

## Project Rationale

The Surrey Dementia Strategy Action Board will be refreshing the Dementia Strategy for Surrey in late 2021. Healthwatch Surrey undertook this project to ensure service users' experience and needs could inform the development of the new strategy

It is estimated that over 16,000 people in Surrey are living with dementia, and this number is predicted to increase rapidly. Despite the signposting offered during and after diagnosis, there are concerns that people and their carers are struggling to access the support available

### Objectives

To gain insight into whether people in Surrey with a diagnosis of dementia (and their carers) are:

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

### Method and Sample

- 26 semi-structured depth interviews with carers: only one person with dementia was able to contribute
- Range of diagnoses – Alzheimer's, vascular dementia, frontotemporal, Lewy Body
- 13 with diagnosis since 2019; 13 in 2018 or earlier
- Carers included spouses and adult children
- Representation of all "Places" across Surrey
- We also visited support groups; had discussions with providers; reviewed our database of experiences



#### Findings: Carer burdens

- Inexperience and lack of knowledge
- Breadth, depth and range of practicalities of caring
- Constant evolution of needs
- Stress, guilt, isolation and grief
- Intensity of caring
- Length of time, burnout

#### Findings: Carer needs

Frequent, repeated access to bite-sized, timely...

- Information
- Signposting
- External perspective
- Activities for person with dementia
- Respite for the carer
- Emotional support

### Conclusions: What works well

#### Good relationship with a guide/navigator (small n)

- Some excellent experiences with Dementia Navigators,
- Similarly, with other professional or peer guides
- Information and signposting that is relevant and timely; responsive to changes
- Able to forewarn, pre-empt

#### Support Groups of all types including VCFS

- Invaluable source of information, perspective and emotional support
- Repeated visits → bite sized, timely, relevant information
- Peer support and empathy – credible, realistic
- Professional light-touch moderation → ensures focus, follow up and backup
- Opportunity to help others – rewarding
- Element of respite

#### Clinical oversight- neurologist, TIHM

- Valued for additional support and information received as by-product of regular clinical contact

#### Training courses/sessions

- Highly valued by the few who had attended, especially day-to-day practicalities such as communication

### Conclusions: What doesn't work so well

#### No navigator

- Navigator access varied – only 1/3 being guided Dementia Navigator; ¼ had no professional guide
- Awareness of Dementia Navigator role patchy – even by those in contact with one
- People can only seek help from their navigator if they know they exist

#### GPs

- Minority praise their GP
- First port of call for help
- Many shaken by lack of oversight and support from GP
- No evidence that annual reviews are recognised or valued by patients/carers

#### System-centric not patient-centric

- Information given at the wrong time for the carer/patient, or in ways that are hard to assimilate

## Further considerations

- Review the information provided at diagnosis to assess how well it reflects both the NICE guidance and good communication practice
- Investigate delivery of **annual GP Care Reviews** under DEM004: How can these be made more valuable and visible?
- **Is there a role for the PCN** and Anticipatory Care specification in signposting/navigating dementia services?
- Confirm there is a sound clinical rationale for the difference in clinical support/neurologist oversight between the **under 65s and the over 65s**

**Full Report:** [Dementia-Report-F.pdf \(healthwatchsurrey.co.uk\)](https://healthwatchsurrey.co.uk/Dementia-Report-F.pdf)

**Video Case Study1:** <https://youtu.be/Je-rV1W6rF0>

**Video Case Study2:** <https://youtu.be/YxQJ7VINE0Q>

## Recommendations

- **Build access to Dementia Navigators** (or other professional navigator roles). Ensure there is adequate resource:
  - In every area: iron out postcode lotteries so people in all parts of Surrey have access to a Dementia Navigator when needed
  - For Dementia Navigators to proactively contact everyone with a diagnosis of dementia on a regular schedule (frequency dictated by individual needs).
- **Undertake a strategic overview of Support Groups** (mapping, funding/stability) **and provide support**; build provision in areas with weaker offers; help groups become resilient; support dissemination of high-quality information; provide pathways for signposting to groups.
- **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 (e.g. local navigator or Dementia Navigator).

For more information, please contact [research@healthwatchsurrey.co.uk](mailto:research@healthwatchsurrey.co.uk) or call us on 01483 301448