

Getting
On ^{with life}

GO Programme A Guide for Facilitators



THE UNIVERSITY
of EDINBURGH



Welcome to the GO programme!

“You’ve got to get out there and live your life - you are still you”
- Eddy who lives with dementia

Getting on with Life (GO programme), enables people living with dementia to build the confidence and contacts they need to live the life they want to live in the best way possible. GO is a seven week programme which people living with dementia have helped to create and test out. Throughout this Guide you will see quotes from them, such as the one above from Eddy.

This guide focusses on an online approach, but it could be adapted for in-person delivery.

Building relationships is at the foundation of the GO programme because that is how human beings function best – we all need each other. It seeks to build a supportive community where people can share experiences, learn from each other, and cry and laugh together.

This booklet is a guide for those who are running a GO programme. You may be a Dementia Advisor, a Community Psychiatric Nurse or a support worker with a charity or other locally commissioned dementia service. You might also be a person living with dementia yourself.

If you are supporting people with dementia, the GO programme can enhance the care you give by providing a different way of engaging with people rather than creating additional work. It is time-efficient, in that you can work with a group of people living with dementia, supporting them to support each other and build on each other’s strengths.

Facilitation takes approximately two days per week with co-facilitation taking half a day a week during the seven weeks the programme is running. Costs are minimal: simply printing the pack for participants, postage and providing folders and (optional) mugs.

The online format means that guests who have been living with dementia for longer can join and share their experiences and solutions.

*“You come seeking help but then
you become a helper and help others”*
- Mark who lives with dementia

This Guide contains all the guidance and materials you need to run the programme.

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Programme essentials

The approach to facilitation

The approach to facilitation is key to the success of this programme. The facilitator's attitude towards people with dementia is their most important attribute, and this is embedded in the values and principles outlined below. Previous experience of working with people with dementia will be helpful, but an in-depth knowledge of the medical aspects of dementia is not required. Medical questions may come up during the course of the programme and links to relevant accessible information that can be used are included in this Guide (see the appendix headed Useful Links).

It is the responsibility of facilitators to create a safe online space and ensure that everyone on screen has their voice heard. People living with dementia have identified core values and principles that will help GO facilitators. In essence, this is about having an enabling and positive attitude, and seeing potential in each person rather than focussing on problems.

Click on the link below to get started:

Part 1: Nature and core values of the GO programme

<https://bit.ly/3td9Kwd>

GO programme values

- Personalised goals – there isn't a one-size-fits-all approach. Those who take part set their own goals. The GO programme helps build the skills and confidence to reach those goals
- Everyone who comes already knows things and has experience to share
- Everyone who comes can teach things – we all have solutions to common problems we can share with each other
- Everyone can learn from each other

GO programme principles

To put the core values into practice, these are the principles identified by people living with dementia.

Provide a safe space

- Offer a warm welcome
- Have fun but also be serious about some things too
- Allow us to express emotions and grief for the things we have lost
- Help us to help each other

Provide a respectful space

- Run sessions in a way that enables everyone to contribute
 - verbally and in other ways appropriate to individual abilities
- Make time for talking and asking questions
- Respect us and never treat us like children
- Recognise that yes, we have dementia, but we've got a life to live
- Accept us – friendliness and 'no-judgement' are the most important things

Provide an enabling and safe online space

- Provide an accessible Zoom guide and offer 'practice runs'
- Give us a weekly preparation call to tell us about the topic of the week
- Use 'I want to speak cards' (See more on Appendix 1)
- Limit the number of faces on screen – 2 facilitators, 4 participants, plus a guest
- Limit the time to one hour
- Send a letter every week summarising what happened
- Make a follow up call after the Zoom call

The role of the facilitators

Lead facilitator's role

- Prepares the GO programme with each person joining (see next section)
- Sends out the weekly Zoom link, making the assistant facilitator co-host
- Admits and welcomes each person
- Facilitates the weekly sessions
- Follows up anyone who was upset with a phone call after the session
- Sends out a personalised summary of the session afterwards to each person on the letter template, colour coded for each week accessed here under 'Our publication': [GO Weekly Letter](http://www.innovationsindementia.org.uk/resources/our-publications/)
<http://www.innovationsindementia.org.uk/resources/our-publications/>

Co-facilitator's role

- Takes notes during the session for the facilitator to write up as a personalised summary for each person
- Telephones anyone who is having trouble connecting, to give support
- Is available to telephone anyone who might be upset during the Zoom session if needed
- Gathers a list of hints, tips and strategies shared each week by people living with dementia. These can be added to the list of examples in the appendix called 'Hints, Tips and Strategies' (gathered during the development of the GO programme), and shared with everyone on Week 7 as part of the celebrations

Specific issues that require consideration

During the development of the GO programme people living with dementia gave guidance on the following issues. These need some careful and sensitive consideration.

Care partner's role

The focus of the GO programme is on the person with dementia and enabling them to have their voice heard. This means that in most cases, where there is a care partner, they will not be visible on screen during Zoom sessions. However, he or she may be sitting in the background within earshot if the person with dementia chooses. However, care partners do have a vital role to play and it is important for the lead facilitator to build a relationship with them during the preparation stages. A care partner's role may include some or all of the following:

- Supporting people to get online and join a Zoom call
- Supporting the person with dementia after the Zoom session with any difficult emotions that have been raised by the discussion
- Supporting the person with dementia with their memory of the Zoom discussion
- Providing a sense of security for the person with dementia when meeting new people
- Giving their perspective on ways the person with dementia is benefitting from the GO programme, or any problems with it

The level of involvement of care partners needs to be considered on an individual basis. Sometimes the care partner will need to be present on screen to ensure that the voice of the person with dementia is fully included and heard. This is the exception rather than the rule, and needs to be carefully managed.

Below are some pointers for including care partners on screen during the GO programme.

- Preparation – ensure that, from the outset, the care partner understands that the focus is on the person with dementia and the aim is to support them to have their say
- Explain in advance to other participants that a care partner will be present on screen in a supportive role
- The care partner should sit slightly behind the person with dementia when on screen, so that visually the focus is on the person with dementia
- The facilitator should address the person with dementia by their name when inviting them to speak, so it is clear who is being invited to speak
- The care partner should hold up a yellow ‘I want to speak card’ and only speak when the facilitator invites them to do so
- If the care partner is speaking too much, the facilitator needs to step in and ask them to allow the person with dementia to speak
- When the care partner and the person with dementia want to speak with each other, they should show their yellow card to each other and then mute Zoom – there should be no conferring out loud. The facilitator needs to make the decision about whether to wait for them or move the conversation on
- It is acceptable for the facilitator to use their authority to mute a couple who are talking to each other on screen. The noise can be difficult, especially if some participants experience hyperacusis. The Zoom mute function is one advantage of being online!
- Care partners may be unaware that they are taking over. The facilitator’s role is to raise their awareness and ask them to stop talking and allow others to speak

- If a facilitator is inexperienced, they should shadow an experienced facilitator and practice role play with an experienced facilitator. Experienced facilitators can be contacted via the DEEP network
<https://www.dementiavoices.org.uk/>

While the GO programme is designed specifically for people with dementia, supporting care partners is clearly central to this. Care partners who continually take over may not be coping, and facilitators need to be ready to support them too. Here are some additional strategies for supporting care partners as an integral part of the GO programme:

- Run at least one separate session where care partners can meet together and share contact details, if they wish, for ongoing peer support
- Be aware of local support for carers and signpost to them
- Encourage care partners to continue engaging with activities they enjoy to lift any sense of despair and hopelessness and bring some joy
- Refer to the Getting Along programme. The Getting Along programme is for any person /couple who is adjusting to getting along with other people when living with dementia. Contact **Damian Murphy** at damian@myid.org.uk

“The earlier (after diagnosis) that people talk about the emotions that dementia brings up, the better”

- Michael who lives with dementia

Providing emotional care online

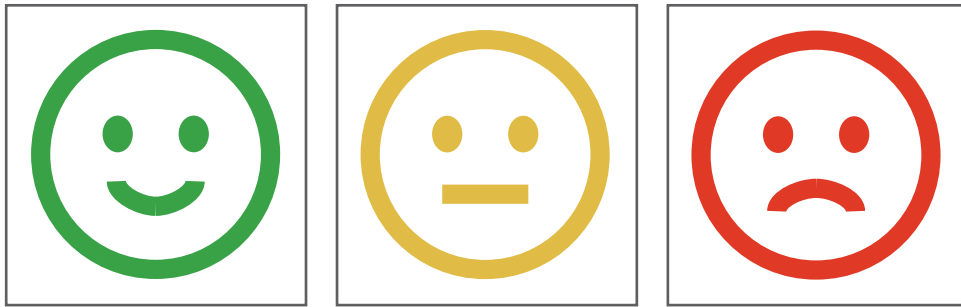
When people with dementia get together, they will often open up about their feelings and people can become upset. As a facilitator, your role is to create a safe space for this to happen. Here are some guidelines created by people with dementia to enable a safe space for people to express their emotions in an online session:

- Offer each participant a weekly preparatory session. This helps you to anticipate and prepare for emotional issues that may arise when online, and reassure them that there is no shame in sharing emotions
- Actively listen to ensure the person feels heard
 - Acknowledge the emotion, don't ignore it
 - Body language – lean forward
- Gently bring other participants into the conversation, so they can support the person with any shared experience. People with dementia are the best people to support people with dementia
- Pause and ask the person who is upset, or who has shared something painful, if they would like to take a break
- Offer a phone call with the co-facilitator at that moment
- Finish the online session on a positive or light-hearted note
- Follow up after the session with a phone call

Reflecting on how the programme is working

Part of running any programme is to reflect on how it is working, understanding how people are benefitting and if there are any problems. When working with people with memory problems, this needs to happen in 'dementia time', i.e. in the moment (rather than asking people at the end of the seven weeks how they found it). People with dementia have advised

us that, at the beginning and end of each online session, it is helpful to ask them to identify where their emotions lie, using the scale below:



If there is a change during the course of the session, then it is important to ask them what has caused the change. If someone is feeling more cheerful than at the beginning, that is great. But if they are feeling sad, this can be followed up in a post session phonecall, to check how the person is and if any additional support is needed.

People with dementia also advised us to ‘watch and learn’ how the programme is going, based on the relationship you have built up with each person. This could involve observing how the group are supporting each other, and how individuals are changing over the week, for example becoming more confident, or more accepting of their dementia by being more open about it with family and friends.

At the end of the seven weeks, one measure of success is whether people have achieved the personal goals they set for themselves at the outset. If personal goals are achieved, great! If not, it is not a failure because we also need to remember that life happens, people get ill, dementia can get worse, there might be a lockdown!

It is also acceptable to ask care partners about any changes they have observed in the person with the diagnosis of dementia.

As Michael told us:

*A carer can't speak **for** me. They can speak **about** me. They can see how my moods change, and the wider perspective. They can certainly have a very big role to play in assessing the benefits of the GO programme.*

What happens when the seven week programme finishes? i.e. Week 8

When the GO programme was being developed with people with dementia, they said that we need to consider what happens to people in Week 8, i.e. after the programme finishes. An important part of the preparation and planning is to find out what each person would like to be connected into once the seven week programme ends. This means identifying people or groups that each person can connect with and inviting them to attend Week 6 of the GO programme. Week 6 works like a 'virtual marketplace' with people meeting and sharing information. This requires a bit of homework in finding out what opportunities are available, either in person locally or online. It also requires meeting up with potential invitees before inviting them to attend the Week 6 'virtual marketplace' – to ensure their values and principles and attitudes towards people with dementia align with the values and principles of the GO programme.

Support for facilitators

We recognise that, although many will be happy to facilitate the programme independently, any new resource might be a little daunting to others. Our colleagues, Innovations in Dementia, who helped in the creation and testing of the GO programme would also be able to offer shadowing opportunities for you to deliver your first programmes alongside experienced GO facilitators. For more information, contact: Damian@myid.org.uk

Getting ready for the GO programme

This section covers all the steps you need to think about when setting up a GO programme.

Click on the link below to get started:

Part 2: Preparing the programme

<https://bit.ly/3JrHJqj>

The 'Weekly Material for GO Facilitators' is a step by step guide for each of the seven weeks of the programme. The 'Material for GO Participants' contains preparation material for use before Week 1 and for each of the seven weeks of the GO programme for participants. This works hand in hand with the 'Weekly Material for GO Facilitators'. Familiarise yourself with both sets of materials.

Invitation

We know that receiving a diagnosis of dementia can be an anxious time for many people, with a lot of information to process. Some people want to find out more about dementia, and seek support right away. Others need more time to adjust before they seek help. Frequently people do not know where to turn to get help or what kind of help they need or want.

The GO programme is suitable for those who have received a diagnosis and can be started when they feel ready. If you can identify four people with dementia who would like to take part, set some dates and start preparing! Consider people who are on the margins and not accessing support. A mix of ages is acceptable. However, if there is an opportunity to run a programme for people with early onset dementia, this may be appreciated. There are common issues across age groups, but there are also some age-specific issues in younger age groups, such as parenting younger children and loss of income due to early retirement and the shock of getting a diagnosis at a young age. Also, it is important to consider how the life circumstances, goals and personalities of the individual participants will work together. This is a judgement call that will be based on getting to know people before the Zoom sessions begin.

Guest speakers

One of the best ways to adapt to a diagnosis of dementia is to learn from other people who are also living with dementia.

“Seeing others with dementia living well gives you hope”

- Eddy who lives with dementia

Guest speakers on the GO programme are people who have been living with dementia for a while and who have found ways of adapting that they would like to share with others. They come along and take part in the discussion along with everyone else, sharing their experiences. A different guest can be invited each week and then they can all be invited back for the second half of the celebration on Week 7.

“It was so interesting to listen to other people with dementia on the GO programme and all the things that they were doing”

- Carla who lives with dementia

As a facilitator, you may already know people you would like to invite along as a guest speaker. If not, DEEP (The UK Network of Dementia Voices) can put you in touch with someone who would like to help.

Contact **Rachel Niblock** (DEEP Coordinator) at niblock@myid.org.uk
Call: 07720 538851

Access to technology

Many people already have access to technology. For those who don't, there are a number of schemes nationally and locally supporting digital inclusion:

- **Scottish Government** <https://connecting.scot/>
- **Age UK** <https://www.ageuk.org.uk/our-impact/programmes/digital-skills/>
- <https://www.citizensonline.org.uk/digital-champions/>

Preparing for participation

The lead facilitator takes three steps:

Step 1

Send out the 'Materials for GO Participants' to each person living with dementia

Print out the 'Materials for GO participants' (see page 29 headed 'Materials for GO participants'). Insert the pages in a ring binder folder for each person and post them out. If preferred, they can be emailed. This folder then forms a personalised record for them to keep.

As a way of creating a sense of togetherness, you can also send everyone the same mug to drink from during the Zoom session.

This is a checklist of all the materials to send out:

Materials	✓
Cover letter from your organisation/you	
Glossary	
Before we begin...	
Creating community (Optional)	
Values and principles	
Zoom Guide	
Programme outline with dates	
Weekly sheets 1 to 7	
'I want to speak' card	
Mug (optional)	

*“The GO programme folder made you feel, yeah,
this is all going to be okay, I can manage this”*

- Sophia who lives with dementia

Step 2

Practise using Zoom with each person

Ensure everyone knows how to connect via Zoom. An accessible guide is provided in the participants' pack. Before the weekly GO Zoom sessions start, set up a Zoom practice session with each individual participant and their care partner where applicable.

Step 3

Get to know each person and how best to support them

A key ingredient of success is to build a relationship with each programme participant. This involves understanding what they hope to get out of the course, and what support they need to enable them to take part online. It also involves identifying what or who they would like to connect with after the seven weeks, so you can start identifying people to invite to the Week 6 'marketplace' session.

Before the Week 1 session, spend time getting to know and finding out a little about each person individually. This might be on Zoom or over the phone, whichever they prefer. Use the 'Before we Begin...' template to guide this conversation.

Preparation is essential for enabling each person to contribute in the weekly sessions. Word finding difficulties and losing the thread of a conversation are common with dementia, especially in a group situation. To support and enable communication, it is the facilitator's responsibility to find out what helps each person with dementia to be included. Guidance is given above on how to manage this where a care partner will be involved in online sessions.

The facilitator should contact each participant in advance of the weekly session to rehearse with them what they would like to say. There are various options for supporting communication:

- The facilitator can note the responses the person would like to make to the weekly questions and provide support by bringing in these points or gently prompting the person to bring them in
- The person with dementia may make notes in advance of the group Zoom. Some people find this helpful, although others do not as they may have issues with reading
- Involve care partners. The GO programme is focussed on people with dementia, and in most cases their care partner will not be on screen in the weekly Zoom. However, some people will need their care partner to support them to take part fully. (See above in the 'Approach to facilitation' for further guidance on managing a care partner's role)

Once you have worked through steps 1-3 with each person participating, you are ready to begin the weekly sessions. Have a look at the video below for a recap about preparation and an outline of each week.

Part 3: Delivering and facilitating the programme

<https://bit.ly/332adqr>

Weekly material for GO facilitators

Each week of the GO programme covers a different topic:

- Week 1: A warm welcome
- Week 2: Making sense of what is happening
- Week 3: Relationships
- Week 4: Restoring confidence to live well with dementia
- Week 5: Being valued and respected by others
- Week 6: Getting on and living your life
- Week 7: Celebrating achievements

Below is a guide for each week of the programme. These work hand-in-hand with the 'Material for GO participants'. Refer to these materials when preparing each weekly session. Times given for each activity are approximate guides. What the participants want to talk about determines the focus of the discussion.

Part 4: Overview of the GO programme

<https://bit.ly/3fhCXh2>

Week 1 A warm welcome

Objective: To establish a community in a safe space online.

Outcome: A community is established where people are connecting in ways that suit them best.

Preparation in advance of the group Zoom session

Contact each person to prepare:

- Brief introduction – Who am I?
- Hopes and worries in preparation for the session

On-line session

Welcome (15 mins):

- Admit everyone to the online meeting and ensure that video and sound are working and everyone has a yellow card. Ice-breaker e.g. if you are having a cuppa, what biscuit do you like to dunk? (Take a note of the biscuit to send out for the celebration on Week 7)
- Check in with the emoji scale
- Introductions – Who am I?
- Welcome the guest and introduce

Hopes for the programme (15 mins):

Share personal hopes/goals for the programme (bring in what was shared in preparation sessions).

Worries about the programme (15 mins):

Ask people to talk about any worries/anxieties they have about the programme. This may bring up their questions too.

Recap (5 mins):

Go through people's hopes and worries and link these to the sessions over the next six weeks.

Take away message (10 mins):

- Ask each person what they will take away/do differently after the session
- Check out with the emoji scale
- Outline of next week and goodbyes

Weekly personalised summary letter to everyone

Week 2 *Making sense of what is happening*

Objective: To provide an opportunity for people to bring their questions and make sense of some of the issues they are facing since diagnosis. Learning from the knowledge and experience each person brings.

Outcome: Participants have a better understanding of what is happening to them, and misconceptions and myths are explored.

Pre-session contact with each participant

Contact each person to support them to think about:

- What questions do you have about dementia?
- What have you learned about living with dementia that would help others?

On-line session

Welcome (15 mins):

- Admit everyone to the online meeting and ensure video and sound are working and everyone has a yellow card
- Introduce the guest
- Check in with the emoji scale

Recap from previous week (5 mins)

Questions (15 mins):

Ask each person to talk about the questions they have about living with dementia, ensuring everyone has an opportunity to speak if they would like to. Some questions might have been picked up in the previous week – go back to these too.

Any answers (15 mins):

- Address each of the questions, where possible allowing an opportunity to learn from each other and the guest
- Identify any written material/links that seem appropriate and helpful to address the questions. These can be sent out afterwards

Take away message (10 mins):

- Ask each person what they will take away/do differently after the session
- Check out with the emoji scale
- Outline of next week and goodbyes

Weekly personalised summary letter and information sheets to everyone

Share links to relevant Dementia Diaries/printed material or other useful material from e.g. Alzheimer's Society

Week 3 Relationships

Objective: To explore the changes being experienced in relationships and find strategies for getting along in healthy relationships.

Outcome: Understanding of the value of staying connected and strategies for achieving it.

Pre-session contact with each participant**Contact each person to support them to think about:**

- What changes have you experienced in your relationships with family and friends since your diagnosis?
- What has helped you to continue to get along with family and friends?
- If they wish, help them identify a care partner or friend they would like to attend the online session with them
- In preparing for this session where care partners are invited, refer back to the guidelines on p.7 for including care partners in online sessions and ensuring people with dementia have their voices heard in a balanced way alongside care partners. Also, refer to the guidance on supporting care partners with their needs

- Some participants may choose to come without a care partner. It is your responsibility as facilitator to include them by bringing them into the discussion with their perspective

On-line session

Welcome (15 mins):

- Admit everyone to the online meeting and ensure video and sound are working and everyone has a yellow card
- Introduce the guest
- Check in with the emoji scale

Recap from previous week (5 mins)

Getting along (20 mins):

- As a group, talk through the changes people have experienced in their relationships with family and friends since their diagnosis, including issues related to speaking and communicating
- Introduce the Getting Along video and watch it

Talk about what people thought of the video (10 mins):

Gauge interest in doing the Getting Along programme and connect them up with **Damian Murphy**: damian@myid.org.uk

Take away message (10 mins):

- Ask each person what they will take away/do differently after the session
- Check out with the emoji scale
- Outline of next week and goodbyes

Weekly personalised summary letter and information sheets to everyone

Getting Along video:

<https://www.youtube.com/watch?v=gEe9NbCq2Pg>

Week 4 *Confidence to live well with dementia*

Objective: To consider what participants still enjoy doing, the strengths they have, and how they can adapt to change. Introduce a positive role model.

Outcome: Increased confidence and a mindset of 'what I can do.' Change happens but I'm still me!

Pre-session contact with each participant

Contact each person to support them to think about:

- What are your strengths?
- What do you like doing? What makes you happy?
- What ways have you found to adapt to your diagnosis and do the things which make you happy?

On-line session

Welcome (15 mins):

- Admit everyone to the online meeting and ensure video and sound are working and everyone has a yellow card
- Introduce the guest
- Check in with the emoji scale

Recap from previous week (5 mins)

Building confidence (25 mins):

- Ask each person what still gives them joy
- Help them identify the strengths they are drawing on to adapt to their diagnosis and continue doing what they like doing
- Bring the guest into the conversation
- Begin to introduce the idea of Zoom Communities and what this looks like in our 'new normal'. Share examples of some of the things people with dementia are doing e.g. DEEP groups

Take away message (10 mins):

- Ask each person what they will take away/do differently after the session
- Check out with the emoji scale
- Outline of next week and goodbyes

Weekly personalised summary letter to everyone

Week 5 *Feeling valued and respected*

Objective: To raise awareness of dementia as a hidden disability and to help people identify areas of their life that are not easy because of dementia. To develop the confidence to speak up so that they can feel valued and respected as a person.

Outcome: Participants can identify aspects of their life that are more difficult due to dementia and feel more confident to speak up and ask for help to make life easier.

Pre-session contact with each participant

Contact each person to support them to think about:

- What has become more difficult since having dementia?
- What would make this easier?

On-line session

Welcome (15 mins):

- Admit everyone to the online meeting and ensure video and sound are working and everyone has a yellow card
- Introduce the guest
- Check in with the emoji scale

Recap from previous week (5 mins)

Dementia is a hidden disability - What has become more difficult for you that others might not realise since it is not visible? (15 mins):

- Ask people for examples of things that have become more difficult due to dementia – e.g. processing information, replying quickly to questions
- It can be helpful to give an example of how life is eased for someone with a visible disability who uses a wheelchair by having disabled access to a building. The equivalent for someone with dementia might be a health professional speaking a bit more slowly when giving information and providing them with written information that is easy to read

What would make this issue easier for you? (15 mins):

- Share strategies for making life easier so that you can feel included in your family and community, and valued and respected as a person
- Draw out the importance of co-operating with family or friends – doing things together – e.g. going out to a restaurant and looking at the menu in advance; making a meal together. Talk about doing the things you can still do and getting help with the things that are trickier – co-operative actions. We all need help sometimes – asking for help is OK – it's not a failure

Take away message (10 mins):

- Ask each person what they will take away/do differently after the session
- Check out with the emoji scale
- Outline of next week and goodbyes

Weekly personalised summary letter and information sheets to everyone

Share the link of Hidden Disabilities Sunflowers:
<https://hiddendisabilitiesstore.com/>

Week 6 Getting on and living your life

Objective: To set up a 'virtual marketplace' to support GO participants to tap into support locally, in person or virtually, in a way that best suits them and their interests so they have something to move on to. Preparation needs to start when personal goals are being set (see Week 8 section).

Outcome: Each participant has a plan, matched to their personal goals, of what they will do after the programme ends and where to get help if needed.

Pre-session contact with each participant

Contact each person to support them to:

- Discuss possibilities in their local area for staying connected and remind them that this will be discussed in the group
- Ask each person to think about what the next steps are for them
- Get contact details from those who would like to keep in contact with the group

On-line session

Welcome (15 mins):

- Admit everyone to the online meeting and ensure video and sound are working and everyone has a yellow card
- Introduce the guests
- Check in with the emoji scale

Recap from previous week (5 mins)

Getting on and living your life (25 mins):

Ask each 'virtual marketplace' presenter to talk about what they do and how participants can connect with them once GO finishes.

Take away message (10 mins):

- Discuss what each member is looking forward to doing next
- Ask members if they know of other resources in the community that they want to share with the group
- Check out with the emoji scale
- Outline of next week and goodbyes

Weekly personalised summary letter to everyone

This will include a 'Where next?' personalised plan for each participant based on what they have said. It may include setting up a phone call with those they want to connect with. Include their favourite biscuit/cake identified in Week 1 for the celebration next week.

Week 7 Celebrate achievements

Objective: To celebrate what each person and the group has achieved over the last six weeks along with all the visiting guests

Outcome: People leave with a sense of achievement and purpose and the confidence to go forward in their lives

Pre-session contact with each participant

Send out a pack of their favourite biscuits from Week 1

Contact each person to support them to:

- Think back to their hopes for the programme (remind)
- Think about next steps?
 - Learning a new skill?
 - Adopting a fresh outlook on life?
 - Gaining more confidence in something?
 - Making a new connection?
- What can we do to improve the programme for others?

On-line session

Welcome (15 mins):

- Admit everyone to the online meeting and ensure video and sound are working and everyone has a yellow card
- Check in with the emoji scale

Recap from previous week (5 mins)

Celebrate achievements (25 mins):

- Go back to people's hopes and goals for the programme. Go through them and check out the extent to which they have been achieved
- Ask each person about possible next steps for them. Prompt learning a new skill, a fresh outlook on life or more confidence as examples
- Remind everyone of the hints/tips/strategies that people have shared over the previous weeks and the questions that have been answered – in a celebratory way to affirm the contributions that have been made
- Discuss any feedback about what could improve the programme for others

Welcome back guests from previous weeks for a final farewell (10 mins):

- Check out with the emoji scale

Weekly personalised summary letter to everyone

This will include a 'booklet' that compiles all the hints/tips/strategies that people have shared over the previous weeks and the questions that have been answered, as a celebration of what has been achieved.

Below are hints, tips and strategies that have been discovered from experience and shared by people living with dementia who have already taken part in the GO programme. They can be used to add to your booklet and as a source of inspiration for facilitators during the 7 weeks.



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Materials for GO participants

The below listed materials can be found on the following pages:

- Glossary
- Before we begin...
- Creating community (Optional)
- Values and principles
- Zoom Guide
- Programme outline with dates
- Weekly sheets 1 to 7

Useful things to know



GO lasts for seven weeks. It aims to explore, with others on the programme, day to day life and experiences of living with dementia. Each week focusses on a specific aspect of living with dementia.



How was the GO programme developed? With funding from the Alzheimer's Society, people living with dementia worked alongside researchers from the University of Durham and the University of Edinburgh and an organisation called Innovations in Dementia to develop the GO programme. GO is based upon what people living with dementia have told us is important to them. Learning from similar programmes in the North East of England and Canada has also shaped GO.



Facilitators are the people who are supporting GO to run smoothly. Your facilitator will support you to take part in the best way for you. This might be via a weekly online meeting or telephone call with your facilitator to prepare for the group session.



Others in the group - There will be four other people living with dementia taking part in the GO programme alongside you each week. Special guests who live with dementia will also join and share their experiences. We hope you will benefit from getting to know people and sharing with people who are in a similar position. Everyone on GO is a teacher (can help others to learn) a learner (can learn things from others) and a knower (has experiences they can share with others).



Zoom is the computer software which we are using to communicate during weekly online sessions. It links together sound and picture from one computer to other computers, no matter how far apart the computers are. Using it can be a bit strange at first, but the facilitator will support you with this - prior to the first session and all the way through the programme.



Your folder is yours in which to keep all the sheets of paper you receive throughout the programme.



“I would like to speak” These yellow cards are there for you to use throughout the online sessions. Hold yours up when you have something you would like to say.

We want to support you to take part and get what you want from the programme. Below are some questions to think about.

_____ will call you on the telephone to discuss them.

What do you need to take part?

- What support do you need to connect to the weekly Zoom group?
- What support do you need to take part in group conversations on Zoom?

Personal Goals for the programme

- What do you still want to do day to day?
- What do you want to achieve?
- What would help you do that?

What would you like to contribute to the programme?

- Life Experience
- Skills
- Strategies you already use



Fancy a cuppa?

In these challenging times when we have been required to be physically separated, staying socially connected has never been more important.

The simple act of having a cup of tea or coffee together, something we have always taken for granted, is so important for building friendship and a source of comfort in difficult times.

You will have received a mug as part of your introductory pack. Everyone taking part has received the same mug.

Each week of the programme, when you are taking part in a Zoom call, we would like to invite you to use your mug to 'have a cuppa' as a symbol of our togetherness.

GO Programme Values

- Personalised goals - there isn't a one-size-fits-all approach. Those who take part set their own goals. The GO programme helps build the skills and confidence to reach those goals
- Everyone who comes already knows things and has experience to share
- Everyone who comes can teach things - we all have solutions we can share with each other to common problems
- Everyone can learn from each other

GO Programme Principles

- Provide a safe space
 - Offer a warm welcome
 - Have fun but also be serious about some things too
 - Allow us to express emotions and grief for the things we have lost
 - Help us to help each other
- Provide a respectful space
 - Run sessions in a way that enables everyone to contribute - verbally and in other ways appropriate to individual abilities
 - Make time for talking and asking questions
 - Respect us and never treat us like children
 - Recognise that yes, we have dementia, but we've got a life to live
 - Accept us - friendliness and 'no-judgement' are the most important things

Zoom is a really useful way to connect. But sometimes it needs a few steps to get it installed and accessible on your device.
We will come to that!

Zoom tips

First of all, here are some tips from Agnes, a person living with dementia:

- Prepare yourself to avoid headaches and fatigue
- Have a drink of water and a snack with you
- If it's too much come off Zoom and a facilitator will phone you later.

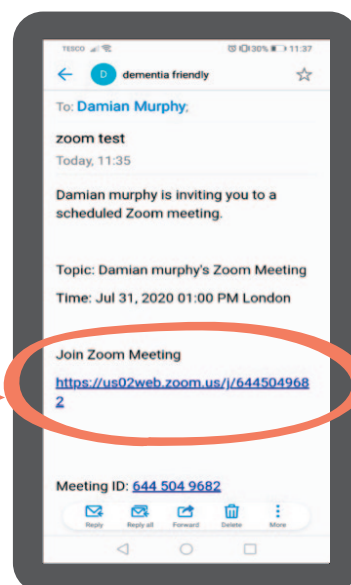
10 STEPS: getting zoom on your device and getting on to a meeting

STEP 1

Sometimes the organiser of the meeting only has to send you an invite by email with a link to click on. For the GO! Programme the invite will most likely look like this:
(this picture is as if the message is accessed by your phone, but you can also access on a computer or a tablet).

If you have Zoom already installed on your device, you should just be able to click on the 'Launch meeting' button and CAN GO STRAIGHT TO STEP 6!

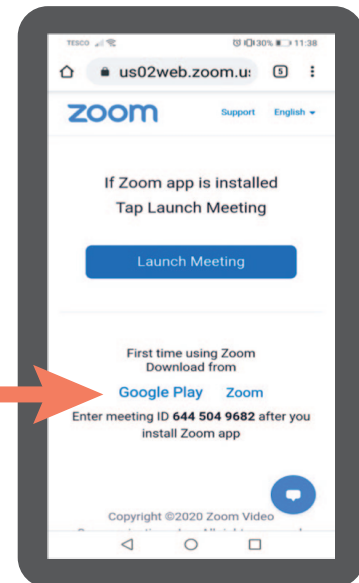
Click this link →



STEP 2

If you don't have zoom, you may receive the option to download it. (here it is on 'Google play' or from 'zoom direct')

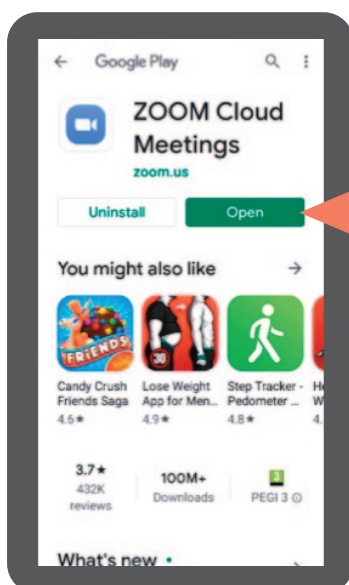
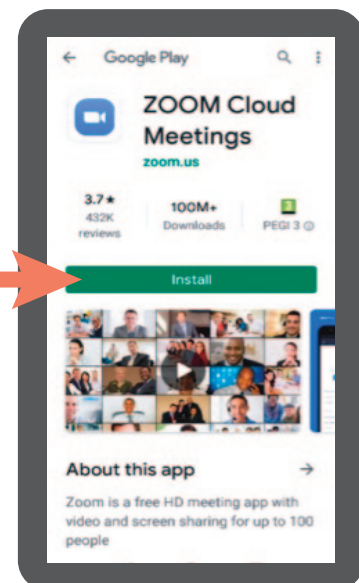
Tap on 'Google Play' to download



STEP 3

Install zoom on your device.

Tap on 'Install'



STEP 4

After about 30 seconds the Zoom app will be installed and your screen will let you know.

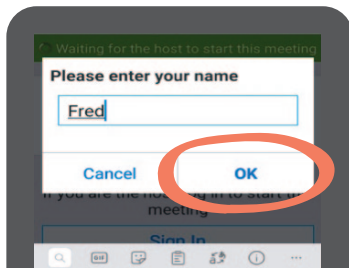
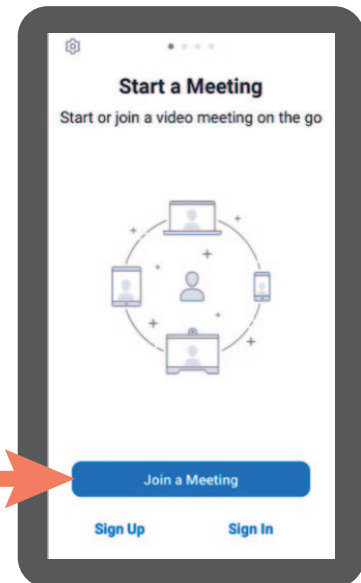
Tap on 'Open'

STEP 5

Once you click open you will see a screen like this. All you have to do now is tap on 'Join Meeting'.

Alternatively you can go back to your original invitation email and tap on the link. That should take you to your meeting.

Tap on 'Join a Meeting'



Insert your name and tap 'OK'

STEP 6

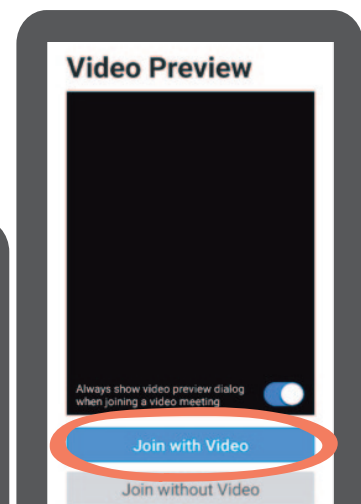
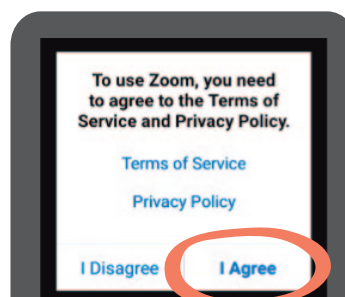
Now we've got to make sure you can be heard and seen!

If this is your first time you may be asked to insert your name so that the meeting host and the others will know who you are!

STEP 7

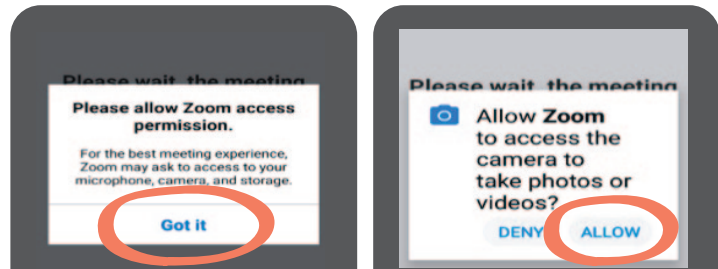
You may then have a short series of screens where you just need to agree to the various permissions requested to ensure the sound and volume and camera works.

Tap on 'Agree' for each, and just tap on 'Join with Video'



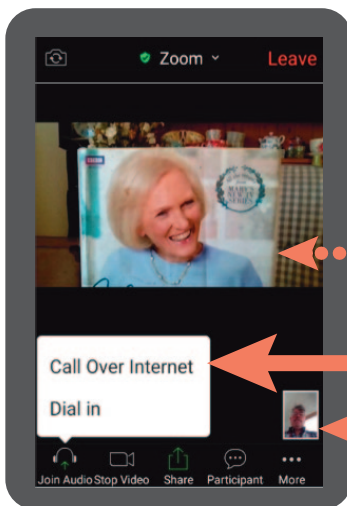
STEP 8

Almost there!
Just tap on
'Got it' and
'Allow' on
the next two
screens if
they appear



STEP 9

Abracadabra!
Any second now you will appear
on screen with your host and other
meeting guests. Like this!



..... Your beautiful host

Just make sure you
tap on
'Call Over Internet'

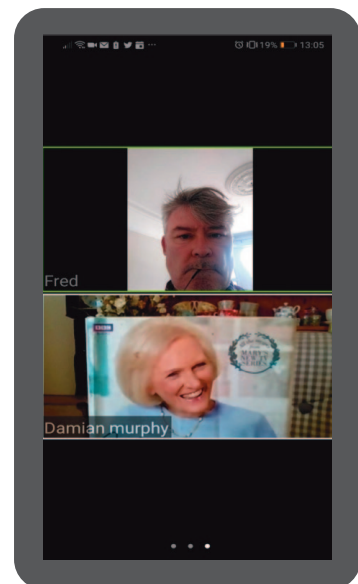
..... You

STEP 10

To see a **'Gallery' view** –
the same size picture for all
participants – just swipe
your screen across from
right to left.

Here you have a gallery view
of your meeting:

All this may seem fairly
complicated but it should only
take a matter of minutes.



If you turn your phone / device horizontally, the images will fill
the screen and you will see larger images of the participants.

These are all examples from an **Android** mobile phone.

For a look at some simple videos about downloading zoom and accessing meetings via an **iPhone** have a look at these.

‘Get Zoom onto your iPhone’

https://youtu.be/jT0t7eNj-_c

‘Joining a Zoom meeting on your iPhone’

<https://youtu.be/goknDTsE-Kk>

You can also enjoy this short video made by Frances from the Zoomettes group who meet weekly by Zoom.

<https://www.youtube.com/watch?v=iIK0WAS3Kt4>

From to

Week 1

Day Date Times

A warm welcome:

Getting to know each other. A chance to look at where you are now and address some questions and hopes for this programme.

Week 2

Day Date Times

Making sense of what is happening:

A chance to ask and answer questions about living with dementia. To learn about symptoms and experiences we share – and some we don't!

Week 3

Day Date Times

Relationships:

This week we will be thinking about how relationships can change when you have dementia and considering ways of continuing to get along well with family and friends.

Week 4

Day Date Times

Restoring confidence to live well with dementia:

A look at building on strengths we still have between us. Dementia is nobody's fault. Change happens but I'm still me!

Week 5

Day Date Times

Being valued and respected by others:

This week we will be thinking about how a diagnosis of dementia can lead to exclusion and how you can continue to have your voice heard and be included in a variety of situations.

Week 6

Day Date Times

Getting on and living your life:

Finding out about local information, support and activities that suit your needs, rights and interests.

Week 7

Day Date Times

Celebrating achievements:

Party time. A chance to celebrate our achievements, to look back at what we've learnt and to look forward to our lives ahead.

In week one of GO we are introducing ourselves to each other and thinking about our hopes and worries about taking part in the programme. Your facilitator will be in touch to help you prepare. Here are some questions to think about:

★ How you would like to introduce yourself to the other participants?

★ What are your hopes for the programme?

★ What are you worried about for the programme?

This week we will be thinking about making sense of your experience of living with dementia. Your facilitator will be in touch to help you prepare. Here are some questions to think about:

★ What questions do you have about dementia?

★ What have you learned about living with dementia that would help others?

This week we will be thinking about some of the effects a diagnosis of dementia can have on relationships with family and friends and the importance of getting along with each other. Your facilitator will be in touch to help you prepare. Here are some questions to think about:

★ What changes have you experienced in your relationships with family and friends since your diagnosis?

★ What has helped you to continue to get along well with family and friends?

Change happens to us all. This week we will be thinking about the strengths we have that enable us to adapt and continue to find joy in life. Your facilitator will be in touch to help you prepare. Here are some questions to think about:

★ **What stops you from feeling confident?**

★ **What are your strengths?**

★ **What do you like doing? / What makes you happy?**

★ **What ways have you found to adapt to your diagnosis and still do the things you like doing which make you happy?**

Dementia is a disability that is hidden. This can mean you don't get the support you need to make life a bit easier and you can feel left out. For example, replying quickly to a question can become difficult and you can be left out of conversations. An example of support might be people speaking more slowly and giving you time to reply.

This week we will be thinking about aspects of life that are more difficult due to dementia. We will talk about how to build confidence to request help to make life easier so you can feel included and valued and respected as a person.

Your facilitator will be in touch to help you prepare. Here are some questions to think about:




★ **What has become more difficult since having dementia?**

★ **What would make this easier?**

This week we are thinking about planning what you would like to do when the programme finishes next week. Your facilitator will be in touch to help you prepare. Here are some questions to think about:

- ★ **What are the next steps for you as the GO programme finishes?**

Let's keep in touch

 Name	 Phone Number	 Email Address



★ Who - which organisation/group I'd like to go to next

★ When they meet

★ How they meet

★ Contact Number / Email

This week is a celebration!
We will be thinking back over the last six weeks, celebrating achievements and everyone's contribution. We want to celebrate the little things as well as the big things. In preparation, please look back at your hopes for the programme that we thought about in Week One which is the red sheet. Your facilitator will be in touch to help you prepare. Here is a question to think about:



★ **Think back to your hopes for the programme**

★ **What are the next steps for you?**

A new skill? A fresh outlook on life? More confidence?

★ **What can we do to improve the programme for others?**

Authors

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Acknowledgments

With special thanks to the GO programme facilitators, Anna Harrison and Dr Joanna Alexjuk from Innovations in Dementia and all the guest speakers living with dementia. Thanks also to Dr Sarah Keyes for contributions to the development of the programme and the underpinning research.

Many people living with dementia and their care partners have contributed to the development of the GO programme. We would like to thank the members of York Minds and Voices, Dementia Friendly East Lothian, and Educate Stockport. Thanks to our co-researchers living with dementia: Jacqui Bingham, Paul Ratcliffe, Michael Booth, Eddy Flory, Elaine Stephenson, Barbara Wileman and those who wish to remain anonymous.

Particular thanks to all those people living with dementia, with the support of care partners, who tested out the GO programme with us. Your time, commitment and insights were invaluable. Thanks too to all the health and social care and voluntary sector employees who helped us find people to invite to a GO programme. We are grateful for a grant from the Alzheimer's Society to fund the development of the GO programme.

Appendices

Appendix 1: Useful links

- To connect with other people living with dementia to share experiences and support each other:
Dementia Voices <https://www.dementiavoices.org.uk/>
- To hear stories about how people living with dementia deal with a range of issues:
Dementia Diaries <https://dementiadiaries.org/>
- For information about medical aspects of dementia including different types of dementia, symptoms and treatments:
Alzheimer's Society <https://www.alzheimers.org.uk/>
Alzheimer's Society Helpline 0333 150 3456
Alzheimer Scotland <https://www.alzscot.org/>
Alzheimer Scotland Helpline 0808 808 3000
Dementia UK <https://www.dementiauk.org/>
Dementia UK Helpline 0800 888 6678
The above websites also have sections on accessing support.
- For information on research about brain health and dementia and how to get involved:
Brain Health Scotland <https://www.brainhealth.scot/>
Join Dementia Research <https://www.joindementiaresearch.nihr.ac.uk/>
- For guidance on how to get support for care partners:
Carers UK <https://www.carersuk.org/>
Carers Trust <https://carers.org/>
Dementia Carers Count <https://dementiacarers.org.uk/>
- Paper copies of 'I want to speak' card can be found at this link:
<https://www.dementiavoices.org.uk/wp-content/uploads/2021/11/I-want-to-speak-card-english.pdf>

The card copies can be obtained directly from **Innovations in Dementia** at:

(Tel.) 01392 420076

(Email) ideas@myid.org.uk

(Postal address) PO BOX 616 Exeter EX1 9JB

(Twitter) @Innov_Dementia

Appendix 2: Hints, tips and strategies

- Get out and about, get exercise and fresh air.
- Acceptance – look for ways to adapt and do things you CAN do.
- Enjoy life more, it is important.
- Be proactive, don't wait for others.
- Advocate for your rights, speak up if you don't receive the treatment you deserve.
- Remember technology, it can take the strain off – Alexa and phone reminders, 'home' on Google Maps.
- "I keep a daily log of what I need to do".
- Automated or sensor lights are helpful.
- Tell your family "Don't take over, I will ask for help when I need it".
- People living with dementia need to be 'allowed' to spend time with other people living with dementia without being under a watchful eye from someone else.
- Patience is the key – don't bite someone's head off when they finish your sentences, remember it is difficult for them too (from the perspective of a person living with dementia).
- Get information in writing (e.g. feedback from doctor or dentist) so you don't have to rely on the memory of someone else and you can refer back to it again.

Appendix 3: Information about the underpinning research

The Go programme was developed and tested in a three-year project funded by the Alzheimer's Society. It draws on previous research by the project team.

- Firstly, it draws on an earlier development of a self-management programme that found that people living with dementia have information and experiences to share with others.¹
- Secondly, through the development of a model of relational care based on co-operative action - a novel approach to understanding the impact of dementia on social networks.^{2,3}
- Thirdly, through the work of colleagues in Canada, who developed self-management approaches for people living with dementia drawing on adult education principles.^{4,5}

- Finally, the intervention development was informed by the approach of our partner organisation, Innovations in Dementia, a Community Interest Group whose mission is to work with people with dementia to inspire different conversations about dementia which shape policy, practice and attitudes. <http://www.innovationsindementia.org.uk/>

The GO programme was developed and tested out over three steps, with each step leading onto the next.

- In Step One, we worked with 23 people living with dementia and 13 care partners across nine workshops to develop the programme content and approach. We developed the GO programme to be delivered on-line through Zoom because the pandemic made it impossible to meet in person and highlighted the need to develop new ways of connecting.
- In Step Two, we tested out the GO programme developed in Step One. We ran the programme four times with a total of 14 people living with dementia who were supported by 13 care partners. Information collected from talking with the facilitators, watching the video recordings of each session and talking with the participants at week seven and after three months helped us refine the programme and understand the benefits to participants.
- In Step Three, we further refined the GO programme in collaboration with eight people living with dementia supported by five care partners at six workshops.

As part of Steps One and Two we also interviewed 31 professionals who work with people living with dementia. This helped us understand how the dementia care pathway varies across localities and is often fragmented and difficult to navigate by both professionals and people living with dementia. It does however indicate that a range of professionals could be in a position to deliver the GO programme in future. A first step is to understand the unique pathway in each locality and agreeing who is best placed to deliver the programme as part of the local commissioning process.

The testing of the GO programme found it to be feasible, acceptable and beneficial in helping participants living with dementia achieve their personal goals and live as well as circumstances will allow.

Further information about the research is available from Professor **Charlotte Clarke** who led the research: charlotte.clarke@durham.ac.uk

We would love to hear about your experiences of using the GO programme. Please contact Charlotte on the above email if you have run a GO programme and if you have any feedback that would help us improve it.

-
1. Clarke C.L., Alexjuk J. & Gibb C.E. (2011) Information in dementia care: sense making and a public health direction for the UK? *International Journal of Older People Nursing* 6:3;237-243
 2. Clarke, C.L. Wilkinson, H. Watson, J. Wilcockson, J. Kinnaird, L. Williamson T. A Seat Around the Table: Participatory Data Analysis with People Living With Dementia *Qualitative Health Research* 2018; 23(9): 1421-1433 <https://doi.org/10.1177/1049732318774768>
 3. Clarke, C.L. Wilcockson, J. Watson, J. Wilkinson, H. Kinnaird, L. Williamson T. Relational Care and Co-Operative Endeavour – Reshaping Dementia Care Through Participatory Secondary Data Analysis *Dementia* 2018; 9(4): 1151-1172 <https://doi.org/10.1177/1471301218795353>
 4. Wiersma, E.C., McAiney, C., Loiselle, L., Hickman, K., & Harvey, D. (2016). Shifting Focus: Agency and Resilience in a Self-Management Program for People Living with Dementia. In Clarke, C.L., Rhynas, S., Schwannaeur, M., & Taylor, J. (Eds.), *Risk and Resilience in Health and Social Care – Global Learning across the Age Span* (pp. 33-46). Edinburgh: Dunedin Press.
 5. Wiersma, E.C., O'Connor, D., Loiselle, L., Hickman, K., Heibein, B., Hounam, B., & Mann, J. (2016b). Creating space for citizenship: The impact of group structure on validating the voices of people with dementia. *Dementia*, 15(3), 414-433. DOI: 10.1177/1471301216642339.

Getting On with life