

# National Dementia Strategy Engagement Pack



**A resource to assist with  
engagement on the Scottish  
Government's National  
Conversation on Dementia**

*Interactive session plans designed to encourage  
conversation with people living with dementia  
and unpaid carers*

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*"I'm sitting here thinking, I'm not surprised. I should be - but I'm not. I think those are the things that are not talked about enough"*

*Engagement response  
to Session 2: Stella's  
Story*





*About Dementia Engagement Event, 2022*

## Who are About Dementia?

About Dementia is Age Scotland's Forum for Improving Lives. We work with people living with dementia and unpaid carers of people living with dementia to shape the policy and practice that affects them in everyday life. The project covers many areas of life, including transport, housing, technology, financial inclusion and human rights.

Established in 2019, we seek to use a human-rights based perspective, along with an understanding of related legislation to empower the groups we work with. We employ novel and creative approaches to open conversation on a range of policy areas which can often seem abstract or on sensitive subjects. We've found our approach to be rewarding, effective and enabling for the people we engage with – and now, we would love to share those techniques with you.

## Why have we developed this pack?

You may have heard that the Scottish Government have announced there is a new National Dementia Strategy coming, to read more follow the [link](#). It's the first Strategy since the 2017-2020 Strategy and we know a lot has changed since then. About Dementia will be on the ground talking to different community groups across Scotland. However, with only a few months to engage on this important topic, we know we can't reach everyone – that's why we need you!

# Introduction

We've been visiting our friends across Scotland, creating, trying, and testing our workshops plans to engage with people on the National Dementia Strategy. To increase the scope of those who can be part of the conversation we've created an Engagement Pack based on our sessions. Themed around topics which we feel will be instrumental in developing the new strategy, the pack will encourage discussion around care, community support, isolation, complaints, human rights, and post-diagnostic support.

The Engagement Pack will lead you step by step to both prepare, deliver and feedback discussion from the sessions. We hope anyone with an interest in dementia can deliver the sessions. This could be a group leader, support worker, or family carer. As a person who knows the people you support better than anyone, there is no one better to open conversation in a natural way. If you live with dementia, you may also be able to start discussion with your peers.

**In order for any engagement to be included in our response to the National Conversation, please feedback to us by Friday 18th of November 2022.**

This is our chance as a united dementia community to influence real change. We all have a part to play in improving the lives of people living with dementia and unpaid carers, and we hope that you will join us in doing just that.



*National Dementia  
Strategy Engagement  
Ceartas Advocacy,  
East Dunbartonshire,  
September 2022*

# Values

By simply requesting this Engagement Pack, you have already shown your commitment to improving the lives of people living with dementia and unpaid carers, enabling them to have their voice heard.

There's a classic Scottish phrase, "Dinnae teach yer granny tae suck eggs" (no, we're not too sure of the origin either!) As supporters of people living with dementia, we recognise the many skills you have developed and exercised time and time again. Nevertheless, we all need a little bit of encouragement. The values listed below are offered as your mantra for trying something new – and rest assured, you are joining an entire community of like-minded people who are delivering this Engagement Pack for the first time too.

## **BE A TRAILBLAZER**

We mean it. This level of engagement has never been done in this way before. Engaging at a policy level with people living with various stages of dementia isn't an exact science – we're still figuring it out. So, we applaud you for being trailblazers and trying this novel approach.



## **HAVE AN OPEN MIND**

There's a statement within the dementia world, "If you've met one person living with dementia - you've met one person living with dementia". What might not work with one person, may unlock rich discussion with another.

Similarly, even with the same group or individual, you may find people are brighter or more engaged at a different time or day. Keep trying. There is value in including someone in this process, even if they only manage a word or two, perhaps a word they've never given before. If you enter into the process with an open mind, you may find people surprise you.

## **IF AT FIRST YOU DON'T SUCCEED, TRY AND TRY AGAIN**

It's okay to try. It's alright if certain questions or themes don't land.

As the old saying goes: "Failing means yer playin'". Even if it doesn't all go to plan, you're still taking part. In this case, you're still recognising the potential for people living with dementia to have meaningful thoughts, preferences and wants for their lives. That's a powerful acknowledgment.

## COMBAT STIGMA

You may notice throughout the pack that we encourage the involvement of both people living with dementia and unpaid carers. This is a recognition that dementia can affect the entire family unit, friends and partners.

Over the course of the About Dementia project, people living with dementia have told us they find terms such as ‘patients’, ‘victims’ or ‘suffering with dementia’ stigmatising. Terms which can reduce the agency of people living with dementia and leave little room for positive experiences post-diagnosis. When speaking about one individual who lives with the condition, we use the term ‘living with dementia’. When delivering sessions, we ask you adopt similar terminology to actively combat stigma.

## FOCUS ON STRENGTHS NOT LIMITATIONS

When we support people, it can be easy to start to view a person in terms of their limitations, what they cannot do. When using this Engagement Pack, we challenge you to approach each session by looking at what people CAN do. Perhaps they are not too chatty though may take to collage work well. They may find entire sentences challenging but can give related words.



In the work of About Dementia, we follow the Social Model of Disability, adapting conditions to enable people living with dementia. During sessions, this may involve writing down each question you ask, serving as a visual prompt while you speak. Or asking a volunteer to repeat your questions directly to a person who is hard of hearing. It may be worth setting some time aside to look at what adjustments you can make to ensure everyone is able to achieve their best.

## FLEXIBILITY

You know the people you support better than anyone. So, we’ve built in opportunity throughout the Engagement Pack for you to choose elements which will resonate better. However, please feel free to use your judgement and make extra tweaks where needed. It may be that a character has the same name as the person you support, and it would be confusing to read the story as is – change it. You may not have all the materials at hand and feel you could deliver a stripped back warm-up activity better – go for it. Cater the pack to you and the people you support.



## TO SHIELD OR NOT TO SHIELD – THAT IS THE QUESTION

On a related note, when delivering workshops, the About Dementia team have often been asked about our use of the word ‘dementia’, or to avoid it completely. We recognise the word itself can be triggering for people living with dementia and on occasions, we have omitted the word. Instead, referring to ourselves as part of Age Scotland. Similarly, we have tailored stories to include characters seeking advice as they ‘are in a similar situation to yourself’ or ‘have trouble with their memory, communication or concentration’. All of which are true and may feel like a lighter approach.

However, it is worth noting that in each stripped back session, people living with dementia have independently used the word dementia, without prompting. As the pack uses a ‘one-step removed’ approach, people may not relate the character’s story to their own experience. Inversely, people may recognise elements of their own life and find it cathartic to talk about it. We can have a preconception about how people may feel about the word dementia, a feeling that may not exist when presented as part of a story. Nevertheless, trust your knowledge in each session you deliver.



*National Dementia Strategy Engagement Ceartas Advocacy,  
East Dunbartonshire, September 2022*

# How does the Engagement Pack work?

People living with dementia are exactly that – people!

Both people living with dementia and unpaid supporters are people with a rich history full of adventures, who have faced and overcome various challenges throughout their lives. It is this wealth of lived experience that positions people affected by dementia as experts, a principle which underlines this pack.

The Engagement Pack seeks to tap into the shared knowledge of people living with dementia and unpaid carers, to pull out issues which are important to improving their lives. The pack will do so in a creative way, mixing games with a ‘one-step removed’ Storytelling approach.

## Sessions are based around the following themes:

- **Session 1: Community Support - Neil and Jock's Story**
- **Session 2: Care and Complaints - Stella's Story**

The sessions will explore a topic by immersing a group or individual, building throughout the session by slowly introducing the theme through icebreakers and activities. Each session will culminate in the group or individual you support receiving a letter asking for advice from a fictional character. All stories feature a character living with dementia, experiencing a different issue and looking at the people you support as an ‘Agony Aunt/Uncle’.



# How does the Engagement Pack work?

The pack is split into session plans, each following a similar format:

- **A Cuppa Conversation Starter:**

A gentle icebreaker which touches on the session topic

- **A prompt to play one song related to the theme:**

With a list of recommended songs for you to choose from

- **A choice of warm-up activity:**

With two different choices each session. To keep sessions manageable and within time, we recommend picking just one warm-up

- **A letter from a fictional character:**

Asking advice from the group or individual you support

- **A postcard prompt:**

An opportunity to offer any last words of wisdom for the character

- **Song For Change:**

Asking for a song to mark their contribution to influencing change



## Do I have to run both sessions or can I choose just one?

It's up to you! You may feel a particular session would resonate better with the people you support. The Pack has been designed in a way that you can run either session, in any order and still be able to engage.

## How long does each session take?

As a facilitator, you have the freedom to choose. To fully explore each theme, we'd recommend no less than 45 minutes is allocated per session. To keep sessions short, you could spend less time on the Cuppa Conversation, run a condensed warm-up activity and keep the discussion that emerges from the story structured.

On the other hand, you can certainly allow the session to breathe and play out over the course of 1 hour and 30 minutes, or more. It's worth keeping in mind that people may struggle to concentrate for much longer than 1 hour 30 minutes, and breaks should be added if extending the session.



# How does the Engagement Pack work?

## Who can take part in a session?

We've tried to keep the resource as flexible as possible to allow more people to get involved. As such, engagement activities could appeal to both people living with dementia and family carers or partners. Individuals who support people living with dementia in an unpaid capacity are just as integral to influencing the next National Dementia Strategy and can certainly take part in sessions.

Of course, it is up to you whether you decide to run a session with a mixed group. As both groups will have their own thoughts and wishes, you may feel it is more appropriate to speak to both groups separately, to allow each group a safe space to air their views. However, we are realistic about the capacity you may have, and mixed groups are workable, especially if you are able to involve each group member at one point in the discussion.

Throughout the pack, you may see reference to activities being aimed towards groups or individuals. To get a full picture of the dementia landscape in Scotland, it's important we hear from people who are already well connected with established groups and others who may not have that level of support available. Therefore, sessions can be adapted to appeal to one individual, or a larger group.

When running sessions as part of About Dementia, we've led to groups of up to 20 people. If delivering a session to more than 20 people, we would recommend more helpers throughout the room to assist participation.



*National Dementia  
Strategy  
Engagement  
Prestwick Meeting  
Centre,  
October 2022*



# How does the Engagement Pack work?

## What is Storytelling and how does it work?

Storytelling is a creative approach growing in popularity in dementia engagement. Whilst this pack uses stories to prompt conversation, no story is fantastical or based on myth. In fact, each has been developed by drawing from experiences people have shared with About Dementia. Many anecdotes coming directly from co-production with lived experience groups.

People, particularly those living with dementia, may feel put on the spot when asked questions directly. It can feel like a lot of pressure to have to recall your own past or share personal experiences. Instead, throughout the sessions in the pack, people are asked to share their opinion on a particular character's situation. Of course, our opinions are based on our own life experience and perception of the world, which gives an insight into how people may feel generally about the theme.

Adopting a 'one-step removed' approach may allow people to explore sensitive topics at a distance, minimising emotional upset. This approach may also have cathartic benefits in providing a different lens to view a topic or issue. Have you ever become more irritated for a friend who has had a bad experience, than if the experience happened to yourself? Often, it's easier to recognise that something 'unfair' has happened to another person, than it is to understand it when it happens to ourselves.

***"Jock might feel he can't go outside because he's worried he will get lost. When I was first diagnosed I didn't know what was happening or where I was. I wouldn't leave the house in case I got lost. I still worry about that, but now I have more support"***

*Engagement response to Session 1: Neil and Jock's Story*

# How does the Engagement Pack work?

## Why is music included in each engagement session?

To explore the power of music, and its untapped potential, we've turned to our friends Playlist For Life. Playlist for Life is a music and dementia charity. They want everyone living with dementia to have a unique, personalised playlist and the people who love or care for them to know how to use it.

Over two decades of scientific research has shown the multiple benefits of personally meaningful music for people living with dementia.

### ***Personally meaningful music can:***

- Promote connection and reduce social isolation
- Improve focus and engagement
- Stimulate memory and communication
- Affect mood – helping to motivate or relax
- Help manage symptoms as dementia progresses



## Using personally meaningful music in your engagement session:

Music opens up conversation and aids connection with others. Music may help to engage people to take part in discussions, introducing them to a tool they can use to help them beyond the activity.

You'll bookend each session with music, starting by listening to song related to the theme, and finishing with a request for our 'Song For Change' Playlist. We'd like to hear about the reasons behind your song choice, and your experience of using music during the session.



*Making a Playlist with Prestwick Meeting Centre, October 2022*

***To learn more about the use of personalised meaningful music, visit:***

[www.playlistforlife.org.uk](http://www.playlistforlife.org.uk)

# Feedback Process

As part of using the Engagement Pack, you will be asked to give feedback to About Dementia about the discussion had. We've not made assumptions about the capacity or additional help you may have, and in theory each session can be led by a single person.

However, if you have the opportunity to have another person present to note take, this may be beneficial and take pressure off you as a facilitator.

## **If you are leading a session as a solo facilitator:**

- Follow the session plan, using whiteboard/flipchart/paper throughout.
- When given words or advice by the people you support, write down as you go. Creating a visual with all words and sentences from the prompt.
- At each stage, before you ask a new question, take a photo of your board/chart/paper.
- Wipe clean or use fresh paper for the new question, as it can be confusing to see too many competing concepts.
- You don't need to take photos of people or attach names to comments. To protect individual privacy, we would ask you to avoid doing so.
- To close each session, ask people to write advice to the character using the postcard template provided. You will need to print the postcard(s) ahead of time. It's better for each individual to have their own postcard to refer to throughout the session.
- If an individual finds it difficult to write, offer to be a scribe or compose a group postcard response together.
- Once postcards have been completed, take a photo of the advice given.
- After each session, if you have time, you can retroactively fill out the note sheet attached to each session plan. You can add any standout comments, or overall themes that were discussed.
- You will be prompted to record how many people attended the session. If possible, please note how many people living with dementia, or unpaid carers and staff members took part.
- You can also comment on how you found the experience.
- Email the photos of your notes, quotes and postcards to **[aboutdementia@agescotland.org.uk](mailto:aboutdementia@agescotland.org.uk)** including your location/group in the subject line.



# Feedback Process

As we are working within a short timeframe, for engagement to be included in our consultation response, we kindly ask any feedback is emailed to About Dementia by Friday 18th of November latest.

## If you are leading a session with note taking support:

- Follow the session plan, using whiteboard/flipchart/paper throughout.
- Whilst you are leading, the additional person can take notes, following the format provided in note sheet attached to each session.
- When given words or advice by people you support, write down as you go. Creating a visual with all words/sentences from the prompt.
- At each stage, before you ask a new question, take a photo of your board/chart/paper.
- Wipe clean or use fresh paper for the new question, as it can be confusing to see too many competing concepts.
- You don't need to take photos of people or attach names to comments. To protect individual privacy, we ask you to avoid doing so.
- To close each session, ask the group or individual to write advice to the character using the postcard template provided. You will need to print the postcard(s) ahead of time, it's better for each individual to have their own postcard to refer to throughout the session.
- If the person/people you support find it difficult to write, offer to be a scribe or compose a group postcard response.
- Once postcards have been completed, take a photo of the advice given.
- At the end of the session, your note taker should have completed the note sheet with any standout quotes or themes discussed.
- Your note taker will be prompted to record how many people attended the session. If possible, please note how many people living with dementia, or unpaid carers and staff members took part.
- You can also comment on how you both found the experience.
- Email the photos of your notes, quotes and postcards to **[aboutdementia@agescotland.org.uk](mailto:aboutdementia@agescotland.org.uk)** including your location/group in the subject line.



# Feedback Process

## What are About Dementia looking for?

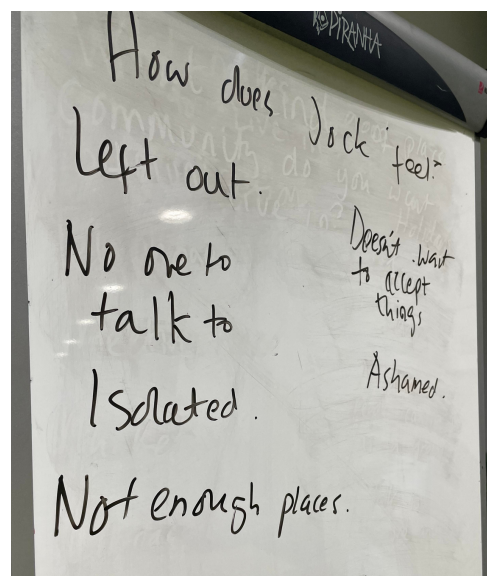
Session themes will prompt discussion and there are questions included to guide note taking. It's important to remember that people will refer to the topic in different ways and the relevance may not seem obvious at first. In engagement, there is no 'right' or 'wrong' answer, it's more crucial that we hear how people feel. An opinion may not always be based on the truth, however it is still interesting to consider.

We are looking to hear directly from people about what matters to them. As such, there is no set agenda on what we want to hear – we're not the experts in this process! Someone may say a comment that doesn't fit neatly with other feedback from the group, yet when looked at on a wider scale, may highlight a larger issue. Therefore, we ask you to keep an open mind when note taking. All comments are valid as they felt meaningful for the person in the moment.

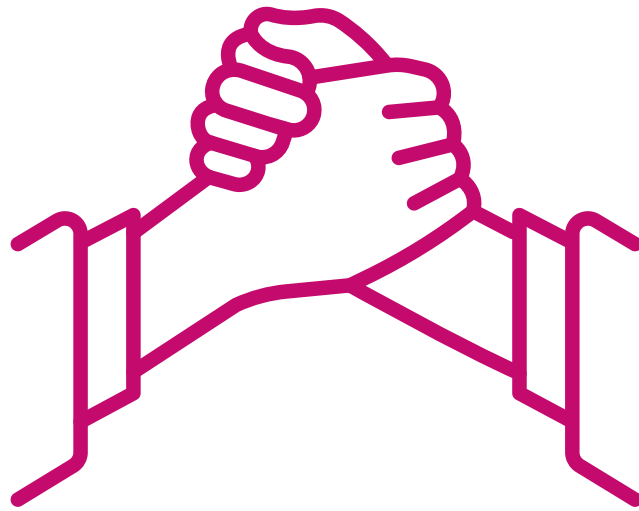
As part of our consultation response, About Dementia will review all notes and photos and will be able to identify recurring themes. Do send all photos of notes and quotes to About Dementia by email. We can then tie each piece of engagement together to form our response.

## What will the feedback be used for?

All feedback from engagement will be reviewed to form our response to the Scottish Government's National Dementia Strategy Conversation. We expect to be asked to reply by early December. We will also draw from feedback given to assist with future About Dementia responses or campaigns. If you would prefer we did not extend the use of feedback, please do let us know. We are not requesting personal information or photographs of people, and any identifying data will be respectfully anonymised.



*Engagement from Session 1:  
Neil and Jock's Story*



# **Session 1: Community Support**

## **Neil and Jock's Story**





# Session 1:

## Community Support

### Character and context:

Neil really admires the approach of dementia-friendly communities. In Newtonmore, they don't have anything for older people in the community and Neil would love to start something new – especially for his neighbour, Jock. Neil used to go hillwalking with Jock, but Jock has become more isolated since he was diagnosed with dementia.

### Themes covered:

The role of community. Isolation. Social approaches to dementia care. Meeting Centres. Day Centres. Loss of confidence/hobbies post-diagnosis.

### Cuppa Conversation Starter:

Gently introduce the theme by asking a question below:

*Have you ever been part of a club or society? Perhaps a sport, drama or book club. What did it feel like?  
Did you feel part of a community?*



### Song:

Listening to a song sets the scene and prepares people for the theme. You know the group/person best, so pick one song from the list to play that you feel will resonate. Often, it's songs from our youth, ages 10 to 30 years old that spark the strongest feelings. Playlist For Life call this stage the 'Memory Bump'. For extra fun, ask the group or individual if they can guess the song and artist!

Then ask the group/individual if they can figure out today's theme.

***"When our village hall closed, it was  
a like a jigsaw being taken apart.  
Our community just fragmented"***

*Engagement response  
to Session 1: Neil and  
Jock's Story*

# Session 1:

## Community Support

### Songs:

[Click here to be taken to the Spotify Playlist](#)

*or search for NDS Engagement Pack: Session 2 - Care and Complaints*

- With A Little Help From My Friends: The Beatles (1967)
- Reach Out (I'll Be There): Four Tops (1967)
- You've Got A Friend: Carole King (1971)
- Lean On Me: Bill Withers (1972)
- You're My Best Friend: Queen (1976)

**Today's theme is... Community and friendship**

### Warm-up Activity, Option 1:

May suit... individuals, chatty people

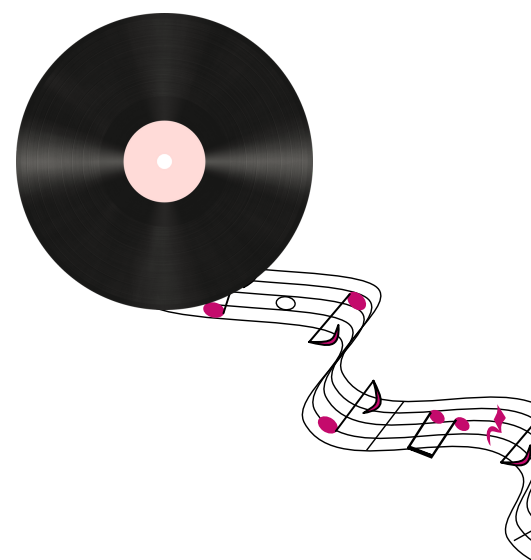
### **Questions From The Hat/ Blether Wheel:**

If you have access to technology (tablet, phone, laptop or screen), you can display a pre-made spinning 'Blether Wheel'. This will add excitement by making the activity into a game show: [age.scot/bletherwheel](http://age.scot/bletherwheel)

Alternatively, keep it simple and write the questions on the following page on strips of paper, or print the page. Take turns to pick a question and discuss. If a person feels confident, they can read their question aloud.

- If playing as a group, ask a group member to spin the wheel/pick a question and discuss the point.
- Invite other people in the group to discuss the point too.
- To add a game show spirit, if playing as a group, consider inviting a volunteer to be a 'contestant'.

**To keep the session short,  
we recommend picking 5 questions or less**





# Session 1:

## Community Support

### Questions:

What does community mean to you?

Would you rather do creative or sporty things?

Finish the sentence:

“The first thing I like to do when I get home is...”

Are you a good dancer?

What hobbies did you have growing up?

Discuss: “You can’t teach an old dog new tricks”

What do you do to relax?

Would you rather go to a museum or watch tennis?

Complete the sentence: “Without my friends I’d be...”

Would you consider taking up a new hobby?

Discuss: “A real friend is one who walks in when  
the rest of the world walks out”

What would your perfect day look like?

Complete the sentence: “If I was lost, I’d turn to...”

Do you know your neighbours?

Discuss: “Friends are the family you choose”

Do you think there was more of a  
community when you were growing up?

# Session 1:

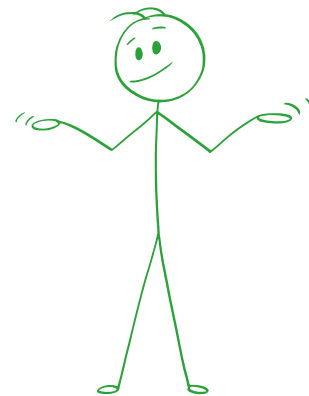
## Community Support

### Warm-up Activity Option 2:

May suit... a group that are already part of a community, Day Centre, Meeting Centre etc.

### ***Creating a Mascot for your existing community***

This activity will allow you to creatively explore what the group means to people.



Using a whiteboard, flipchart or paper, work together to create a group mascot. The mascot should represent all that you do at the group and provide a friendly face for new people looking to join.

### Questions to ask the group:

- *What should our mascot be? We can think outside the box.  
Are they an animal? Human? An object or something else entirely?*
- *Are they male/female/without a fixed gender?*
- *What facial expression do they have?*
- *What are they wearing?*
- *What are they saying?*
- *How do they encourage people to join the club?*
- *What's their name?*

### For the facilitator:

- Draw the mascot with the group.
- Afterwards, ask the group to present the mascot and explain why they made the choices they did.



# Session 1:

## Community Support

### Story:

Introduce Neil's story. Explain to the group that Neil and Jock are fictional, however their story is built from real life experiences.

If you have printed the postcard attached to this session plan, fold the page and seal it to make a postcard. Hand each person a postcard, the photo will help maintain focus.

From this point, refer to Neil and Jock as if they are real. If you can print Neil's letter and unseal it from an envelope to read, this will add extra suspense and excitement. Read the letter aloud and with purpose. Your conviction will be important to help the group empathise with the character.

**Encourage the group to think of this as a special moment. Let them know they have been contacted to give their advice and expertise.**



*Postcard advice from Session 1: Neil and Jock's Story*

Hi there,

Name's Neil, Neil from Newtonmore. I hope you don't mind me getting touch but I'm looking for some advice. I've been hearing more and more about these things called 'Dementia Friendly Communities', I don't know much about them yet – but they sound fantastic!

We don't really have anything like that up in Newtonmore, but I think we need it. You see we're part of a small close-knit community, our village is beautiful and we're surrounded by nature and wildlife. However, Newtonmore is quite rural so it's not the easiest place to get around if you don't drive – the buses round here are a nightmare!

We have a local bowls club, a church, a village hall and a pub. Yet people still find it hard to live here into later life. Take my neighbour Jock, we always used to go hillwalking aww the time. But he lost his confidence last year when he was diagnosed with dementia, now he never leaves the house. I'm worried he's becoming a hermit. It's a real shame, cos Big Jock used to be so sociable – he was basically part of the furniture at the local pub. I honestly don't think he's coping well, but I can't seem to coax him out the house.

Sadly, many seem to leave, even people who were born and bred here. I'm not sure why – but then again, I am a young whippersnapper. What? 40 is the new 21!

I have a few questions for you:

- What makes somewhere a great place to live for older people?
- What kind of community do you want to live in?
- What small and big changes could we make to be more dementia friendly?
- How can we prevent people from feeling so isolated as they age?

Thanks for your time – any words of wisdom you have would be super helpful!

Neil

# Session 1:

## Community Support

### Recap:

#### *Read aloud to the group*

- Neil lives in Newtonmore, it's quite a rural area and hard to get around if you don't drive.
- Neil is worried about his neighbour Jock - he used to be sociable but since he developed dementia, he barely leaves his house.
- Neil is at a loss. How can he show Jock he cares and encourage Jock to re-join his community?
- Neil is looking for advice on how to create a better community for people.

### Questions:

Neil has asked some questions about the group.

**Before we give our advice,  
can we think about how Jock might be feeling?  
Do we have any words to describe this?**

One by one, let's consider Neil's questions:

- What makes somewhere a great place to live for older people?
- What kind of community do you want to live in?
- What small and big changes could we make to be more dementia friendly?
- How can we prevent people from feeling so isolated as they age?



### Lastly, ask the group:

- What could change in Jock's situation to make him happier?



# Session 1:

## Community Support

### Additional Storytelling Activity (if time allows):

**If you're short for time, move on to the Postcard Prompt.**

If you have extra time, or wish to run an additional session at a later date, you can reveal another letter from Neil. This activity may be well suited to pre-existing groups who are familiar with community group settings. However, you can still try the activity working with an individual.

Neil is reaching out to the group to help him create a poster for a new Meeting Centre for older people and people living with dementia.

This is a creative activity, guided by prompts. Print the letter on the following page. Reveal that you have received another letter from Neil. Read the letter, then move onto the activity below.

### Additional Activity Questions:

One by one, start to go through Neil's questions, noting the answers given. Then, working with the person you support, or as a group, start to put pen to paper to create a poster for Neil's new Meeting Centre. You don't have to be an amazing artist, as long as you annotate with the chosen answers.



### Postcard Prompt:

*Could you give me any advice to encourage Jock to become more sociable again? Please write to me on the back of our postcard. Take care, Neil.*

### Song for change:

We're creating a playlist of songs that we're calling 'A Song for Change'. The song can be anything, as long as it comes from the group/individual. Do you have song we could add? Why have you chosen this song?

Hi everyone,

*It's Neil again, Neil from Newtonmore. I just had a thought, so I had to send another letter. What if I put this Dementia Friendly Community stuff into action and made our own Meeting Centre in Newtonmore?*

*I think it would really help people in the community. Especially my neighbour Jock, he's still getting to grips with his dementia diagnosis and now he never leaves the house. I told him about my bright idea to make a Meeting Centre in Newtonmore, but he just said "Not my thing pal, I'm happy with my own 4 walls". I'm at a loss – is he just going to isolate himself more?*

*Then, I had a brainwave – I must be on a roll today! I think if I could make a poster, show Jock what he could be missing, maybe, just maybe I could convince him to come. Here's the catch though. I'm absolutely pants at art. I'm more Vincent Van No, than Vincent Van Gogh. And to be honest, I'm still getting my head around what a Meeting Centre is.*

*I know it's cheeky, but is there any chance you could help me out and make the poster for me?*

*Jock's a real stickler for detail, so please include:*

- *The name of the new Meeting Centre?*
- *Where the new Meeting Centre should be based?*
- *What kind of building we should meet in?*
- *What activities take place there?*
- *What type of meals are served there?*
- *How can we get people to the centre? Should we provide transport?*
- *Most importantly, who funds it?*

*How can we get enough money to do this?*

Cheers,

Neil

Wish You Were Here!  
From Neil and Jock  
In Newtonmore



Scotland

Newtonmore

14 Hill Way

Neil and Jock



Any advice for Neil and Jock?



# Note Sheet: Session 1

<b>Date:</b>	<b>Can we name you as a contributor?</b>  YES      NO <input type="checkbox"/> <input type="checkbox"/>
<b>Name/Group:</b>	
<b>Number of total attendees:</b>	

**How many of the following groups attended the session:**

☐

Unpaid  
carers/family

☐

People living  
with dementia

☐

Staff and  
volunteers

**Can you give more context to your situation?**

**Who do you support/interact with and how do you do this?**

---

## Session 1: Community Support

*A space for the facilitator to write notes following/during group discussions*

**Any notes from Cuppa Conversation Starter or song:**

## Warm-up Activity chosen:

*Feedback from chosen warm-up activity*

## Group Discussion: Neil and Jock's Story



*Can we think about how Jock might be feeling?  
Do we have any words to describe this?*

*What makes somewhere a great place to live for older people?*

## Group Discussion

*What kind of community do you want to live in?*

*What small and big changes could we make to be more dementia friendly?*

## Group Discussion

*How can we prevent people from feeling so isolated as they age?*

*What could change in Jock's situation to make him happier?  
Can you give Neil any advice to help Jock become sociable again?*

*Facilitator comments or reflections:*

## Group Discussion

*Additional Activity, Meeting Centre discussion:*

- *The name of the new Meeting Centre?*
- *Where the new Meeting Centre should be based?*
- *What kind of building we should meet in?*
- *What activities take place there?*
- *What type of meals are served there?*
- *How can we get people to the centre?*  
*Should we provide transport?*
- *Most importantly, who funds it?*  
*How can we get enough money to do this?*



# **Session 2:**

# **Care and**

# **Complaints**

## **Stella's Story**

# Session 2:

## Care and Complaints

### Character and context:

Stella lives in sheltered housing and is well cared for by her daughter and her dream team of female carers. This is important to Stella as she's had bad experiences with men in the past. Stella has low mobility and is quite forgetful - this information is noted in her care plan. Her usual carers do their best to support Stella to sit in the garden and enjoy the fresh air, alongside reminding Stella to take her medication. However, when Stella's regular carers can't make it, she receives less than satisfactory care that goes against her care plan. What should she do?

### Themes covered:

Paid carers. Care Plans. Complaints. Being overlooked. Dignity.

### Cuppa Conversation Starter:

Gently introduce the theme by asking a question from below:

*How would you know someone cared?*

*"Kindness costs nothing"*

*– what does this phrase mean?*



### Song:

Listening to a song sets the scene for the people you support, preparing them for the theme. You know the people you support best, so play one song from the list that you feel will resonate. Often, it's songs from our youth, ages 10 to 30 years old that spark the strongest feelings. Playlist For Life call this stage the 'Memory Bump'. For extra fun, ask the group or individual if they can guess the song and artist!

Then ask the group/individual if they can figure out today's theme.



# Session 2:

## Care and Complaints

### Songs:

[Click here to be taken to the Spotify Playlist](#)

or search for NDS Engagement Pack: Session 2 - Care and Complaints

- How D'ya Like Your Eggs In The Morning:  
Dean Martin and Helen O'Connell (1958)
- (I Can't Get No) Satisfaction: The Rolling Stones (1965)
- Help!: The Beatles (1965)
- Respect: Aretha Franklin (1967)
- Hanging On The Telephone: Blondie (1978)



**Today's theme is: Care and Complaints**

### Warm-up Activity Option 1:

May suit... individuals, groups, chatty people

### ***How do you take your tea?***

- Ask the group (or person) "How do you take your tea?"
- If you're working in a group, you can write everyone's cuppa preference down in clear view.
- Some people may choose coffee or herbal tea, that's okay!
- Once you have your answer(s). Tell people you are going to make everyone's tea the same/ give a person an order they don't want.
- If working with an individual, ask "How would you feel if I got it wrong?". Further prompt; "If you couldn't tell me, how could I get your tea order right?"
- If working with a group, ask; "What if I just made everyone the same because it's easier? Would that be fair? Why not?"
- Emphasise that you think this would be fair, as you would be treating everyone the same – let the group challenge you on this and explain their reasoning.



# Session 2:

## Care and Complaints

### Warm-up Activity Option 2:

May suit... a larger group

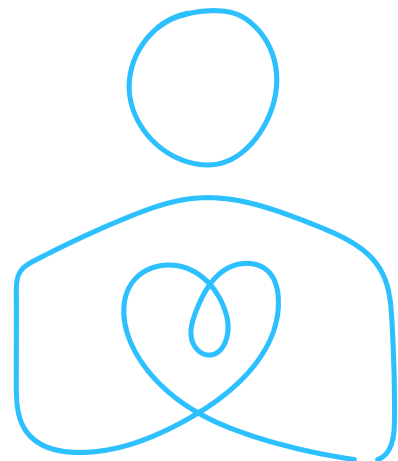
#### ***Care or no care?***



- On the next page, you'll find a list of tasks that a person may benefit from assistance on.
- Write down the tasks on pieces of paper and place into a hat.
- Using a whiteboard/flipchart/paper, draw a line down the middle and write 'Care' or 'No Care' on each side.
- One by one, ask individuals to pick a paper slip from the hat.
- Then ask the person whether they think a paid carer should complete the task as part of their role.
- If working with a group, you can ask the group to shout out if they think care or no care. You can even encourage the group to give a thumbs up or thumbs down.
- Throughout the activity, if you feel it's appropriate, you can ask people why they have come to this decision.

After you have finished the activity, reveal that using a form of support called 'Self-Directed Support', in theory a paid carer could assist with all the listed tasks and activities!

***Ask the group how they feel about this?  
And what they may like a paid carer to do with them?***



# Session 2:

## Care and Complaints

### Care or no care prompts:

You can print the entire page, cut into strips and place in a hat for the group to pick, and if they feel comfortable, read aloud!

**Taking a pet dog out for a walk**

**Helping a person to shower**

**Preparing a meal for someone**

**Going for a walk outside with someone**

**Helping a person to join a video call with their family**

**Accompanying someone to their local bowls club**

**Taking someone shopping for their groceries**

**Travelling with someone so they can meet a friend for coffee**

**Helping a person in the bathroom**

**Changing a catheter**

**Putting on someone's favourite music for them to listen to**

**Reminding someone to take their medication**

**Helping someone to go to their garden to sit in the sun**

**Making a GP appointment for a person**

**Going to a local museum with someone**

# Session 2:

## Care and Complaints

### Story:

Introduce Stella's story. Explain to the group that Stella is fictional, however her story is built from real life experiences.

If you have printed the postcard attached to this session plan, fold the page and seal it to make a postcard. Hand each person a postcard, the photo will help maintain focus.

From this point, refer to Stella as if she is real. If you can print Stella's letter and unseal it from an envelope to read, this will add extra suspense and excitement. Read the letter aloud and with purpose. Your conviction will be important to help the group empathise with the character.

**Encourage the group to think of this as a special moment. Let them know they have been contacted to give their advice and expertise.**

***"It seemed like the carer had been told: Well, she's got dementia - there's no point in speaking to her about anything"***

*Engagement response  
to Session 2:  
Stella's Story*



*Hello everyone,*

*I feel a bit silly getting in touch - I don't like to be negative, so thanks for hearing me out. Oh, my name is Stella by the way, and I live not far from here in sheltered housing. It's a nice wee flat, we've even got a shared garden out the back. My mobility isn't what it used to be, but my carers know that I'm a real sun worshiper, so they help me out to the garden when they pop round. It's the highlight of my day catching up with my tan, and with my neighbours in the garden - it's so important that I even put it in my care plan!*

*I've got a dream team of lady carers around me. I call them Charlie's Angels - they're all so glam. I've always asked for female carers, I'm no fond of men due to an ex-husband.*

*I'm quite hard of hearing, especially when I've lost my hearing aid. Last week I got the fright of my life when I was watching Countdown and a man appeared at my side to plonk a cup of tea down. He must have been a filler carer and let himself in through my key safe - but he didn't even say hello or introduce himself. If I'm honest, it put me on edge.*

*I don't like to complain, but the tea was not to my liking at all. I normally have black tea with 2 sugars, and this was milky with no sugar - I would've told the lad if he'd asked. I didn't see the male carer again until he put down a microwave meal on the side table next to my chair - you should've seen the steam, the heat would've took your tongue off!*

*I was letting the meal cool but I must have forgot about it - out of sight, out of mind eh? Cos the next time I saw the carer he lifted the meal away and I heard the front door slam - and that's saying something, cos I'm as deaf as a doornail.*

*I was still hungry, so I got up to go to the kitchen. But when I stood up, I noticed 2 pills and a glass of water next to me.*

*cont...*

*I couldnae for the life of me remember if the pills were from the morning or afternoon – either way I was supposed to take them with food. I checked my care diary, as the girls normally leave behind wee helpful notes. The only thing written was “Not hungry, meal binned”.*

*But I was Hank Marvin – absolutely starving! I just need a bit of help remembering what’s around me. The sun was beaming through the cracks of the curtains, I pulled them back and noticed what a bonnie day it was. It would have been perfect for sitting out but I cannae manage the back stairs myself.*

*Again, I didn’t want to cause a fuss – but requesting a female carer, going outside – all of that was in my care plan. I phoned the care agency to have a word, but they just “Only your daughter can authorise care plan changes”. The cheek of it – it’s my ruddy pension that pays for it. Can you help me make sense of this? I have a few questions:*

- Am I overreacting or should I take this further?*
- I’m at a loss. I really don’t know whit to dae or who to turn to.  
What should I do?*
- Is there anyone I can ask for help?*
- Going forward, how can I make sure I’m listened to?  
And that my wishes are respected?*

*Thanks for listening, it means a lot!*

*Stella*



# Session 2:

## Care and Complaints

### Recap:

#### *Read aloud to the group*

- Stella has requested female carers, due to bad experiences in the past – but a male carer visited her.
- This is noted in Stella's care plan, alongside that she enjoys regular visits to the garden and needs assistance with getting outside.
- Stella can be forgetful, so she needs a bit of help remembering when to take her medication, or eat regular meals.
- Stella's male carer didn't introduce himself, ask her what she likes or give her the support she needed.
- When Stella called her care company to complain, they told her they would only speak to her daughter.

### Questions:

Stella has asked some questions.

**Before we give our advice, can we think about how Stella might be feeling?**

**Do we have any words to describe this?**

One by one, let's consider Stella's questions:

- Am I overreacting or should I take this further?
- I'm at a loss. I really don't know what to do or who to turn to. What should I do?
- Is there anyone I can ask for help?
- Going forward, how can I make sure I'm listened to? And that my wishes are respected?



# Session 2:

## Care and Complaints

### Postcard Prompt:

*I'm generally a positive person. How can I make this story have a happy ending? - Stella*



### Song for Change:

We're creating a playlist of songs that we're calling 'A Song for Change'. The song can be anything, as long as it comes from the group/individual. Do you have song we could add?  
Why have you chosen this song?



*Creating a playlist with Kirrie Connections Meeting Centre,  
Kirriemuir, October 2022*





Any advice for Stella?

Stella

12 Cedar Street

Glasgow

Scotland



# Note Sheet: Session 2

<b>Date:</b>	<b>Can we name you as a contributor?</b>  YES      NO <input type="checkbox"/> <input type="checkbox"/>
<b>Name/Group:</b>	
<b>Number of total attendees:</b>	

**How many of the following groups attended the session:**

☐

Unpaid  
carers/family

☐

People living  
with dementia

☐

Staff and  
volunteers

**Can you give more context to your situation?**

**Who do you support/interact with and how do you do this?**

---

## Session 1: Care and Complaints

*A space for the facilitator to write notes following/during group discussions*

**Any notes from Cuppa Conversation Starter or song:**

## Warm-up Activity chosen:



*Feedback from chosen warm-up activity*

## Group Discussion

*Can we think about how Stella might be feeling?  
Do we have any words to describe this?*

*Am I overreacting or should I take this further?*

## Group Discussion

*I'm at a loss. I really don't know what to do or who to turn to.  
What should I do?*

*Is there anyone I can ask for help?*

## Group Discussion

*Going forward, how can I make sure I'm listened to?  
And that my wishes are respected?*

*I'm generally a positive person. How can I make this story have  
a happy ending?*

## Group Discussion

*Facilitator comments or reflections:*

## **We've finished an engagement session, do you have any more?**

Not yet - but we're working on it!

This is a new approach for About Dementia and we would love to hear your feedback. We plan to release more packs in the future, if you would like to stay in the loop do sign up to our mailing list by emailing:

**[aboutdementia@agescotland.org.uk](mailto:aboutdementia@agescotland.org.uk)**

## **What if someone doesn't want to take part/ doesn't show an interest?**

We all have different likes and dislikes. What may pique someone's interest may not resonate with another. If a person doesn't want to take part, don't force them. It's better to try again on a different day with a separate session than to put pressure on someone, risking alienating them from the process completely.

If working as part of a group, it may be that once you get started the person becomes curious and starts to join in. Equally, an individual may just enjoy being part of a group or listening to the story – there's no pressure for every person in the group to say something substantial each session. Simply having time and attention dedicated to the person can be a positive experience, a moment of care that they may not otherwise experience that day.

## **Can I change elements of the pack or change parts of the story?**

Of course, you know the people you support best! Refer back to the Values section of this pack to read more about the flexibility offered.

## **I'm really at a loss, who can I ask for advice?**

If you are unsure of any elements or need advice, please email the About Dementia team at [aboutdementia@agescotland.org.uk](mailto:aboutdementia@agescotland.org.uk). We will do our best to get back to you as soon as we can, though there may be a delay due to ongoing National engagement activities.





### **When do I need to send feedback by?**

As noted in the section Feedback Process, in order for About Dementia to include engagement in our response to the Scottish Government on the new National Dementia Strategy within the timeframe they have set, we kindly ask you send us any feedback by Friday 18th of November.

Any feedback received after this date may not be reviewed as part of About Dementia's consultation response but will be referred to when forming future responses or campaigns.

### **I don't have a volunteer to take notes, can I still run a session?**

Of course, we understand that you may be part of a small community group or engaging at home with the person you support. In which case, an additional helper to take notes may not be feasible. You can still deliver engagement sessions and any feedback you can capture will be well received. You can even pinch some of the prompts just to start a conversation. For further instructions on how to feedback as a solo facilitator, please refer back to the section Feedback Process.

### **I don't have access to a printer to print the pack, or a smartphone to take photos, can I still run an engagement session?**

You can request a posted Engagement Pack by emailing us at [aboutdementia@agescotland.org.uk](mailto:aboutdementia@agescotland.org.uk). Without a smartphone, you can still run sessions – though this may involve some extra work for yourself. If you have access to emails, type any notes from the session and email to the address above. If you have a printed version of the Engagement Pack, write your responses in the notes provided and post to:

**About Dementia  
Age Scotland,  
Causewayside House,  
160 Causewayside,  
Edinburgh,  
EH9 1PR**



## **I'm finding it difficult to convince people or a staff team to try the Engagement Pack. What should I do?**

If working with a group or individual, try reframing the session as a 'way to have your voice heard' or a 'way to bond'. Position it in a less formal way by explaining its a fun mix of games and stories. Let people know they can leave or take part in another activity at any time.

If you are finding it challenging to encourage staff to deliver the sessions, think about whether there is scope to deliver the first session yourself. It may be that staff lack confidence to lead a session or have a fixed idea of what storytelling may be. Kindly try to find out which element may be causing concern - perhaps there is a way the pack can be adapted to overcome their anxiety. Reassure them that there is no pressure to get it 'right' or find specific information. The sessions may even be a gentle way for staff to get to know people better, and enhance their skills in communicating with people living with dementia. Offer to be present for a test run to lend support and encourage staff to see the experience as something new to give a go – there's no harm in trying!

## **Can I post on social media about using the Engagement Pack?**

Yes please! We'd love for more people to find out about the Engagement Pack and to expand their perception of what people living with dementia may be capable of. It would be great to see how your sessions are going, if you post on social media, please do tag us on our Twitter [@AboutDementiaSC](https://twitter.com/AboutDementiaSC) and use the hashtag #NDSAboutDementia

## **I'm not sure if we found anything valuable in our engagement, should I still send my notes?**

Don't be disheartened. Viewed in isolation, it can be hard to spot recurring or important themes. It may be that when looked at as a whole, your feedback complements other engagement. Please do send us everything you have and we can review your feedback within the context of all engagement.

# Get In Touch

Thank you for taking the lead and helping us to influence change for people living with dementia and unpaid carers. We hope you find this Engagement Pack useful for the people you support. We would love to hear about your progress or any comments you may have. To get in touch with any feedback, questions or suggestions, email us at:



**[aboutdementia@agescotland.org.uk](mailto:aboutdementia@agescotland.org.uk)**

You can also keep up to date with our website and Twitter account:



**[age.scot/aboutdementia](http://age.scot/aboutdementia)**



**[@AboutDementiaSc](https://twitter.com/AboutDementiaSc)**



*A few members of the friendly About Dementia Team*