



# National Dementia Learning Event

## 15<sup>th</sup> November 2021

### Summary report



## Dementia: Making a difference in your community:

A national, online learning event hosted by Age Scotland's dementia teams, exploring what we can all do to create, empower and effect change.

On Monday 15<sup>th</sup> November, Age Scotland's Dementia Training team pooled forces with colleagues from About Dementia to host the organisation's first ever national dementia learning event online. Over 120 people attended the event, which was chaired by our Director of Community Services, Fiona Cross, and included 7 keynote speakers and 21 interactive workshops on the following topics:

- **Enabling outdoor spaces and activities**
- **Empowering carers**
- **Taking the lead from people living with dementia**
- **Intergenerational approaches to dementia inclusion**

In the course of their work running training sessions, forum meetings and consultations, both the Dementia Training team and About Dementia meet a wide range of interesting people and organisations, all of whom are engaged in diverse and wonderful work to make Scotland a more dementia inclusive place. We always say that we learn as much from them as they do from us and so this national learning event was our chance to showcase some of what we have learned from our partners, collaborators and training participants. It was a celebration of the knowledge, skills and experience within our learning community.

It was a really great day, with lots of sharing, smiles and connections made. We had the support of a fantastic team of Age Scotland colleagues who supported the many workshops which ran throughout the day. We are delighted to share summaries of the keynote presentations and workshops in this follow up report.



## Programme, speakers and workshop leaders

### Topic 1: Enabling outdoor activities and spaces

Opening speaker: Sam Scott, [Edinburgh Leisure](#)

#### Workshops: Topic 1

- **Prestwick Beach Promenade project: helping people with dementia to remain part of their community** - Julie Twaddell, [Dementia Friendly Prestwick](#)
- **Dementia friendly signs and symbols: Helping people find their way around with confidence** - Lucy Richards, [Inclusive Symbols](#)
- **Return to the green: Reassure. Reconnect. Respect** - Daniel Baker, [Bowls Scotland](#) and Jim Purvis, [Sporting Memories Network](#)
- **STANDing outdoors in Fife** - Ruth McCabe, [Fife Council](#) and [Fife STAND group](#) members
- **Confident to be outside** - Liz Rowlett, [Clackmannanshire Third Sector Interface](#)
- **What the outdoors can offer people living with dementia** - Doug Anthoney, [Age Scotland](#)
- **Out in the woods** - Adrian Clark, [Evanton Wood Community Company](#)

### Topic 2: Empowering Carers

Opening Speakers: Ray Fallan and Anne Irvine, [TiDE](#)

#### Workshops: Topic 2

- **Voices of South Asian female carers: An account of their experiences** - Naina Minhas, Samra Ahmed, Munaza Khan, Sadaf Ali, [NKS Health](#)
- **Empowering carers through connection and learning** – Ray Fallan and Anne Irvine, [TiDE](#)
- **Connecting through creativity and playfulness** - Lorna Hill, [BOLD Scotland](#)
- **Empowering carers to sit on Integration Joint Boards (IJBs)** - Kainde Manji, [About Dementia](#) and Elizabeth Ramsay, [Stirling and Clackmannanshire Integration Joint Board](#)

### **Topic 3: Taking the lead from people living with dementia**

**Opening Speakers:** Kainde Manji, [About Dementia](#), Martin Robertson, [The Scottish Dementia Alumni](#) and Gerald King, [Fife STAND Group](#)

#### **Workshops: Topic 3**

- **Work after a diagnosis of dementia** - Martin Robertson, [The Scottish Dementia Alumni](#)
- **Peer support for people living with dementia** - Gerald King, [Fife STAND Group](#)
- **Involving people living with dementia in Age Scotland's recruitment processes** - Doug Sloan and Maxine Meighan, [About Dementia](#)
- **Kirrie Connections: Scotland's first "Meeting Centre"** - Graham Galloway and Robert Hamilton, [Kirrie Connections](#)
- **100 people with dementia in a room – what do you see?** - Ron Coleman, [Deepness Dementia Radio](#)

### **Topic 4: Intergenerational approaches to dementia inclusion**

**Opening speaker:** Bella Kerr, [Generations Working Together](#)

#### **Workshops: Topic 4**

- **Intergenerational work makes a real difference** - Bella Kerr, [Generations Working Together](#)
- **The story of Heather and Jaybees: a valuable volunteer with dementia** - Jackie Bell, [Jaybees Nursery](#)
- **The impacts of intergenerational engagement on older adults' cognitive, social, and health outcomes** - Louise Brown-Nicholls, [University of Strathclyde](#)
- **The challenges and possibilities of connecting the generations digitally** - Julie Turner, [Age Scotland](#), Maurice Donohue, [Sporting Memories Network](#), Stephen Halkett, [Vale of Leven Academy](#) and Christine Ryder, [Outside the Box](#)
- **Intergenerational fun and games in the Anam Cara Dementia Respite Centre** - Claire Mills, [Anam Cara](#) and Sarita Taggart, [St Bridget's Primary School, Kilbirnie](#)

## Topic 1: Enabling outdoor activities and spaces

### Opening speaker: Sam Scott, [Edinburgh Leisure](#)

Sam is the Health Development Officer for mental health and wellbeing with Edinburgh Leisure. He is currently project managing Edinburgh Leisure's Healthy Active Minds project and Movement for Memories for people living with dementia.

Sam's presentation focused on the outdoor activities which are part of the Movement for Memories project and the reasons why providing opportunities for people living with dementia to be active outside became a priority for the organisation.

Supported by volunteers, Movement for Memories members can now choose to play golf or be accompanied to go on a walk near their home alongside the more established indoor sports and gym activities. Some of the 'added value' of being active outside is captured in the image below:



**Movement for Memories – Why Outdoor?**

- Getting regular outdoor physical activity helps prevent heart disease and other chronic illness
- improves mood and reduces stress
- improves sleep
- Walk at your own level
- Safe (less transmission – COVID)
- Social interaction



**Edinburgh Leisure**  
The Biggest Club in Town

Both people living with dementia and their carers have benefitted from these outdoor opportunities.

*"Movement for Memories has improved my confidence meeting new people such as my golf buddy who is good company. We share an interest, and he is understanding of my struggle to find the right word occasionally. Fresh air and friendship really lift my spirits and reduce the anxiety I sometimes feel."*

*"Thank you for everything you have done for us. My mum loves going for a walk with you and even when she is feeling bad, the walks always cheers her up"*

Find out more about Movement for Memories and Edinburgh Leisure's work on dementia inclusion [here](#).

## Workshops: Topic 1

**Prestwick Beach Promenade project: helping people with dementia to remain part of their community - Julie Twaddell, [Dementia Friendly Prestwick \(DFP\)](#)**

### Background

When DFP started dementia friendly health walks, they found that the beach front was a bit 'sad' looking and not very dementia friendly. For example, the benches were old and grey, blending into the pavement and making it hard to distinguish them.

After receiving funding from South Ayrshire Council, Sustrans, Ayrshire Road Alliance and Paths For All, Dementia Friendly Prestwick were able to make some changes.

At first, they only asked for potted plants to brighten the promenade. However, they were delighted to receive even more funding for new colourful benches, accessible signage and even better – a mid-crossing platform, allowing walkers to rest while crossing.



### Some key messages

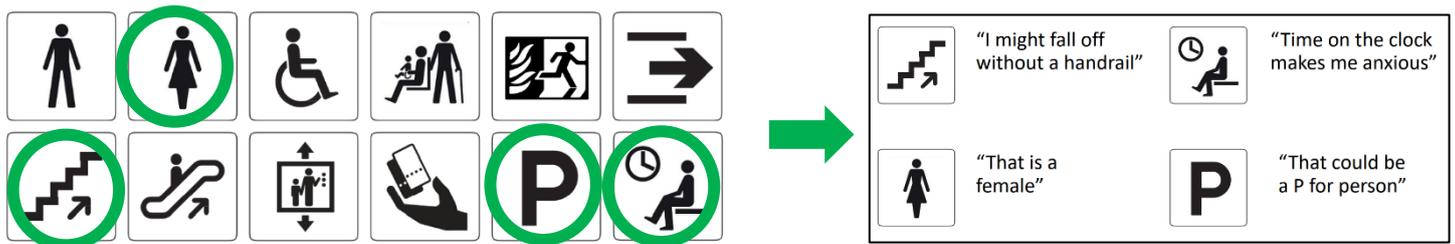
- The Promenade and health walks have been a triumph, bringing people together and keeping people visible in their community. Rain or shine, the walkers wrap up and take to the promenade for a stroll and blether.
- The Promenade project has brought generations together, and children love the bright design of the benches too.
- DFP's health walks on the Promenade are open to all and not limited to people living with dementia. The organisers firmly believe that they should remain that way, as it allows the opportunity for community building, peer support and connection.
- Sometimes, people can get upset or want to vent on a walk, but often the act of venting alone with a sympathetic ear can help people feel better.
- Health walks can be a less intensive form of conversation as you are side-by-side and not face-to-face, so there's less pressure.

## Workshops: Topic 1

### Dementia friendly signs and symbols: Helping people find their way around with confidence - Lucy Richards, [Inclusive Symbols](#)

#### Some key messages

Everyday signs and symbols can be confusing for people living with dementia and have a negative impact on people's confidence and independence. For example, the following reactions:



However, there can also be problems with signage which purports to be dementia friendly. Even that which attempts to combine text and images can be perceived as being patronising, infantile, inconsistent, confusing and ugly. The ambition of Inclusive Symbols was to create inclusive signage which is respectful, clear, calm, simple and attractive – summed up in the image below:

Shift from ...	to ...
 	 <p><b>Toilet</b></p>
 <p>Ambiguous pictograms Unappealing imagery Poor contrast text ALL CAPS hard to read</p>	<p>Simple, realistic, 3D imagery Good contrast Clear, legible typeface Sentence case easiest to read Simple, descriptive text</p>

After consulting almost 2000 people through focus groups and surveys, Inclusive symbols have developed a whole range of effective dementia inclusive symbols, tested and approved by the experts with lived experience.

They can be downloaded free from:  
<https://www.inclusivesymbols.com>

**Conclusion ...**

For design to be effective, listen to the voice of **experts** who have lived experience

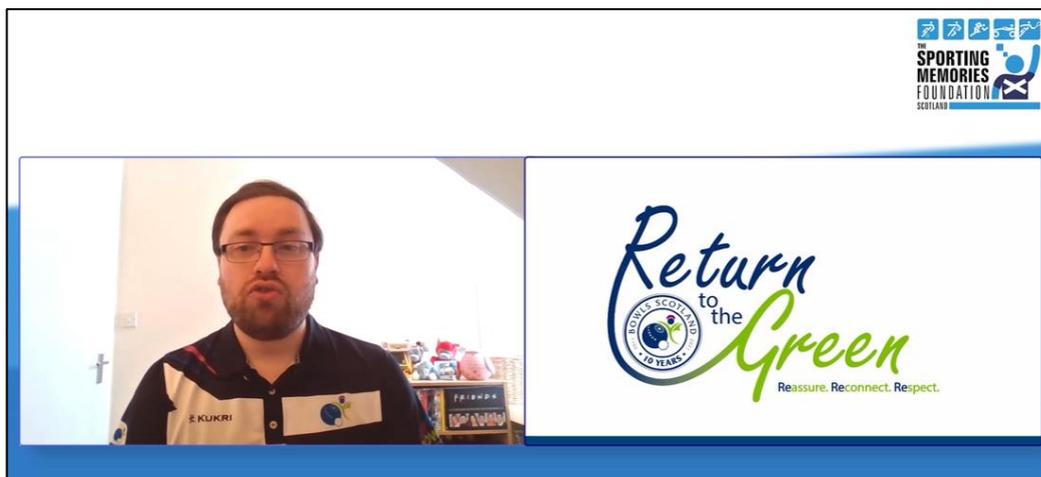
Before				
After				

## Workshops: Topic 1

Return to the green: Reassure. Reconnect. Respect - Daniel Baker, [Bowls Scotland](#) and Jim Purvis, [Sporting Memories Network](#)

### Background

After almost two years of isolation, and coming in and out of restrictions, many older people, including people living with dementia have lost both the habit of taking part in sports activities – as well as the confidence to do so. How to run such events safely and encourage people to come back is a key question for community sports clubs at the present time and the insights shared at this workshop can be widely applied to different activities and different communities as we move into the future.



### Some key messages

- Taking part in sports activities (especially outside) can bring direct health benefits due to increased physical activity, but the peer support and social connections gained are equally important.
- The importance of these activities for wellbeing at these different levels means that, even though it is challenging, clubs really need to think about how to encourage people to come back – and to create the conditions where people feel confident and able to talk part.
- An additional challenge is the fact that many people have really enjoyed the online activities which they have been involved with over the past two years and don't want to see them disappear altogether as in-person activities resume. So finding enough resource to keep these two different channels going can be challenging for community clubs.
- More information on support for clubs from Bowls Scotland can be found [here](#)
- Resources, insights and support from the Sporting Memories Foundation can be found [here](#)

## Workshops: Topic 1

### STANDING outdoors in Fife - Ruth McCabe, [Fife Council](#) and [Fife STAND group](#) members

#### Background

The STAND group was formed before lockdown in 2020 to provide peer support for people in Fife living with young onset dementia and their carers and families. Unlike other, more traditional support groups for people living with dementia - which tend to be aimed at older people and where people are 'taken away' for the day or for the morning to do activities – the STAND group is for everyone – families, friends and carers as well as the people with a diagnosis – and it is all about creating shared memories and experiences.

Activities are completely driven by the interests and wishes of group members and, thanks to the collaboration of the [Kennoway Community Shed](#) and the [Ecology Centre](#), spending time outdoors has been important in many ways.



#### Some key points and tips

- Being in the garden has allowed some participants to develop new skills and interests (such as growing beetroot) that they would never have imagined enjoying
- For others, it's simply the best place to sit calmly and watch the world go by or it's the pleasure of seeing what they've grown (like the beetroots in the photos) turned into delicious food to share
- One handy tip is to make or be near a shelter of some kind (with a toilet) and to wear lots of layers, just in case the weather turns bad
- Whatever people engage in outside, spending time in nature makes you happy, calm and relaxed and ready to face whatever's coming next
- Best advice: Don't overthink it - just do it! People will find a way of making it work.

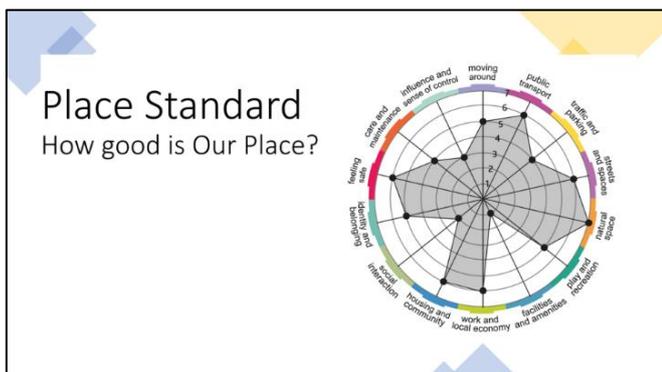
## Workshops: Topic 1

### Confident to be outside - Liz Rowlett, [Clackmannanshire Third Sector Interface](#)

#### Background

Being outside is really important for everyone, including people living with dementia, and there are some principles for dementia friendly neighbourhoods which can enable this to happen. These principles are:

- Familiarity – easier for people to find their way around a familiar space
- Legibility – easy for people to read and navigate
- Distinctive features – capture attention and help with spatial awareness
- Accessibility – people of all abilities should be able to reach the places they want or need to go
- Comfort
- Safety



#### Useful resources:

[Place Standard](#)

[Our Connected Neighbourhood – public outdoor assessment tool](#)

[Resources for creating dementia-friendly communities](#)

[DSDC – Stirling University](#)

[Oxford Brookes University – Neighbourhoods for Life](#)

#### Some key learning from outdoor projects post-Covid:

- Bad weather doesn't necessarily dampen participants' enthusiasm, though it can be challenging for some and support needs to be in place
- One-to-one support might be required for some participants
- It can be challenging to overcome the assumption (e.g. from care home staff or family members) that people with dementia won't be able to do things outside
- We have to accept SOME risk in order to carry out activities that improve people's lives
- Being offered a choice of activities is important as are activities which actively contribute to enriching communities and neighbourhoods.

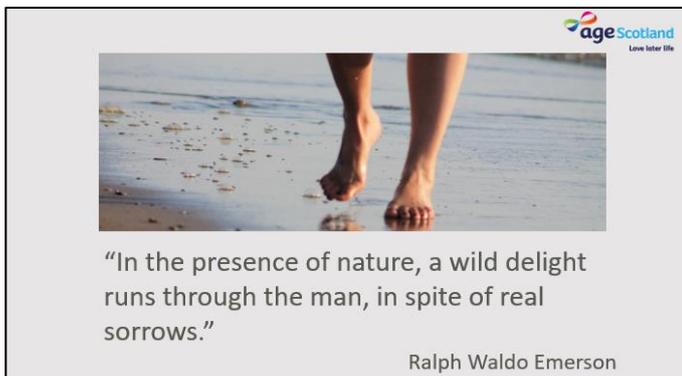
## Workshops: Topic 1

### What the outdoors can offer people living with dementia - Doug Anthony, [Age Scotland](#)

#### Background

There is [strong evidence](#) of the health benefits of being outside and in contact with nature for people living with dementia, including:

- Improved **emotional state**: reduced stress, agitation, anger, apathy and depression
- Improved **physical health**: skin health, fitness, sleeping patterns, eating patterns
- Improved **verbal expression**
- Improved **memory and attention**
- Improved **awareness**: multi-sensory engagement and joy
- Improved sense of **well-being, independence, self-esteem and control**
- Improved social interaction and a **sense of belonging**



Some good practice examples:

[Green Health in Later Life | TCV](#)

[Dementia Adventures](#)

[Dementia friendly walking - projects | Paths for All](#)

[Our Natural Health Service | NatureScot](#)

[Art Adventures in Nature - Luminare](#)

#### Some key points:

- Animals (particularly dogs) can be a great way of encouraging people to get out for a walk
- Shelter and refreshments are crucial as is having enough staff / volunteers to provide the support required
- Intergenerational engagement can be a great way of getting people outside
- Access to transport can be a real barrier, and knowing about local initiatives such as [Fares 4 Free](#) can be useful in overcoming this
- It is important to **think about the words** we use as words like “exercise” or “online” can often put people off from being involved.

Remember, you can request Age Scotland to run a [Power Quiz session](#) for your group, or get training to run a session yourself.

A handout is available to accompany these notes. Please email if you would like a copy: [dementiatraining@agescotland.org.uk](mailto:dementiatraining@agescotland.org.uk).

## Workshops: Topic 1

### Out in the woods - Adrian Clark, [Evanton Wood Community Company](#)

#### Background

Evanton Community Wood was bought by the community about 10 years ago, with the dementia programme running since 2015. Spending time at the wood brings many benefits to the participants who are part of the dementia programme. Participants are able to use their existing talents but are also enabled to try new things they maybe haven't had a chance to try before and are very often up for this. They enjoy meeting new people, making new friends and having something to look forward to.



#### Some activities people engage in are:

- Eating/cooking together
- Storytelling
- Activities involving young people and volunteers
- Arts activities such as music, stories and art.
- Sharing and celebrating together

#### Some key points:

- Evanton Woods were the first Dementia Friendly Woodland in Scotland, receiving this accolade in 2019.
- The woods already had some of the facilities needed for this such as accessible access; good tracks/paths; a toilet; a cabin with a stove, but to meet this accreditation, they also put extra work into landscaping; introducing more accessible round picnic tables; increased comfort through blankets and cushions; and some better signage, particularly in the toilet.
- During lockdown, some of the activities were able to move online such as:
  - Storytelling
  - Music
  - Conversation
  - Virtual Burns Day tea
- You can watch a video about the Evanton Woods dementia programme [here](#).

## Topic 2: Empowering carers

### Opening speakers: Anne Irvine and Ray Fallan, [Together in Dementia Everyday \(TiDE\)](#)

Anne cared for her mum, who was also her best friend, at home for 5 years before losing her in 2017. Anne and her husband now care for Anne's mother-in-law. Anne also volunteers with TiDE, Alzheimer Scotland and the Prince and Princess of Wales Hospice. Anne says she will continue to work with charities to improve the rights of carers and patients and hopefully make the dementia journey smoother for those involved.

#### Excerpt from Anne's opening talk:

"I know that we can all feel broken during and after a caring role, but it's important to know that you can and do bloom again and go on as a better, stronger version of yourself.

What I feel is never be afraid to challenge authoritarian figures. Yes, they appear to know everything and yes sadly they can at times make us feel inferior, there are GPs who fail to pass on important information to us, social workers who think they can tell you and not ask you what's going to happen, hospitals and care homes that stop our loved ones medications without consulting us .... the list goes on! But they don't always know best, they certainly don't know our loved ones like we do. Our knowledge needs to be acknowledged."

#### Empowering tips from Anne:

- A smile often goes a long way to diffuse an awkward conversation
- Never doubt a niggle that you have at the back of your mind when you are feeling you are being fobbed off, or you wish a fuller explanation or a second opinion
- Never feel you aren't good enough if they make you feel unimportant, us carers are very much important.... and getting treated as an equal with them is very empowering

Ray Fallan is both the Network and Growth officer at TiDE and a member of TiDE. Ray became a tide member because of her own personal lived experience. She found herself looking for carer support when her husband was diagnosed with a rare form of dementia at a young age. She found this support within TiDE. Ray became a very active member of TiDE and participated in a variety of campaigning, public speaking and awareness raising activities. Her passion to support other carers was born and she changed her career after losing her husband in 2018. Ray says that TiDE believed in her and gave her confidence not only in herself but in what she what she does now within TiDE.

There is more about TiDE and its work with carers of people living with dementia in the workshop notes below.

## Workshops: Topic 2

**Voices of South Asian female carers: An account of their experiences - Naina Minhas, Samra Ahmed, Munaza Khan, Sadaf Ali, [NKS Health](#)**

### Background

In this workshop, participants heard about the wider experience of South Asian carers, and also personally from a couple of carers themselves. In general, the experiences of South Asian carers are similar to those of other carers, though perhaps with some additional challenges (such as those outlined in the key points below). Poor health and wellbeing, loneliness and isolation and stigma can all be very real experiences.

<p><u>Challenges and Issues</u> </p> <ul style="list-style-type: none"> <li>• Lack of support</li> <li>• Lack of information</li> <li>• Patriarchal society</li> <li>• Inaccessibility to services – cultural sensitive services</li> <li>• Communication issues – not just language barriers</li> </ul>	<p><u>Way Forward</u> </p> <ul style="list-style-type: none"> <li>• Empower through information/knowledge</li> <li>• One to one support</li> <li>• Advocacy – negotiating services</li> <li>• Health and welfare support</li> <li>• Cultural sensitive services</li> <li>• Respite using suitable engagement methods</li> <li>• Training in informal settings</li> </ul>
<p><u>Challenges and Issues Continued</u> </p> <ul style="list-style-type: none"> <li>• Cultural competence among service providers</li> <li>• Lack of support from family and communities</li> <li>• Gap in needs</li> <li>• Poor consultation with carers – their unheard voice</li> <li>• Religious boundaries</li> <li>• Discrimination – direct or indirect</li> </ul>	<p><u>Way Forward Continued</u> </p> <ul style="list-style-type: none"> <li>• Support groups for BAME carers</li> <li>• More trained and paid South Asian female carers – support to get trained</li> <li>• Importance of third sector in engaging with BAME carers</li> <li>• Training for service providers about the needs of BAME carers</li> </ul>

### Some key points:

- In the South Asian community, caring is very much a role carried out by women, who have a duty to care but don't see themselves as carers.
- Carers generally won't take breaks from caring, have little knowledge about the illness or condition of the person they care for, and are isolated even from their own community and family.
- Though the needs of South Asian carers are the same as those of any carer, the way in which these are addressed are different, due to language barriers, literacy, and cultural differences.

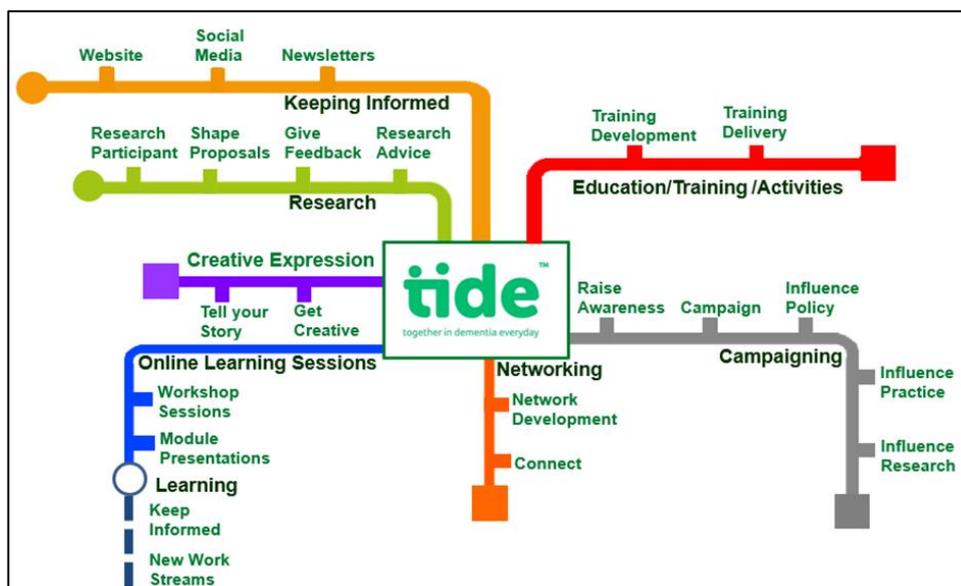
## Workshops: Topic 2

### Empowering carers through connection and learning – Ray Fallan and Anne Irvine, [TiDE](#)

#### Background

TiDE is a UK network for carers and former carers of people living with dementia staffed by people who have all had caring responsibilities. They empower carers by recognising them as experts by experience. Through connecting with other carers and having the opportunity to take part in training, carers gain knowledge, skills and confidence to find their voice, reach their potential and champion their own rights. TiDE provides opportunities and platforms where carers' voices can be heard and influence real change.

#### There are many ways to engage with TiDE



#### Some key points:

- Empowerment of carers involves: connecting people and building confidence; listening to carers and validating what is being heard; enabling carers to find their voice; having access to information.
- Post-diagnostic support needs to be for carers as well as the person with the diagnosis. TiDE is pushing the Scottish Government for this.
- **Living grief and bereavement** – the TiDE network have produced guides around this: [TiDE - Together in Dementia Everyday - Living Grief & Bereavement](#)
- Anne is a believer that ‘from a small grain of sand, pearls emerge.’ She feels that carers should never be afraid to challenge figures of authority as no-one in authority knows your loved one like a carer does. She has found it useful to never doubt a niggly you may have – if you feel you’re being fobbed off, have the confidence to raise this.
- As a carer, being treated as an equal partner in the care of the person you care for is empowering.

## Workshops: Topic 2

### Connecting through creativity and playfulness - Lorna Hill, [BOLD Scotland](#)

#### Background

The **bold** innovative social leadership project brings together people living with dementia, family members, professional carers, NHS staff, artists and people from all walks of life. It provides free leadership opportunities across Scotland to help those living with dementia flourish and make a difference. The programme focuses on using creative arts methods whenever possible.

Empowering carers in different ways is an important part of **bold's** ambition: empowering them to find different ways of connecting and communicating with the person living with dementia; providing tools to enable them to empower the person with dementia to tell their story; empowering them to tell their own story as carers.

## Creativity

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**bold** focuses on creative arts-based methods whenever possible.

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Creative methods help to create open and safe environments within which we can talk about and articulate our shared values and beliefs

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There is no right or wrong with creativity which means we are free to innovate and imagine.

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Creativity helps us see the world from a different perspective.

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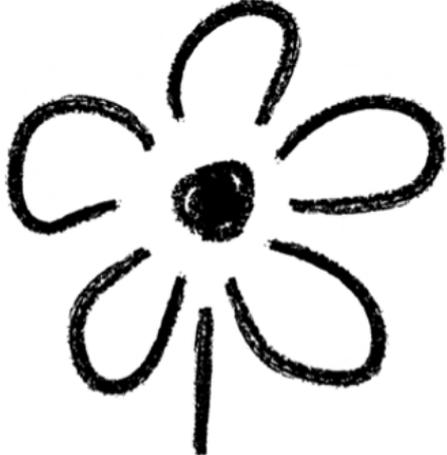
Creativity can help uncover our hidden strengths and vulnerabilities enabling us to realize our potential as we allow ourselves to flourish.

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Creative methods help us work together in enjoyable and fun ways fostering a playfulness and energy in our work and practice.

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These creative methods are used to tell and share our stories to each other and the wider world



#### Some key points:

- Storytelling forms an important strand of **bold's** approach and this workshop gave participants the opportunity to experience the power of stories
- For example, even something as simple as telling a quick story about the mug you're using can be a way of
  - starting a conversation with someone living with dementia
  - finding out something interesting about the person you're talking to
  - telling something interesting about yourself
- All of the above can help carers to care for themselves and the person living with dementia.

## Workshops: Topic 2

Empowering carers to sit on Integration Joint Boards (IJBs)- Kainde Manji, [About Dementia](#) and Elizabeth Ramsay, [Stirling and Clackmannanshire Integration Joint Board](#)

### Background

IJBs are the bodies responsible for the coordination of the work of 30 out of the 31 Health and Social Care Partnerships in Scotland (Highland being the only exception). Each IJB should have unpaid carers' representatives among its membership – to bring a carers' perspective and to make sure the voice of unpaid carers is heard in all aspects of service planning and delivery within the Partnership.

Elizabeth Ramsay is the carers' representative on the Stirling and Clackmannanshire IJB. Interviewed by Kainde Manji, Elizabeth spoke of some of the challenges involved in this "rewarding, interesting and challenging" role and some suggestions for improving carer involvement on IJBs.



### Some challenges

- The IJB comprises one health board and two local authorities each with their own way of working, so processes and meetings can be complex and this can put carers off getting involved.
- IJBs are mostly made up of professionals, who are not used to listening to unpaid carers, so it can be hard to be heard.

### Some key points:

- On most IJBs, carers' representatives currently do not have full voting rights. This should be changed as this would lend them more status and make it more likely for their voices to be heard.
- Carers should always get expenses for attending meetings and should receive paperwork far in advance so that they have time to digest it amid their caring responsibilities.
- Carers' representatives should be provided with assertiveness training.
- Professional members of IJBs should also receive training on how to work with people with lived experience of dementia and also generally on dealing with non-professionals.
- Carers should also always be part of any implementation boards, which exist to ensure that policies determined by IJBs actually happen.

### Topic 3: Taking the lead from people living with dementia

#### **Opening Speakers: Kainde Manji, [About Dementia](#), Martin Robertson, [The Scottish Dementia Alumni](#) and Gerald King, [Fife STAND Group](#)**

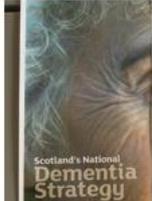
**Kainde** is the manager of About Dementia, Age Scotland’s forum for policy and practice for people living with dementia, funded by Life Changes Trust. **Martin** lives in Aberdeenshire and has been a dementia activist for a number of years. He is passionate about involving people living with dementia in decision making and has a particular interest in dementia and employment rights. **Gerald** has young onset Alzheimer’s and lives in Fife with his wife and children. Gerry became a dementia activist after identifying a lack of support for people living with younger onset dementia and working to set up a local peer support group called STAND.

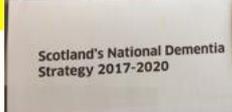
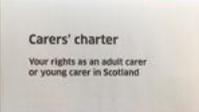
Kainde gave an overview of the work of About Dementia, in which a core element is bringing the voices and experience of people with lived experience of dementia to the centre of all discussion and decision making.



## What we do

- 5 year project established 2019
- Funded by Life Changes Trust
- Addressing gaps in policy, practice & implementation
- 15 policy area sub-groups
- Working collaboratively
- Centre the lived experiences of people affected by dementia
- Life Changes Trust National Legacy Partner



Martin talked about his experience of work and his diagnosis. He said that About Dementia “Do exactly what it says on the tin”. He also talked about how he had been involved in research projects with the Life Changes Trust and about how important it was to involve people living with dementia “Nothing about us without us”.

Gerald shared how he had felt when he got his diagnosis and how great it had been to be able to get involved with the STAND group in Fife. He felt that he still had something to say and being involved with the group gave him a reason to get out of bed and how therapeutic it was having the opportunity to talk about his dementia. STAND in Fife support people living with dementia and from little acorns grow mighty oaks. Through working with About Dementia, DEEP, STAND and the LCT, Gerald’s self-confidence has grown, and his personal development taken root.

## Workshops: Topic 3

### Work after a diagnosis of dementia - Martin Robertson, [The Scottish Dementia Alumni](#)

#### Background

In this workshop, Martin shared insights from his book "[Work after a diagnosis of dementia](#)", designed to help working people receiving a diagnosis of dementia to navigate their rights and their options.

Martin worked in social care when he was diagnosed with a rare form of dementia, [Posterior Cortical Atrophy](#). He received his diagnosis at 6.30 in the evening and he immediately made the decision not to go back to work. Martin made this decision because:

"... I saw, in a moment of clarity, that I could now do what I wanted, when I wanted, and if I wanted. Also, I worked in social care on the front line and realised that I could make, literally, a fatal mistake, which I could not have lived with. I was also told to stop driving, and again I saw the wisdom of this."

Despite his own decision to give up work immediately, Martin wrote his book to support others to jump through the many hoops which exist and "to show them that there can be meaningful work, paid or unpaid, after a diagnosis."

#### Real life experiences of work with dementia (from people interviewed by Martin)

"People often put in extra hours to hide their problems from other staff: coming in early, leaving late and even working at home, all for no extra pay"

"In other cases, the staff working with the person knew they were not working well, so covered up for them"

"You need someone who knows the rules to help you because the businesses don't want to help you"

"You hated letting anyone down at work"

#### Some key points

- There is no legal obligation to inform your employer of a dementia diagnosis
- When diagnosed, you do have a legal obligation to tell the [Driver and Vehicle Licensing Agency](#)
- Employers have an obligation make "reasonable adjustments" to support employees with a diagnosis of dementia, for example:
  - carrying out an Occupational Health Assessment and finding them a more suitable role
  - engaging a 'buddy' to support the person to get to work safely
  - enabling them to work from a more suitable place

## Workshops: Topic 3

### Peer support for people living with dementia - Gerald King, [Fife STAND Group](#)

#### In Gerald's own words (for there are no better words):

"There are different types of peer support, but they all involve both giving and receiving support. This could be sharing knowledge or providing emotional support, social interaction or providing help. Peer support is all these and much, much more. The peer support group, STAND, was conceived out of the need for me to talk to and just spend time with other people who were living with a diagnosis of young onset dementia. I felt alone in the world and that needed to change.

STAND is a support group made up of people from all walks of life who are living with young onset dementia and their supporters. The ideology of the group is to share experiences and provide support for one another. The biggest reward for me personally is the friendships that have developed and flourished over the short period of time from the group's inception. The power of friendship should never be underestimated. Being in the company of people who can actually relate to you and actually understand exactly what you are experiencing is more powerful and has more healing powers than any medication available. The members of STAND – my friends – they wear the same shoes as me – some bigger, some smaller, but nevertheless the same. When we meet up, the room is filled with smiles and laughter and the conversation never ends. You are accepted for who you are, and you are never judged.

In simplistic terms, peer support is like getting the biggest hug from your mum after you've fallen and grazed your knee. I don't know why, but for some reason, that hug takes all the pain away. Peer support has given me an increased sense of wellbeing and has been the biggest contributor for me to be able to have a good life with dementia. I feel valued, understood and well supported but more lately I have been feeling empowered. As a peer support group for people with young onset dementia and their supporters, we have been raising awareness in our local communities to make Fife dementia friendly.

Through STAND I have been extremely lucky to meet up with many other support groups and support networks, which has allowed me and the dementia community to take our message nation-wide. Our hope for the future is to shatter the image that people have of dementia and with the assistance of other peer support groups and networks we hope to inspire people to look on dementia in a completely different light and to encourage both local and national government to renew their dementia strategies to help ensure sustainability and accessibility to peer support groups and to ensure people living with dementia and their supporters feel supported and valued".

#### More on this topic:

You can hear more from Gerald on the importance of peer support in [this film](#).

The Life Changes Trust recently published their [evaluation of peer support groups](#).

## Workshops: Topic 3

### Involving people living with dementia in Age Scotland's recruitment processes - Doug Sloan and Maxine Meighan, [About Dementia](#)

#### Background

About Dementia have implemented a policy of involving a panel of people with lived experience of dementia in their recruitment process. This panel is supported to carry out a second-round interview with the top two candidates from the first round.

Why? Being led by members is one of the core values of the About Dementia project, and people with dementia want to be involved: the message of “nothing about us without us” becomes a reality by committing to this type of action. It also enhances the interview process itself and helps to secure the best person for the job. The process serves as a test of the candidate’s communication and interpersonal skills and people with lived experience can pick up on cues – both positive and negative – which the other panellists might not.

## How we involved our members



- **The panel**
  - Three people living with dementia
  - HR observer
  - Line manager – to support the candidates
  - Member of team – to support the activists
- **The interview (1 hour 15 minutes total)**
  - Pre-meeting to review the process and ask questions
  - Candidates joined for 20 minutes each
  - Panel asked their questions (also posted in the chat function)
  - Candidates have the chance to ask their questions
- **After the interviews**
  - deliberation





The hope is that this experience will encourage other organisations to similarly commit to involving people with lived experience of dementia in their recruitment processes.

#### Some key points:

- The planning meeting is key: to go through the job description line by line; support panellist to devise their own questions; discuss any support requirements
- The panellists enjoyed their experience and want to be involved again. They said:
  - “To be included in things like this gives you back a sense of self-worth”
  - “It’s a privilege, it’s wonderful. I can’t thank you enough, it’s been a joy!”
- A view from the successful candidate:
  - “Pre-interview, I felt a bit apprehensive and worried that I might unintentionally offend the activists. However, almost as soon as the interview begun, I felt more relaxed and excited to meet the activists on a personal level. In the end, they ended up supporting me during the interview rather than the other way around. I think the process was extremely useful for me in developing my understanding of dementia. Ultimately, I think that such a process benefits panellists along with both successful and unsuccessful candidates. It certainly benefitted me when taking up the role”.

## Workshops: Topic 3

### Kirrie Connections: Scotland's first "Meeting Centre" - Graham Galloway and Robert Hamilton, [Kirrie Connections](#)

#### Background

Kirrie Connections is Scotland's first [Meeting Centre](#). At the heart of the Meeting Centre model of support is a social club where people meet to have fun, talk to others and get help that focuses on individual needs. All activities are designed to help people adapt to the challenges that living with dementia can bring. This involves a chance to get together socially, to be creative, to get active and to share lunch. Family carers get assistance with practical and emotional issues, as well as being able to contribute to social club activities.

For Kirrie Connections, being a Meeting Centre means a commitment to ensuring that people living with dementia have a real say in every aspect of the way the centre is run. Part of this commitment has been the recruitment of Robert, who is living with dementia, as a board member.



#### Some key points:

- Help and support for families and people affected by dementia is often fragmented. People often feel overwhelmed and confused about where to get help. Meeting Centres are a way of providing accessible support on a local level to act against this.
- Robert said that his dementia was first picked up when he started losing his car keys, so his daughter asked him to get a diagnosis. He got given medication. Kirrie Connections keep their members as active as possible in order to keep their minds active and hopefully avoid the need for medication.
- There is a need for more Meeting Centres across the country. Kirrie Connections are offering training and support to organisations seeking to set one up.
- The Meeting Centre supports people (members and family members) by helping them cope with the consequences – cognitive, social and emotional - of living with dementia and to make the best possible lifestyle adjustments for them as individuals.

## Workshops: Topic 3

### 100 people with dementia in a room – what do you see? - Ron Coleman, [Deepness Dementia Radio](#)

#### Background

In September 2021, the first conference run by people living with dementia, for people living with dementia took place in Dundee. It was a life changing experience for all those who attended. The 100/6000 Conference discussed and debated ideas for the future direction for people living with dementia.

As one of the organisers of the conference, Ron led a discussion on some of the learning from this event. The 100/6000 conference was the first conference where all speakers were people living with dementia. It showed how people living with dementia can and should take the lead on discussions around the issues that affect them, rather than professionals. The outcome of the event was position papers on the Scottish Government's National Care Service proposals, reflecting the real views of people with lived experience.



#### Some key points:

- The conference used creative workshops to make sure everyone could express their views in different ways. For many of the people living with dementia at the event, this was the first time they had had their voices heard. Being able to share their experiences in a room full of supportive peers was very powerful. For the few professionals in the room, the feedback was also very positive and gave them a better understanding of the experiences of people living with dementia.
- We spoke about how the voices of people living with dementia are often ignored, even when the conversation is about them. For example, in a medical/diagnosis setting (Ron Coleman's short film *The Consultant* was shown to the workshop attendees, which shows an example of this). This extends to policy decisions as well, as consultation processes around policies that impact people with dementia are often inaccessible and professional-focused.
- It can be summed up with: **'nothing about us, without us.'**

## Topic 4: Intergenerational approaches to dementia inclusion

### Opening speaker: Bella Kerr, [Generations Working Together](#)

Bella is Intergenerational Development Officer with Generations Working Together (GWT). She works across Scotland with GWT networks specifically around intergenerational practice in learning and building relationships. One of her main areas of focus is breaking down stereotypes and ageism towards and between younger and older people and looking at bringing generations together to enhance health and wellbeing and bring social cohesion to our communities. Her hope is that her work will help to build a better future with communities that are safe to grow up and grow old in.



**Definition of intergenerational work:** ‘Intergenerational practice aims to bring people together in purposeful, mutually beneficial activities which promote greater understanding and respect between generations and contributes to building more cohesive communities.’

[Beth Johnson Foundation](#)

- Learning from each other is a key part of intergenerational work. Older people and people with long term conditions often don't have contact with younger people and vice versa
- There are lots of **benefits to intergenerational working** for both generations: cognitive stimulation, re-engaging in conversations, improved communication and being more engaged. It brings people together in purposeful, mutually beneficial ways, promotes greater understanding and respect between generations and builds on positive resources that different generations have to offer each other and those around them.
- Intergenerational work doesn't have to be just very young people and older people. A generation is considered to be around 25 years.
- For intergenerational projects to work there needs to be intentional planning. Types of activity can range from:
  - Life story work
  - Befriending
  - Physical activity
  - Music, crafts, baking, gardening, reading

## Workshops: Topic 4

### Intergenerational work makes a real difference - Bella Kerr, [Generations Working Together](#)

#### Background

Bella outlined the principles of intergenerational practice:

- Mutual and reciprocal benefit
- Equal participation
- Asset-based
- Well planned
- Culturally grounded
- Strengthens community bonds
- Challenges ageism
- Cross-disciplinary



#### Some key points

- Intergenerational work can be a way to address concerns or challenges in communities. For example, breaking down social barriers and addressing loneliness and isolation; allowing people to feel more respected and included in their communities; and tackling ageism.
- There has been academic research which has demonstrated the health benefits of intergenerational work. For example, Bella showed a video clip of a school in America where there was a partnership between a school of medicine and a local school. This brought health benefits to the older people taking part, increasing their sense of purpose, whilst there was an increase in the reading scores of the children who participated.
- Bella talked about some of the stereotypes older and younger people have of different generations and showed a video clip of some of the perceptions of older people amongst a group of younger people – and how this was challenged. Because of these stereotypes, when planning intergenerational work it's a good idea to hold separate meetings with the different generations involved before bringing everyone together. This will provide opportunities to discuss their expectations and address any concerns or barriers to building good relationships.
- If considering intergenerational works, it's advisable to:
  - consider setting up separate meetings with different generations beforehand
  - think about who you involve and what partners would you involve
  - ask the people at the heart of it what they would like – don't decide for them.

## Workshops: Topic 4

### The story of Heather and Jaybees: a valuable volunteer with dementia - Jackie Bell, [Jaybees Nursery](#)

#### Background

Heather lives with dementia and has been a volunteer at [Jaybees Nursery](#) in Lochmaben before and throughout the pandemic. In this workshop we heard about the valuable contribution Heather makes to the nursery and the difference being a volunteer makes to her. Few organisations recruit volunteers living with dementia, but maybe more will be encouraged by Jaybees' lead and begin to a lot more of this.



- The children love Heather, and she loves them. They don't mind at all if she repeats herself a bit – in fact, they seem to quite enjoy it and children often ask the same questions over and over again anyway.
- Heather does a bit of everything at the nursery, from getting involved in the children's activities to tidying up and loading the dishwasher. She can get annoyed if it hasn't been loaded the way she likes it to be!
- Sometimes Heather just needs a quiet space away from all the bustle – usually just for a few minutes. We have a room where she knows she can go when she feels herself getting overwhelmed.
- Heather has become more independent since volunteering at the nursery. She used to get a lift from her daughter but now she catches the bus there and back again.
- Heather loves having a Jaybees fleece like the rest of the staff – it really makes her feel part of the team. She has brought so much joy to the nursery because of who she is, and her dementia simply has to be accommodated – it doesn't stop her from being herself and bringing so many skills and insights to her volunteering role. We definitely need more volunteers with dementia in all sorts of organisations!

## Workshops: Topic 4

### The impacts of intergenerational engagement on older adults' cognitive, social, and health outcomes - Louise Brown-Nicholls, [University of Strathclyde](#)

#### Background

The media often gives a negative portrayal of older people, with stories about older people and the economy, pensions and pressure on social care services. This prevails despite robust evidence to the contrary: research tells us that older people contribute significantly to society, for example, by volunteering and donating more to charity than any other age group. Research also shows that older people want to give back to the younger generation and the more they feel they are doing so, the greater their sense of wellbeing.

So, how could intergenerational engagement impact on health and wellbeing outcomes?

Dr Nicholls and her team carried out a piece of research on this question:

[A systematic review of the impacts of intergenerational engagement on older adults' cognitive, social, and health outcomes](#)

#### Highlights

- We reviewed 44 studies addressing potential benefits of intergenerational engagement.
- We considered older adults' cognitive, social, and health outcomes of engagement.
- Reliable benefits were observed across multiple studies for several outcomes.
- More high-quality research is needed, including randomised controlled trials.

#### Some key points

- More high-quality evidence is needed, but there were findings in the research that intergenerational engagement can help anxiety levels, cross-age attitudes and physical activity.
- Of the 44 studies reviewed, 4 out of 8 found significant intergenerational engagement effects on cognitive outcomes, 15 of 24 on social outcomes, and 21 of 31 on health-related outcomes.
- Some of the positive cognitive outcomes are:
  - working and episodic memory – both improved and sustained.
  - auditory verbal learning – improved and kept improving.
  - cross-age attitudes – improved and kept improving
  - daytime dysfunction (sleepiness) – less sleep
- Some older participants in intergenerational activities cited said they felt more stimulated and had more sense of purpose after taking part:
  - “Best days of the week”
  - “Prevented two pyjama days”

## Workshops: Topic 4

The challenges and possibilities of connecting the generations digitally - Julie Turner, [Age Scotland](#), Maurice Donohue, [Sporting Memories Network](#), Stephen Halkett, [Vale of Leven Academy](#) and Christine Ryder, [Outside the Box](#)

### Background

Digital projects have been vital during the pandemic and a key element of making them work is understanding how to make them more accessible. This workshop explored the benefits and challenges of intergenerational projects that connect people digitally. Maurice and Stephen shared the experience of their Sporting Memories project, and Christine talked about Digital buddies, an intergenerational digital project taking place in the Scottish Borders and East Lothian. Also, the experience the Old's Cool Project run by the Citadel Youth Centre was shared and thoughts from Generations Working Together gathered before the workshop.



**Benefits of generations being digitally connected**

- Younger generations can offer **assistance** to help older people who are less tech savvy to use it.
- Increase **social connectedness**
- A way to **keep in touch** with other generations and find new friends from all over the country or further afield.
- Improve **quality of life** for both generations
- A way of building a new relationship and enhance a younger person life and build their **confidence and self-esteem** so it's a **two-way win**.



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Love later life



**Benefits of generations being digitally connected**

- A way to **close the digital divide** and overcoming barriers that people may have to taking up technology.
- Older adults are more likely to experience **isolation and loneliness** but younger people feel this too and intergenerational work may help to reduce this.
- Technology can also **help bridge intergenerational divides**.
- **Shared goal:** Can work together with younger generations on a project such as keep our pavements safe or an environmental one using photography and online connections.



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### Some key points

#### Challenges include:

- Connectivity and lack of access to devices / support to get online.
- Patience of younger people when older people need longer processing time.
- Some older people unwilling to give it a go – so as not to look like they don't know what they're doing or just because they prefer face to face.

#### Top tips from participants for connecting generations digitally:

- Don't underestimate preparation time.
- Build this into funding applications as well. Takes a lot more time than organising face-to-face events.
- Have a Zoom practice session, to give people chance to press buttons and see what happens, to build confidence before doing their meetings online.
- Try to be aware of how people may be feeling online and check in regularly
- It is a learning curve for everyone, including the younger generation. The skills needed online are different to Instagram/Tiktok/Snapchat.
- Provide and encourage people to use headphones if possible as hearing can be an additional challenge.

**Sources of support** (in addition to participating organisations)

[Community Makers](#)

[Institute for Community Studies](#)

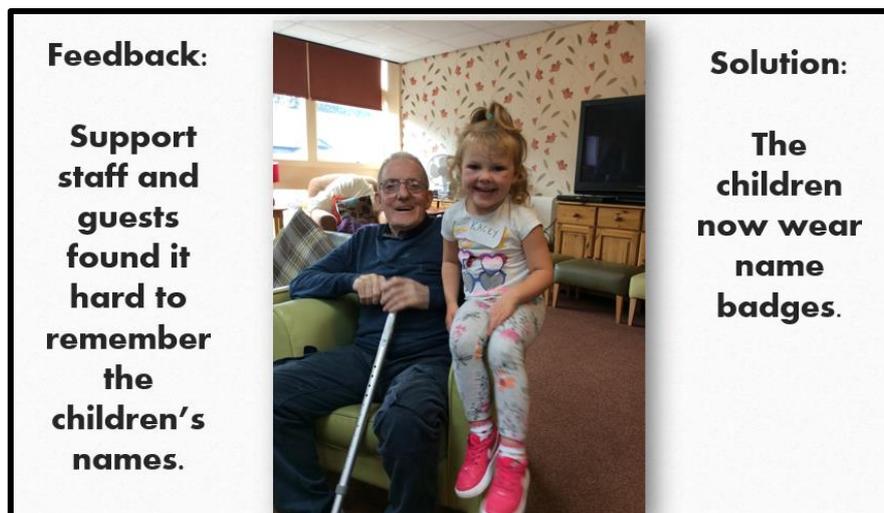
"In a nutshell, digital intergenerational work has its challenges, but it's super rewarding and lots of fun!" **Young people from Citadel Youth Centre**

## Workshops: Topic 4

**Intergenerational fun and games in the Anam Cara Dementia Respite Centre - Claire Mills, [Anam Cara](#) and Sarita Taggart, [St Bridget's Primary School, Kilbirnie](#)**

### Background

This intergenerational project between St Bridget's Nursery and Anam Cara Dementia Respite Centre grew (as so many great projects do) out of an organic relationship formed between Sarita and Claire. Sarita was passing and asked if intergenerational visits would be something of interest. Though the project is no longer running because of Covid (and due to Sarita moving away), the overwhelming learning was that intergenerational visits bring JOY!



### Some key points

- Everyone is included, the children and adults can play or just simply sit, have a cuddle and enjoy each other's company. Children and adults also bond over music, there is singing and dancing. Children gravitate towards the adults.
- Through this intergenerational relationship between the nursery and the centre, musicians have been invited to compose songs. The whole project has brought Anam Cara members more into their community.
- The nursery visits promote physical activity with the Anam Cara residents, games such as skittles encourage the adults to move and have fun. The children walk with nursery leaders to Anam Cara, and this provides exercise for them too.
- The children and adults have a natural empathy for each other. One child who was non-verbal and autistic found comfort and companionship in an older lady of Anam Cara.
- Participants felt sad that visits, such as the intergenerational visits seen during the workshop, could not continue due to 'risk aversion' in the current covid climate.
- Participants agreed that a successful relationship should be based upon both parties giving an equal amount to making intergenerational visits work.

## Some feedback from participants

**“I liked hearing from the keynote speakers and then going into the workshops to look at things in more detail. The key speakers were very inspirational and thought provoking.”**

**“There are a large number of organisations all striving to provide excellent support for people and carers of people living with dementia”**

**“Good to be with kindred souls”**

**“Together we can do anything. It was inspiring to hear from people with experience of caring for someone living with dementia and also from those living with dementia themselves”**

**“There was a chance for all the participants to have a voice. The facilitation of all the workshops I attended was excellent.”**

**All concerned did a wonderful job of planning and delivering, no mean feat in this daunting digital age - well done and thank you!”**

**“Being given opportunities and a voice is priceless and I can't thank you and Age Scotland enough for that”. (Speaker and workshop leader with lived experience of dementia)**

