



Dementia Friendly Penicuik Conversation



Saturday 26th October, 10.30am-12.30pm
The Craigue, 50 Bog Road, EH26 9BZ
Summary Report



Dementia Friendly Penicuik Conversation

On Saturday 26th October 2019, Alzheimer Scotland facilitated a community conversation between people living with dementia in Penicuik, their family and carers, representatives from local services, businesses, organisation and groups.

The was designed to be first step towards Penicuik becoming a dementia friendly community.

We would like to offer our sincere gratitude to The Craigie for kindly allowing us use of their excellent facilities free of charge; and to Tesco Penicuik who donated refreshments on the day.

What is a dementia friendly community?

For people to live well with dementia, local communities need to understand and support those living with the condition and facilitate the expression of their abilities. This can only be achieved by communities becoming more aware of dementia and making, often simple, adjustments to enable people with dementia to remain active citizens.

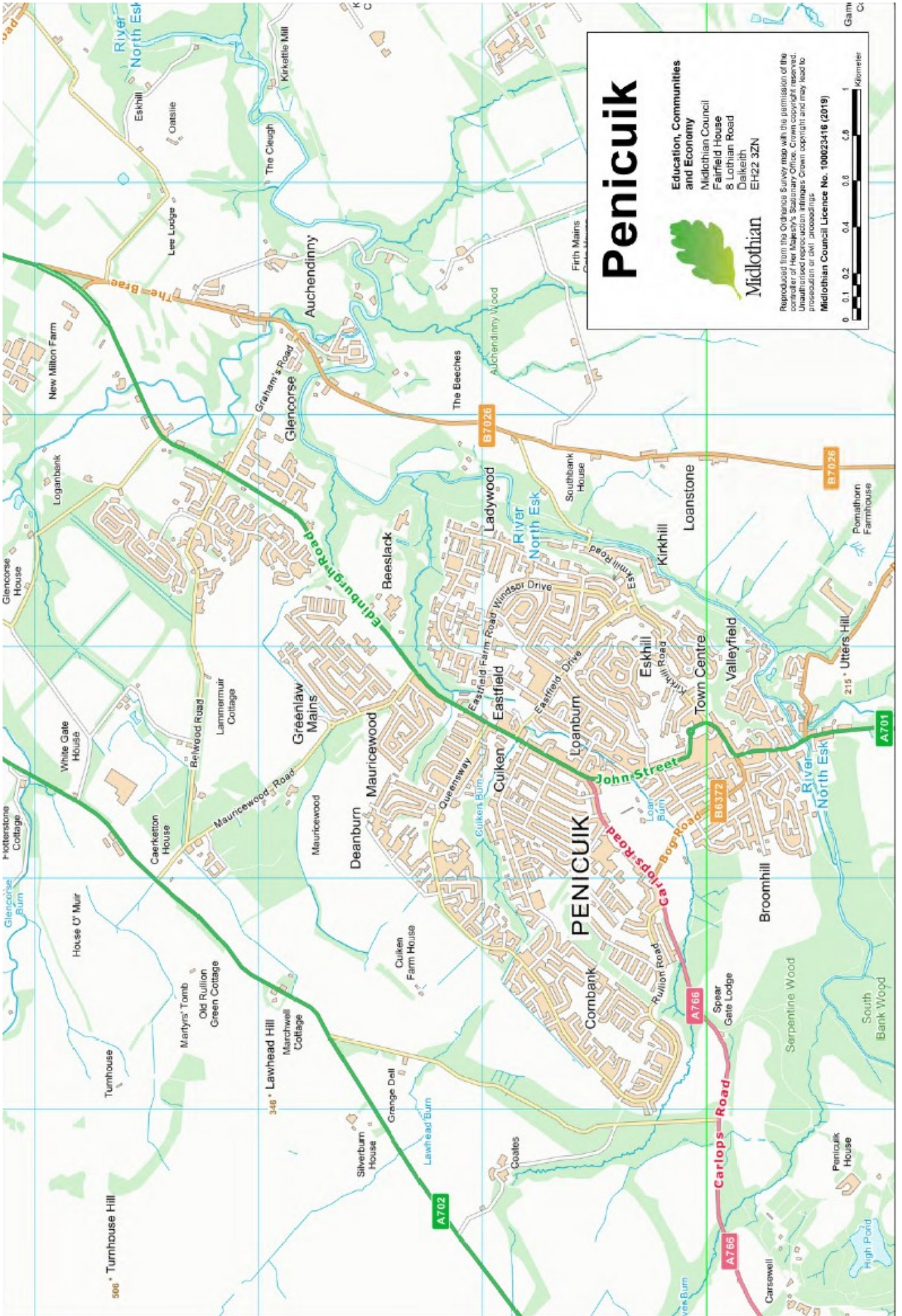
As such, a dementia friendly community is made up of anyone who wants to come together to make their local area more welcoming for people living with dementia. Everyone from shop assistants, public service workers, faith groups, businesses, police, fire and ambulance staff; to bus drivers, school pupils, local clubs and societies, and community leaders.

Our aim today is to gather a broad range of views about what is important to people living with dementia and their carers in the local community -those things that work well, as well as those that could work better – and to identify some priorities for positive change.

Dementia in Penicuik

Midlothian's overall population, as recorded in 2016, is 88,160. Midlothian is predicted to be the fastest growing local authority area in Scotland. By 2026 the population of the count is expected to have increased by 13.3%. An increasing birth rate, declining death rate, and a net migration inflow all have a part to play.

Local Authority	Males	Females	Total
SCOTLAND	32326	60956	93282
Midlothian	529	923	1452
East Lothian	684	1248	1932
City of Edinburgh	2531	5115	7647



Attendance

37 people attended the first Dementia Friendly Penicuik event.

People living with dementia	10
Family/ carers/ friends	15
Community	8
Businesses	2
Services	1
Elected representatives	1

Politicians, community, businesses and services were represented by:

- Christine Grahame, *Scottish National Party MSP for Midlothian South, Tweeddale and Lauderdale*
- Lianne Swadel, *Programme Manager for Midlothian Health & Social Care Partnership*
- Broomhill Day Centre
- Beeslack Community High School
- Penicuik Community Development Trust
- Tesco, Penicuik
- Penicuik Rotary Club

Methodology

Attendees were invited to sit at one of six tables. Of those sat around any one table, a member of staff or volunteer from Alzheimer Scotland acted as a facilitator. Each table included at least one person living with dementia and a carer.

Facilitators were asked to ensure each person had the time they needed to offer their input; to prevent people dominating the discussion; and to manage any disagreements.

Conversation at each of the six tables yielded considerable overlap in the views and opinions of the people who attended the event. Unsurprisingly, however, a range of experiences, some of which are contradictory, were also represented. The following sections reflect all of the points raised across the morning. By contrast, the final section, "Priorities", captures the areas that were agreed to be the most important for the community and its partners to work on first.

What works well for people living with dementia in Penicuik?

Living in Penicuik

- After I told people I had a diagnosis of dementia, I have had good support from members of the community.
- It was a positive to step to tell people about my diagnosis.
- We are fighting stigma: people are more open to talk about dementia.
- I feel at welcome and at home in Penicuik – people here are friendly.

Information and advice

- There is good information and advice from organisations such as the Alzheimer Scotland, VOCAL, Red Cross and Volunteer Midlothian.
- I have really benefited from the Carer Information Sessions about dementia run by VOCAL.

Voluntary sector

- I benefit from attending the carer peer support group at the Alzheimer Scotland's D'Café at Cowan Court. It is a source of information, emotional support, sociability and respite. People living with dementia enjoy their own social group at the same time.
- Carers can stay in touch with support groups after the person they have cared for has moved into long term care or has passed away.
- Alzheimer Scotland's other groups, such as the Brain Gym, are not in Penicuik but people who live here can attend.
- Broomhill Day Centre provides vital respite for carers and do positive intergenerational work.
- The community groups I attend are good forums where the voices of people living with dementia are heard – i.e. the Penicuik Library Group (Monday, 1-3pm).
- I like that there are a range of non-dementia specific groups, such as new age kurling at Penicuik Town Hall, the Golden Girls Group at Beeslack Community High School, and the Men's Shed. They allow people to mix with other demographics and not over-identify with their diagnosis.
- Edinburgh is accessible. On the 3rd Monday of the month I go to a Tea Dance at the Festival Theatre and there are a range of other dementia inclusive activities I could attend.

What works well for people living with dementia in Penicuik?

Statutory sector

- Both local GP practices have been understanding and supportive of people living with dementia and their carers. The process of seeing the GP was very good and they were quick to diagnose.
- The Post Diagnostic Support I receive from a Link Worker is important to me. It is reassuring to know that a skilled professional will visit periodically. They check-up on me and I can rely on them.

Businesses

- Some local businesses provide home visits and are accommodating when using their services – e.g. Maglin Domestic and Graham's Barbers.
- There are lots of accessible, inclusive local places to visit and spend time. For example: IKEA café, Klondyke Garden Centre, Dobbies, Penicuik Store House.
- Tesco staff are patient with people with dementia. I know of people who have been confused in the shop and staff have been proactive about contacting the person's family.
- In my experience, local bus drivers are very courteous and helpful.
- Staff in local cafés are helpful when they know that you might need a bit of extra time or help.
- Penicuik Library, Costa, IKEA, TSB and the local pharmacies are all very welcoming, understanding, helpful and inclusive
- I have a positive experience of continuing to work at Edinburgh Airport after being diagnosed with dementia. The understanding shown by my employers should be the norm.

Environment and design

- Imrie Place and Eastfield medical surgeries both have a very good layout, clear signage and seating areas.
- The layout of Tesco is excellent and helps me navigate.
- I like the idea of a "relaxed" lane at Tesco. This would make shopping there easier for me.

Infrastructure

- I find that buses are regular and easy to use.

What could be done to make things better?

Living in Penicuik

- People can “back away” when they find out you have dementia.
- People don't always talk to the person living with dementia – they speak to the carer.
- There is a lack of input from the younger generation in Penicuik.

Information and advice

- I have found there is too much information at the start. It might be better to provide appropriate information as and when a person is ready.
- People need to be given more time to understand and deal with their diagnosis and to understand the journey ahead.

Voluntary sector

- There are some valuable community groups for people living with dementia and support for carers, but there could be more.
- The carers group at the Alzheimer Scotland D'Café is not long enough, we need more time to share our concerns and get appropriate emotional and practical support.
- Penicuik needs its own activities timetable to highlight all the things people living with dementia and their carers could be involved in.
- There are no befriending services for people living with dementia.
- Services like The Bungalow and Broomhill Day Centre have waiting lists.
- There are not enough small group activities.
- There is a lack of investment in community groups.

Statutory sector

- Post Diagnostic Support is important and beneficial; but what comes next, after you've been discharged?
- There is a lack of care and support for people living with advanced dementia. Services and options seem to fall away as the disease progresses, when it becomes more challenging.
- Reception and administrative staff in GP and dental surgeries are not always aware which patients have a diagnosis of dementia and which carers are supporting a person with the condition.

What could be done to make things better?

Statutory services

- I have to *tell* staff about my issues – do receptionists and administrative staff in medical practices know and understand enough about dementia?
- It is really difficult to get a medical appointment when you need one.
- When my husband was in hospital, I was asked to leave.
- There is not enough time between tests at hospital.
- There is not enough care at home – and it takes too long to have a service in place when people are already living with advanced dementia, which puts more of a burden on family carers and that people go into residential care prematurely.
- Help is not there when needed – when it is urgent. Carers are managing as long as they can, sometimes too long.
- Inconsistency of paid carers. Staff need to be regular to build familiarity and relationships. It is confusing for the person living with dementia when new people are constantly coming in.
- Professionals need to speak with and listen to the person living with dementia first of all; not look to the carer.
- Under 65s are faced with different forms, different people, different options and fewer options. They have to go to Edinburgh or West Lothian for respite because of their age.
- Support is disjointed support. It feels like the local authority, health and care providers are not talking to one another.
- There are lengthy waiting lists for everything.
- There is a lack of day services tailored to people living with dementia.

Businesses

- It can be difficult for me and other people with dementia when there are lengthy waits at the bank.
- Banks could find ways to be more supportive and reduce stress for people with dementia and carers in this environment
- Shops should be more aware of impact of noise levels on people living with dementia's experience of the environment.

What could be done to make things better?

Businesses

- Supermarkets could have a “slow” or “relaxed” lane to help people with dementia and other conditions that cause physical or cognitive impairment.
- More shops and businesses should receive dementia awareness training.
- Awareness of dementia among customer facing staff is improving but there is a long way to go. Young people seem more likely to be aware.
- The signage in lots of shops and cafés could be approved to help me find my way around.
- I find cafés difficult to manoeuvre around in my wheelchair. There’s not enough room.
- In one local hairdresser the sinks are upstairs, which is a problem if you have poor mobility, and other hairdresser not very understanding of people with dementia.

Environment and design

- Signage around the town could be improved; could be more dementia friendly.
- Much of the physical environment could be updated and upgraded to make it more dementia friendly and inclusive.
- Many pavement surfaces are uneven. This is a problem for people living with dementia with mobility difficulties and/or visual perception issues.
- Road and pavement repairs are being neglected. Drains on the main roads are blocked and overflowing.
- There should be more disabled parking.
- There should be public toilets at the park.
- Penicuik public park dreadful, not accessible
- There are few signs to point the way to the toilets in the precinct.
- Pedestrian crossings should be set to allow more time for people to cross.
- When there is ice on the pavements, there is not enough grit put down, especially in the precinct.
- There are not enough benches or seating when walking about.

What could be done to make things better?

Infrastructure

- In some areas, there is limited or no public transport provision
- Some bus drivers have a very negative attitude
- All public transport needs to be made accessible for people with dementia and other impairments

Housing

- More local accommodation options when downsizing

What are your priorities for positive change?

The agreed priorities of the people who attended Dementia Friendly Penicuik Conversation are tabulated below. This report will be circulated to attendees; other businesses and community groups in Penicuik; Midlothian Health & Social Care Partnership; Midlothian Council; and a range of statutory and voluntary sector partners.

It is hoped that relevant people, organisations and departments will take ownership of, and work in partnership to address, specific priorities.

It will be necessary to form a local dementia friendly steering group to provide leadership and continue to check and renew priorities over time. Several people who attended the initial event on 26th October have expressed an interest in being part of such a group and Alzheimer Scotland will make contact to help set this up.

Issue	Problem	How to address	Who could support	Links
Dementia Awareness	Lack of understanding of dementia among public-facing staff in the community	Dementia Friends and/ or in-depth dementia awareness training delivered to businesses, such shops, cafes, GP surgeries, pharmacies, banks, etc. to improve people's experiences of being out and about and using local amenities	Alzheimer Scotland; local businesses and services	
	General population's continued stigmatising of and discrimination against people living with dementia	Open Dementia Friends sessions run for community groups	Alzheimer Scotland; community groups	
Voluntary sector	Lack of befriending services for people living with dementia		Alzheimer Scotland; Midlothian H&SC; Volunteer Midlothian; Red Cross	
	Not enough time for carer support at Penicuik D'Cafe		Alzheimer Scotland; Cowan Court	

What are your priorities for positive change?

Issue	Problem	How to address	Who could support	Links
Statutory sector	Medical practices don't always accommodate people living with dementia and their carers		GP Practices; Midlothian H&SCP	
	Unresponsive and inconsistent care at home. Care at home not available when you need it		Midlothian H&SCP; MSPs; local councillors	
	Lack of services and supports, particularly for people with advanced dementia		Midlothian H&SCP; MSPs; local councillors; voluntary sector	
	Few timely opportunities for short and substantial carer respite		Midlothian H&SCP; MSPs; local councillors; voluntary sector	
Environment and design	Pavements, pedestrian crossings, signage, public toilets, parking etc. is not dementia friendly or inclusive	Collaborative review of public spaces involving statutory partners and representative groups including people living with dementia and their carers	Midlothian Council; MSP; local councillors; Alzheimer Scotland; voluntary sector	
	Some public amenities, such as cafes, restaurants, shops, etc. are not adapted to include people living with dementia	Educate businesses so they factor in dementia when designing/changing layout of their premises Involve people living with dementia and carers in environmental auditing process and redesigns	Midlothian Council; local businesses; Alzheimer Scotland; voluntary sector	

If you would like more information on any of the information contained in this report or to express your interest in supporting and contributing to Dementia Friendly Penicuik, please get in touch with:

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- ⇒ For more information about Alzheimer Scotland, please visit: www.alzscot.org and www.alzscot.org/our-work/dementia-friendly-communities to learn more about our work around Dementia Friendly Communities
- ⇒ To become a Dementia Friend, please visit: www.alzscot.org/our-work/dementia-friendly-communities/dementia-friends-scotland or speak with Michael to arrange a group session
- ⇒ To download Purple Alert, an app that helps locate people living with dementia who go missing, please visit: <https://www.alzscot.org/living-with-dementia/staying-independent/helpful-apps/purple-alert>
- ⇒ To read about and sign-up to support Alzheimer Scotland's Fair Dementia Care Campaign, please visit: <https://www.alzscot.org/our-work/campaigning-for-change/current-campaigns/fair-dementia-care>