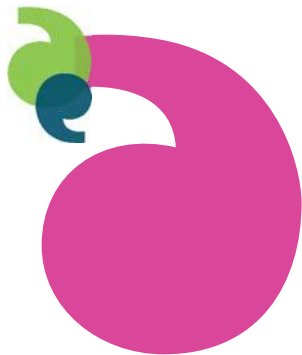


Chart 3: Mental Health Services

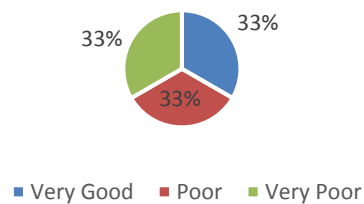


Chart 3 shows that although a third of respondents rated Mental Health Services as Very Good, two thirds rated them as either Poor or Very Poor. There was no response to the choice of good or adequate.

Chart 4: Social Services

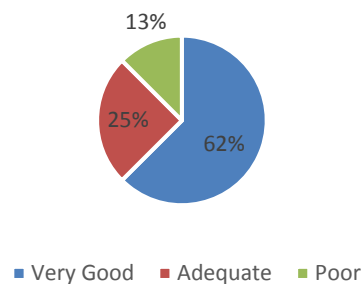


Chart 4 shows that the majority of respondents who had used social services rated them as Very Good. However 38% rated them as adequate or poor.

Chart 5: Carers Support Service

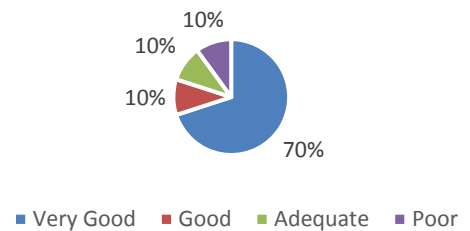
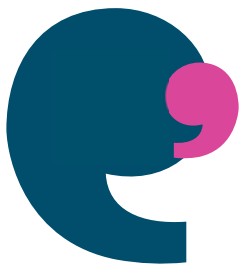


Chart 5 shows that the majority of respondents rated the Carers Support Service as Very Good.

The charts show that with the exception of Mental Health Services, the majority of respondents rated the other services as either Good or Very Good.



Section 2: Engagement with service users



Question 3:

Do you feel that you currently get the support you need?

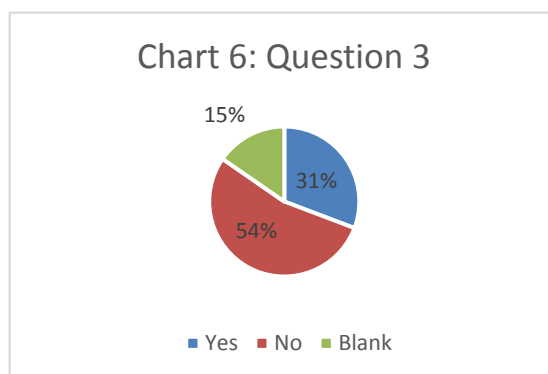


Chart 6 shows that just over half of the respondents felt that they were not getting the support they needed. This is interesting as it would suggest that although people rated most of the services they used as Good or Very Good they still didn't feel as though they had sufficient support.

Question 4:

If no what would improve this?

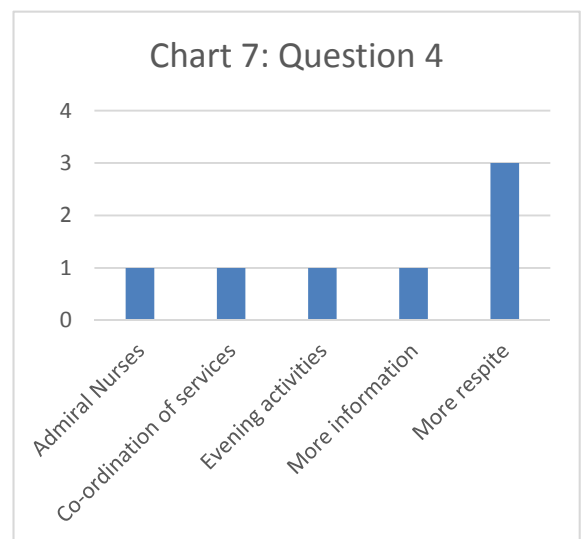


Chart 7 shows more respite care was the aspect most people felt would improve their support. The issue of East Riding Council providing carers support venues but without provisions for the patients, restricts the carers ability to attend. It was also felt that carers needed more of a break to be able to take care of themselves e.g. to attend the gym or swimming.



Section 2: Engagement with service users



Question 5:

How did you find out about the support available?

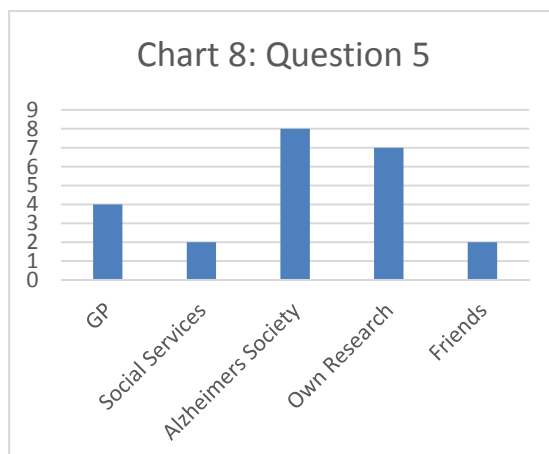


Chart 8 shows the majority of respondents found out about support either from the Alzheimer's Society or through their own research. Only a quarter of respondents actually found out about support from their GP and even less found out information from Social Care Services.

Question 6:

What problems did you find when trying to find out information?

Issues included having difficulty in understanding the financial aspects in order to work out what they were entitled to, being given conflicting information, and whilst the GP had been supportive they had no information on what support was available.

Question 7:

What (if any) additional services would you like to see available in the East Riding?

Suggestions were more mental health support, more day centres, more appropriate home care assistance and neighbourhood network groups such as the one that exists in Leeds. It was also felt that there should be a greater co-ordination of services.

Section 3: Engagement with GPs and Providers

As part of this report Healthwatch East Riding of Yorkshires have met with a range of providers. These included the Hull and East Riding Alzheimer's Society where information was gained about the support and information for patients with dementia and their carers. In addition, meetings of the Dementia Programme Board at Hull Royal Infirmary were attended, where we were able to see the work being done on the earlier diagnosis of dementia in patients over 75 years of age who have been admitted to hospital as non-elective cases. A visit was also made to the Carers Support Service which gave information as to how people are referred to the service, the support available and how to access the service.

The Patient and Services Analyst attended training held by the Dementia Academy in Hull to examine what it offered. Whilst there, conversations were also had with those people attending the training, discussing the benefits they received from it.

A conversation was also held with the charity Dementia Forward from Harrogate to discuss the services that they provided in Harrogate and how service users could access them. It was confirmed that they were self-funded for the first two years and have subsequently won a contract to provide a Dementia Navigator role in York and North Yorkshire.

The GP Survey

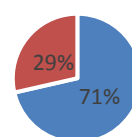
A survey was created to gather information from East Riding GP Practices about the knowledge they had regarding dementia and the services that were available. The survey was distributed via Healthwatch East Riding of Yorkshire volunteers attending the GP Locality Commissioning Forums and was featured twice in the Clinical Commissioning Group's Hot Topics newsletter. Telephone calls were also made to individual practices to remind them about the survey.

21 GP practices returned the completed survey and one GP practice wrote a letter detailing their knowledge and experience of dementia.

Question 1:

Can you tell us if the GPs and staff have received recent training in dealing with patients who have dementia?

Chart 9



■ Yes ■ No



Section 3: Engagement with Providers including GP Practices



Chart 9 shows that the majority of the GP practices have had recent training, however there are still 29% of the practices who responded who have not.

Question 2:

Is there a GP or member of staff with a particular responsibility for patients with Dementia and their carers?

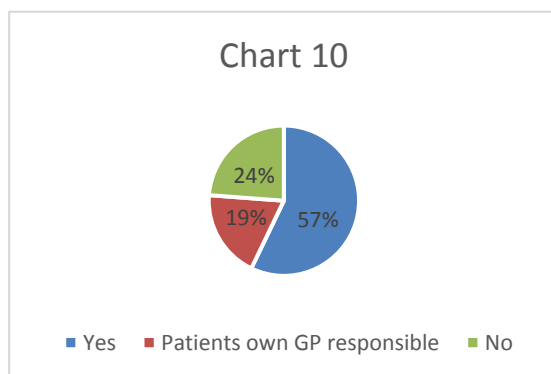
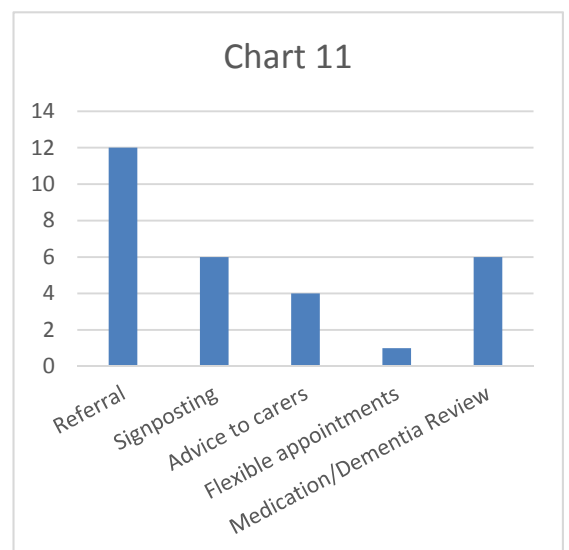


Chart 10 shows that only 57% of GP practices have a dedicated member of staff, with 19% answering that it is the responsibility of the patients' registered GP and 24% answering no.

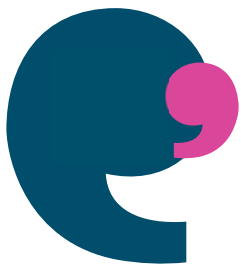
Question 3:

Can you tell us what support you offer to a patients once they have received a diagnosis of dementia?

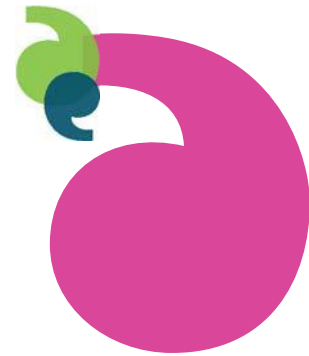


As Chart 11 shows, the referral of the patient onwards was the most common action offered. The services referred to were:

- Memory clinic
- Psychologist for the elderly
- Specialist GP
- Long term conditions clinic



Section 3: Engagement with Providers including GP Practices



Question 4:

Is the practice aware of the support services available for patients with Dementia in your local area? It would be very helpful if you could identify them for us?

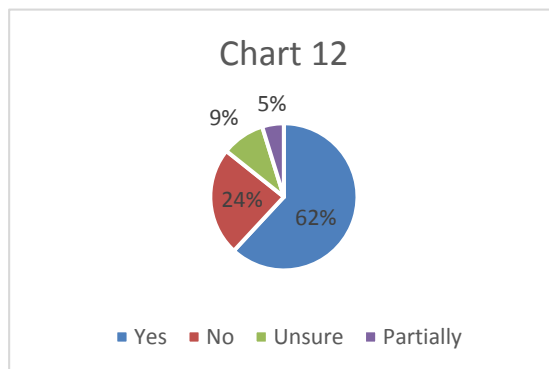


Chart 12 shows that 62% of the GP Practices surveyed were aware of the support services available. However 38% either were unaware or not sure.

Practices were aware of the following services:

- Memory Cafes
- Age UK
- Social Services
- Community Mental Health Teams
- District Nurses
- Dementia/Alzheimer's Associations
- Respite Care
- The Carers Support Service

Question 5:

Are you, or other members of the practice, able to identify the support, (social, practical and financial) which carers are entitled to?

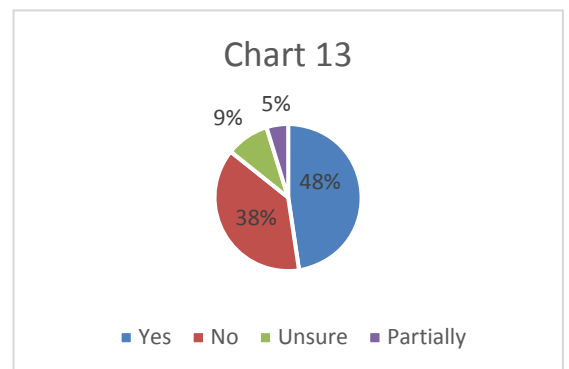


Chart 13 shows that 48% of the GP practices who responded to the survey felt they were able to identify support for carers, with 38% feeling unable to do this.

The Practices who were able to identify support listed the services below:

- Referral to Social Services
- Leaflets provided
- Citizens Advice Bureau
- Referral to East Riding Carers Service
- Signposting to relevant services



Section 3: Engagement with Providers including GP Practices



Question 6:

Does the practice offer information to carers regarding support for themselves?

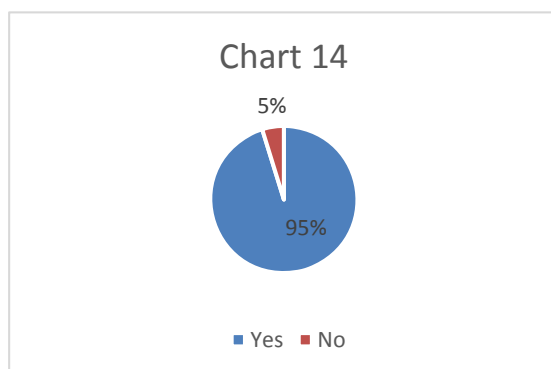


Chart 14 shows that 1 GP Practice did not offer information to carers regarding support for themselves.

The information practices said they offered was:

- Referral to social services
- Leaflets and posters in waiting rooms
- Signposting to East Riding Carers Support Service



Section 4: A Carer's Story

This is an account given by the husband of a patient suffering with dementia. It gives a clear view of the concerns and experiences of someone who has found himself placed in a carer's role for the last 10 years.

1. The lack of support when first diagnosed, (now 10 years ago). Although told very sensitively by the consultant, nobody checked on how his wife and he were managing or reviewed her medication, until she fell 4 years later and the district nurse visited.
2. Difficulties in meeting other people, whereby even relatives are reluctant to visit or phone. Unlike some other illnesses, sufferers with dementia will never show signs of improvement. People find it difficult to talk about as you can't give 'good news'. This attitude has often hurt the carer's feelings.
3. It is not always easy to go to Memory Cafes and talk about personal issues when living in a small town and likely to meet the same people in the street. There can still be a feeling of stigma and embarrassment, however unfounded.
4. Isolation can often be rooted in the feelings of the carer that he or she is failing in some way. Everyone needs to understand that all who are in this position will be going through similar experiences.
5. Many people don't like the term 'carer'; they would prefer, husband, wife, mother, son etc, and where possible that is how they should be addressed. Although it is realised it is not always possible to do so.
6. Overall there is the need for the world to realise how cruel and hurtful dementia is. It is extremely difficult to deal with. It would be helpful if the community in general knew how to deal with patients with dementia, e.g. shops.
7. For people to realise that carers, who have often had no secrets from one another over many years, sometimes have to learn to tell white lies, so that the patient can be comfortable and confrontation is avoided. Carers should be given help in handling these difficult situations as it is part of a learning curve. It is crucial not to be confrontational.
8. Consultants, GPs and practice staff should make sure that they are aware of the most up to date support and information available and have systems in place to inform carers about it.
9. There should be consideration given to the terminology used in letters and forms, especially when addressed to both patient and carer. Insensitive terminology can cause distress to both parties.
10. Everyone should realise the power of music in communicating with patients with dementia. The gentleman sings nursery rhymes to his wife and feels that they still communicate with one another through this medium.

**The husband concludes with the very powerful quote from a senior nurse
“Dementia sufferers are cared for, their carers have heart attacks”**

Section 5: Conclusion



Whilst there are many services provided for patients with dementia and carers in the East Riding, there are still some identifiable gaps in support that could be addressed through learning from other areas.

Key themes that emerged from discussion with patients and carers as well as the survey carried out at the Memory Cafes include the lack of co-ordination between services, lack of residential respite care, no community transport and lack of support for carers to engage in physical activities.

Twenty one out of twenty two GP Practices who responded to the survey offered information to carers about ways in which they could gain support for themselves. However 38% of those GPs were not aware of the support available in the East Riding for patients with dementia.

This report can only be a starting point. It is hoped that through its identification of key themes and subsequent recommendations, all who are involved with patients with dementia and their carers will continue to improve the early diagnosis, support and information available.



Section 6: Recommendations

Healthwatch East Riding of Yorkshire makes the following recommendations under its legal powers:

- At the point of diagnosis carers should be automatically provided with information about carers' assessments and local support agencies. Healthwatch can play a key role through its signposting service and would be keen to work with commissioners and providers to determine the best way forward.
- East Riding of Yorkshire Council to consider how support for carers can be coordinated and enhanced. In particular, attention should be paid to quality and frequency of respite provision, and how carer support services can be adapted to support carers attending with their cared for relative.
- East Riding of Yorkshire Council and East Riding CCG to take a partnership lead to improve the co-ordination between agencies, to avoid duplication and ensure synergies are realised across services.
- The creation of a "Dementia Hub" as a central point for all information. Using a combination of funding in line with the principles of the integrated care agenda, East Riding Clinical Commissioning Group together with the Local Authority should give consideration to a pooling of budgets, in order to create a dementia hub to provide a central access point for patients with dementia and their carers.
- East Riding of Yorkshire Council to examine the Dementia Academy model which operates in Hull and assess the viability of delivering a similar service in the East Riding.
- Training to be made available to carers and residential staff that includes practical issues and managing emotional issues.
- Carers often experience confusion around benefits and how to access them. Macmillan are currently piloting a fast track system whereby benefit advisors attend people's homes to assist with their claims and entitlement. Recognising many of the problems that all carers face, particularly with isolation, a similar model could be implemented to support carers across the East Riding.
- Letters and forms issued by Health and Social Care providers should be reviewed to ensure insensitive terminology is not used. Healthwatch East Riding of Yorkshire would be happy to facilitate focus groups to obtain feedback from service users and carers on the most appropriate terminology.
- Current training for library staff in dementia should be rolled out across the whole Authority. Other local employers e.g. shops and restaurants should be encouraged to include dementia awareness training for their staff, through the Dementia Championship scheme.



Section 6: Recommendations

- When assessments are made regarding modifications to the homes of patients, thought should be given to suitable adaptations to make it more “Dementia Friendly”. Again, the implementation of this would be supported through the provision of dementia training to all customer facing Local Authority employees.

What will happen next with this report?

The report will be submitted to the East Riding of Yorkshire Council and East Riding CCG under the Healthwatch power to make reports and recommendations. Services have 20 days from receipt to respond. The report will also be presented to the Health and Wellbeing Board.

Healthwatch East Riding of Yorkshire will monitor responses to our recommendations and keep members of the public and stakeholders informed of progress and actions to deliver improved services.

Moving forward, Healthwatch East Riding of Yorkshire will:

- Review the provision of dementia support and provision within domiciliary and residential respite care.
- Assess the issues pertaining to transport needs affecting patients and carers of dementia.
- Review the implications of the Better Care Fund and Social Care Act through Healthwatch’s seat on the Health and Wellbeing Board ensuring that the support for patients with dementia and their carers is an ongoing process.





Section 7:

Acknowledgements

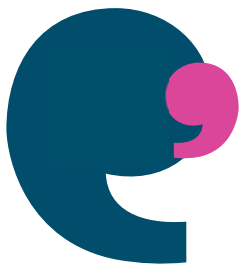
Healthwatch East Riding of Yorkshire would like to thank the following people and organisations for their contribution to this report.

Attendees at the Alzheimer's Society's Memory Cafes
Mrs Margaret McHugh, Support Services Manager for the Hull and East Riding Alzheimer's Society
East Riding of Yorkshire Alzheimer's Society
Mr Stuart Gill, Head of Locality Commissioning for East Riding of Yorkshire CCG
Twenty two East Riding of Yorkshire GP Practices
The East Riding Carers Support Service
Mr. Derek Milner- A Carer's Story
Mr. Barry Sedgewick- Dementia Champion
The Dementia Academy in Hull
Mrs Jill Quinn- CEO Dementia Forward

The volunteers involved in the Dementia Services Task and Finish Group:

Mrs Joan Fletcher, HWERY Board Director
Mr John Brown
Mrs Marguerite Makel
Mr Stuart Carr
Mrs Patricia Simmons
Mrs Maggie Whitlock
Mrs Jean Wormwell MBE

Healthwatch would also like to thank all other volunteers who had input into the report for their valuable contribution.



Section 8: Appendices

Appendix A: Survey for the Memory Cafes

Dementia Services in the Community

Healthwatch East Riding of Yorkshire is the new consumer watchdog for health and social care locally.

We want to know people's experiences and opinions on Dementia Services in the Community in the East Riding. Please help us by filling out this short questionnaire.

1. Please select the option that applies to your situation

I have dementia ☐
I care for someone with dementia ☐

2. Please rate the support services that you currently use

| | Very Good | Good | Adequate | Poor | Very Poor |
|------------------------|-----------|------|----------|------|-----------|
| GP | | | | | |
| Alzheimer's Society | | | | | |
| Mental Health Services | | | | | |
| Admiral Nurse | | | | | |
| Social Services | | | | | |
| Carers Support | | | | | |
| Other (please specify) | | | | | |
| | | | | | |

3. Do you feel that you currently get the support you need?

Yes ☐
No ☐



Section 8: Appendices

4. If no what would improve this?

5. How did you find out about the support available?

- | | |
|------------------------|--------------------------|
| GP | <input type="checkbox"/> |
| Social Services | <input type="checkbox"/> |
| Alzheimer's Society | <input type="checkbox"/> |
| Own research | <input type="checkbox"/> |
| Other (please specify) | <input type="checkbox"/> |

.....

6. What problems did you find when trying to find out information

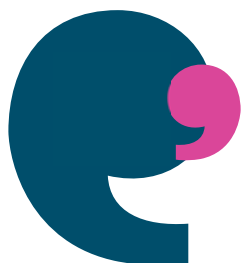
7. What (if any) additional services would you like to see available in the East Riding?

About you

All the information you give us in this section is confidential and for monitoring purposes only. We are asking this to ensure that we are listening to all sections of the community.

10. What is the first part of your post code?

- | | | |
|--------------|--------|--------------------------|
| 11. Are you: | Male | <input type="checkbox"/> |
| | Female | <input type="checkbox"/> |



Section 8: Appendices

12. Which age group are you?

| | |
|------------------|--|
| Under 20 years | |
| Aged 20-25 | |
| Aged 26-34 | |
| Aged 35-44 | |
| Aged 45-54 | |
| Aged 55-64 | |
| Aged 65 and over | |

13. How would you describe your ethnic background?

| | |
|---|--|
| African | |
| Bangladeshi | |
| British | |
| Caribbean | |
| Chinese | |
| Indian | |
| Irish | |
| Pakistani | |
| Other ethnic group (please specify) | |

14. Do you have a disability?

Yes ☐
No ☐

Thank you





Section 8: Appendices

Appendix B: GP Survey

Can you tell us if the GPs and staff have received recent training in dealing with patients who have Dementia?

Is there a GP or member of staff with a particular responsibility for patients with Dementia and their carers?

Can you tell us what support you offer to a patient once they have received a diagnosis of Dementia?

Is the practice aware of the support services available for patients with Dementia in your local area? It would be very helpful if you could identify them for us.

Are you, or other members of the practice, able to identify the support, (social, practical and financial), which carers are entitled to?

Does the practice offer information to carers regarding support for themselves





Appendix C: What is dementia?

Introduction

Dementia is a word used to describe a group of symptoms including memory loss, confusion, mood changes and difficulty with day-to-day tasks. Dementia affects the individual but also friends and family. Access to appropriate support and advice can have a positive impact on families affected by dementia.

This appendix does not replace any advice given by doctors, nurses or pharmacists but aims to give information which we hope may be found to be useful.

Causes of Dementia

Alzheimer's disease is probably the best known cause of dementia and accounts for two thirds of cases in the elderly.

Typical early symptoms of Alzheimer's include:

- Regularly forgetting recent events, names and faces.
- Regularly misplacing items or putting them in odd places.
- Confusion about the time of day.
- Disorientation, especially away from your normal surroundings.
- Getting lost.
- Problems finding the right word.
- Reduced judgement, for example, being unaware of danger.
- Mood or behaviour problems such as apathy, irritability or losing confidence.

Although often thought of as a disease of the elderly, around 4% of people with Alzheimer's are under 65. This is called early-onset or young-onset Alzheimer's. It usually affects people in their 40s, 50s, and 60s.

In most cases early onset Alzheimer's is not inherited and inherited or "familial" forms of Alzheimer's are rare.

Several genes have been identified that play a role in the development of rare familial Alzheimer's. Mistakes in these genes (called mutations) can cause a build-up of a toxic protein called amyloid in the brain. If someone has a strong family history of Alzheimer's at a young age, genetic testing may be suggested and genetic counselling may be offered to close relatives.

In the vast majority of cases, the cause remains unclear.



Section 8: Appendices

A risk factor is anything that can increase the chance of developing dementia. Risk factors for cardiovascular disease (like heart disease and stroke) are also risk factors for dementia. So it is a good idea to keep healthy by:

- Exercising regularly
- Not smoking
- Maintaining a healthy weight
- Controlling high blood pressure
- Reducing cholesterol level
- Controlling your blood glucose if you have diabetes
- Eating a healthy, balanced diet with lots of fruit and vegetables and low amounts of saturated fat
- Only drinking alcohol within the recommended limits

Some studies suggest that enjoying an active life, with lots of interests and hobbies might be beneficial. Other researchers have found that spending more time in education is associated with a lower risk.

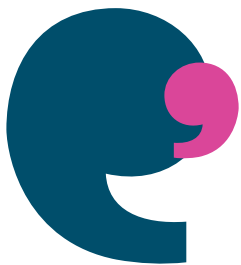
We hear about other risk factors for dementia. Despite occasional publicity, research has shown that meat, aluminium or living close to power lines are not risk factors for dementia. There is also no evidence that turmeric, ginkgo, ginseng, statins or coffee can protect against dementia.

Vascular dementia

Vascular dementia is the second most common cause of dementia after Alzheimer's disease. It can occur when blood flow to the brain becomes reduced. Some people have both Alzheimer's and vascular dementia- often called mixed dementia.

Vascular dementia can also be called vascular cognitive impairment. Vascular dementia is sometimes split into more specific types. The most common of these are:

- Stroke-related dementia. This includes multi-infarct dementia (MID), which happens after a series of small strokes. It also includes dementia which happens after a stroke (called post-stroke dementia)
- Sub cortical vascular dementia (also called Binswanger's disease, small vessel disease-related dementia or lacunar state). This is caused by changes to very small blood vessels in the brain.



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Vascular dementia can have symptoms similar to Alzheimer's. These can include memory loss, disorientation and problems with communication. There can also be more specific symptoms and these may differ depending on the area of the brain that is affected.

The symptoms may include:

- Becoming slower in thinking.
- Personality changes including depression and apathy (becoming disinterested in things).
- Becoming more emotional.
- Difficulty walking or changes in the way a person walks.
- Frequent urge to urinate or other bladder symptoms. This can be common in old age, but can be a feature of vascular dementia when seen with other symptoms.

The symptoms of vascular dementia get worse over time. Vascular dementia normally progresses over several years however, the speed of progression can vary during the disease and from person to person.

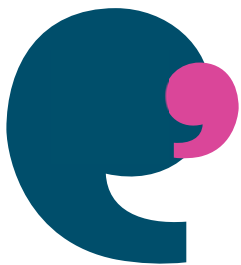
Dementia with Lewy bodies

Lewy bodies are small, circular lumps of protein that develop inside brain cells. It is not known what causes them. It is also unclear how they damage the brain and cause dementia. One theory is that Lewy bodies interfere with the effects of two of the messenger chemicals in the brain- dopamine and acetylcholine. These messenger chemicals, which send information from one brain cell to another, are called neurotransmitters. Dopamine and acetylcholine are thought to play an important role in regulating brain functions, such as memory, learning, mood and attention. Dementia with Lewy bodies is closely related to Parkinson's disease. This is a condition where part of the brain becomes more and more damaged over a number of years, leading to physical symptoms, such as involuntary shaking (tremor), muscle stiffness and slowness of movement. A person with dementia with Lewy bodies may also develop these symptoms.

Frontotemporal dementia

Frontotemporal dementia is caused by damage and shrinking in an area of the brain. The areas of the brain affected are called the temporal lobe and the frontal lobe. This type of dementia is one of the more common types seen in people who are under 65 years of age. In an estimated 20% of cases, people who develop frontotemporal dementia have inherited a genetic mutation (an altered gene) from their parents.

Motor neurone disease is also sometimes associated with frontotemporal dementia. It is a rare condition that progressively damages the nervous system.



Section 8: Appendices

Treatment

Once diagnosed with dementia, there are several drugs that could help. The patient can talk with their doctor about the treatments available and together decide which ones might be best. A carer or member of the family could be involved in these decisions.

If prescribed a drug for dementia, treatment should be started by a specialist doctor. Specialist doctors who see dementia patients include psychiatrists for the elderly, geriatricians and neurologists. Once treatment has been started, it may be continued and monitored either by a specialist or by the patients GP.

If any concerns about the prescribed medication or unexpected side effects arise then the patient should talk to their doctor, nurse or pharmacist. If a doctor cannot be reached, telephone 111. This service is available 24 hours a day, 365 days of the year.¹⁴



¹⁴ <http://www.nhs.co.uk/Conditions/dementia-guide/Pages/about-dementia.aspx>



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