



outside the box

In 2022 Outside the Box were commissioned to engage with people in East Lothian to help shape the new East Lothian Dementia Strategy.

We used small focus groups and storytelling sessions, speaking with people living with dementia, unpaid carers, volunteers and workers.

Keeping things local is a key thread that runs throughout report.

Almost everyone talked about the importance of keeping support local from peer support to accessing medical appointments.

It was viewed as a core solution to overcoming the many barriers highlighted by people.

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# Challenges at the time of diagnosis and the first 'year of support'

- **Is it dementia?**

'Dementia test' only diagnoses certain types/stages

- **Gaps**

"There is currently the risk of a gap between initial diagnosis and support – very scary for people."

- **No single point of contact**

"Is the GP a good first point of contact? – at diagnosis they send you to a psychiatrist but they [the healthcare professionals] are 'run off their feet' ...I think there's lots of pressure on the CMH team + OTs etc – people get a diagnosis then they are 'on hold'."

- **Need for an information pack**

"With a cancer diagnosis you get a big pack, with dementia you get hardly anything initially."

## **Top 3 solutions:**

- 1. Diagnostic activity carried out in local, community spaces (eg Meeting Centres etc), by nurses or other healthcare staff – less stressful, easier access, taking workload off GPs, quicker diagnosis.**
- 2. Holistic local support for carers and people with dementia – at time of diagnosis.**
- 3. Consistency and clarity around year of support and ongoing processes/systems/workers.**

# Information

- **Don't know where to start looking**

“When you don't know, you don't know where to start – we're fumbling in the dark!”

- **Difficulties accessing benefits**

“The sheer volume of what you have to think about means that you often just don't have the head space to sit and write forms for what you need.”

- **Lots of good local initiatives** - "If you know about them"

## **Top 3 solutions:**

1. Work collaboratively across communities to join up networks & signpost, avoid duplication.
2. Local Community hubs with information, contacts and a meeting point. Sharing medical, community and benefits information.
3. Dementia-friendly awareness-raising/training in the community – shops, facilities and cafes.

# Access and Transport

- **Transport difficult** - Irregular bus services and tricky parking
- **Many appointments in Edinburgh** - A&E, some dentistry/hearing, outpatients
- **Volunteers** - Often only one way or dropped off and hard to find way out

## Top 3 Solutions:

1. Reliable, more frequent public transport and more (resources for) community transport.
2. Volunteers for community transport and to accompany on hospital visits.
3. Dementia-awareness education and training for drivers, workers and volunteers.

# Health and Social Care

- **Need improved communication** - Between HSCP departments, organisations and people
- **Isolated assessments and cases closed off after initial need met**
- **Carers not supported until crisis point**

“You are passed on like a hot potato”.

- **Dementia not being treated holistically**

“It would make such a difference if someone could say- -if you need anything, just phone and this is the number!”

- **Better provision of physical aids and adaptations** to help people stay at home longer  
Carrying out heavy lifting for self-care at home e.g. showering – with no physical aids in place, waiting months, covering costs themselves.

One ‘tactic’ people are having to use - refusing to take loved ones home until all physical aids are in place.

## **Top 3 solutions:**

- 1. Communication between departments, cases should not be closed as dementia is a journey – there should be a system for tracking people.**
- 2. Reduced waiting time for physical adjustment support and everyday self-care, such as incontinence pads.**
- 3. Local services and responses - community-based supports often have better ways of dealing with the issue.**

# Community Understanding and Education

- **Change in culture & attitudes around dementia**

“You don’t realise how much lack of understanding there is in the community, until you are affected or have a diagnosis.”

- **Dementia friendly communities key**

Greater acceptance and understanding in shops, cafes and the wider community – enabling people to be independent for longer and take part in everyday activities in the community.

- **Change the language used around dementia** – Less medicalised

Language can create barriers to information and support

Language in forms for different benefits and support - "severely mentally impaired or incapacitated, it’s so negative that it puts people off applying for help."

- **Access to training for all** - Including people in the community, groups and businesses

People as ‘experts by experience’ are at the heart of sharing knowledge.



## **Top 3 solutions:**

- 1. Lived experience of people living with dementia. People with experience need to be part of meaningfully shaping training at a local level, with services.**
- 2. The strategy should be about moving away from clinical models – supporting a ‘mental health first aid’ approach, showing warmth/kindness.**
- 3. Whole community inclusion – anyone with dementia welcome everywhere in the community.**

# Activities and Connections

- **Activities have a key role in maintaining independence, health and reducing social isolation**

“I’m gobsmacked how I feel after it!” - peer support having a very beneficial effect for carers.

A good mix of formal and informal, peer support, advice and social activities, for people living with dementia and their carers. Meeting Centres – ideally in every town. Respite services should be a part of life, not a luxury.

- **There is a lot going on but need to join activities up** - Build networks and connections
- **Impact of dementia on existing family and friendship connections**

“Our relationship can be a bit fraught” -Partner and carer

- **Role of day centres** – key resource for advice, support and guidance as well as respite

Resource – ensuring day centres can stay open for longer hours during the week and weekend so that carers and people with dementia are able to access support 7 days per week – past 4pm in the afternoon.

## **Top 3 solutions:**

- 1. More joined up opportunities – diversity of choice.**
- 2. Meeting centres in more locations. A place where people further on journey can go, where they can get personal care.**
- 3. The vital importance of the strategy supporting/promoting local, informal community-based activities and peer support.**

# Health and Wellbeing

- **Toll of dementia on mental health** (carers and person with dementia)

Losing connections, feeling isolated, losing self-confidence, feeling physically exhausted, having no time or space to think – were common issues with many people we spoke to.

Feelings of guilt, frustration, anger...and grief for the person they had 'lost'.

"This group and peer support is invaluable to us both emotionally and practically – for finding out information, where to go to for support, knowing who to speak to."

- **Emotional support required** – Counselling/grief groups/ transitioning back to a life after caring

"You can't switch off and have to manage a lot of guilt...you've not got a life either...you are always stressed and tired."

- **Lack of respite**

Resources for respite are being stripped back – people are not getting the support they need.

"Respite takes months of planning then when my husband is away I just worry about him. I get an hour and a half alone during the week".

## **Top 3 solutions:**

- 1. Holistic approach to dementia for all – not just clinical.**
- 2. People should be employed using the same approach as Macmillan – people who know the system around dementia, so that there are clear pathways for medical and support needs.**
- 3. More awareness of activities people can have to support. Communities need to have confidence, and know when and where to signpost people.**