East Riding Dementia Inclusion Network.

Notes from Carers group facilitated by Elaine Agar (Alzheimer's Society) and Kerri Harold (HEY Smile Foundation)

Right Mind Carers

Angela, Sarah, Joan, Sylvia, Gilly, Tony and Rita

Professionals

Michelle Smith (Holderness Health)

Lucy Rigby, Steve Aldridge, Jen Lonsdale, Jared Jones (ERYC)

Sally Ford (Memory Assessment Service)

Linda Stross, Diane Scott-Thomas (As Time Goes by Memory Café)

Isabel Underwood (Alzheimer's Society)

To what extent are you involved with at the start and the heart of the process of creating dementia friendly environments and services?

One carer noted, there was a lack of clear information, support, and joined-up guidance following husband's diagnosis.

Most stated say they **"weren't aware of involvement in this"** it was explained by Elaine that the Right Minds group was involved in the 'While You Wait' pilot, so they had played a key role in the production of the information for those diagnosed with Dementia.

Many said they need a **"tell us once" style service** to avoid having to explain everything repeatedly across different services **across all illness, not just dementia**.

Support and information gaps

Carers said that when they were waiting, this was difficult. They mention that the situation is **more than just dementia**, referring also to **blindness**, and other chronic illnesses which adds further distress.

Whilst one stated they **received good support from Sight Support**, this was separate from the dementia-related support. They also note that it was not until joining **Right Minds** that they found out they were a carer, and that they **weren't aware of any support they could access** prior to that.

Many said that the support from their local GP in Bridlington was the worst service they had to access.

Impact on carer

The carer describes the situation as **overwhelming**, saying they have been caring for **35 years** and have had to manage **all levels of care on a daily basis**. They describe this as **exhausting, relentless, and depressing**.

They stated: **“Life is very hard.”**

Concerns about care home costs

They say they do not want to put their husband in a care home and pay **£1,500 a week**, as this would mean losing the home they have worked for all their lives.

Diagnosis and lack of follow-up

The husband was diagnosed in **2020**, and the person says **nobody was there for him or for them**. It appears there is a gap in what was given during the pandemic, which then shapes the patient and carers journey.

Dementia Adviser service

There was a discussion around the **Dementia Adviser Service** based on six years ago. The carers felt that there was **no information given**, that was helpful at that time and that when they were asked what was needed, they didn’t know exactly what it was they needed. Would be helpful for options to be given at this point to allow carers to know what’s available when they MAY need it.

They describe there being **no free sharing of information** and no follow ups.

Carers review

“Carers Review – I had to ring as I hadn’t one in a few years, the lady (Vicky) rushed through the review as she said she was going on her holidays and had to get home, she said she’d ring back on her return and finish. This hasn’t happened.” Most carers agreed they did not have regular reviews.

Support and signposting

The person describes having to seek advice and feeling as though they were being passed around between services. They say they were very stressed and could not remember the whole memory clinic process.

They explain that, up to that point, they needed support but knew nothing about how to navigate the system after the sudden collapse or deterioration of their husband, their life, and their business.

The disparity between areas was noticeable throughout the discussion and members stated that only through hearing from peers at RM did they learn what was on offer.

Impact on carer

They describe being physically and mentally exhausted. They state the Right Minds Group “Saved my life”.

They suggest a **“one-stop shop”** or single number to call when someone suspects something is wrong. (pre-diagnosis) This would give carers a clear route into support and a better understanding of what was available.

They say that, as a carer, they do not feel important and feel dismissed, not respected, and shunted around.

Need for a named person or service

They say it would help to have one person to guide them through the process, even if that person only signposts and helps connect them with the right people. (did not need to be medically trained, just knowledgeable)

Financial and emotional pressure

The person says they no longer recognise themselves and feels extremely tired. They mention being on **51 pence per hour** as a care partner!

We’re nothing like the people we once were; we’re broken.

One member of **Right Minds** shared that whilst trying to access the sitting service, shared that because their husband’s issue is medical, they could not access the service. They had to argue to access the service, which took several months and took its toll on wellbeing. After this lengthy and difficult process, they state that all they were entitled to was **4 hours a month**.

Memory service journey

Sally gave input into the memory service journey, which she described the waiting well and referrals to the Dementia Advisor, Adult Social Services and Carers Support Service etc. The carers shared that there were disparities and inconsistency across the area.

How much of a sense of ownership, investment, responsibility and connectedness to your own communities and services do you have? Want can YOU or your community do?

One carer shared that they waited **18 months for a diagnosis**, others gave examples and it appears this depended on the GP.

Michelle from Holderness Health shared the journey from concerns to post diagnosis with the group and all agreed that this was best practice and asked that all other PCN’s adapt the same approach. This included annual reviews to ensure information was shared as needed, it was clear that patient experience across the East Riding was inconsistent; This was described as a postcode lottery.

They mention a **Cognitive Impairment Test**, and that someone from Humber Health gave an example of the process, describing it as helping to “hand hold” patients through the process.

Need for diagnosis to access support

The notes say the person needed the diagnosis for disability badge/benefits. They describe being “in limbo” and say they did not get a radar key for toilets until they heard about it from Right Minds.

They also mention having been to the town hall three times for a bus pass.

Tell Us Once

The notes refer to **“Tell Us Once”** and say this is currently used when someone dies. The person suggests there should be something similar for carers.

Information systems and access

The notes mention an email from Patient Knows Best and having to log in for information. The person says this went wrong, was not easy to use, and involved ringing/searching for help. They say their GP may not have a modern NHS system, and they did not know this.

Meaning of dementia diagnosis

The person asks: **“What does dementia finally mean to you?”**

They note that dementia is different for everyone, although there may be some shared ways of showing that someone has dementia.

Value of Right Minds

The person describes Right Minds as a **“lifeline”** and says they feel the Right Minds group has saved them. This was echoed throughout the session.

Inconsistency between GPs

They note there is no uniformity between GPs and that practice is not consistent. The PCN’s are in a great position to be able to ensure consistent practice that aligns with both patient requests and case studies that show the need for more intervention when simple procedures are not followed through: Thus, saving money up stream on services.

One carer spoke about a time that they had been house bound due to their husband having a fall, so was immobile. She shared that without the group and their support, regular visits and telephone check ins, she wouldn’t be here today. **“They brought food,**

had coffee with us – that saved me and stopped us feeling isolated; and definitely stopped me climbing the walls!”

Discussions were had about having a directory of all the groups available to those living with dementia and also carers to allow them all to travel and keep active. This also helps other carers know what’s available East Riding wide.