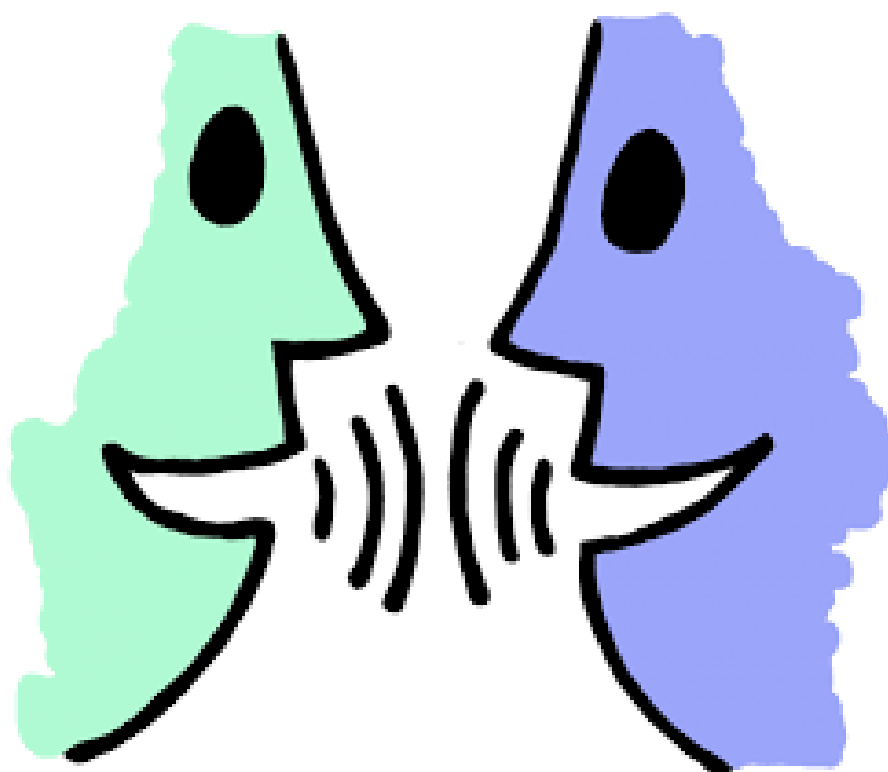


“Who to tell, how and when?”

A HOP Programme

Participant’s booklet



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Introduction

The “Who to tell, how and when?” programme is designed to support people living with dementia¹ who are worried about telling others about the diagnosis.

Programme development

This programme has been adapted from the original Honest, Open, Proud programme written by Professor Pat Corrigan and Dr Jon Larson. It has been developed by Dr Tamatha Ruffell, Dr Jemini Bhatt, Dr Georgina Charlesworth and Professor Katrina Scior at UCL in consultation with the PPI group and the Promoting Independence in Dementia, PRIDE, programme WP2/3.

Throughout the programme you will find quotes from people living with dementia. These have been taken from interviews carried out as part of research studies and have been used to illustrate the different views people living with dementia may have and their lived experience. Some of these you may relate to more than others. They are purely provided as a guide and a way of considering the many positions and viewpoints people may have about this topic.

Overview

This programme is split into three sessions. Each session is about different aspects of sharing a dementia diagnosis:

Session 1: Talking about dementia and the advantages and disadvantages of telling others

Session 2: Who, how and when to tell: your options

Session 3: Bringing it all together

¹ A “person living with dementia” is someone who may have received a diagnosis or someone who is supporting a person with dementia.

Each session will include a discussion of the issues we have covered. The aim of these discussions is to give you time and space to think about whether or not to share the diagnosis, and to consider, if you choose to do so, how you might do this with family, friends, neighbours or acquaintances.

For support on how to tell employers, and the issues that may surround this, please contact the organisations listed on the last page.

Guidelines for each session

Please be aware that during these sessions participants may wish to talk about their own personal experiences.

We ask that you:

- Talk about your thoughts and reactions to sessions with others outside the programme but keep confidential the things you hear from other people
- Be mindful that everyone's opinion counts
- Respect each other

Session 1: Talking about dementia and the advantages and disadvantages of telling or not telling others

Dementia can be difficult to talk about. For many years, doctors have received training on how to tell a person they have dementia, but this is not the case for people living with dementia. People living with dementia are often fearful of telling others, not knowing what to say, or how to say it.

This session looks at:

- How dementia is talked about and the effect of receiving the diagnosis
- The advantages and disadvantages of telling or not telling others

Talking about dementia

What's in a name?

The word 'dementia' describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language.

Many people find it difficult to talk about a diagnosis of dementia. Part of the difficulty can be not wishing to use the word, dementia. It is not unusual for people to use other terms rather than dementia.

"I couldn't even say the word. Since I got my diagnosis I feel as though I don't know where to turn, who to talk to about it." - Jim, aged 62, receiving a diagnosis of early onset Alzheimer's

The effect of a diagnosis

Most forms of dementia do not directly affect a person's personality². However, being given a diagnosis of dementia can affect a person's sense of 'who they are' and their 'outlook' on life.

"I used to be a confident person but since the diagnosis my confidence has been shaken. Now I find it difficult to talk to people and start discussions. I just don't feel like the person I used to be" - Leila

For some, like George below, the diagnosis may lead to difficult thoughts about what this might mean about them and their future.

"I was shocked. Then I thought about all the plans I'd made for my retirement with my wife. I realised it would no longer be possible. Now, much later, I'm enjoying life with my wife but it's different and sometimes I feel bitter about it." - George

² If certain frontal areas of the brain, or connections to them, are damaged, this can cause personality change such as disinhibition, or, at the other end of the scale, extreme apathy.

A person's thoughts and feelings about dementia and the diagnosis may also affect whether they feel able to talk to others. For some it might feel easier to accept the diagnosis and reach out, like Anisha below.

"I finally had a name for what was happening. It was a bit of a relief. It meant I could finally talk to others and get help with the things I was struggling with" - Anisha

DISCUSSION POINTS:

- **What words have you noticed have sometimes been used instead of the word dementia and how has this affected your understanding of dementia?**
- **What does the diagnosis mean for a person's sense of "who they are" and their outlook on life?**

NOTES: _____

The advantages and disadvantages of telling or not telling others

There can be advantages and disadvantages to telling or not telling others.

Below Samira, Raj and Philip talk about the **advantages** they have experienced as a result of **sharing the diagnosis**.

*“When I get muddled with change at my local shop, the shop keeper reaches over to help me. He usually says, “yes that one and that one”, and I say, “thank you very much”. It relaxes me that he knows.” - **Samira***

*“I go sailing with the lads regularly. I have told them about my dementia in case I forget something, just to remind them I am not doing it on purpose and I won’t be offended if they remind me. They understand. It means I can carry on doing something I love.” - **Raj***

*“I’ve told very close friends I have a memory problem so they make allowances and understand.” - **Philip***

However, some people experience **disadvantages**. Here Sarah and William talk about their experiences of losing friends and not feeling listened too.

*“I have lost a couple of friends who do not want to see me anymore. I think that is very hurtful. I am not sure why this is the case. One of them in particular used to be a close friend who I used to see almost every week. It just means that I don’t want to tell other people about it.” - **Sarah***

*“After telling my family, I have been feeling that people have put me down. They don’t listen to my opinion. I don’t want other people to think I don’t have anything to say because of the dementia.” - **William***

For some it might feel like there are **advantages to not sharing a diagnosis**. Below Jane and Nicki talk about their concerns about how they will be seen and what this might mean for them.

“I’m not telling anyone because it’s nice just to be part of a group, as a person and not as someone with dementia.” - Jane

“I am worried that other people will look at me differently. I don’t want people to exclude me or think that I am a burden to them” - Nicki

However, there may be **disadvantages to not sharing a diagnosis**. For Inge it meant that she did not feel able to continue doing the things that she loved.

“I used to have lots of different hobbies that I loved, like knitting and sewing, but now I find it difficult to understand and remember instructions and keep making mistakes. No one offers to help so I’ve just stopped doing these hobbies. I feel really disheartened.” - Inge

DISCUSSION POINT: What advantages and/or disadvantages do you see for telling or not telling others?

Session 1: Summary

In this session we talked about:

- The words that are sometimes used instead of the word dementia
- The effect of receiving the diagnosis on sense of self and outlook
- The advantages and disadvantages of sharing and not sharing the diagnosis

NOTES: _____

What are we going to cover next time?

- Who to tell, how and when: potential approaches and specifics that can be used should you chose to share the diagnosis

Session 2: Who and how to tell

This session looks at;

- Telling 'one and all' or no one at all: what other options are there?
- What to say and how to say it
- The responses of others and how that might make me feel

Who to tell: some approaches

Here are some examples of who and how others have or have not told about the diagnosis;

Telling no one

"I haven't told anyone...I don't want anyone else to know right now."

Malika

Telling trusted others: friends

"I was having coffee with an old work colleague. We've been friends for years and all of a sudden I just came out and said it. I didn't want to keep it from her." **Sarah**

Telling trusted others: family

"If it doesn't concern them they don't need to know, that is the policy my wife and I use when deciding who to tell about my dementia. We organised a special dinner and invited our children over so we could tell them privately and give us all chance to talk about it and what it means for us as a family." **Atul**

Telling everyone

*"I wanted to show people that you can live with dementia and there's support out there. So I arranged to go on the local radio to talk about my dementia." **Jeremy***

DISCUSSION POINT: What might we want to think about when considering who to tell?

NOTES: _____

Your support network

Feeling supported can make a difference in a person's well-being and it may be that others already know about the diagnosis.

Take a moment now to note down the people that already know.



Who already knows?

Now we are going to spend some time thinking about the people you may want to tell about a diagnosis.

Using the circles on the next page put the people who you **want to tell the most** in the **centre**. In the **second circle** put those people you **may want to tell**, the **third circle** is for those **people in your life you are unsure about** and the **outer area** is for **those who you may feel must not be told**.

Must not be told

Unsure about telling...

May want to tell...

Want to tell...

Telling someone: what to say and how to say it

There are different ways people tell others about a diagnosis of dementia and how much they tell others. Here are some examples below.

“My neighbour is one of the first people I told. My wife passed a few years back and I have grown closer to him recently. We were talking about our health generally and I just said that I am having some memory problems. I didn’t really think about it.” - Tobias

What do you think about how Tobias told his neighbour?

NOTES: _____

*“My husband and I decided to tell my friend Jessica together. All three of us have known one another a long time. We told her that we had something important to tell her and invited her over for dinner. Before she came over we talked about what we would say and told her over coffee at the end of the night. I said, Jess, I’ve been forgetting things recently so I went to the Doctor because I was worried. I had some tests and they’ve told me I have Alzhemier’s. I just want you to know just in case I do things I wouldn’t normally do” - **Maria***

What do you think about how Maria told her friend?

NOTES: _____

Sometimes it can be hard to think of how we might tell others about a diagnosis of dementia.

We would like you to pick someone from your chart on the previous page – this should be someone you want to tell or may want to tell. We are going to think about how you might tell that person and how much you might want to tell them:

The person I have picked is: _____

DISCUSSION POINTS:

- **What might you say to that person?**

NOTES: _____

Telling someone: the reactions of others

Not everyone reacts well to hearing that a friend or relative has dementia but there are also many 'dementia friends'³ in all parts of the country.

Everyone will react in their own unique way. Below is an example where Joanne is telling her friend Claire about the diagnosis of dementia.

Joanne had known Claire for years, they had worked together and saw each other regularly for coffee. One afternoon, over coffee, Joanne had decided to tell Claire about her diagnosis. She said, "Claire the Doctor has told me I have dementia". After a long pause from them both, Claire avoided eye contact and looked uncomfortable.

What may be going through Joanne's mind when she sees Claire's reaction?

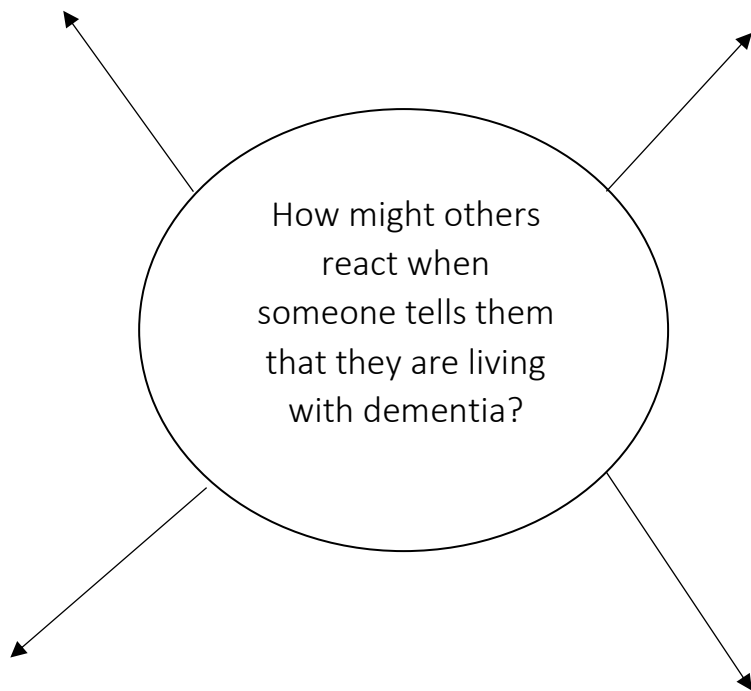
NOTES: _____

³ <https://www.dementiafriends.org.uk/> The Dementia Friends programme is the biggest ever initiative to change people's perceptions of dementia. It aims to transform the way the nation thinks, acts and talks about the condition. The programme is about learning more about dementia and the small ways people can help.

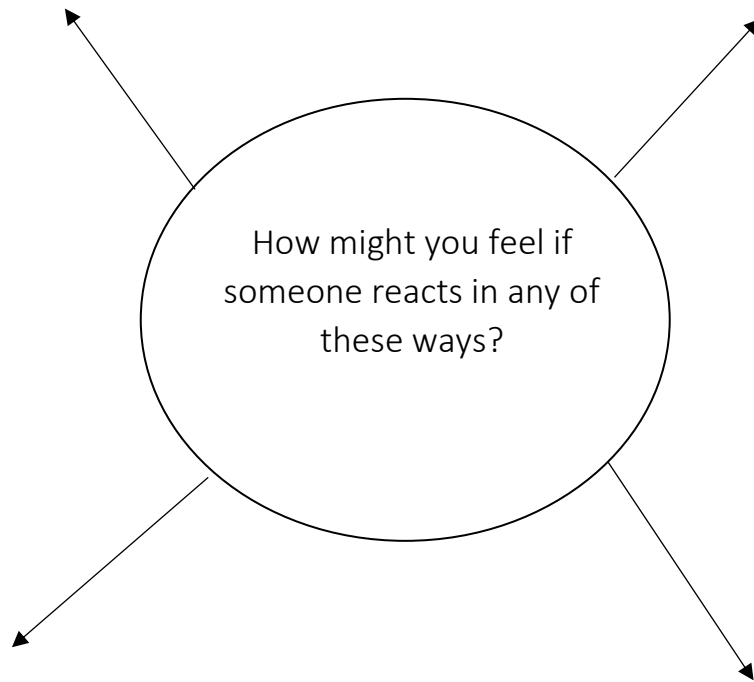
What may be going through Claire’s mind when she hears Joanne’s news?

NOTES: _____

Different people may react differently, **what are the different ways people may react to hearing about a diagnosis of dementia?** Use the diagram below, draw more arrows if you need them:



Different reactions may affect you in different ways. Use the diagram below to note down any reactions you might have.



DISCUSSION POINT: How might this effect what you do?

NOTES: _____

Something to try

Between now and the next session we would like to invite you to think about;

- **The advantages and disadvantages of telling someone**
- **Who, how and when you would choose to tell someone if applicable**
- **Considering and preparing for the reactions of others**

Whether at the end of this process you decide to tell someone this week, decide not to tell someone or make a plan to tell someone in the future is up to you.

Whatever you decide and chose to do or not do, will be considered in the next session when we bring everything we have discussed together.

Session 2: Summary

In this session we have covered:

- The options around telling others
- Deciding who and how to tell: approaches and specifics
- Considering and preparing for different reactions

What are we going to cover next time?

- Review current decisions around who to tell, how and when
- Think about when others do the telling
- Consider when we might revisit who to tell, how and when decisions

Session 3: Bringing it all together

This session looks at;

- Our current decisions around who to tell, how and when: a review
- When others are doing the telling: things to consider
- When to revisit decisions around who to tell, how and when

A summary so far

In session one we discussed the language used around dementia and the advantages and disadvantages of telling others. In session two we discussed who to tell, how and when. We also thought about the reactions of others and considered how this may affect us.

Our current decisions around who to tell, how and when: a review

At the end of the last session we invited you to think about;

- The advantages and disadvantages of telling someone
- Who, how and when you would choose to tell someone
- Considering and preparing for the reactions of others

DISCUSSION POINT: How do you feel about your decision to tell or not tell others about the dementia diagnosis now?

NOTES: _____

Some of you may have taken the next step and told someone. We will now review this experience.

DISCUSSION POINT: How did this go?

NOTES: _____

When more than one person is doing the telling

Sometimes other people may tell others about your diagnosis. There may be times when you agree; however, there may be times when disagreements occur. There is no right or wrong approach but it is important to acknowledge that these differences may occur and consider the implications. Here are some examples below:

Being taken by surprise: not talking about telling

“I was at Church one day. I had told a friend who attends the same Church but we hadn’t talked about him telling anyone else. Anyway, one of the other parishioners came up to me and said they were so sorry to hear about my diagnosis. I felt really taken aback and I didn’t know what to say” - Jacinda

Talking about telling: agreements

“We sat down as a family and talked about who else should know. We all agreed that my family can share the information about the diagnosis with their close friends and our wider family as long as they make sure the people they tell do not tell anyone else. I was happy for this to happen as telling others was really difficult for me.”- Anoushka

insisted that I tell my neighbour or they will. - Ian

DISCUSSION POINTS:

- What might you want to consider when telling others?
- How would you navigate any differences of opinion?

NOTES: _____

When to review the decision

Over time our decisions about telling or not telling others may change as circumstances change.

DISCUSSION POINT: What, if anything, might lead you to revisit your decision?

NOTES: _____

Session 3: Summary

In this session we have considered:

- Our current decisions around who to tell, how and when
- When others are doing the telling: things to consider
- When to revisit decisions around who to tell, how and when

Programme Summary

Over the course of the programme's 3 sessions we have thought about what might affect whether we tell others, how we might go about doing this, if we do decide to tell others, and what we might want to consider when thinking about how others share that information.

What happens now?

This workbook is yours to keep. You can refer to it whenever you wish to. Please also feel free to add to the previous sections.

The next page has important details of organisations who can provide support for those living with dementia and their supporters.

For more information about this research please contact us;

Address: 1-19 Torrington Place, University College London, WC1E 7HB

Telephone: 020 7679 8275

Email: tamatha.ruffell.16@ucl.ac.uk or jemini.bhatt@ucl.ac.uk or tamatha.ruffell.16@ucl.ac.uk

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Where to find support?

<p>Alzheimer's Society (local services and information provision)</p> 	<p>Email: enquiries@alzheimers.org.uk Telephone: 0300 222 11 22 Website: www.alzheimers.org.uk</p>
<p>Pathways Through Dementia (legal support and information provision)</p> 	<p>Email: swilcox@pathwaysthroughdementia.org Telephone: 0203 405 5940 Website: www.pathwaysthroughdementia.org</p>
<p>AgeUK (local services and information provision)</p> 	<p>Email: contact@ageuk.org.uk Telephone: 0800 055 6112 Website: www.ageuk.org.uk</p>
<p>CarePlace (care and community services, information and guidance)</p> 	<p>Telephone (The Silver Line): 0800 4 70 80 90 Website: www.careplace.org.uk</p>