



**Support services for older people living with
dementia and memory problems**

Introduction

Devon County Council (DCC) commissioned Age UK Devon (AUKD) to consult on the support services available to older people with dementia and memory loss and their carers. The consultation aimed to increase understanding about which services older people had accessed, which they had found helpful, and whether there were any problematic gaps in service provision. AUKD sought participants from a range of settings. These included services and groups designed for people affected by memory loss as well as those with a wider remit. While AUKD was not commissioned to gather feedback on health services, participants inevitably had views on support they had received or not received from the NHS and were not always able to differentiate between services. This feedback is therefore included for context and because of the direct, relevant impact of the lack of NHS capacity on services within the social care, community and charity sectors, and vice versa.

Methodology

It was agreed AUKD would include feedback from:

- Older people with a diagnosis of dementia.
- Older people waiting for a diagnosis of dementia.
- Older people with memory problems who had not been diagnosed with dementia.
- Carers and family members.
- Any other relevant stakeholders encountered during the engagement process.

To make the engagement process as client-centred and adaptable as possible, AUKD used a range of approaches to gather feedback, depending on what worked best for each group and individual, e.g., focus groups, one-to-one phone calls and written surveys.

The survey questions (also used for the focus groups) were proposed by DCC and agreed in consultation with AUKD. The questions were designed to determine which services had been accessed immediately after diagnosis and in the longer term. They explore how easy it was for participants to find and access support, and what other support may have been useful to them. (**Appendix 1.**)

AUKD encountered limitations with the engagement process:

- By the nature of their difficulties, participants frequently could not recall what support they had received. This was true for people with memory problems and for their carers. The trauma of the initial diagnosis and the ongoing stress of a caring role were both cited as reasons for problems with retaining information

about support available. Especially when contact was largely by phone, it was difficult for carers to differentiate between organisations.

- Many people reported that the support groups and memory cafes provided an escape from their problems and the chance to socialise and relax. Some group facilitators expressed reservations about asking participants to think back to diagnosis and problems they may have encountered. Other groups had busy schedules without the space for a focus group session, or time for any engagement.
- When groups preferred to be sent individual questionnaires, these often were not returned.
- AUKD were mindful of involving the person with memory problems in the consultation as much as possible, but this proved difficult (see first bullet point).

Further questionnaires were left with all groups if people preferred to complete them in their own time. All group members were offered the opportunity to speak with an AUKD staff member individually to give feedback. However, few people took up this option.

AUKD approached the following groups and services:

Teignmouth Memory Café, Alice Cross Centre (9 September 2022): A weekly group for people with memory problems. This was a focus group of approximately 15 people with memory problems, one carer and four or five volunteers.

Age UK Exeter Budding Friends (24 October 2022): This group meets weekly for gardening and other activities. Carers attend with the person with memory problems. There are a handful of volunteers and one paid staff member (volunteers were mainly carers or former carers). Approximately 20 people were present at the focus group.

Sporting Memories, Exeter (3 November 2022): This group has over 20 members and is open to anyone over the age of about 50. Most members have experienced some kind of significant life change, often health conditions including depression, Parkinson's disease and dementia.

Kingscare dementia carers support group (1 December 2022): This group is run alongside an activity group for the person who is cared for. Numbers vary, but on 1 December 10 carers and one staff member attended and participated in the focus group.

Age UK Exeter Enabling and Home Support service (EHSS) (questionnaires completed October/November 2022): A paid-for service providing enabling and help with housework. Staff completed individual surveys with eight clients.

Age UK Devon Enabling and Home Support service (EHSS) (questionnaire completed October 2022): A paid-for service providing enabling and help with housework. Staff completed an individual survey with one carer.

Crediton Memory Café: This group was unable to fit a focus group session into their schedule; however, five individual questionnaires were returned.

Age UK Devon Maintenance Cognitive Stimulation Therapy (MCST) group: A weekly programme for people with mild to moderate dementia; clients participate in activities designed to stimulate memory and improve mental functioning. The group has four participants and two carers who attend regularly, and another four members who attend infrequently. One individual questionnaire was returned.

Carer Ambassadors: An AUKD staff member attended a meeting of the Ambassadors, arranged by Devon Carers. Carer Ambassadors run groups and support unpaid carers in their local area. The ambassadors represent dozens of unpaid carers, who they support in groups and individually.

Other groups approached who did not respond or were unable to contribute included the Filo Project, Budleigh Memory Café, Exmouth memory Café, Westbank (three memory cafes in Exeter and Starcross), Heavitree Memory Café and Belmont Chapel Memory Café. Newton Abbot Memory Café distributed questionnaires to group members but none were returned. Totnes Caring declined to take part because they had recently commissioned their own report (a copy has already been sent to DCC and is included as **Appendix 2**) and were reluctant to ask service users to sit in further focus groups. They distributed questionnaires but none were returned.

Collective Questionnaire Responses

Are you: Someone with a diagnosis of dementia? Someone waiting for a diagnosis of dementia? Someone with memory problems? A carer or family member?

Which area of Devon do you live in?

Teignmouth Memory Café: Most participants attended the group without a carer and were not necessarily aware of the extent of their difficulties. One or two clients disclosed they had a dementia diagnosis, but most did not have or were not aware of having a diagnosis. No one appeared to be waiting for a diagnosis. Others had unspecified 'memory problems' or did not appear aware of any particular problems. All participants were from the Teignbridge area.

Age UK Exeter Budding Friends: A focus group and individual surveys were completed with five carers of people who had been diagnosed with dementia. All were from the Exeter area.

Sporting Memories: On 3 November, four members with dementia/significant memory issues were present, and neither they nor their carers were able to give detailed feedback for the survey. The group was to some extent familiar with support that peers and family members had received ahead of or following a dementia diagnosis. However, the group is a place where members can come to

have a break from talking about problems and health concerns, so it was difficult to gather specific feedback on the day. Several individuals provided general feedback relating to the experiences of friends, family members and clients. Members are mostly from the Exeter area.

Kingscare dementia carers support group: Most of the ten carers in attendance on 1 December reported that the person they cared for had received a diagnosis of dementia. One carer was at the beginning of the process and did not yet know how likely a diagnosis of dementia was. All were from Teignbridge.

Age UK Exeter EHSS clients: Surveys were completed with seven carers (six of the cared-for people had received a full diagnosis) and one person diagnosed with dementia. All were from Exeter.

Age UK Devon EHSS clients: A survey was completed with one carer living outside Devon; both parents receiving the service have a diagnosis of dementia and live in Mid Devon.

Crediton Memory Café: Five carers returned an individual questionnaire; each of the cared-for people had been diagnosed with dementia. Four were from Mid Devon and one from East Devon.

Age UK Devon MCST: A survey was returned by one client with a diagnosis of dementia and living in Teignbridge.

Carer Ambassadors: A focus group conducted through an online video call. Seven ambassadors from across Devon and a facilitator were present.

If dementia has been diagnosed, what support did you receive immediately after the diagnosis?

How satisfied were you with the support received immediately after the diagnosis?

Teignmouth Memory Café: Clients could not remember whether they had received support immediately after diagnosis.

Age UK Exeter Budding Friends: No participants reported being satisfied with the support they had received. One participant was very positive about a staff member at the Alzheimer's Society who keeps in touch, but it was not clear whether she had received immediate support.

Sporting Memories: Participants were unclear on which support had been offered but were generally 'not satisfied'.

Kingscare dementia carers support group: Out of the 10 group members present, two or three were 'very satisfied', one was 'satisfied', and four were 'not satisfied'.

Four carers said that they could not recall any follow-up support at all. One mentioned a 'huge pile of paperwork' being given to them at the diagnosis appointment, which was somewhat helpful but overwhelming. When diagnosis was given during an online appointment this was particularly hard to absorb, and again there was little follow up.

Participants also noted that they felt they were 'left to get on with it' by their GP, with most not having been offered any follow-up appointment that they could remember after their diagnosis.

Several mentioned online courses (possibly provided by Dementia UK and/or Devon Carers) with a lot of information but no follow up. The sense from group members who could remember receiving a lot of advice soon after diagnosis was that this was overwhelming and impossible to absorb.

Age UK Exeter EHSS clients: Two participants reported that they were 'satisfied' with the support received, one was 'very satisfied' and three were 'not satisfied'. Four were unsure or could not remember what support they had received.

None mentioned specific immediate support aside from that provided by the NHS (and one online workshop). One participant was positive about the prompt response from the Older People's Mental Health team (OPMH). One recalled some limited support from OPMH and/or GP several years ago. One could not remember having spoken to anyone apart from the GP.

Participants also mentioned feeling inadequately supported during the pandemic, particularly if this was when the diagnosis took place, and that support for carers was promised but 'didn't happen'. One participant mentioned a scan before the pandemic which revealed damage to the brain but did not result in a full dementia diagnosis and said that they had not been contacted by healthcare or other professionals since.

Age UK Devon EHSS clients: The service users' son remembered some meetings with OPMH and a lack of support otherwise, although has found online resources useful.

Crediton Memory Café: Most of the five respondents were satisfied with their initial support. As above, there was some confusion about which service or organisation had provided it.

One carer said that although they valued the initial support from the mental health nurse and Alzheimer's Society Support Worker, *'we quickly realised that in most respects my wife (diagnosed) and I were on our own'*.

Two carers were positive about the support from Devon Carers.

One carer stated that the immediate support had consisted of 'one meeting then a weekly talk for four weeks' although did not say who had provided this.

Age UK Devon MCST: The respondent was very satisfied with the immediate support received, which included telephone and letter contact with a dementia support worker from the Alzheimer's Society (signposting) and support and advice from Age UK Devon.

Carer Ambassadors: Ambassadors agreed that there is 'no help' until there is a diagnosis. In peer support groups, unpaid carers shared experiences of GPs' apparent reluctance to make a formal diagnosis or refer for assessment. Ambassadors suspect GPs attempt to 'gatekeep' for overwhelmed memory clinic services. They described a 'postcode lottery' and recommend that patients change GP surgery if they are not getting an appropriate response. Carers reported that they had not had contact from services if a general, non-specific diagnosis of memory problems had been given; one ambassador described this as an 'off you go into the sunset' attitude. One carer recalled 'the odd call' from Alzheimer's Society following a formal diagnosis but noted the lack of face-to-face support.

Following your dementia diagnosis, have you received support from any Community or Voluntary organisations in your community?

If you are waiting for a diagnosis, or are a carer for someone who is, have you received support from any Community or Voluntary organisations in your community whilst you have been waiting?

If you are living with a memory problem (not diagnosed as dementia) or are a carer of somebody with a memory problem, how easy do you find it to access support?

**If you have had support, what support was it, and from whom?
How easy have you found it to access support? Do you know where to find it if you need it?**

Teignmouth Memory Café: Most people initially answered that they had not had any support. Through discussion, they later agreed that the memory café counted as community support, and they attend other groups at the centre. The majority of support overall appeared to come from friends and family. One or two clients reported that they could not recall any support from the NHS or the local authority but that the Alzheimer's Society and Age UK Devon had been more helpful. A volunteer mentioned finding Devon Carers and a sitting service helpful in the past.

Most clients reported that it was not easy to find any support and they did not know where to access it. None reported that they knew where to find help if they wanted it. A volunteer pointed out that generally family members would be the ones contacting support services.

Age UK Exeter Budding Friends: It appeared that some participants had been referred to the Alzheimer's Society and others hadn't. One felt very well-supported by the Alzheimer's Society and another said they would probably be his first point of contact if he had a question. Others described the support as patchy.

Participants were positive about the peer support they receive from the Budding Friends group and said that if they needed information, they would go to the group facilitator (also Age UK Exeter's Dementia Wellbeing and Carers Support Co-ordinator) or another group member.

All participants were the main carer and provided the majority of support for their partner. Most identified that they struggled to know where to go for help and information.

Sporting Memories: Participants noted that there appeared to be a lack of support and contact until someone was 'in the system' and that NHS and social care support had significantly dropped during Covid and not picked up again. Feedback was given about the community support provided by the Sporting Memories group; in particular, participants value the format and the fact that the group is not marketed as only for those with memory problems. Participants commented on the social and cognitive benefits and noted that their cognitive recall is sharper in the days following a session.

Kingscare dementia carers support group: Carers reported that it had generally not been easy to find support. Most reported having found Kingscare themselves rather than having been put in touch by a professional and were very positive about Kingscare and the carers group. One carer said that Devon Carers had been '*exceptional*', citing a carer's assessment and care needs assessment that had taken place recently. Another said that Devon Carers had visited them at home twice.

One carer said that they have received a '*random*' call from the Alzheimer's Society about a year after diagnosis which they appreciated but did not find helpful as they were not prepared.

Admiral Nurses were mentioned by one carer.

Age UK Exeter EHSS clients: In addition to the paid-for help they receive from the Enabling and Home Support Service, clients and their carers talked about the following support:

- Contact with Devon Carers (mentioned by two carers).
- An annual check-in telephone call from the Alzheimer's Society (mentioned by two carers; one other said that they had received written information from them).
- Family support (most clients).
- Paid-for carers (mentioned by two carers).
- A direct payment funding respite care.
- Self-funded aids and equipment.
- Advice and equipment from DCC.

- Westbank (transport and lunch club).
- Estuary League of Friends.
- AUKD's Knightshayes gardening group.
- The GP surgery's memory café.
- Welfare benefits and council tax discount.
- Contact with an occupational therapist who offered a hospital bed.

Three participants said that they had not found it easy to access support, while two said that they did not have any support from community or voluntary organisations (except for the enabling service and Age UK Exeter's Dementia Wellbeing Co-ordinator) but would know where to go if needed. None spoke about feeling well supported.

One carer had significant concerns that her mother was deteriorating and did not know how to go about accessing further assessments. In particular, they were unsure about when would be the right time to contact very busy statutory services.

'It would be useful to get regular reviews of my mother's required care ... Age UK and carer support is fantastic. But she gets no health reviews or support. She was taking no tablets during Covid period, so I took her to the GP a couple of years ago and got blister packs for the 2 most important tablets. There was supposed to be a review I think but no further contact has been made. I don't like to bother a really busy health service unnecessarily, but I am not sure if this is the right approach.'

Age UK Devon EHSS clients: The client's son had arranged the paid-for enabling and home support and fulfilled other caring responsibilities himself, phoning throughout the day to check in and travelling from Somerset regularly to take his parents to appointments. He is currently arranging help with benefit claims with AUKD's Information and Advice service and making travel arrangements for his parents with Mid Devon Mobility.

Age UK Devon MCST: This participant was very positive about community and voluntary support, including the MCST group, describing the facilitator as *'someone to cheer me up and make me think about matters which otherwise are long forgotten.'* He had received support from AUKD's Information & Advice service and Better Later Lives project and was especially appreciative of home visits. It was particularly important to him that there would be support available for his wife (also his carer). The client also mentioned Assist Teignbridge and their home support service, for which he is on a waiting list. He said that otherwise, he did not need any further help for the moment.

Crediton Memory Café: Three carers said that it was not easy to find or access support. One said it was very easy.

Participants mentioned Age Concern in Crediton (namely the memory café and day care services). A couple mentioned attending other memory café(s) too.

One participant mentioned short-term help with cleaning arranged with support from Devon Carers

The participant who had found it very easy to access support was positive about the help they had had from a social prescriber. They had accessed to several local services; these included Age Concern Crediton, the Unite Carers charity and Devon Carers.

One participant said that they had had no support from community or voluntary organisations and were not aware where to find it.

Carer Ambassadors: All participants talked about having found support lacking and hard to access. One reported that Alzheimer's Society staff occasionally visit Memory Cafés, but that there is a lack of one-to-one support. It was noted that there appears to be a high turnover of support workers in the organisation and so relationships are not built.

Where available, the Admiral Nurse was agreed to be the best support. An Admiral Nurse offers '*loads of support*'. There was frustration over the lack of availability of the service and that e.g., the Honiton nurse service is dependent on local fundraising.

The group raised concerns over the responsibility laid on informal groups who support vulnerable people but have very little support themselves. Most are well-run, but often there is no oversight and this presents risks for all concerned.

What other support services would be of help to you?

Teignmouth Memory Café: The Memory Café clients talked about a range of factors and services that would make their lives easier generally. These included:

- Better transport/for local community transport options to be better publicised. Client(s) reported finding it inconvenient needing to contact Volunteering in Health weeks in advance for transport to medical appointments.
- Having easily accessible telephone numbers (several people stated that being told to go online was unhelpful). An example given was that it is very difficult to find a telephone number for Teignbridge District Council.
- Several clients said that they would like '*better signposting*' and said it would be helpful if a book could be produced with 'help at home' contacts – who to contact for specific repairs, problems and health issues. One client said that he was never sure whether he should go to his GP or another professional

(e.g., a podiatrist). Several clients referenced the list of contacts which used to be at the back of the telephone directory, which they no longer receive. Another client said that he would like a printed book with social activities in his area.

- Some clients raised the issue of it being difficult to book in-person GP appointments, and one disliked the practice of receptionists *'gatekeeping'* for GPs.
- A client and his wife were frustrated at having to go through the GP every time to speak to the Older People's Mental Health Team. They had had past appointments with the team and had been told *'get in touch if you need us'* but found out it was not possible to contact them directly.
- The majority of clients were keen for clinicians and other professionals (such as community nurses and members of the adult social care team) to attend groups like the Memory Café to give information on services and *'build connections'*. Two clients said that it wasn't ideal to only see professionals when a problem arose. *'They should be more visible.'* This led to a discussion about the group wanting more information-giving talks, particularly about home adaptations.

Age UK Exeter Budding Friends: The group and individuals were keen to make it known that they valued the support from Age UK Exeter but that this was not enough. Other support they would like included:

- More funded care provision.
- Day centres.
- More peer support and social groups.
- More face-to-face contact with professionals.
- A single place to go for information, advice, signposting, referrals. *'To be held by a team'*.
- Regular check-ins with a healthcare professional. For GPs to be readily available and knowledgeable about the different types of dementia and medication.
- Emotional support and counselling. (NB this is also mentioned in section 4.2.4 of the Totnes Caring report; see **Appendix 2**).

Sporting Memories: Group members did not talk about this question in much detail, aside from during a short discussion about the need for more social care services. However, it was clear that bringing a group together around a shared interest rather than a specific need or diagnosis was something members valued.

Kingscare dementia carers support group: Carers agreed that the following help would make a significant difference:

- Help with energy bills.
- Follow up appointments with the GP.
- A designated person to co-ordinate support.
- ‘Slow and gentle’ help rather than much of the information and signposting being given on the day of diagnosis. One suggestion was that another appointment a week later could work well.
- More information readily available in hard copies. Carers said that being told to go online was frustrating at times.

Carers identified a couple of significant advantages to having home visits instead of needing to go elsewhere for appointments and advice. Firstly, this would be a way for professionals to see the person with memory problems in their own environment. Secondly, when in an unfamiliar and clinical environment, carers can often be distracted by needing to provide reassurance for the person they care for, and unsurprisingly can find it difficult to retain much of what is said during the appointment.

Age UK Exeter EHSS clients: Respondents interpreted this question in a number of ways. These themes and points emerged:

- Regular reviews of care, health and medication.
- Information on *‘who to contact for support to assessment if she can still live by herself.’* This participant talked about conflicting advice from the ‘emergency team at DCC’ who said that her mother was not looking after herself but did not put any support in place.
- Further support to understand vascular dementia, and ‘someone to point us in the right direction’.
- Financial support: family have had to give up work to provide care, and Carer’s Allowance is not enough (and only covers one person).
- ‘I would like to join more groups and go out more’: this person was interested in Age UK Exeter’s Budding Friends, an art group, lunch clubs and chair-based exercise groups.
- More respite care.
- More social activities available to carers and people with memory problems.
- Further funded help with housework.

Age UK Devon EHSS clients: The clients' son said that emotional support for carers as well as practical changes to make it easier to claim benefits would help.

Crediton Memory Café: Not all participants answered this question. Overall, they thought the following would help:

- More readily available, local and accessible respite care, ideally provided for a couple of hours a week. *'It must be affordable.'*
- Additional day care services
- Funded help with housework

Age UK Devon MCST: None currently needed, although the respondent was concerned about his carer being able to access sufficient support in the future.

Carer Ambassadors: The group identified that easily accessible health and social care services, better mental health support and a single point of contact would make the most difference to their quality of life and that of the person living with memory problems. They expressed frustration that much help and advice has been moved online and is therefore not accessible to some carers.

The ambassadors spoke about the crisis in care provision. A lack of professional carers and specialist care home places means not only that people can be stuck in hospital for longer (with a detrimental effect on their health and wellbeing) but also that demands on unpaid carers are greater than ever. Carers are stressed and exhausted but struggle on because it is expected that they will do. In their experience, there is little respite care or even emergency respite care available, it is difficult to contact mental health support services, and carer breakdown is increasing. Care home beds and specialist hospital places are sometimes at the other end of Devon or in another county, causing significant logistical and financial challenges.

Conclusions

The majority of respondents either had not been offered or could not remember having been offered much in the way of support soon after diagnosis, and support was even more lacking if a formal diagnosis of dementia had not been given. People reported having received patchy support at a later stage. This included care, enabling services, and advice and social support both from independently funded charities and commissioned services. Support from the Alzheimer's Society, Devon Carers and Admiral Nurses was valued when it was consistent and accessible.

That there are even fewer support options when dementia has not been diagnosed is evidently problematic. Carer Ambassadors have started to encourage the use of the term 'working diagnosis' to open doors.

Home visits and in-person contact with professionals, social groups and peer support all appeared to make a significant difference when available, giving people the confidence to reach out for help if they needed it. Participants consistently mentioned wanting a named contact and a reliable person or organisation to approach for advice as a single point of access.

Peer support both among carers and people with memory problems emerged as valuable not just for emotional support but also as a source of information on where to go for specific problems. However, some participants felt that this was their only real option as other services were difficult to get hold of. Groups need to have boundaries, and those giving support are often under pressure themselves. Charities and community groups are filling the gaps left by lack of adequate provision by Government and NHS.

The decrease in funded services for carers is problematic: participants mentioned counselling/therapeutic support, respite care and better care provision overall as services that could make a real difference to their quality of life and help to prevent burnout.

The care crisis and its accompanying problems are well understood, and one group in particular voiced strong doubt that the situation in Devon or nationally will change. Some participants expressed anger at being asked to take part in the focus group, stating that they are frequently asked for opinions, never receive feedback and do not see any change in service provision. They considered 'box ticking' to be pointless and felt that there is a failure to provide proper information and support.

It is possible that some people will have been offered support or information that they did not remember at the time of survey. However, it is arguably the case that as so many participants felt unsupported, something about the way this support is offered needs to change. This consultation has identified that the timing of advice and support offered would benefit from careful consideration, as would options for further face-to-face contact.

AUKD's Information and Advice Service has observed that many clients are unaware of a clear pathway for people with memory loss or dementia. Sometimes this is due to lack of diagnosis, and therefore lack of information provided. It was noted by some of our respondents that DCC's online information on dementia is misleading as it includes a link to 'The Devon and Torbay Dementia Advice Service' which clicks through to the national homepage of the Alzheimer's Society. It is not clear that this is a commissioned service, or anything other than a signpost to a national charity where users have to know how to navigate the search facility. Clients who do get contact from the Alzheimer's Society often report being given a lot of leaflets and are unsure who does what. Our advice service frequently receives calls from people recently diagnosed with dementia, and carers, who do not know what help they are asking for. Given that the time around diagnosis will likely be overwhelming, some more structured support may well be beneficial.



Share Your Views with Us

Are you living with dementia or memory problems or are you a carer or family of someone living with dementia or memory problems?

By completing this short survey you will be helping Devon County Council to understand what is important to help you to continue to live as part of your community.

1. Are you?

Someone with a diagnosis of dementia?	
Someone waiting for a diagnosis of dementia?	
Someone with memory problems?	
A carer or family member?	

2. What area of Devon do you live in?

Exeter	
East Devon	
Teignbridge	
West Devon	
South Hams	
North Devon	
Torridge	
Mid Devon	

3. If dementia has been diagnosed, what support did you receive immediately after the diagnosis? (Who from, face to face or telephone, written information?)

4. How satisfied were you with the support received immediately after the diagnosis?

Very satisfied	
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Satisfied	
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Not satisfied	
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Any comments

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5. Following your dementia diagnosis, have you received support from any Community or Voluntary organisations in your community?

Yes	
No but I know where to go for support if needed	
No and I don't know where to get support	
I do not wish to receive any support.	

6. If you have had support, what support was it, and from whom?

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7. What other support services would be of help to you?

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8. If you are waiting for a diagnosis, or are a carer for someone who is, have you received support from any Community or Voluntary organisations in your community whilst you have been waiting?

Yes	
No but I know where to go for support if needed	
No and I don't know where to get support	
I do not wish to receive any support.	

9. If you have had support, what support was it and from whom?

10. What other support services would be of help to you?

11. If you are living with a memory problem (not diagnosed as dementia) or are a carer of somebody with a memory problem, how easy do you find it to access support?

Not easy	
Easy	
Very Easy	
I do not wish to receive any support but I know where to go if I want to	

12. If you have had support, what support was it, and from whom?

13. What other support services would be of help to you?

Thank you for your time.

**Please send your completed questionnaire back to us in the envelope provided
or email a copy to info@ageukdevon.co.uk**

If you would like to talk about this further, or need any help completing the form,
please contact **Sarah Gunn** on **0333 241 2340**.

GENERAL DATA PROTECTION REQUIREMENTS

Who is collecting and using your personal data?

Age UK Devon will collect and store your information securely. Your information and views will be anonymised and shared with Devon County Council. We will not share your details with any other organisation, or individual, without your express permission.

Exceptions to this will only occur where there is a legal requirement to share information, or a concern for the safety of an individual or the public.

STRUCTURED FEEDBACK ON USERS' AND OTHER STAKEHOLDERS' PERSPECTIVE OF THE DEMENTIA SERVICES PROVIDED BY TOTNES CARING

1.0 Introduction

This document presents feedback collected during discussions held in June 2022 with:

People living with dementia:

- a group of people who come to Memory Café and who live alone
- a group of people who come to Memory Café and who live with a carer or in an adjacent annex to a family home
- a group of people who come to Memory Café and to lunch on Carers' Support Group days

Carers of people living with dementia:

- the Carers' Support Group who meet monthly over lunch and who come to Memory Café
- a group of carers who come to Memory Café and who go to Carers' Support Groups (lunch or zoom) occasionally but not regularly
- a carer who participates in the monthly Online Carers' Support Group (zoom), but not the lunch group or Memory Café

Other stakeholders / key informants:

- a member of NHS Older People's Mental Health Team
- the Wellbeing Coordinator at Totnes Caring

Unfortunately, it has not been possible to talk to any person living with dementia or carer who has declined to join or has dropped out of Totnes Caring Dementia services, which inevitably means a bias in the feedback. Some suggestions are made in Section 4 to address this in future.

The document is structured to address questions raised in the Terms of Reference:

- How appropriate and relevant are the services to the physical, psychological, social, and emotional needs of people living with dementia and carers of people living with dementia?
- Are they delivered in ways that are effective to meet the expectations of people living with dementia and carers of people living with dementia?
- What gaps are there in dementia services available to people with dementia and to the carers of people living with dementia which would address unmet needs?

Further discussions can be arranged as necessary to follow up on any points requiring greater depth.

2.0 How appropriate and relevant are the services to the physical, psychological, social, and emotional needs of people living with dementia and carers of people living with dementia?

There was unanimous agreement on the importance, relevance and value of the current dementia services provided by Totnes Caring.

2.1 Memory Café

2.1.1 Perspective of people living with dementia

For people living with dementia, the Memory Café is a relaxing, fun, sociable environment. They enjoy the "community" of it and they said it makes them "feel happy". Many people said that they like the

chance to get out, talk, meet each other and make friends. The point was made that even if family members telephone or visit regularly, it is important to build and retain social interaction beyond family. Some people acknowledged that they don't always feel like going out, but it is worth making the effort for Memory Café. As well as friendship and socialising, one person also mentioned the importance of being able to discuss a problem with others.

All activities are enjoyed, particularly the exercise classes and the country and western singalongs, both of which are good as "everyone joins in". One person summed up many people's sentiments well: "live music, singing, fiddle playing, seeing people dance is uplifting". The outings stood out as a highlight, especially the steam train and cream tea.

The importance of Memory Café to people with dementia, particularly for those who live alone, was highlighted when talking about feelings of loneliness and depression during the Covid19 period. Memory Café held over zoom made an important contribution to people's mental health during lockdowns and times of restricted socialising. Since then, it has been an important way to rebuild a friendship group, as having little or no social contact with friends during Covid resulted in, as one person put it "damaged communication links".

2.1.2 Perspective of carers of people living with dementia

Carers were also in agreement about the benefits of Memory Café. They said that the person they care for has fun and is in a better mood, making it more relaxed at home after Memory Café. Sometimes behaviours at Memory Café are easier than at home, due to socialising and engagement in activities, relieving pressure on carers. Comparisons were made to some other activities, for example the Filo project, when people living with dementia can be reluctant to go and keen to leave, though the lunch itself is generally enjoyed. Carers commented that no one is in a hurry to leave Memory Café and they often chat about it on the way home, reflecting a positive experience.

A carer who is involved in the online Carers' Support Group said that he and his partner had a regular activity on Thursdays with longstanding friends, otherwise they would be happy to go to Memory Café.

Carers enjoy Memory Café for themselves as well as for the pleasure it provides to the person they care for. One carer whose partner is now in residential care has continued coming to Memory Café as it has become such an important social activity for him. One carer described Memory Café as a "lifeline", both for them and the person they care for, particularly during Covid when there was little other support or social contact. In another group there was a similar point about its importance: "having the social support on a weekly basis plus support of family helps to prevent burnout".

Memory Café also serves as a forum for sharing experience and advice for carers, particularly for those who are not regularly at the Carers' Support Group lunches. One comment made about future challenges which will eventually have to be faced was: "I will ask here to see how other people have managed. It will be a difficult period, but it will be resolved".

2.1.3 Perspective of other stakeholders / key informants

Other professionals were also able to give examples of the positive benefits of Memory Café. This was both positive feedback to them from clients and their own observations of improvements in clients who go to Memory Café. An example was given of a client who, with the structure of attending Memory Café, had improved mood, was less tearful, felt less lonely and could be discharged.

2.1.4 Suggestions for the future

Everything about Memory Café was considered good. If possible, a few more outings in the year would be welcome. Suggestions were: outings which, like the steam train, “take you back to the past”; a trip to the seaside to breathe the air; a trip for a matinee theatre performance (this seems to have happened in the past through the Rotary Club). A suggestion from carers was to have a picnic or barbecue, somewhere safe for any people living with dementia who tend to wander.

In one group of people living with dementia, an opportunity “to do some ordinary things like shopping” was suggested. There was a discussion of how the change in life from being independent to dependent, which in itself is hard, is made more difficult knowing how busy family members, carers etc are. So having time to do ordinary things without the feeling of anyone being in a hurry would be a pleasure. One person had been taken to M&S for a cup of tea and late afternoon /early evening shop, when it is very quiet, and a few people in the group (not everyone) thought that might make an enjoyable outing.

Another idea discussed by the group of people living with dementia who live alone was the possibility of an occasional Memory Café lunch for a small number of people in each other’s house, with a focus on the “host”: hearing their personal story and history, looking at their photos and mementoes of past experiences. They said it would be important to have a lunch provided to avoid any stress for the host in managing the catering. Carers, when asked about this idea, were a little more cautious, as its success would depend on how sociable the person they care for was feeling on the day when other people living with dementia were coming to visit their home.

Everyone was realistic about time, budget and logistics considerations and these suggestions were made in response to a question about an ideal world. This discussion was appreciated by people living with dementia who, at the end of one group discussion, were keen to add that being asked to contribute to such a discussion was welcome and a reflection of the style and approach of Totnes Caring. Comments were made such as: “it feels very good to be asked what we want and think”, “it’s really important to know what I want”.

2.1.5 Success Indicators

Clear examples were given during the discussion that suggest people living with dementia do feel:

- stimulated and engaged by activities at Memory Café
- feel more connected socially
- feel generally happier after a session at Memory Café
- feel well supported and listened to by staff & volunteers at Memory Café

There was one comment about it being a place to discuss problems but not clear enough to say with any certainty that people living with dementia feel “able to discuss living with dementia at Memory Café and what it may mean in the future”. However, this was not specifically raised as a question to the groups. It may perhaps be an indicator which is unlikely to be met because coming to Memory Café is viewed as a place for fun and a release from concerns and worries – which of course is positive in itself. This is not currently a success indicator for carers participating in Memory Café, but it does seem to be an appropriate indicator in relation to the needs of some carers who are unable to participate regularly in the Carers’ Support Group.

Likewise, examples were given during the discussions that suggest carers of people living with dementia:

- have had fun and enjoyed relaxing with people in a similar situation
- have observed the person living with dementia who they care for enjoying social interaction
- perceive positive changes in the quality of life of the person living with dementia who they care for (for example, improved mood, outlook, behaviours) after attending Memory Café

Additional benefits of the dementia services provided by Totnes Caring may be to reduce caseload pressure on statutory services, if support helps to create a level of stability which allows client discharge and possibly longer-term wellbeing than might otherwise be the case.

2.2 Carers' Support Groups

2.2.1 Perspective of carers of people living with dementia

For all carers who participate in the monthly lunch group and/or zoom group, the opportunity to share experience, seek advice, offer practical hints, pick up information is invaluable but above all having the emotional support of people facing similar challenges is the key element. It is a safe place to talk about the cycle of irritation, for example when the person they care for refuses to do reasonable things, such as going to bed at night; the carer then feels guilty about getting cross, only for the same thing to happen the next day. Spending time with other people who are caring for someone at a different stage of dementia also helps in thinking about the future, hearing and learning about behaviours related to dementia which they may encounter later and being prepared to face new challenges. One comment from a group discussion commented on the importance of the group for "mentally preparing for what's to come, how to cope".

One carer who participates in the zoom group but not the lunch said that the reason for not going to the lunch was the time commitment, not lack of interest or relevance. Other carers who participated in the online group during covid felt that the moment for it had passed, and meeting over lunch would now be preferable. Also, for one carer, as their partner's dementia has progressed, it has become more difficult to sit on the computer without distraction, as their partner seeks their full attention when both are at home.

Carers who go to Memory Café but not regularly to the Carers' Support Group lunch said they are likely to participate more regularly when the person they care for is at a more advanced stage of dementia.

2.2.2 Perspective of people living with dementia

People living with dementia who participate in the lunch with volunteers at Quayside, while carers are meeting, said that they enjoyed being out and seeing people. One person summarised it as the opportunity to have "a banter and a laugh over a good lunch".

2.2.3 Suggestions for the future

Carers are clearly coping with extreme stress, fatigue, moments of intense frustration and also sadness or grief. In addition, many have their own personal health issues to manage. Everything done by Totnes Caring and other organisations to support them is much appreciated. Issues raised in the discussion go beyond the remit of the Carers' Support Group and are included in Section 4.

2.2.4 Success Indicators

Concrete examples were given during discussions with carers of people living with dementia that through the Carers' Support Groups, they

- have shared and discussed their experience, anxieties, and dilemmas

- have provided to and/or received support from other carers of people living with dementia
- have extended their social network
- have received and used practical information related to living with dementia
- understand better how dementia progresses and feel more confident in facing decisions required in the short term and which are likely to arise in the future

2.3 Information and Advice

2.3.1 Perspective of people living with dementia

People living with dementia find it reassuring to know they can get advice from someone who they trust. They said that they may not always want to ask family for advice or information, both because they want to remain independent and because, sometimes, it concerns a matter they prefer not to discuss with family members.

There was also a discussion about the stress of receiving letters from “authority”, for example long Government forms to be completed (though others said that they ignored them or burnt them). Many people have family or carers to help them sort mail, but they feel comfort knowing that they can seek advice from Totnes Caring as a reliable back-up or second opinion.

The groups gave examples of practical advice, like arranging the installation of a stair lift and legal planning advice, such as arranging a will and a PoA. They also remember being able to call to get a list of contact numbers for odd jobs men, decorators etc., but think this is no longer available and weren't sure of the reason.

2.3.2 Perspective of carers of people living with dementia

Examples were provided of practical help, for example with information and paperwork to get the attendance allowance, reduction in council tax, blue badge. Having the Information & Advice service is a very helpful starting point to get pointed in the right direction when seeking help on things, such as home help, a fire safety check, support with organising a PoA, finding a carer or Personal Assistant or looking into residential care. The Information & Advice service is an ongoing source of help, unlike for example OPMHT or Social Prescribers which are time limited, or the support of the Alzheimer's Society Dementia Adviser, which is an annual telephone contact, making it even more valuable as a consistent accompaniment.

Having personal contact for advice and support as well as being signposted to printed and online materials was raised by some carers. Knowing that you can telephone and speak to someone who has relevant knowledge to provide help and advice is important. There is also the added value in talking through information from a range of sources and identifying relatively easily and quickly what is relevant and appropriate. Some carers said they are not confident to seek information online, so it is especially important to have a point of contact in Totnes Caring to speak to.

2.3.3 Suggestions for the future

There was much discussion within all the carer groups of the difficulties in the interface, fragmentation of services and some said they were overwhelmed and often confused by the vast range of services they encounter, for example OPMHT, Devon Carers, Alzheimer's Society Dementia Adviser, Social Prescribers. A practical suggestion was a road map with pointers about who to go to, about what. This could include some ideas of who to turn to in a personal emotional “emergency”, when it is too late at night to call family or friends, but it would help to have someone to talk to. Physical emergencies are clear cut but situations which are not “emergencies” per se, but which do require mental /

emotional health first aid, are less obvious and so this type of support is tantamount to the well-being and fortitude of the carer.

Carers mentioned some useful Devon Carers online training courses on a variety of subjects which could be useful to signpost to or perhaps in future there could be a collaboration between Totnes Caring and Devon Caring to produce materials. Another suggestion was to develop a Directory of Resources available. One carer commented that there are many areas related to living with dementia not already covered by books and materials, which is surprising as the life-changes are transformative.

People living with dementia suggested a Directory of Tradesmen, as they would like to have easy access to contact numbers for odd jobs men, decorators etc.

2.3.4 Success Indicators

Concrete examples were given to suggest that people living with dementia and carers of people living with dementia:

- have benefited from practical information related to living with dementia
- feel more confident that they have the information and are better prepared for changes in their lives
- are better prepared to cope with and manage any changes in their circumstances

3.0 Are they delivered in ways that are effective to meet the expectations of people living with dementia and carers of people living with dementia?

There was unanimous agreement that the current dementia services provided by Totnes Caring are well organised, well supported by staff and volunteers and at appropriate locations and frequency.

3.1 Memory Café

3.1.1 Perspective of people living with dementia

Memory Café was described by people living with dementia as very well organised and “never boring”. The outing on the steam train was used as an example of how Memory Café considers the needs of people with physical and mental disabilities, ensuring that help is always on hand as and when required and no-one feels excluded or a nuisance.

The location of Memory Café was felt to be good, with a welcoming spacious room; the weekly frequency appropriate; and above all appreciation was expressed for the time and kindness of Totnes Caring staff and volunteers. Favourable comparisons were made to other groups (not part of Totnes Caring) who lacked an appropriate number of volunteers to ensure everyone’s wellbeing and active participation. A comment which reflects the skills and sensitivity of the way staff and volunteers run Memory Café was that “you are never pushed into doing something you don’t want to”.

3.1.2 Perspective of carers of people living with dementia

Carers of people living with dementia were also in agreement that location, frequency, range of activities and support from staff and volunteers at Memory Café is excellent.

The familiarity of Memory Café seems important, for example one carer said that whilst the person they care for has found other activities outside home a bit too much, he likes the safeness of coming to Memory Café, sitting at the same table each week, he is acknowledged by everyone, able to chat with the same group of friends and he feels very comfortable.

3.1.3 Suggestions for the future

There were no suggestions in relation to the way Memory Café is organised or run, as it is already good.

3.1.4 Success Indicators

These are covered in section 2.1.5

3.2 Carer Support Groups

3.2.1 Perspective of carers of people living with dementia

Carers who attend the lunch group were appreciative that they could bring the person the care for to have lunch with volunteers, so that they know they are nearby should anything arise and can briefly switch off from their caring duties. Indeed, this was highlighted by some members of the group who excused themselves for monitoring their phones throughout the discussion, explaining that they needed to be available in case there was any call related to the people they care for who were attending a Filo project lunch.

Carers felt that the frequency and venue is good. Being on one level from the car drop off point through to the bistro is very helpful for those with mobility problems.

The main barrier to participation in the Carers' Support Group lunch is time. The carer who participates in the zoom group but not the lunch group (or Memory Café as noted previously) said that the reason for not going to the lunch was the time commitment. Carers who come to the Memory Café but not regularly to the lunch group said that they juggle other care commitments, such as looking after grandchildren. Many carers mentioned that the person they care for is out at a Filo project lunch on a Wednesday. The free time this allows is used to catch up at home, work or to have time for other personal interests.

For those who participate in the online Carers' Support Group, the one-hour limit on the zoom call is good and having an external facilitator / chair ensures there is a balanced discussion with everyone joining in and a consistency in style. There was an important observation that it might lose its integrity if self-managed by the group. Likewise, it is helpful for the Carers' Support Group who meet over lunch to have facilitation both to help the discussion to keep moving and to have the opportunity to hear and understand everyone's situation, needs and ideas.

3.2.2 Perspective of people living with dementia

People living with dementia who participate in the lunch with volunteers at Quayside while carers are meeting said that they enjoyed coming to Quayside which is "welcoming, clean and sparkling" and serves a good lunch.

3.2.3 Suggestions for the future

As many of the carers who come to Memory Café cannot make the Carers' Support Group on a Wednesday, there was a suggestion that perhaps there could be an additional lunch group on a different day, either monthly or every two months, to facilitate the participation of carers who juggle other work or caring commitments and for those who prefer not to let go of the free time they have on Wednesdays, when some Filo project lunches take place.

3.2.4 Success Indicators

These are covered in 2.2.4

3.3 Information & Advice

3.3.1 General Perspective

The Information & Advice service is available on the phone and through follow up visits to support people living with dementia and the carers of people living with dementia, so it is very flexible in how it is delivered. Many comments were made about the excellence of knowledge and helpfulness of the Dementia Service Coordinator who provides the service. A typical comment, made by a carer is: “Mary is really helpful I don’t need a social worker as Mary has answers, resources, experience”.

3.3.2 Suggestions for the future

There were discussions amongst the carers about the usefulness of having regular check-in calls every few months with perhaps occasional visits as well as telephone conversations. This would also be a way to identify common themes around challenges that a number of people are facing which could become a focus for a Carers’ Support Group meeting with an external facilitator, such as someone from OPMHT, to advise or to share any strategies they know of to manage difficult situations. It would also help to keep a running list of uncertainties and queries to talk about during a regular catch up, rather than making too many ad-hoc phone calls which they thought might overload the Information & Advice service. A number of carers mentioned that this would be particularly helpful in the initial period (prior to as well as after the person they care for has had a dementia diagnosis), as there are many general aspects of the information and advice that could help to set arrangements in place which lighten the load, such as organising home help.

3.3.3 Success Indicators

These are covered in 2.3.4

4.0 What gaps are there in dementia services available to people with dementia and to the carers of people living with dementia which would address unmet needs?

“Appreciative enquiry” was used in group discussions to focus both on the strengths of what is already in place and then to stretch that into a vision of a dementia service that would provide a “dream” level of support. It was clear in the discussion that this was to generate ideas, which may not be within the remit of Totnes Caring or other local organisations or may not be possible to deliver given resource constraints, but which at least could be put on the agenda for further discussion.

4.1 Vision for “Dream” Dementia Services: People living with dementia

Activities suggested to make Memory Café a “dream” service have been included in Section 2.1.4.

The biggest “dream”, particularly for those who live alone, would be the opportunity to have a holiday or a few days away, both because it is a long time since taking a holiday and as the covid period was so gruelling and depressing.

The needs of people who have declined to join or dropped out of Totnes Caring activities have not of course been captured. A suggestion was made by a carer which may address the needs of people who are at the early stages of living with dementia, and this is included in 4.2. A suggestion for how Totnes Caring might in future be able to identify these needs is made in Section 4.3.2.

4.2 Vision for “Dream” Dementia Services: Carers of people living with dementia

Key things which were mentioned as “dreams” to make life easier were:

4.2.1 Interface and connectedness of services

The range of services is wide, can be overwhelming and it is not always clear who is responsible for what. Appendix 1 and 2 provide a simplified map of referral routes and reflect the complexity to understand.

Not everyone was aware that there was an OPMHT in Totnes, not many know the role of Social Prescribers and for some carers, advice on medical issues has been difficult to get from the GP or a hospital consultant. One carer described feeling they have “no voice”, another carer described the difficulty she had in getting information about her partner in hospital, despite having power of attorney. Some carers are frustrated that they have no one to turn to for medical advice; they may have been referred to OPMHT by the GP, but once discharged, after the 6-month rapid access service they have to go through the same process of an appointment with the GP for a new referral to OPMHT.

A “dream” service for carers would be a “Bristol system” with a more integrated approach, rather than divided up across specialisms. Links would also be strengthened between Totnes Caring and OPMHT with earlier referral to Totnes Caring and access to medical as well as social support. There would be a specialist nurse practitioner attached to a GP surgery or, ideally, to Totnes Caring who could come to Memory Café and be available to help carers with their medical or clinical related questions. If they were attached to Totnes Caring - with appropriate training, funding and under the guidance of a GP - they could advise, even if they were not able to prescribe medication. Not only would this serve as a contact point, but it would be easier as carers know Totnes Caring; the person living with dementia they care for knows Totnes Caring; and Totnes Caring knows all of them. Another suggestion made was for a phone number to contact any time for advice of the type OPMHT team generally give, for example around medication.

Another aspect of a “dream” service would be access to “advocates” for support in expressing a carer’s views, noting the information provided and to help defuse stressful encounters in a highly charged hospital environment where consultants are working under great pressure and carers / relatives are stressed and emotional. (Lack of voice was not raised by any of the groups of people living with dementia, but access to mental health advocates may be a useful back up for anyone without family living nearby.)

4.2.2 Early-stage support

Carers suggested support at an earlier stage, pre and post dementia diagnosis would be helpful but observed that there would be people living with dementia who for different reasons, for example “pride”, “denial”, may not want to participate in an activity specifically for people living with dementia. One carer said he had experienced this when his partner was diagnosed. Eventually when a neighbour offered to go with her, she finally agreed.

A “dream” service might have volunteers to accompany the person living with dementia to a social activity of interest, in order to travel there easily, for example on foot or by bus, and to be sure they are comfortable within the group. This would help to avoid a struggle for the carer in persuading the person they care for to go out to a social activity, preventing tiredness before getting to the “next stress level”, as one person described it, and eventual burn-out.

This conversation picked up on some ideas which were also discussed with Totnes Caring’s Well-being Coordinator and CEO. Possibly, if there was a group that a person at the early stage of diagnosis might be interested in joining, such as a choir, walking group, art group, cookery group, a request could be made for someone from the group to volunteer to be a “buddy”. The shared interest in the activity

may make this feel less patronising or condescending to someone who needs time to process and adjust to changes in their life.

Facilitating participation in activities which take place anyway, rather than setting up new groups, may help to meet the specific needs of individuals who are living with mild to moderate dementia. It could cover any individual interest (assuming a regular group exists) and cover a period when a person is experiencing memory problems but is not ready to consider joining dementia specific activities. It could be an opportunity to present Totnes Caring to various groups within the community and to provide information on the challenges for someone living with dementia. It may be less resource intensive and might also open up a new group of volunteers to Totnes Caring, i.e. people who are willing to support someone living with dementia to participate in their group but who do not have time or inclination for more general volunteering. It could be described as “Sharing the Passion”.

This could possibly be piloted to test the idea, gauge interest and learn using the experience of “Hedgewise” which the Totnes Caring Well-being Coordinator is involved in?

4.2.3 Personal time for mental and physical health

Carers talked about the high level of stress they live with, providing care 24/7, often having disturbed sleep, for example due to incontinence issues, sometimes feeling frustration, for example at being asked the same question many times in as many minutes, and sometimes in a state of high emotion. Even when the person they care for is out, for example at the Filo project lunch, they described feeling “taut”, not able to relax, waiting for a phone call about an emergency or difficulty. On top of this, they take on a greater share of household tasks and routine administration. Carers are acutely aware of the need to look after their own physical and mental health which, aside from being important per se, is also important to prevent a crisis that may leave no option other than residential care for the person living with dementia.

However, carers said they find it hard to put aside time for themselves and the closer they are to “breaking point”, the less energy they have left to meet their own needs. One carer commented that if the person they care for couldn’t go to an activity such as a Filo lunch, “it would affect my wellbeing more than hers”. A number of carers described how care provided through social services is quite often cancelled or the time changed with little prior warning. As they have no control over this, they can only plan a personal activity when day care or a private carer or Personal Assistant has been organised, which is costly. Other carers added that family members cannot always be reliable either, for example when they are called on for last minute childcare or they too may have health issues to manage.

Carers with physical health problems who are unable to leave the person they care for at home, attend their medical appointments together, making it less easy to focus on the consultation about their own health. Some find it too difficult to attend an appointment, one carer for example said: “I don’t go for my health, I do my own diagnosis and get on with it.”.

Unsurprisingly given the 2-year period of covid, it’s been very hard for any carers to take a holiday, but for most going on holiday remains a dream rather than a reality. Some carers said they have managed to organise respite care either in a residential home which they already use for day care or through an agency providing short stay live in-in care. Some carers, however, said that they wouldn’t want to go on holiday without the person they care for.

A “dream” service would have the possibility of requesting volunteers to come to a hospital appointment so that the carer could attend their consultation alone or to stay at home with the person living with dementia to allow the carer to attend their appointment. Likewise, it would offer the

possibility of cover for the carer to take time out for themselves, through improvement in the reliability of care provided by social services and/or through volunteers performing a similar role to Personal Assistants and/or through financial support for employing a Personal Assistant. It would facilitate a carer's holiday through provision of a respite care service or through financial support for private agency or residential respite care.

4.2.4 Support in understanding and adjusting to transformative change in life

This was raised in relation to how roles within a relationship, be it marital, parent/child, sibling etc., change and the time it takes to understand and adapt to such changes. A number of carers spoke about sadness and grief. One person said "we had a relationship of talking to each other, that's now all gone." Likewise changes in the nature and dynamics of the relationship, for example who is "boss", who does which tasks in the household. Another carer described his distress when his partner didn't recognise him and screamed until he left briefly. The loss felt is compounded by not having time to reflect on what impact that has on life, to understand and accept what has been lost both for the person with dementia and their carer. Friends don't necessarily take cognisance of the changes or recognise how the person living with dementia has changed, so it is not always easy to talk about.

A "dream" service might provide or signpost to bereavement counselling, to help with grief at the loss of some parts of the person you know, as well as mourning after death. It may also have some form of 24h helpline service to talk to someone in an emotional "emergency" when a carer feels they have reached a crisis point and there is too much to cope with.

4.3 Other suggestions

4.3.1 Totnes Caring and OPMHT

OPMHT supports clients through home visits, phone calls or client appointments, overseeing any medication changes and monitoring behavioural issues. The main need tends to be for social inclusion. Clients stay in the service until a post diagnostic, clinic but not necessarily actively. There can be a waiting time of some months for the post-diagnostic clinic. At the post diagnostic clinic, clients see a medical practitioner and then may be discharged with referral on to local support services, including a Dementia Support worker from Alzheimer's Society who checks in once per year. In the past some clients have been referred to Totnes Caring before the post diagnostic clinic for support on topics that may be covered at the clinic, such as attendance allowance. This has been on an ad hoc basis but could become more systematic either to refer all clients – with their consent – or to be a safety net for those who need the support sooner. The Totnes Caring Information & Advice service would serve as an entry point to other Totnes Caring services and would make it easier for Totnes Caring to maintain ongoing contact with clients, from very early stages through to later stages. This would help to build in "touch points" from an early stage that would be part of an ideal system. If regular check-in calls are available as part of early accompaniment by Totnes Caring, this would help to identify any needs of people living with dementia that are not currently being met.

OPMHT has a very good relationship with the Totnes Caring Dementia Services Coordinator, which has been informal and ad hoc as needs arise and occasional updates are given to OPMHT on clients who have been referred. However, a suggestion was made that communication between OPMHT and Totnes Caring Dementia Services could be slightly more formalised for effective sharing of key information, without becoming overly complicated.

There is not very much contact between OPMHT and Social Prescribers, so it may be useful for the two teams to meet to ensure complementarity rather than duplication in relation to referrals for social inclusion activities.

4.3.2 Totnes Caring Information and Advice Service

This service provides extremely valuable information relevant to a wider group of people, as well as information and advice specific to dementia. It could be structured in such a way that it serves as the gateway into Totnes Caring and the other services. It could gradually be expanded to encompass the specific needs of other groups of people, such as those living with arthritis or after a stroke.

At the initial contact stage, a home visit or phone call could start to build trust and relationships, ensuring a connection to the person and who they are. It could also help to meet any immediate needs and to make available ongoing support, while people living with dementia and their carers are experiencing difficult changes in their lives and are starting to encounter new bureaucracy, for example in relation to government forms etc. Data could also be collected at this initial entry into the Information & Advice service on any needs that are not being met through the currently available dementia services, see Appendix 1 and Appendix 2. It may be possible to trial data collection through a pilot project with the Totnes Caring Well-being Coordinator who could have initial conversations about what Totnes Caring can offer across all services, and what clients may like.

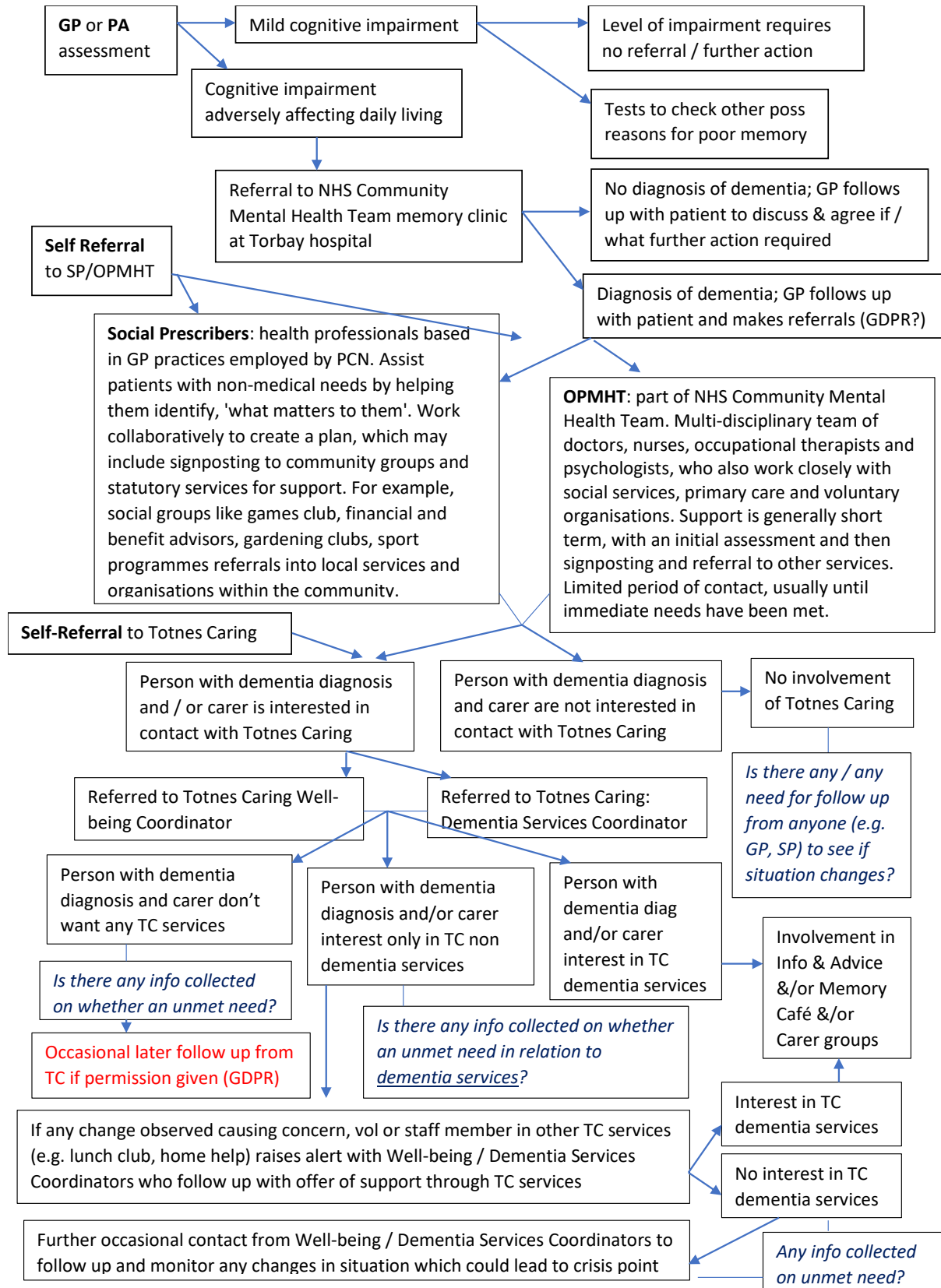
A database of clients through all stages of their 'memory journey', accessible to OPMHT and GP as well as Totnes Caring if GDPR allows, could facilitate cross organisational sharing of information and joined up-care. It would also mean sharing of alerts, for example from home helps who are valuable eyes and ears able to see any changes that are of concern through their work for people living with dementia and carers.

Structured internal signposting and referrals would mean clarity of roles and consistency of approach as well as more effective sharing of information to provide clients of Totnes Caring with the best possible support and client experience.

The Information & Advice service is so successful because of the expertise, experience and commitment of the Dementia Services Coordinator. It is important not to lose this level of quality if it is expanded into an overall Totnes Caring service serving the needs of a wider population.

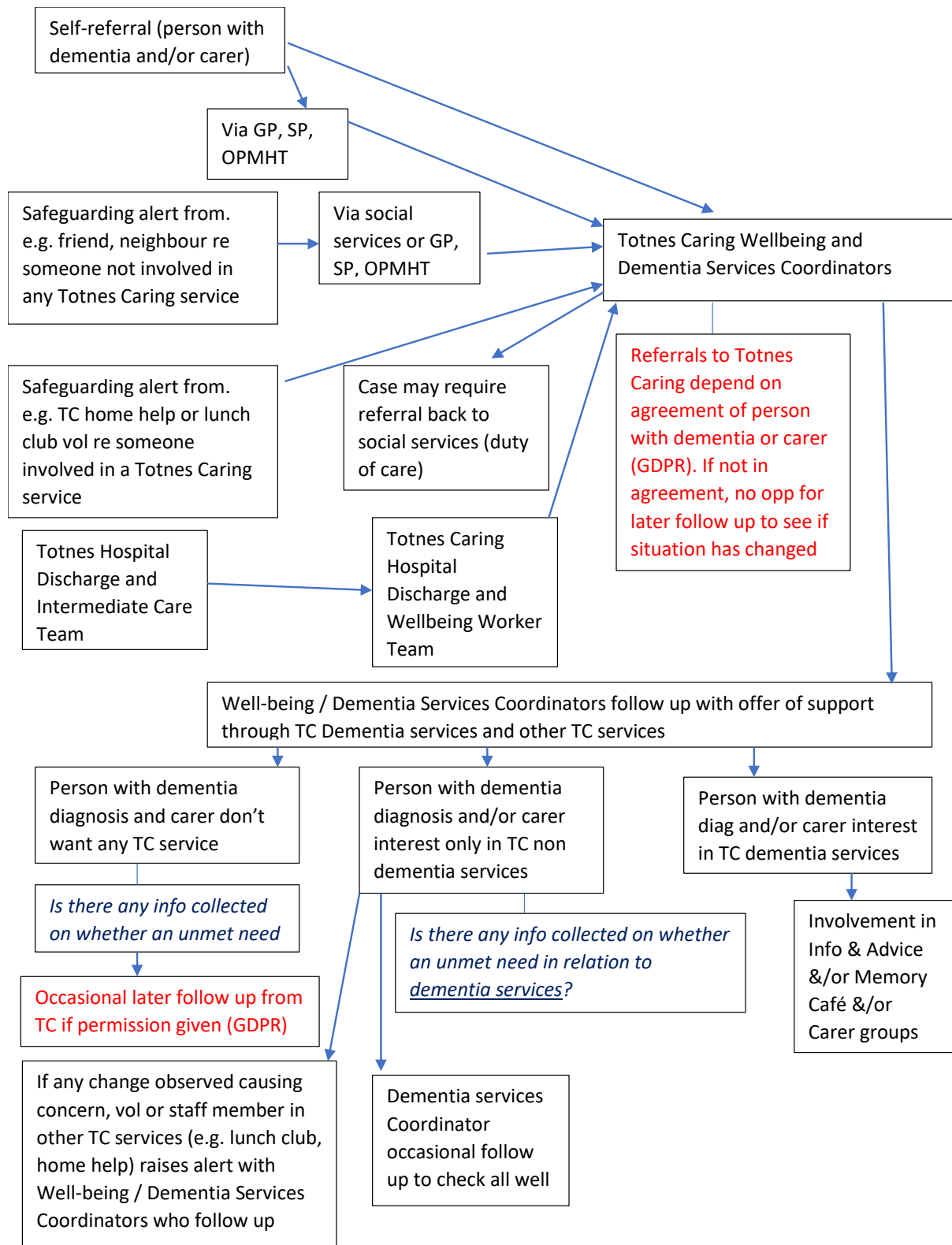
5.0 Conclusion

Totnes Caring is evidently held in high esteem by users of its services and has a very good reputation with other stakeholders. The dementia services were enthusiastically endorsed by all who use them and there were no suggestions about any activity that should stop or be changed in any way. Indeed, one carer noted that people affected by dementia in Totnes are probably better served than some people facing a similar situation elsewhere, having seen various reports on local news. There were very many comments about the empathy and professionalism of the Totnes Caring Dementia Services Coordinator and how vital her input has been and continues to be in the effective running and development of these services. A comment was made that a “dream” service would be able to clone Mary – that being impossible it is important for Totnes Caring to consider how to have a larger critical mass of very experienced personnel in TC both for leadership and 1:1 / group support.



Appendix 2:

Nearing or at crisis point



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