How people find advice and support to live well in the early years after dementia diagnosis

Autumn 2021

Table of Contents

Context

It is estimated that over 16,000 people in Surrey are living with dementia, and this number is predicted to increase rapidly over the coming years because of increases in life expectancy and changes in population demographics.

Dementia diagnosis services for the over 65s are provided by Surrey and Borders Partnership (SABP). After the initial diagnosis people should be referred to a Dementia Navigator and signposted to supporting organisations. Following satisfactory post-diagnosis reviews, people are discharged from SABP back to primary and community care.

After discharge, GPs are required to undertake an annual care plan review for people with dementia as part of their Quality Outcomes Framework. This review can include support needs for both the patient and their carer.

People aged under 65 are generally referred to a neurologist for an imaging test to facilitate an accurate diagnosis, and normally remain under the care of a consultant neurologist.

Despite the signposting offered during and after diagnosis, there are concerns that people and their carers are struggling to access the support available – as one clinician put it *"we discharge them, and then the next time we see them there's been some sort of crisis. We want to stop those crises happening".*

The Surrey Dementia Strategy Action Board will be refreshing the Dementia Strategy for Surrey in late 2021. This project was developed to help ensure service users influence the development of the new strategy, particularly focussing on how Surrey can deliver the Living Well and Supporting Well ambitions of the Well Pathway for Dementia.

Research Objectives

This research set out to understand the extent to which **people in Surrey with a diagnosis of dementia, and their carers, are:**

1. **Receiving all the information** and resources to which they are entitled
2. **Accessing** the full range of **support and services** available as they need them
3. **Managing their care** safely and effectively; and
4. **Referring themselves appropriately** as the condition progresses.

Method

We undertook 26 semi-structured depth interviews lasting 45-90 minutes with carers of people with dementia. The interviews were conducted by phone, video or face to face in July and August 2021. Interviews were carried out by Healthwatch Surrey's Research Officer and a team of experienced Healthwatch Surrey volunteers.

The interviews were supplemented by a review of Healthwatch Surrey received experiences, and visits to three dementia support services (The Hunter Centre in Haslemere, the Tuesday Club in Banstead and Thames Ditton Centre).

Recruitment was through

- Shoutouts in newsletters and social media requests from system partners as well as our own messaging
- 'snowballing' and word of mouth

The report authors are Tessa Weaver (staff) and Robert Hill (volunteer).

Purpose, Risks, Limitations

This is a qualitative study, designed to seek insight to enrich strategy and guide the way forwards. The aim is to:

- Shine a light on what can go well and what can go wrong
- Reveal weak links
- Inspire opportunities to improve systems and services

The sample was broad and we aimed for good representation from all parts of Surrey, but it was not randomly selected or designed to be representative of all Surrey people with dementia or their carers.

Inevitably, most of our insights are from the perspective of carers. Our research sought the experiences of people and their carers whose diagnosis was between 1 and 5 years ago: almost none of those with dementia had the capacity to contribute to the interviews.

Sample

Diagnosis:	
Alzheimer's	11
Mixed Alzheimer's and Vascular	3
Vascular	6
Frontotemporal (+ variants)	5
Lewy Body	1

Sex of diagnosed person:	
Male	16
Female	10

Relationship of carer to patient:	
Spouse	20
Adult child	6

Year of diagnosis:	
2020/21	4
2019	9
2016/18	6
2015 or earlier	7

Age of patient:	Age range at diagnosis	Age range now:
Under 65	3	0
65-74	5	6
75-84	14	11
85 or over	4	6
Deceased		3

Interviewees were offered a 'Thank you' of a £30 voucher on completion of their interview.

Executive Summary – Conclusions

- **Most of the carers we talked to told us they did not feel they had been well supported.** Experiences varied, but nearly all had found it difficult to access the support they needed.

  > *"Do I feel well supported? Not really, I think our quality of life is down to my persistence and research"*

- **Perceived lack of support increased their already overwhelming emotional burden.** We were told of feelings of abandonment, shock, anger and resignation when first engaging with support services.

- Despite the wide range of support services available it was striking how often we heard **people were not aware of or accessing basic, universal support services** such as Council Tax Rebates or Continence Services. Similarly, experiences of carers' assessments and GP respite funding were patchy.

  > *"No, I haven't registered with the GP as a carer, I didn't know it was a thing"*

- **Many were not aware of Dementia Navigators.** If carers do not 'lock on' to a Dementia Navigator at diagnosis they may remain **unaware that Dementia Navigators exist.** They cannot self-refer if they are unaware of the service.

  > *"G was feeling very low and was crying her eyes out. In desperation she found the Alzheimer's Society number, and she is now [waiting to hear] from a Navigator"*

- **The most valuable sources of support** post-discharge are:
    - **Support groups of all types**: from **small Alzheimer's Café meetings to Day Centres for people with dementia**.

      Support groups provide an **invaluable combination** of **information sharing** from **experts by experience; empathy and emotional support** and **light touch professional input**. Group **regularity** allows **emerging problems** to be discussed in real time, and for **bite-sized information** as and when it's most **relevant**.

      > *"I would strongly advise making contact with your local Alzheimer's café, that's where most information support and help comes from"*

    - **Guides and navigators (small n)** – sometimes Dementia Navigators, but may be other professionals or peer carers

> *"The Navigator was very knowledgeable in advising us on odds and ends and applying for grants and allowances. She would help us fill in forms to claim for things like a Blue Badge for parking"*

  - **Training courses** – especially on the day-to-day practical aspects of living with and caring for someone with dementia

    > *"I went on a brilliant course run by Elmbridge. Especially useful on how to communicate effectively."*

  - **Clinical oversight** – but this is mostly limited to those diagnosed with early onset dementia, or those in clinical trials or TIHM[1]
- People told us they were **disappointed by the support offered by:**
  - **GPs** –GPs are **often the natural first port of call for help**. There are exceptions but carers told us their GP seemed at a loss to help and the lack of direction or support often comes as a shock.

    > *"No regular contact with GP once diagnosed – you drop off a cliff!"*

  - Processes that appear to be **system-centric not patient-centric** – support and information delivered at times and in formats that suit the system but don't work for patients or their carers.
- **There are questionmarks over**
  - **Delivery of Nice Guidance at diagnosis.** People had not received or taken in all the information the guidance recommends: in particular
    - they had not come away with an understanding of how their type of dementia would affect them
    - impact on driving, including the requirement to inform the DVLA of the diagnosis, is not being communicated consistently
  - **Annual care plan reviews by GPs**
    - Not one of our interviewees was aware of having a care plan or of having had a care review by their GP

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[1] TIHM: Technology Integrated Health Management monitoring service from Surrey and Borders Partnership. This is a remote monitoring service available to those who have been diagnosed with dementia or mild cognitive impairment. https://www.sabp.nhs.uk/TIHM

Executive Summary - Recommendations

1. **Build access to Dementia Navigators** (or other professional navigator roles).

   Ensure there is **adequate resource**:

   a. In every area: **iron out postcode lotteries** so people in all parts of Surrey have access to a Dementia Navigator when needed

   b. For Dementia Navigators to **proactively contact everyone with a diagnosis of dementia on a regular schedule** (frequency dictated by individual needs).

2. Undertake a **strategic overview of Support Groups** (mapping, funding/stability); **build provision in areas with weaker support**; **help groups become resilient; support dissemination of high-quality information through groups; provide pathways for signposting to groups.**

3. Empower **Primary Care to signpost effectively** by ensuring primary care networks, GP surgeries and community care have a single local point of access to signpost patients to (eg local navigator or Dementia Navigator).

Considerations

- **Review the information provided at diagnosis to assess how well it reflects both the NICE guidance and good communication practice** – assess what is crucial and what less so. Map guidance processes against local pathways and consider how to optimise where indicated.

- **Investigate delivery of annual GP Care Reviews under DEM004**: why are carers so sure these have not taken place? How can these be made more valuable and visible?

- **Is there a role for the PCN and Anticipatory Care[2] specification in signposting/navigating** dementia services? GP surgeries are first port of call for many seeking support - is this an opportunity to close the loop?

- **Is there a need to confirm there is a sound clinical rationale for the difference in clinical support/neurologist oversight between the under 65s and the over 65s?** That there is no danger we are perpetuating age-based inequalities?

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https://www.england.nhs.uk/primary-care/primary-care-networks/

Main Findings

The Experience of Diagnosis

While this research focusses on post-diagnosis experiences, inevitably people shared their stories of diagnosis with us.

However well handled, a formal clinical diagnosis of dementia is unlikely to be seen as a positive experience.

Where there was praise, the diagnosis discussion was likely to be described as:

- **Thorough and not rushed:**

- *'we had a long conversation'*
- *'I felt I had ample opportunity to ask questions'*

- **A confirmation of existing suspicions:**

- *'It was a relief to know what it was'*
- *'Good to have the MRI as confirmation'*

Unfortunately, many of our interviewees struggled to get a diagnosis, or had negative experiences along the way:

- **Delays to diagnosis, missed diagnosis, family concerns ignored**

- *'Early 2017 … G and J were referred to the memory clinic where he had a test and was told he didn't have dementia. In Oct 2018 JC [was] tested for Parkinson's, which was discounted. Finally it was suggested that he had Lewy Body Dementia. They asked for a second opinion and … it was confirmed, Feb 2019.'*
- *'J took G to the GP who did a capacity assessment and said there was nothing to worry about. J was still concerned and so she arranged to go to another local GP …. He did some more tests and said things were not quite right and he was not happy with G's condition.'*
- *'M's issues were explained as mild cognitive problems. No follow up was given.'*

- **Poor service integration, system errors**

- *'the psychiatrist requested MRI scans but this was not acted upon',*
- *'the diagnosis letter from the 'specialist doctor in psychiatry' to the GP was never sent'*

- **Slow progress**

- *'It was five weeks after discharge before their GP asked to see them and made the referral to the Older Persons Mental Health Team'*
- *'A telephone assessment was undertaken in October 2020. This identified 'a cognition problem and anxiety.' M was referred for a brain scan and commenced on Citalopram. A follow-up telephone appointment (due to COVID) in December 2020 resulted in a letter to the GP that states: 'Probable Alzheimer's Disease and anxiety.' A follow-up post diagnosis phone call in*

March 2021 (as recorded in a letter to the GP) discharged M back to GP'

- Insensitive clinician communication

- *'The first doctor they saw just took notes and looked at his screen while K explained what has happening to her husband - he didn't look at them'*
- *'He turned to us and said, "look there the brain is withered. Your wife has frontotemporal dementia". That's how we found out about B's dementia.'*

There was also a notable difference in experience and the depth of clinical investigation by age of patient:

Those presenting under the age of 65 were far more likely to:

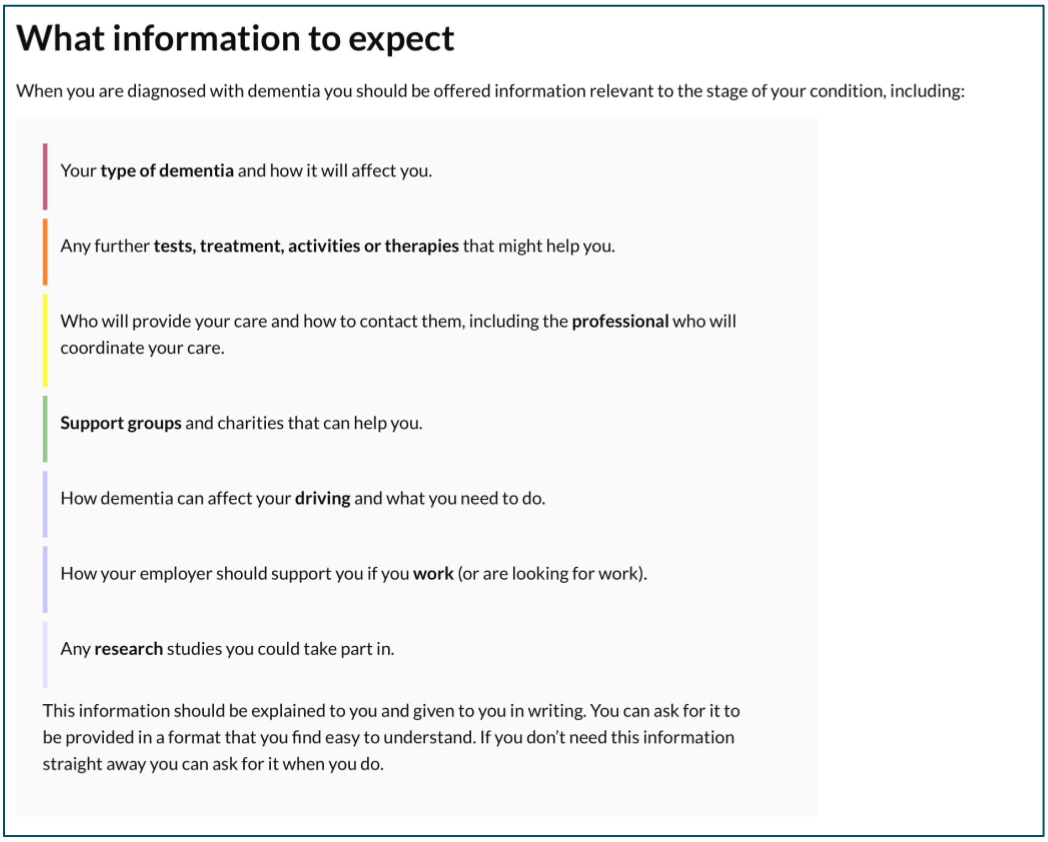
- have their diagnosis led by a neurologist
- receive detailed scans
- receive regular clinical follow-up after diagnosis for at least several years

For those over 65 there was much less consistency:

- in the use of imaging as a diagnostic tool, with many not being offered any scans
- a lack of clarity about the roles of psychiatrists, psychologists and consultant nurses in the diagnostic pathway
- far less clinical follow-up or review of disease progression after diagnosis

NICE Guidance - information and signposting at the time of diagnosis

The NICE Quick Guide for people with dementia and their family and carers lists information people can expect to receive when they are diagnosed:



What information to expect

When you are diagnosed with dementia you should be offered information relevant to the stage of your condition, including:

- Your **type of dementia** and how it will affect you.
- Any further **tests, treatment, activities or therapies** that might help you.
- Who will provide your care and how to contact them, including the **professional** who will coordinate your care.
- **Support groups** and charities that can help you.
- How dementia can affect your **driving** and what you need to do.
- How your employer should support you if you **work** (or are looking for work).
- Any **research** studies you could take part in.

This information should be explained to you and given to you in writing. You can ask for it to be provided in a format that you find easy to understand. If you don't need this information straight away you can ask for it when you do.

https://www.nice.org.uk/about/nice-communities/social-care/quick-guides/dementia-discussing-and-planning-support-after-diagnosis?utm_medium=webpage&utm_source=toolsr&utm_campaign=quickguides&utm_content=qg15

Across our sample very few had received all the information listed by NICE:

Your type of dementia and how it will affect you	✔ ✗	People were generally told the type of dementia they had but **NOT how it would affect them** - *The family were told that it was vascular dementia but they weren't ever given any medical information about the type of dementia or how it would affect B.* - *"I don't think the full horror was painted at that stage"*
Information on further tests & treatment	✗	**Not generally provided** – apart from a few cases where medication was prescribed to help address anxiety or psychotic behaviours - *M has been prescribed a drug … to ease his anxiety – it was left to K to work out the optimum dosage by trial and error.*
Named professional, and/or who will coordinate your care	✗	**Most NOT given a named professional** apart from a) in Camberley where the Mental Health Team seems better at linking with people diagnosed and b) those under the care of St George's neurologists - *M assumes that the contact would be her Dementia Navigator, who is very helpful when M rings her.*
Support groups and charities	~	**Varied: mix of excellent and poor experiences** - *A was referred (by a person called L) fairly soon after diagnosis to the Elmbridge day centre and the Alzheimer's Café in Elmbridge.* - *No help or advice was provided following the assessment. The couple only found out about the local Alzheimer's Cafe through a local councillor.* Referral to dementia navigator not always obvious or understood at the time. Support information sometimes reported as feeling overwhelming or irrelevant
Effect on driving	~	The need to inform DVLA was **sometimes discussed,** often at the prompting of the carer. - *Yes - at the diagnosis session there was a discussion on driving and the requirement to notify the DVLA. P had*

		already given up driving at the behest of his family two years previous. - *I raised the point [at the diagnosis] about my mum driving because I felt that if you've got a disjointed brain function would you be dangerous? The consultant didn't really want to commit himself to being the bad guy…he just said it was up to her which was a bit silly - it was a notifiable disease for the DVLA.*
Guidance on dealing with employers	~	Not applicable to 65s+. Under 65s experienced problems at work and soon ceased being employed, but this was not discussed at diagnosis.
Research studies to participate in	~	Those with rarer dementias and under a neurologist were more likely to be offered research opportunities. A few carers had found their own way to research studies and we also interviewed some in the TIHM programme - *"Offered a place on one at St Peters but dad said no"* - *"On their 3rd visit to the memory clinic she saw a notice about research into Alzheimer's and contacted them as a "shot in the dark". W has been attending the Abraham Cowley Unit for the last 5 years, as part of several research projects led by Professor Nilfroshaemm who has been excellent."* - *"She is in the THIM study. She has sensors on the doors and hall, and it reports her temp/pulse/sats/bp daily"*

Diagnosis and timing of support information

When reflecting on their feelings at diagnosis, we heard three main themes repeated:

Shock, distress, and a feeling of being lost and alone

- *"The shock of it all left me with a feeling of total abandonment"*
- *She and S felt "devastated" by the news.*
- *"The worse thing was getting the diagnosis and being left on your own. I felt overwhelmed and J didn't understand what was happening."*

Resignation and acceptance

- *"It was a relief to know what it was"*
- *"Finally a confirmation that it was Alzheimer's. "What I'd been saying for ages".*

Lack of understanding of what the future would be like

- *"It wasn't too bad at the time"*
- *"I thought it was just a bit of memory loss"*

Some people recalled being given support information at diagnosis, others did not. Whether information was offered or not for many the **timing was wrong**

- Still too **shocked and overwhelmed** to take in the information
- The information was **not** meaningful, **relevant** or valuable **at that time:** the patient's symptoms were still mild and manageable

Finding support after discharge – challenges and needs

Unpaid carers are frontline staff for health and social care, shouldering much of the burden of ensuring people with dementia live well and stay safe. They face a range of challenges, and these challenges evolve as the disease progresses. Understanding these challenges helps us to understand why some forms of support are so highly valued.

	Experiences	Needs
Inexperience and lack of knowledge Carers must learn on the job: most have no experience of dementia, no understanding of what the future holds, no idea how to manage the mundane tasks of dementia care or how to navigate the health and social care systems	• *"I thought Alzheimer's was just a bit of memory loss. I had no idea what hell was coming."*	Information/training - what challenges they need to be prepared to face - how to manage challenges as they arise - support options available
Breadth, depth and intensity of the practicalities of caring Carers must deal with tasks as varied as claiming benefits, managing finances, attending to personal hygiene, locating care support, administering medication and finding things to occupy the person cared-for all day.	• *"I applied for Attendance Allowance, it's not straightforward"* • *"M had a skin issue on his leg … caused by M waking during the night to go to the loo"* • *"He never gives you peace – you have to occupy him the whole time."*	Signposting to multiple different services, agencies and providers Activities for the person with dementia Respite

Constant evolution of needs As the condition progresses carers have need to learn new skills and access different services	• *“he's started not wanting to have a bath or his hair washed. “*	Ongoing access to new information and responsive support
Stress, guilt, isolation and grief Some carers end up on anti-depressants or crying to their GP.	• *"… he shouts at me a lot. I try to walk away rather than shouting back and getting angry, but sometimes I can’t help it and then feel guilty.”*	Emotional support; counselling
Intensity of caring – especially in the middle to later stages of dementia Carers report having to manage incontinence, aggression, delusions, mood swings, obsessions, wandering, sundowning restlessness, falls, loss of cognition and communication and, in some cases, physical violence.	• *“I was very shocked when M become aggressive and started to hit me. She also became energized, angry and was hallucinating.”*	Guidance about when it is appropriate to seek help - external perspective to clear the fog and inform on the ‘norm’. Signposting Respite
Length of time they have had to care; carer burnout Some carers, particularly of partners with early onset dementia, have been caring for 10 years and counting	• *“B is not the person I married. I wish it were all over.”*	Respite Emotional support

These needs can be categorised into broad areas:

…and for every person and their carer, new needs will emerge over time.

Support after discharge – what works well, what could be better

What works well	What doesn’t work so well
Good relationship with a guide and navigator (small n) - Dementia Navigator - Peer – experienced friend, family members - Social worker, mental health nurse, practice nurse	No navigator - Don’t lock into their Dementia Navigator - Dementia Navigator local capacity inadequate - Don’t find an alternative guide
Support Groups of all types - Local funded groups - Day centres - Alzheimer’s Cafes - Carer’s groups	GPs
Clinical oversight - Neurologist - THIM	System centric not patient centric - Leaflets not conversations - System timing not patient timing - Information overload
Training courses/sessions - Practical courses for carers	

Guides and navigators

The system recognizes that linking people to the services and support available is crucial; referral to a Dementia Navigator is part of the pre-discharge pathway for those newly diagnosed.

However, the actual experiences of our sample varied widely:

- Some had been proactively contacted, either at the time of diagnosis or later
  - *"While C was being assessed an Alzheimer's Navigator, came out to see me and said 'My job is to look after you, sir'. That was the beginning of a very productive relationship"*
- Some had had to seek out, or had stumbled across, someone to guide them
  - *"in desperation one day she found the Alzheimer's number and rang them. They have subsequently sent an email and she is now waiting to hear from a Navigator."*
- Some had no guide at all
  - *"I haven't really been professionally advised in any way so you just do what you think is best at the time."*
- Some guides were Dementia Navigators (although there was often confusion over job titles)
  - *"Saw someone called PG, possibly an enabler, who gave her lots of useful information which she has read." (PG is a local Dementia Navigator).*
- Some were other professionals
  - *"she received a home visit from a Community Mental Health Team member … and provided with a raft of information."*
- Some were non-professional – friends, peers
  - *"My best friend is a nurse and her mum is a few years ahead of my mum [in the progression of her Dementia]"*
- Some of those interviewed had been diagnosed five or more years ago. At the time they had access to a comprehensive Dementia Navigator service, but cuts in recent years had left them unsupported
  - *"The best advice I received on this was from K, the original Dementia Navigator who supported me.. But I've had no access to a Navigator since the service was reduced and K moved away"*

- At least one in four had no professional guide
- More had only found a guide through their own research
- Only about 1/3 were receiving guidance from a Dementia Navigator

For those with access there was very high praise for Dementia Navigators:

- *“Had it not been for her I would have been an emotional mess and unable to cope”*

There is patchy awareness of the “Dementia Navigator” role and job title among carers, **even among those receiving guidance**:

- *“Do I have a Dementia Navigator? Not that I am is aware of (mystified expression)”*
- *“A recalled a lady called ‘L’ referring her to the Elmbridge services and she may have been a dementia navigator.”*

When their support needs grow people can only seek out their Dementia Navigator if they know such a person exists.

While some people told us they had contacted “The Alzheimer’s Society” few were aware of Dementia Connect.

If you need dementia support, we’re here for you.

Dementia Connect, from Alzheimer’s Society, is a new personalised dementia support service for anyone affected by dementia.

Get support

dementia.connect@alzheimers.org.uk

alzheimers.org.uk/dementiaconnect

0333 150 3456

Alzheimer’s Society is a registered charity in England and Wales (296645), the Isle of Man (1128) and operates in Northern Ireland.

Alzheimer’s Society United Against Dementia

DEMENTIA CONNECT

Support Groups

Support groups were consistently praised as invaluable sources of information, practical support and emotional support.

- *"A community mental health nurse linked them into a Young Person Dementia Group which has been a life line…. It organises monthly activities that have been incredible and the carers have become good friends"*

The people we heard from attended a variety of different types of group ranging from day centres for people with dementia to monthly meetups for carers. What they had in common was

- a welcoming, empathetic, non-judgemental space to meet, and offload
- a forum to share information, discuss problems and find solutions
- professional moderation

- *"It has been really good, and I'd say it's the most practical help and the most informative. It's really good to have that because they really understand that form of dementia."*
- *"People don't know about Powers of Attorney, the Blue Badge Scheme and Council Tax discount. I have ended up advising other carers about these things"*

Group regularity was also important – at least monthly – allowing emerging challenges to be discussed in 'real time'.

- *"You are meeting with the same people - you don't need to repeat your story. Everyone is open and you share information about what is happening to you. We try and assist each other and come up with solutions knowing that someone may be going through something that is worse than your situation. Having someone leading it who is experienced makes all the difference."*
- *"During Covid [Camberley Dementia Café] phoned everyone on their books weekly to check how we were doing"*

All forms of group – online, face to face, focussed on those with dementia or focussed on carers – were praised and highly valued.

Five of our interviewees were not attending any groups:

- Carer groups were daytime; the carer was still working
- Either the carer or the cared for was unwilling to join a group
- Difficulty of arranging care for the person with dementia
- Online burnout at the end of covid

Given the sample structure it's hard to say whether these people were struggling more than those attending groups, but certainly all five were facing challenges.

Clinical Oversight

A minority of our sample had taken part in clinical research, were part of TIHM, or were under the ongoing care of a consultant. However, **they felt they benefited from additional support and information that was a by-product of clinical oversight:**

- A better understanding of disease progression, including what was likely to happen next
- Expert input into disease management, early clinical interventions
- Real-time signposting and information exchange
- A sense of security and support – the knowledge that they are not alone

- *"the consultant would see B every six months or so to review progress and medication was prescribed at a later point"*
- *"xx benefitted from weekly contact with TIHM (usually with the same monitoring person) and doesn't underestimate the impact of this monitoring group in observing activity and the support and advice he received."*

Training Courses

Few of our sample had been offered a training course for carers, but a handful had attended a course (notably in Elmbridge) and found it very helpful.

- *"The course 'Communication and Care Giving in Dementia' was excellent and comprehensive. Have a large resource folder that I can refer back to."*
- *"Elmbridge dementia course. It was brilliant, so helpful"*

Management of practical, everyday issues - such as how to communicate with a person with dementia, or financial considerations – were especially valued.

One or two had had to turn down the course because they were still working, or because they couldn't find care for the person with dementia while they were at their course.

GPs

For most people the **natural first port of call** after discharge when support starts being needed is their GP.

- *"I would expect them to monitor dad, check his medication, be on the case."*

A minority praised the care and support they had been given by their GPs

- *"her GP is remarkably helpful … she … also makes regular phone calls to check all is well, and always books the next appointment before they leave."*

Unfortunately, **far more had been shaken by what they felt was a lack of oversight and support from their GPs**

- *""No support at all. Never contacted. Submitted my form to the practice to be registered as a carer in May 2018 and received a letter telling me that their register was full"*
- *"It was only when M started crawling on the floor and then climbed on the chair and took the light bulb out of his table lamp did [the GP] start to pay attention and acknowledge the pressure that A must be under. A was shocked at his lack of interest."*
- *"His medication hasn't been assessed in the three years since he's been diagnosed."*

Several had the impression their GP was **not interested** in their patient's dementia, and/or was **at a loss as to what to recommend or do**:

- *"Neither GP has done much if anything in terms of reviewing the progress of S's dementia but he has received support for his borderline diabetes."*
- *"Not very helpful, always deflected concerns and advised me to contact the Mental Health Team."*
- *…the GP was understanding when she raised the issue of F not knowing what medication she had taken. But it was at that point the GP referred J to social services and the pass the parcel process started."*

GP-led Care Plans – DEM 004

Under the GP QOF, GP practices report the % of patients on their register with dementia who have had a face-to-face or telephone dementia care plan review in the past year. The target for review is 75%; for 2019-2020 Surrey Heartlands reported 75.5% and Frimley Health reported 76%. The review is comprehensive, covering discussions about physical and social needs including medication reviews, care needs, consideration for addition to frailty/end of life registers, and carer support.

Not one of the people we spoke to had any awareness of the existence of such a care plan, or could recall a GP appointment where it might have taken place.

Most were mystified when asked about their care plans; a small handful had care plans with their personal care providers, and one had a plan with Crossroads, but none knew of any other plan. One respondent said:

> *"I never expected much in the way of dementia support from the surgery because they never seemed very "clued up" on dementia and never offered any help. But* ***now that things are much more challenging I would want the annual review B is meant to have to help address her growing and serious behaviour problems."***

It is possible that some did not recognise the language (even with probing), and that some of the more recently diagnosed have not had the opportunity to have a review given the suspension of reviews during the pandemic.

However, there appears to be a considerable mismatch between the reported figure of 75% and the experience of the people we spoke to. We believe this warrants further investigation.

System-centric approaches

Information is sometimes given at times and in forms that suits the system and fits the care pathway, rather than responds to the capabilities of the recipients.

Information given at the wrong time for the person

- because the recipient was in shock or emotionally charged, especially around the time of diagnosis (angry, in denial, grieving for their future)
- because the information was not relevant at that time – e.g. information about dementia day care when the person still had capacity

Information that is hard to decode or access

- information that assumes the person knows what they need, is not curated to the needs of individuals, or assumes they understand the language of the support world.

- *“"They don’t catch the eye about what’s in the leaflets."*

- Resources that demand considerable investment (time, effort, management)

- *“Initially I thought the training course would be useful, but I was still working and I thought why do I have to give up my holiday to learn how to look after mum for them” [“them” = family + social services/health services]*

Information overload. Too much information given at once

- *“"There were so many leaflets I just wanted to put them all in the bin”*

Summary

To answer the four questions this project set out to address:

Are people receiving all the information to which they are entitled?

Possibly, **but not always at times or in ways that allow people to assimilate** it or access it when it has most value.

Are people accessing the full range of support and services available as they need them?

Rarely – for example, only 1 in 4 of the people we spoke to appear to have had a carer's assessment; very few had accessed GP respite. Even universal support such as attendance allowance was unknown to many. Many had no access to a professional navigation service.

Are people managing their care safely and effectively?

Many are **muddling through**, but probably not to best effect and **at great personal cost** to carers. We heard many stories of services that had only been put in place *after* a desperate call for help as the carer approached breakdown, or after a patient-related crisis.

Are people referring themselves appropriately as the condition progresses?

Not consistently – inexperience, lack of system oversight and emotional constraints result in people struggling on to crisis point.

While we have heard that the challenges are significant, we know that some solutions are **already be under consideration locally:**

- **More equal access to Dementia Navigators to guide more people through the maze of services and support available**
- **System-funded support for grassroots groups**

We look forward to seeing progress on these local initiatives soon.

If you read one thing read this – "What advice would you give to someone receiving a diagnosis today?"

Your shoulders will need to be broad

- "Nobody tells you what's out there. Nobody is going to say, 'This will help you with this problem' or 'Go there for help with that problem' or 'This is what you need and this is where you go to get support'. You have to work it out for yourself"
- "You are going to have to do lots yourself. Get someone to point you in the direction of one or two lifelines, to open up avenues"

Push for clinical information and oversight

- "Make a list of questions and then write down the answers. Hang on to the booklet! Use the contact number at the beginning to ask the follow up questions that occur to you afterwards."."
- "Go back to the hospital and ask a lot more questions."
- "Research the diagnosis yourself."
- "Get yourself away from a Memory Clinic and under a consultant. Don't let them discharge you. If you are not satisfied with one consultant get yourself referred to another."

Get help sooner rather than later

- "Don't leave it too late to get help."
- "Seek and take as much help as you can as early as you can."
- "Don't be afraid to ask for help
- "Make sure you have the carers assessment undertaken."
- "Don't be too proud to seek help and support."
- "Don't feel guilty about being demanding of the support you need from health and care services. And don't beat yourself up when you struggle and fail as a carer."
- "Contact the GP. Say "I need help".
- "Don't take too much on your own shoulders"
- "Seek support early e.g Crossroads."
- "Ask a lot more questions at the beginning - who can I come to for help, who is going to call me"

Gather your team

- “Supporting each other is so important. I am supporting a lady in Shepperton who cannot get to the FTD carers’ group and I am providing online support to someone in Cornwall.”
- “I am immensely grateful for the people within the strange, fibrous and non-formal network that developed around me and M for the support and advice we received. All the care and advice that was accessed came from those informal networks as opposed the formal structures.”
- “Identify someone you can offload to so you don’t feel alone”
- “Surround yourself with contacts and don’t be afraid to reach out. If you don’t reach out you will become isolated.
- “Get everyone on board. Be open with family and get roles assigned. Embrace it, try to understand what's round the corner, support the other person.”

Join a support group

- “Plug in to a dementia support group as soon as possible. Make it your first port of call. It will provide you with the specific information and the emotional support you need.”
- “Get support. Join the Tuesday Club or something similar where you can meet other people who are in a similar situation to you.”
- "I would strongly advise making contact with your local Alzheimer’s café, that’s where most information, help and support comes from."
- "Join a support group, this has been a lifeline. Meeting other in similar situations brings the best out in each other."
- “Try and join a support group that has people who have similar [forms of dementia. Then] you can either speak to other carers or speak to people who deal with people who have the disease – [i.e.] something like RDS or a group where [you can just] chat to someone about annoying things that happen.” Having that level of support provides a therapy of some sort and helps you to know what services are on offer”
- “Join all the extra local voluntary supported activity groups."
- "Contact a local support group or dementia café so you have someone with whom to share your dementia journey.”
- “Join a carer's group for peer support”.

Find your own way forwards

- “Take each day as it comes.”
- “Hold on to your hats, it’s going to be a rough ride”
- "Try to plan ahead – don’t wait until a crisis occurs or you get to breaking point”
- "Sit down, take a deep breath, it’s not the end of the world, you have to live with it."

Little things will help

- “One thing that I find useful is an automatic pill box from Amazon. I fill it up but it opens at 8 and at 5 every day so that my mum can take her tablets. It bleeps and it flashes at her and we have found that very, very useful. Although the chemist supply their blister packs, my mum was just puncturing all the holes and all the tablets were falling out and it was all totally mixed up.”

Carers Support Group, Thames Ditton Centre for the Community

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About Healthwatch Surrey

Healthwatch Surrey is an independent local champion that gives the people of Surrey a voice to improve, shape and get the best from health and social care services.

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