



**Derbyshire Dementia Support Service
Annual Report 2021-22**

Introduction

This Annual Report sets out the activity carried out by Derbyshire Dementia Support Service in the period between 2021- 2022.

This is a contracted service commissioned jointly by Derbyshire County Council and Derby and Derbyshire CCG, based on a 2-year fixed contract with the option to extend on a further 36 months by joint agreement. For the purposes of the report the activity reported on covers the 3rd year of the fixed term contract. We are now in the fourth year of this contract. and working on aligning the annual report with our quarterly reporting processes.

Alzheimer's Society

Alzheimer's Society is here for everyone affected by dementia.

By 2025, 1 million people will be living with the condition in the UK, and many millions more carers, partners, families, and friends are affected.

Lack of treatments and a postcode lottery for care means that people with dementia and their families aren't getting the support they need when they need it. Expert advice and guidance, support through their most challenging days, and a safe space to turn when they need us – this is what we deliver to the people who need it.

Our Vision & Our Mission

Is 'A world without dementia'.

Is to 'Transform the landscape of dementia forever'.

Everything we do is shaped by people affected by dementia. Their knowledge and experience is critical to bringing about real world solutions. From choosing the most promising research through to

telling their stories to raise awareness; they are the heart of this organisation.

Alzheimer's Society Derbyshire

The service provides access to bespoke one to one support, information and advice for people diagnosed with dementia and their carer's. This includes people who are concerned about their memory pre-diagnosis. Understanding more about memory loss and the impact of a dementia diagnosis can benefit those affected, by enabling them to plan ahead for their future, which includes support from diagnosis to end of life.

We provide memory cafes virtually and face to face, helping to create a safe, supportive environment where people living with dementia (PLWD) and their carers can access peer support, engage with professionals, obtain expert information, advice, and practical day to day tips.

We provide singing for the brain, which is designed to help people with dementia feel stimulated through music, enjoy social interaction and peer support. We also provided virtual Singing for the Brain.

We provide a virtual carers group which offers educational presentations and Q & A sessions for carers. Alzheimer's Society staff and guest speakers from different organisations answer questions posed on a variety of topics and case studies. These sessions will continue and will be hosted monthly from June 2022.

We support the delivery of Living Well Programme for PLWD and their family/ carers and friends. We work closely with local communities and in partnership with other organisations.

Dementia Connect Local Service Managers

Summary: Susan O'Malley, Anne Graves & Phil De St Croix

2021-22 continued to be a challenging year in regard to the pandemic and the after affects.

Even though restrictions were gradually lifted, COVID 19's legacy left behind significant impacts on those affected by dementia and those worried about their memory.

Waiting lists for diagnosis are long and whilst a move to reduce these numbers is happening, adjusting back to pre-COVID life is slow.

This year has seen a large amount of activity, in preparing to re-introduce face to face services and move away from limited applications such as over the phone or virtual applications. Working with staff to overcome any fears and feel confident in stepping back to face-to-face services has been a worthwhile investment, taking account and investing in people's wellbeing in the process, has been crucial to growing confidence within our staff group.

Face to face, 1-1 support is now offered to all service users, however there is still some anxieties and cautiousness around COVID, our approach is to continue with safe measures applied for both staff and for the service users that we come into contact with.

There has been an increase in the contact with partners, and local community services. Equally there is an appetite for services to respond to needs that have been placed on pause while the pandemic has dominated service. This has been evident on the impact of the number of referrals received for our service, especially in relation to diagnostic services, this year we have supported **1771**

service users, which is a significant increase on previous years, we anticipate that these numbers of referrals will continue to grow.

As a service we will continue to strive for excellence in our practice and in the quality of the service we offer. We look forward to the stability of another year of the contract, where we can hopefully continue to demonstrate our commitment and compassion for people living with dementia and their carers'.

As our services continue to grow, with two new projects which commenced this year (MAS pre assessment & Pre diagnostic GP Practices) we have been joined by another Dementia Connect Local Services Manager, Phil De St Croix.



Increasing Access to a dementia diagnosis

Alzheimer's Society's nationally completed three reports on dementia diagnosis which identify and address the challenges faced by people accessing a dementia diagnosis. These were published in September 2021.



Below are the key findings, recommendations, and links to the full reports

Regional variation: increasing access to a dementia diagnosis.

Our research finds that diagnosis rates are influenced by regional factors and impacted by the processes at each step of the diagnostic pathway.

- Increase dementia case-finding and improve identification processes to mitigate instances of people reluctant to seek help for dementia symptoms.
- Improve and streamline referral pathways to shorten the diagnostic process and ensure people access a diagnosis in a more seamless way.
- Enable primary care to undertake more diagnoses to ensure that local areas keep up with demand.

- Diagnose mild cognitive impairment and monitor cases to ensure that those people with the condition who go on to develop dementia are diagnosed in a timely way.
- Review access to services to ensure people with dementia in rural communities are not impacted in accessing a diagnosis.
- Improve the quality of dementia coding and reporting to ensure all cases of dementia are reported.
- Encourage partnership working across all services and professionals involved in diagnosis to understand where issues exist in pathways and implement measures to improve them.

[reducing regional variation in diagnosis](#)

Ethnic minority communities – increasing access to a dementia diagnosis

Our research finds that people from ethnic minority communities experience an inequity of diagnosis, either receiving one late or not at all. Both community and service barriers contribute to this inequity.

- Provide community link workers and include organisations representing ethnic minority communities in the planning of services to reduce community barriers to diagnosis.
- Improve identification and referral processes to improve access to a diagnosis in a more timely and equitable way.
- Make services more culturally appropriate to mitigate instances of people delaying help seeking for dementia symptoms.
- Improve access to, and quality of, interpretation services and ensure services can access validated assessment tools to facilitate a more quality diagnosis.

- Encourage better demographic data collection to enable commissioners and services to plan and deliver services more appropriate for their populations.

[supporting those from an ethnic minority community to access a diagnosis](#)

Hospitals and care homes – Increasing access to a dementia diagnosis

Our research finds that identifying, assessing and diagnosing dementia in both a hospital and care home setting is challenging.

- Implement dementia and delirium pathways to mitigate impact of delirium on dementia identification and assessment.
- Prioritise dementia identification upon admission to ensure more cases of possible dementia are assessed.
- Provide dedicated dementia teams and implement mandatory training to improve identification of dementia.
- Ensure discharge planning processes are not inhibited by dementia assessment to ensure more people with dementia are appropriately assessed.
- Audit referral rates and provide hospital link workers to memory services to reduce instances of missed referrals to memory assessment post-discharge.
- Improve care home staff skill and confidence through training and improving processes to increase identification to ensure that more people with possible dementia are identified.
- Ensure care homes can access clinical teams to facilitate a more appropriate assessment of dementia.

- Increase access to assessment tools and information to improve diagnosing clinicians' confidence and ability to diagnose dementia.

[increasing diagnosis for people residing in a care home or hospital setting](#)

Referrals

Referral Source	Total Y2	Total Y3
CMHT/CPN/	108	171
Consultant	28	23
GP/Practice Nurse	96	49
Memory Clinic	334	488
Self-referral	488	654
Social Services/Social Worker	23	14
Voluntary Organisation	142	100
NHS/Statutory Authority	29	91
Internal referral (new referral source)	104	146
Other	63	27
Total	1415	1771

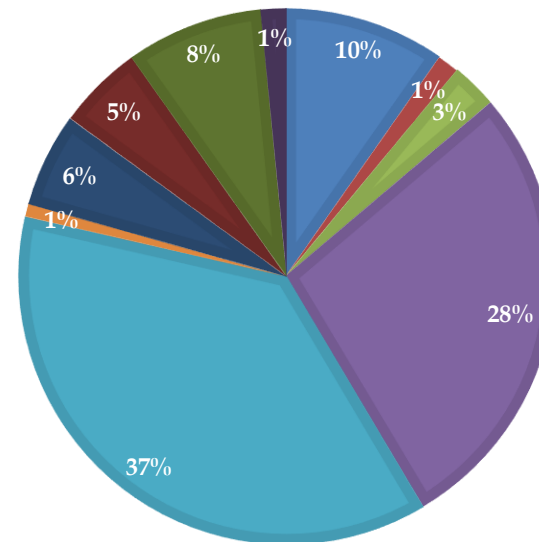
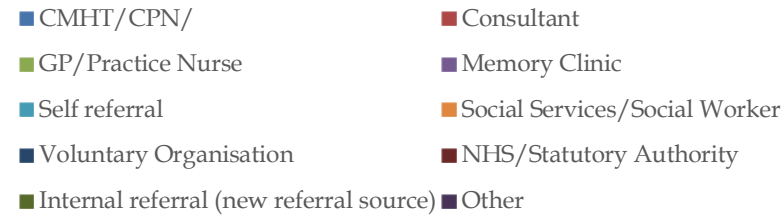
Over the year 2021/22 there have been a total of **1771** referrals received into the service, an average of **148** per month and an overall increase of 356 on last year's figure.

As can be seen the highest group of referrers are people living with dementia and their carer's. The 2nd highest group of refers are the Memory Assessment Service (MAS).

Although MAS referrals have seen an increase from last year, these remain lower than in previous years pre-pandemic. Y1 (**614**) Y2 (**334**) this year's total MAS referrals (**488**).

As the MAS services recover to 'normal' levels of functioning, we anticipate the backlog of people awaiting diagnosis will generate an increased number of referrals received from this source in the months to come.

REFERRAL SOURCES - TOTAL YEAR 3



MAS Pre -Assessment

In July we were given additional income generated through an NHS England initiative, to look at pre diagnostic support, managed through the existing contractual arrangements.

The full time post commenced mid-January 2022, for 1 year.

The aim of the post is to work with the memory assessment services at the point of their triage for memory assessments. People referred to this service are offered a pre assessment support call or visit where conversations includes topics such as:-

- How to access to memory aids
- Identify aids to improve cognitive skills
- Look at a healthier lifestyle options
- Explain what to expect at a memory assessment appointment
- Assess environmental aspects that may impact on a person life
- Be aware that 'other' things may cause memory problems
- Identify other services for support assisting them to refer this includes information on benefits and legal support
- Access carer information, advice, and navigation to other services for direct support

Work has commenced on referral pathways and raising awareness of the service to other professionals.

Referrals by Geographical Areas

Number of New Referrals	Total
Amber Valley	310
Bolsover	110
Chesterfield	178
Derbyshire Dales	175
Erewash	312
High Peak	164
North East Derbyshire	221
South Derbyshire	190
Out of area (signposted on)	111
Total	1771

The number of referrals this year continues to vary in regard to the geography of its referrer.

Amber Valley and Erewash are the highest referring areas, Bolsover remains the lowest referring area and we are keen to attract more referrals in this area.

There is a Dementia Support Worker located across 8 areas of Derbyshire, each establishing links to that locality and developing pathways for community members to be able to fully understand and utilise the services provided, and the presence is evidenced by the increase in people being referred in.

Demographic Data 2021-22

Referrals by Service User Type

Type of Service User	Total
Carer of Person with dementia	753
Person with dementia	1018
Total	1771

Age and Gender

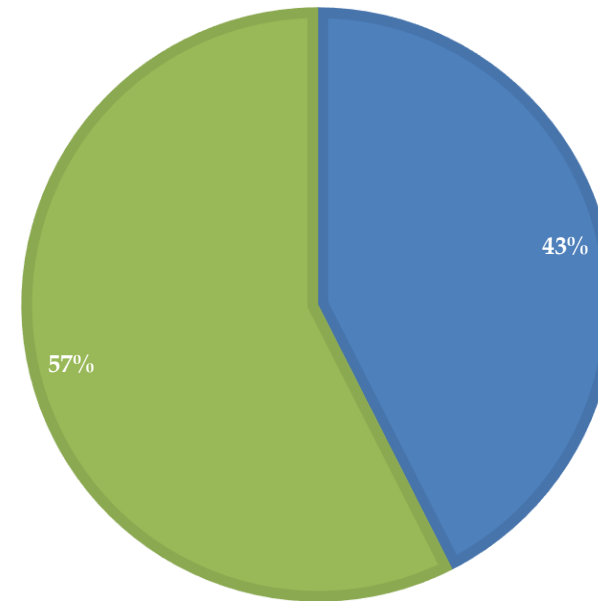
- Almost **66%** of referrals have been for people aged between 65 – 84
- **13%** aged over 85
- **9%** were aged 55- 64
- **9%** were aged 45-54
- **3%** were at the youngest age 24-44
- **62%** of all referrals were female service users
- **38%** referrals for male service users

Ethnicity and Religion

- Ethnic Groups consisted of **90%** of people referred to the service identify as White British, **4%** did not disclose. The remaining **6%** of referrals identified as Black African, Asian Indian, Chinese, and other European.
- In terms of religion, **52%** identify as Christian, **23%** did not have a religion, **19%** prefer not to say, with **6%** being made of Hindu, Muslim and 'Other'.

SERVICE USER TYPE

■ Carer of Person with Dementia ■ Person with Dementia

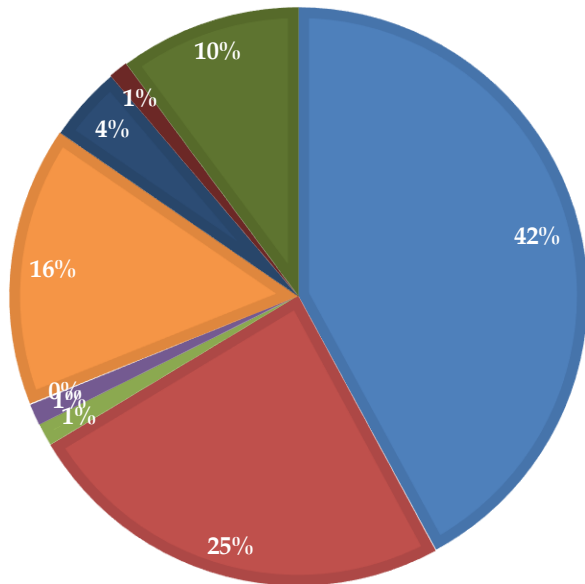


Dementia type and diagnosis

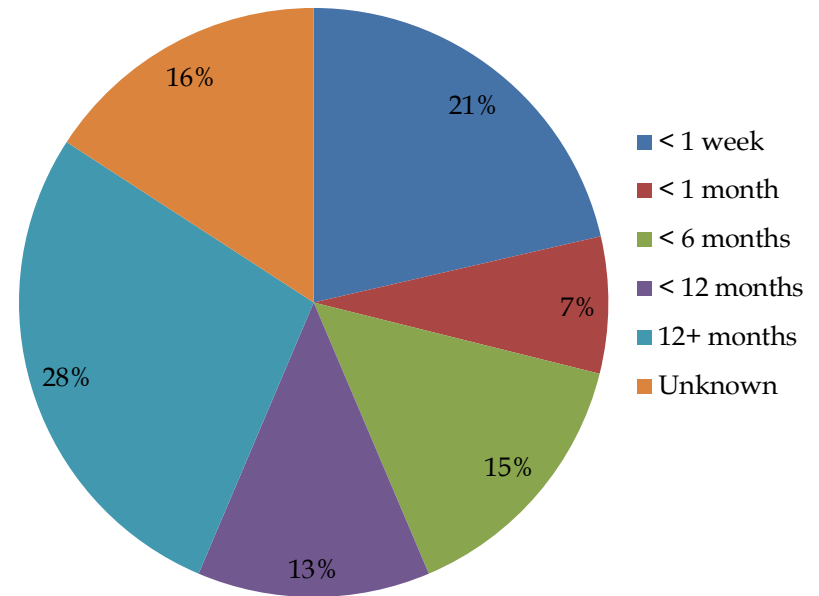
The most common type of dementia diagnosed is Alzheimer's disease, then vascular dementia, followed by mixed dementia. The graph below shows national statistical data regarding other types and their prevalence -

DIAGNOSIS TYPE

- Alzheimers Disease
- Dementia with Lewy bodies
- Korsakoffs Syndrome
- None - Mild Cognitive Impairment
- Awaiting Diagnosis
- Vascular Dementia
- Fronto Tempural Dementia
- Mixed Dementia
- Parkinsons Disease related Dementia



% Breakdown of length of time since diagnosis for PWD only



The majority of the referrals we received in this year, are from people that have had their diagnosis over 12-month period; Of all those referred to us (16%) are still awaiting their diagnosis, (28%) didn't receive a diagnosis until after 12 months.

New Pre -Diagnostic Service (GP Practices)

Based on the devastating effect of the pandemic and the disruption to all health and social care services, in March 2022, funding was agreed for a pilot project, to run for 1 year commencing in April 2022.

The project includes 4 x FTE Dementia Support Workers who will work closely with GP practices in 4 key areas of Derbyshire.

- Derbyshire Dales
- South Derbyshire
- Bolsover & North East Derbyshire
- Erewash

This element of the service will target people who are worried about their memory and who may not be able to access the services needed to obtain a diagnosis or who are awaiting diagnostic appointments.

In addition, the project will also work closely with local hospitals to target people admitted to hospital for something other than dementia but who have a dementia diagnosis, so that on discharge support can be offered as they return home.

Added Value

Alzheimer's Society is commissioned to deliver a range of operational services which are underpinned by a person-centred approach to delivery. The primary aim is to support people in accessing our services and signposting to the services which meet specific and individual outcomes. One of our key values at the Alzheimer's Society is that we are "trusted experts" - our links to national research, campaigns, media, fund raising and a plethora of information/ leaflets on dementia, means a very strong profile publicly and affords the

organisation the ability to challenge, confront and react to the needs of People living with dementia and their carer's.

Anyone referred to us are made aware of the additional opportunities to get support from Alzheimer's Society National Services, which include:

- National Helpline (open 7 days a week)
- Talking Point 24/7 – an online forum with volunteer moderators based around the world that covers a variety of topics and subject points.
- Alzheimer's Society website where people can access factsheets and booklets for free with accurate, current researched information to support people affected by dementia, national campaigns and media articles.
- Dementia Together a bi-monthly magazine for everyone affected by dementia.

Social Value

As an inclusive organisation we aim to meet the needs of anyone in any community who is affected by dementia whether that's the person with the diagnosis or the people around the diagnosed or those concerned about their memory. We offer consistent levels of support across Derbyshire and seek to connect with local services to provide appropriate networking opportunities and community resources.

Newsletter

The newsletter has changed to a quarterly newsletter in line with our current monitoring. The newsletter is more detailed and includes

- Local updates
- Staffing changes and staff profiles
- Feedback from service users
- Infographic information on referrals received and services provided
- Case studies and service user feedback, showcasing some of the excellent work across the county.

These are published in Spring, Summer, Autumn, and Winter.

Awareness Raising & Partnership Working

During this year we have continued to work with organisations and services across the county. Working collaboratively to share knowledge and develop pathways between service, means we are equipped to provide more consistent support and ensure that collectively we are working together to provide the best outcomes for people living in Derbyshire.

Our partnerships this year have included -

- Derbyshire Carers Association
- Derbyshire Fire Service
- BAME independent consultation to explore reach
- Community Health Champions – Partnerships team NE Derbyshire
- Memory Assessment Service
- STP Dementia & Delirium
- Derbyshire Mental Health forum

- Community Mental Health Team's
- Community Voluntary support Derbyshire
- Derbyshire NHS TRUST Carers engagement forum
- Derbyshire Recovery Partnership

Introduction of our local website and Video

From a local perspective we have created a new website which can be found at www.dementiaderbshire.org.uk. The website was launched in October 2021 and in the 8 months it's been live it's had just over **1400** visits accessing all content. **646** views were of the main page, which is the most visited, and due to the launch of the video, has seen a recent spike in visits. The website has the largest percentage of views from the UK, as anticipated, but has also been viewed in 9 other countries.



Derbyshire Dementia Support Service provides support to everyone in our community that needs it. A new [video](#) explains what the service offers and features some of the Derbyshire team.

Case Study

Our team has continued to support some of society's most vulnerable members as they adjust to a life changing diagnosis of dementia coupled with the restrictions imposed by Covid-19 at a time when they need social support the most.

An example of this is Mrs P who was diagnosed with Alzheimer's Disease shortly before the pandemic forced the UK into lockdown. Mrs P's partner entered our service after her daughter rang us, asking her to help her father who was "at breaking point". When we spoke to Mr A, he admitted finding the situation too overwhelming and was struggling with a full-time job, caring for Mrs A and their home, and having a few hours' sleep each night. During this call, Mr A agreed that he was experiencing severe carer strain and that he had felt like the last few weeks he had been at his lowest and was at a loss as to how to "get through it all". Mr A said that Mrs A's friends had slowly stopped speaking to her and that Mrs A very much missed social interaction. We introduced them to the virtual Zoom dementia cafes that we are hosting during C19 until we return to face-to-face care provision when they could attend and make relationships with others within their locality.

Mr A was advised that it may be possible for carers to visit and ensure that Mrs A was taking medication and eating and agreed to a referral to Adult Social Care to assess how they may be able to help. The referral was made stressing urgency that Mr A was contacted as soon as possible owing to the concern of sleep deprivation, enduring severe carer strain and how overwhelmed Mr A was feeling in coping with his current circumstances. Mr A was referred to the Derbyshire Carers Association and onto the Citizen's Advice Bureau for a financial assessment, as well as being emailed with a link to the Dementia Talking Point forum where he could communicate online

with other carers and read about their experiences of caring for a loved one with dementia as agreed in the original call. Mr A was given our contact details and told that if he found it easier to email than phone then that was fine and to reach out if he had any questions or identified any further support needs. At the end of the call, Mr A said he was grateful for us calling and for being someone who he felt he could be truly opened and honest with about how he was feeling. He said that he had felt that "there was a light at the end of the tunnel" and that "a weight had been lifted". Mr A was also reminded that we would endeavour to do everything we could to ensure that he and Mrs A got the support that they both deserved. When we called Mr A a fortnight later, he said that he had gone from having no support at all in the last fourteen months, to having received contact from several services because of our conversations. He felt less isolated by being able to connect using the Talking Point website in talking to other carers online and sharing similar feelings and situations and was happy that he had had financial strain lifted by being referred to the Citizen's Advice Bureau. He also said that he was appreciative of being able to socialize virtually in our online Dementia Cafes with his wife and having something new to do together.

"You've done more for me in these last 2 weeks than everyone put together in the last fourteen months! I have been able to open up and talk to you about my feelings and I don't find that very easy to do but you have made it so easy for me".

Quality Assurance

Throughout the year we have completed service evaluations known as Making Evaluation Count & Exit interviews.

Services are evaluated by staff collecting feedback using a range of different methods including face to face, postal, telephone and group methods. The data was collated and analysed by the society's evaluation team prior to distribution to services for action planning on points for improvement.

During 2021/2022 exit interviews were carried out using postal and telephone methods. Feedback from this has provided us with an invaluable insight on the person living with dementia and their carers experience of our service, it also helps provide us with information that helps us to shape our services and suggests where improvements and learning opportunities can be met.

There have been **81** exit interviews carried out across the year with mostly positive feedback regarding the service provided and the work carried out by the team.

Here is a sample of some of the responses we received.



Derbyshire Dementia Support Staffing

During this last year we have had a small number of staff leave, all 3 have moved to NHS contracted posts. As we move into a new year of the contract, we have one Peer support group facilitator vacancy and 2 DSW posts, due to seconding current staff over to new posts in the Pre-Diagnostic GP Practices posts.

Compliment of staff

The service is made up of the following staff: -

Dementia Connect Local Service Managers x 2 Fulltime Equivalent (FTE)

Dementia Support Worker x 10 8.5 FTE

Group co-ordinator 1x 0.5 FTE

Peer support group facilitator x 1 FTE

Signing for the Brain Leader 1 x 0.5 FTE.

Projects (MAS pre assessment & Pre diagnostic GP Practices)

These services are made up of the following staff

Dementia Support Worker x 5 FTE

Dementia Connect Local Service Manager x 1 (14 hrs)

Our achievements 2021/22

- Increased number of referrals to the service.
- Work with Derbyshire Carers Association to migrate carers to their peer support group.
- Working with Memory Assessment Service consistently to understand the impact of COVID in diagnostic services.
- Working with the Integrated Care Service (ICS) - Dementia and Delirium Group to help bring evidence of the impact of COVID on People living with Dementia (PLWD) and their carer's.
- Continuation of welfare calls and campaign calls

- Successful re introduction of face to face and virtual groups
- Completion of a local survey on the needs of People living with Dementia and their carers pre and post pandemic within Derbyshire.
- The Introduction of a derbyshire specific local Web Page.
- Planning background for co-production project within BAME/diverse communities to help develop a starting point for conversations on access to services.
- Introduction of a new pre diagnostic support worker. This temporary role is aligned with the Memory Assessment Service, providing support to people on the waiting list while they await a diagnostic appointment.



Alzheimer's Society Derbyshire

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Our Web Page www.dementiaderbyshire.org.uk

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