

Title: Briefing to Torbay Adult Social Care and Health Overview and Scrutiny Sub Board

Meeting date: 14th March 2024

Subject: Spotlight on Dementia in Torbay

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Purpose of this briefing

Healthwatch Torbay and Age UK Torbay have been asked to contribute to the Spotlight Review on Dementia Care in Torbay from a Voluntary Sector Perspective. We have been asked for information on:

- Who is seeking assistance?
- How many are seeking assistance?
- For what type of needs?

Information provided by Age UK Torbay



Statistics provided by Torbay Age UK for the period **March to December 2023** show that:

- The average age of someone seeking support from Torbay Age UK is **79 years.**
- The breakdown of those seeking support is **64% Female and 36% Male.**
- **113** interventions were provided for people affected by Dementia.
- Average number of referrals per month was **12.**

The most popular route for referrals is via direct contact from families or through the Community Helpline.

Below is a breakdown of the referral routes by percentage:

Referral Source	%
Other (family/self)	34
Helpline/VCSE	28
GP/Link Workers	14
Mental Health Team	14
Adult Social Care	10

Background

Age UK Torbay have been providing Wellbeing support to people and their Carers around Dementia and memory loss since 2019. This was initially funded through Improved Better Care Fund (iBCF) and subsequent small funding applications. But the funding has now come to an end.

The Covid pandemic has severely impacted people with Dementia and their families, in particular with a lack of face-to-face support, and involvement in support groups.

A recent report by Alzheimer’s Research UK states

“Covid-19 has had a disproportionate impact on people with Dementia, their Carers and their families. Age, genetics, and lifestyle all contribute to someone’s individual risk for developing Dementia. Some evidence suggests that other pre-existing health conditions can also contribute to increased Dementia risk”.

Even before the pandemic, we were facing a crisis in Dementia diagnosis – now fewer than two in three Dementia cases are being formally diagnosed, and people aren’t receiving the support, or medication they need.

Age UK Torbay’s Dementia Wellbeing Service

Age UK Torbay has been working with the wellbeing of people with Dementia since 2019. The Wellbeing Coordinator post was developed in conjunction with Torbay and South Devon Foundation Trust to provide targeted, knowledgeable, and specific support for people with Dementia, and their Carers.

Since 2022 there has been a **tangible decline in support for people with Dementia from both the statutory and voluntary sector, with no funding**

opportunities, or strategy to address. There is work going on in Devon, but Age UK Torbay has not been invited/consulted with, on what needs we are seeing.

Our funding for one full time Wellbeing Co-Ordinator ends in March 2024. We have now stopped taking referrals for this service.

There are limited options for onwards referral, with only one drop in café available – run by Purple Angel.

Dementia diagnosis is taking considerable time, with people waiting months for appointments.

Outcomes

The Age UK Torbay Dementia wellbeing project supports the following outcomes:

- ✓ Trusted, connected person-centred relationships with health and wellbeing at the heart.
- ✓ Long-term support embedded in local communities where local people support each other.
- ✓ Giving choice and control of independence to people.
- ✓ Enhancing quality of life for people with Dementia, especially post Covid.
- ✓ Reducing the risk of admission/readmission to hospital.
- ✓ Reducing statutory contact time.
- ✓ Improving Carer support and understanding of Carer issues.

Service Delivery

The Service has 2 key areas of activity:

1. Supporting people and their families/Carers to engage with services, to have the information they need and to plan for the future.
2. To support good health and wellbeing.

Planning, Information and Services

1. To assist people with Dementia and memory loss, their Carers and their families to identify their needs and to access services and information.
2. Working with complimentary providers, to provide information on different stages of the disease process at a time that is tailored to suite the person with Dementia, their Carers and family.
3. Provide support to navigate through mainstream services such as counselling, services addressing specific issues, support for other health related issues.
4. Provision of advocacy, mentoring and peer support
5. Support people with Dementia and memory loss, their Carers and their families to plan for poor health and end of life.
6. To reduce the need for people to access urgent and emergency services and responses by helping people forward plan with a focus on the right things and connect with the community resources available.

Enabling Wellbeing

1. To support people with Dementia and memory loss to be active in managing their own wellbeing, health and care and improve their experience of care and support in the community.
2. Support people with Dementia and memory loss, their Carers and their families to Identify and communicate their aspirations for making the most of their lives.
3. To help the people with Dementia and memory loss, their Carers and their families to think 'outside the box' where conventional support networks won't achieve maintained and improved wellbeing.
4. To carry out guided conversations using the toolkit, to put the wishes of the person with Dementia or memory loss at the forefront of a wellbeing plan – whether this is to develop friendships and reduce isolation, solve practical problems that matter to them, manage their long-term medical conditions better or plan health living or different care. Support Carers and wider family members to identify their wellbeing plan and steps to achieve the goals within that plan.
5. To enable individuals to measurably improve their sense of wellbeing, to feel empowered to sustain independence and achieve optimum levels of functioning.
6. Support people with Dementia and memory loss to learn adaptive coping skills.

7. To regularly work at GP surgeries, MDT Health/Care Teams and Dementia clinics to ensure clinical professionals focus on what 'matters to a person' not 'what is the matter with a person' and that people are connected to the right community support.

Healthwatch Torbay – Feedback and experiences of Carers

Healthwatch Torbay has recently surveyed unpaid Carers, around a third of those who took part care for someone with Dementia. 224 Carers took part in the survey. The Unpaid Carers report – Phase 2 is due to be published Spring 2024.

As part of our engagement with Carers we asked if they would like to take part in a guided conversation so that we could gain a better understanding of their experiences. Our report will draw on these so that we can provide the perspective of the Carer's experience – what works well, what could better- in more detail.

Initial findings from our survey include:

- Many Carers have told us that they feel overwhelmed and unheard,
- Some Carers have told us that they either don't know who to contact for support or don't receive calls back,
- Replacement care / respite is difficult to arrange in advance.
- Carers find it difficult to make GP appointments if they are experiencing health issues of their own, resulting in delays in seeking help until a health problem gets worse.
- Carers want to know that there is someone to call when they need help to avoid a crisis.

The findings from the following two recent reports are also pertinent to this review and should be considered within the wider remit of Dementia care:

- [Torbay Adult Social Care Strategy Engagement Report](#) – produced for Torbay Council.

- [Unpaid Carers Report – Phase 1](#) a survey report focusing on the impact of providing unpaid care.

Carers experiences

Experience 1

We heard from a lady in Torbay who has been a Carer for her husband with Dementia for more than five years. She provides 24 hours care with no additional support. She describes a long waiting time for a brain scan, *“we were waiting too long, so not knowing fully what stage condition was at.”*

Carer described how she feels anxious, overwhelmed, unable to get any respite and hardly sleeps, not knowing what she is dealing with, she told us *“Only my love for husband is keeping me going”* and she copes by *“Telling myself I must be strong as worse to come in the future.”*

The carer said she puts her husband’s needs first and the one thing that would help is *“knowing where to turn for help.”* She told us she is *“dreading the future.”*

Experience 2

Another Carer described how they feel there needs to be more information and advice given in the early stages of a Dementia diagnosis:

“It would be really helpful to know what carers are entitled to, from day one.”
A list of entitlements, or guidebook. It is a strain and a worry to not know what help is available.”

The Carer describes the stress of their experience of the diagnosis timeline.

“Following an initial MRI [the cared-for] didn't receive a “clear diagnosis” but vascular dementia was mentioned. We then received a letter from the “Dementia Pathway” stating that the wait list for assessment was 2–3 months. We waited 18 months until an assessment was done with a mental health nurse.”

Following the MRI scan the Carer resorted to using Google to learn about his partner's condition. This was how he discovered that she might not be legal to drive and that the DVLA need to be informed. No one told him this. The Carer described feeling confused by the process and not being updated/informed appropriately. His son helped and "acted as an advocate" as he is a health professional. Carer said he was told that there were over 700 people on the waiting list and that there was a lack of staff.

Carer did receive support through Help for Heroes with links to Improving Lives Plymouth. It was this group that told him he was a Carer, and then "*things clicked into place*". He also completed the Dementia Pathway 4-week course, 2hrs per session and was able to meet other carers and people with dementia where he was struck by how "*everyone is different*".

Although not Torbay, this experience highlights the need for timely access to support as when this is in place people are able to cope much better. It also highlights the benefits of peer support to help Carers and people with Dementia feel less isolated and that everybody's experiences of Dementia is different – there is no 'one size fits all' therefore a person centered approach is key to supporting people to manage their situations.

National Context

Healthwatch England

In May 2023, Healthwatch England published information to explain what people can expect to happen following a Dementia diagnosis. The [article contains a useful checklist](#) that helps patients and families to plan the next steps in their care journey.

Care Quality Commission

The CQC are currently engaging with a range of key stakeholders, including care professionals, people with lived experience, voluntary and community sector organisations and local Healthwatch to help them to develop a national strategy for Dementia which will help them to address inequalities in the quality of treatment and care provided to people affected by Dementia.

Regional Context

Some local Healthwatch organisations in the region have carried out their own research into people's experiences of Dementia Care.

Healthwatch Cornwall Report

In March 2023 Healthwatch Cornwall published their report:

['Hear our Voice: Improving Dementia and memory loss services and support in Cornwall through carer experience.'](#)

Their key findings echo what we are hearing from Carers in Devon, Plymouth and Torbay.

Healthwatch Cornwall's findings include:

- Respite – having opportunities to take a break from their caring role,
- More opportunities to access meaningful activities,
- Easier access to help or advice, and a phone number to call for help – particularly during a crisis,
- To see health and care staff face-to-face,
- Easier access to an appointment with a GP.

Feedback from Torbay Carers Service

Concerns have been raised to Torbay Carers Service about the reduction in support for people with Dementia – Alzheimer's Society Dementia Advisor Service and Age UKs Dementia Wellbeing coordinator. Both services provide both direct and indirect support to Carers of people with Dementia.

Healthwatch Observations

Based on what we have learnt through speaking to people, Dementia support is becoming more and more difficult to access as services appear to be reducing and no information is available to us as to what will happen to continue the support if services decline. At the time of submitting this briefing we are

awaiting further information from NHS Devon about the provision of Dementia Services across Devon, Plymouth and Torbay. We fear that a lack of dementia support on an already burdened group of Carers will have a detrimental impact on people's wellbeing.

Questions raised by Healthwatch Torbay

1. Healthwatch Torbay is aware from engagement locally and at a national level that many Carers, particularly those who care for someone with Dementia, feel **isolated, unheard and struggle to navigate systems and services**. The role of a care navigator / way finder or a main point of contact for Carers is invaluable in helping Carers to navigate services, access information, advice, and support.

How will services be developed in Torbay to ensure people can access support, given that the funding for services that are currently providing this vital support in the community is believed to be coming to an end?

2. Is there a plan to develop an integrated Devon wide Dementia Strategy as a priority?
3. Is there a plan to revisit the recommendations set out in the [Devon Dementia Needs Assessment of 2014](#) or to develop a new Devon wide Needs Assessment for Dementia?
4. Based on what Healthwatch England have set out as what should happen following a Dementia diagnosis, is this what happens when patients are diagnosed with Dementia in Torbay?