hidden

MADE BY MORTALS

Don’t Stop Me Now - Learning Resource

This resource supplements the immersive audio experience ‘Hidden - Ruby & Dennis.’ It can be worked through on your own or in a small group after listening to the audio.

The resource has been co-produced with people living with dementia and their carers and is for people who wish to make their service, group, organisation or venue more dementia friendly.

Through reading this, you will have a greater understanding of what is happening to Ruby & Dennis (the two main characters in the audio) and the challenges they face. It also contains useful links to further your understanding of dementia and examples of best practice from other organisations, groups, services and venues.

There is also a ‘Training Workshop Guide’ for people who would like to use our ‘Don’t Stop Me Now’ resources to train larger teams of people. You can download this here.

Background:

‘Hidden’ is a series of immersive audio experiences that challenges you to take a walk in someone else’s shoes. This episode tells the love story of two characters, Ruby and Dennis, who are husband and wife. Ruby lives with dementia and Dennis cares for her. The story explores the challenges they face in staying active, doing some of the things they used to love, and enjoying their lives separately and together.

It has been created by people with lived experience of dementia or caring for people with dementia or Mild Cognitive Impairment (MCI), in collaboration with professional musicians, writers and health and social care partners. You will hear the voices of real people who are living with dementia. All the men’s voices play the character Dennis, all the women’s voices play Ruby.

Made By Mortals have used this episode as a catalyst for discussion in workshops with other people living with dementia or MCI, which has provided further insight into situations people living with dementia face. These have been edited into ‘additional audio’ packages that will also form part of this learning resource.

Before continuing with this learning resource, please listen to ‘Hidden - Ruby & Dennis. ’

WITH Together Dementia Support

SUPPORTED BY Dementia United Wigan Council TRAFFORD COUNCIL

What Is Dementia?

We don't know which type of dementia Ruby is living with. We know that she is under 65 years old, so she is a younger person with dementia and like a lot of the 42,000 younger people in the UK, it took longer than it should for her to get her diagnosis.

USEFUL LINK

Young Onset Dementia

There are 200 types of dementia, most of them very rare. Dementia is simply a term for diseases of the brain that cause progressive illnesses that are currently incurable.
Alzheimer's disease accounts for around two-thirds of all types of dementia and its classic early symptom is short term memory loss. It can also cause these symptoms:

- Communication difficulties
- Problems with decision making
- Limited attention span
- Difficulties with sequencing and tasks
- Loss of orientation to time and place
- Sensory misperceptions
- Changes in mood and behaviour

For other types of dementia, memory loss may **not** be one of the early symptoms, instead it may be changes in behaviour; changes in communication; or hallucinations. It is also possible to have more than one type of dementia.

For more information about other types of dementia such as Vascular, Frontotemporal dementia, Dementia with Lewy Bodies please watch this video:

USEFUL LINK

What Is Dementia

What is Dementia: Video by Alzheimer's Research UK. It explains the science and symptoms of Alzheimer's disease, Frontotemporal Dementia, Dementia with Lewy Bodies and Vascular dementia.

Mild Cognitive Impairment (MCI)

Some people who start to experience difficulties with thinking abilities or memory which do not significantly impact on their daily lives, may be diagnosed with MCI, 'mild cognitive impairment'. It is estimated that between 5% and 20% of people aged over 65 have MCI. Receiving a diagnosis of MCI does not mean that you have dementia, since there are several medical explanations for this condition, however, a person with MCI is more likely to go on to develop dementia. Many people who are diagnosed with MCI use this as an opportunity to change their lifestyle to reduce their risk of going on to develop dementia. There is also a lot that someone can do to help reduce their chances of MCI progressing to dementia.

USEFUL LINKS

Mild Cognitive Impairment - Alzheimer's Society

Mild Cognitive Impairment - Dementia United

Living With Dementia

During this audio experience, we have been immersed in Ruby & Dennis's lives and their daily experiences of living with dementia:

The Fog:

Many people living with dementia describe brain fog as something they struggle with and something that sometimes stops them in their tracks. During the making of this podcast, Rob, who lives very well with dementia, told us he has learnt that on foggy days, he needs to go and spend time in his bedroom until the fog passes and he can function properly. Other people living with dementia told us that the fog was a time when they can't think straight; feel really muddled and confused; feel exhausted; can't find the energy to speak or be with other people.

Losing Confidence and Self-Esteem:

During the podcast, we could feel Ruby's gradual loss of confidence in her own abilities, despite her determination to fight and get her life back after the Covid lockdown. We experienced Ruby struggling with her symptoms of memory loss, confusion, communication difficulties and doing daily tasks like making a cup of tea. We heard how Ruby felt completely on her own, with no one to help her understand what was happening. Even 'her Dennis' did not really understand and didn't want to accept the help or advice that was on offer from the "charity woman".

Difficulties With Sequencing and Everyday Tasks:

For Ruby, we heard about her struggles with the steps of making a cup of tea, but it might have been getting dressed in the morning or paying the bills.

Memory Loss:

We witnessed Ruby not being able to remember significant past events (like their old friend Barry's death); or forgetting she had turned on the toaster. Alzheimer's disease in particular, targets the memory centre of the brain and can mean that the person may struggle to remember past events, to recognise places or people, or to retain information long enough to follow a sequence in order to complete a task.

Q: Does someone have to answer a series of questions online or in-person to access your service? How could you make this simpler or support a person?

Difficulties With Communication:

We experienced the pressure Ruby feels before making conversation with people, having to rehearse set things to say to people for fear of being put on the spot, humiliated by going blank, worried about forgetting words or events. Dementia can affect the language centres in our brain, affecting word-finding, sentence construction or the ability to understand what someone else is saying. Dementia can also affect our ability to understand numbers, recognise money, or read words. Each person will be different and will cope in different ways.

Q: Have you or any of your colleagues or volunteers had any training in communications and dementia?

USEFUL LINKS

- Communication With People Living With Dementia (short vid)
- Communication With People Living With Dementia (Alzheimer's Society)

Visual and Auditory Misperceptions:

We were immersed in the frightening experience of Ruby having difficulty interpreting what she was seeing and hearing when she went to the toilet when she and Dennis were out dancing.

Our senses – hearing, sight, smell, taste and touch – help us understand the world around us. For some people with dementia, changes in the brain mean that they start to misinterpret the information they are receiving through their senses. For Ruby, the darkness and shadows from the windows looked like black tunnels. Ruby doesn't like the dark. The stripy carpet looked like it was 3 dimensional and felt like it was moving and she felt scared of falling. Ruby heard yapping dogs. This might have been the sound of the toilet flushing or the hand dryer, distorted in Ruby's head into a noise that is making her feel panicky and disorientated. We also heard Ruby experience visual misperceptions when she wasn't sure if the glass door at the swimming pool was open or closed and when she felt the pool water was drawing her in. Ruby might also be having difficulty with her spatial awareness and balance. These abilities can be affected in some types of dementia. But there are things that we can do to make the physical environment more accessible and welcoming.

Q: What might your environment feel like to a person living with dementia?

USEFUL LINKS

- 'Dementia From The Inside.' - A short video demonstrating what it might feel like to have dementia.
- How can dementia change a person's perception

Loss of Orientation to Time and Place:

We heard Ruby leave the dance hall in a panic to try and get 'home'. Many of us will have got lost when out somewhere and will rely on our memory, our mobile phone, or our sense of direction in order to get home. For Ruby, she is already frightened, scared of the dark and has forgotten where she is. She does a practical thing and asks a stranger for help, but they refuse. Then, her loss of short-term memory and her confused sense of time and reality leads her to 'home' but for her, this means the comfort and familiarity of her childhood home and her mum. Sometimes this experience is called time-shifting.

Q: What would you do if someone seemed lost and asked you for help?

Useful resource for carers: Herbert Protocol for people with dementia at risk of going missing: Metropolitan Police - here

Emotions and Behaviour:

We were immersed in Ruby's feelings of anxiety and frustration with herself and her anger towards Dennis when he tests her memory or doesn't seem to understand what she is struggling with.

We heard how going to places that felt unsafe and unfamiliar heightened Ruby's confusion and led to fear and panic. Ruby dreaded the foggy days where she feels low and cannot do the things she wants to do. In some types of dementia, physical changes in the brain cause changes in the person's behaviour, like apathy or agitation, or even cause changes to their personality.

In Ruby's case, her feelings are understandable reactions to the experiences she is having. There is still a stigma to living with dementia. Depression and anxiety can often arise as a result of coping with the symptoms of dementia and other people's lack of understanding. Ruby and Dennis were both trying to 'beat' dementia at the beginning of this story and felt under enormous pressure to just try and cope on their own, through fear of embarrassment or fear of how they would be judged if they got things wrong.

Q: How could your organisation or group support someone like Ruby?

It is not all about symptoms though, is it? Let's see the person, not the dementia:
We know Ruby for her love of dancing, her beautiful auburn hair, looking after her family so well, her love for her 3 girls and for Dennis, and for her love of life. Ruby will be Ruby for the whole of her life, no matter how long she lives with dementia.

Play Additional Audio 1 - What does a good life look and feel like for Ruby & Dennis?

Every person with dementia is different and an individual, with their own unique history. A different age; a different diagnosis; a different personality; a different cultural background; a different support system; or no support system. To hear more diverse voices of people living with dementia and learn more about a range of issues for people living with dementia from different communities see these resources:

USEFUL LINKS

- The 4 Amigos - DEEP *(dementiavoices.org.uk)*
- Black & Minority Ethnic (BME) Communities & Dementia - SCIE
- LGBT Foundation - *Bring Dementia Out*
- Downs Syndrom & Dementia
- Dementia Information In BSL

The Impact On Carers:

Getting a diagnosis of dementia and coming to terms with the changes that brings is often a very difficult time for family and friends. Becoming a carer typically involves taking on new roles, tasks and responsibilities and may involve a change in the relationship with the person with dementia. Some people don't want to see themselves as a 'carer' because they are just looking after each other as they always have. However, it's helpful to be registered as a carer so that the person can access help.

USEFUL LINK

Family & Carer Support

Dennis has told us that Ruby used to do everything for him and their girls, but that gradually he has taken over everything: cooking, cleaning, life admin and even the 'kids'. Slowly we can see that he is becoming Ruby's carer. Ruby still makes the first brew of the day, but that has become a test rather than a pleasure.

As happens to many people in similar situations, Dennis, is struggling to come to terms with what is happening to him and Ruby. He is a proud man and he doesn't understand what this thing called dementia is all about. He finds himself getting irritable that most of the time Ruby can't even make a cup of tea anymore and he doesn't understand why she can't remember things, even when he prompts her.

He feels he has lost his Ruby, lost the love that used to be, lost the chance of a happy retirement together. His own pride and fear of losing control means he isn't open to support from the local charity worker. Dennis feels on his own in his situation. In fact, Ruby has noticed that Dennis is looking tired and not smart and trendy like the man he used to be, but she doesn't really know why. Dennis is angry and upset that something like just going swimming is made so difficult for them with Ruby having to struggle to use a phone app; some long form to be filled in once they get to swimming; and then being made to pay contactless which he doesn't like.

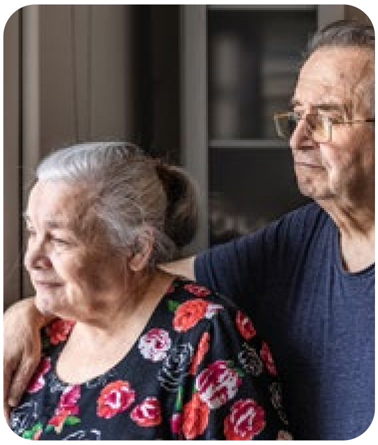
Some people living with dementia or their carers may of course be very happy with using a phone app and even find it more accessible than face to face, but for Dennis and Ruby and others, this is a barrier.

Q: How accessible is your service/group to a person with dementia?
Could/do you offer a service that people with dementia can access on their own?

Support for Carers:

It is very common for carers to stop looking after themselves, going to the barbers or hairdressers, going to the GP, not seeing old friends because they can't leave the person and they can't take them along. They often stop doing the things they used to love, like for Dennis, live music or dancing. If people don't have a break from the responsibility of caring for a loved one with dementia, they can become:

- Exhausted
- Neglect their own health conditions
- Become anxious, irritable or depressed
- Burnt out



Seeking the right help at the right time can be the key to getting support and living well:

- Peer support, one to one or at groups
- Respite for a day or a week to recharge their batteries
- Understanding dementia- strategies for daily life
- Emotional support
- Healthy lifestyle choices
- Support to plan for the future
- Financial support
- Reaching out to family and friends to share some of the caring

Q: Do you also offer a service for carers, with or without the person they care for?

Play Additional Audio 2 - What are the barriers for Ruby & Dennis?

Becoming Dementia Friendly

> "We know that people affected by dementia often stop doing the things they enjoy in their local community as their condition progresses because they worry about not getting the support they need."
> (Dementia Friendly Sport and Activity Guide 2019, Alzheimer's Society and Sports England)

Promoting Brain Health and Dementia Risk Reduction:

- Dementia is not an inevitable part of ageing.
- Dementia risk increases as we age and can be impacted by our genes. However, even though we cannot change our age or our genetics, there are some actions that can be taken to reduce our risk, or possibly delay the onset or progression of dementia.
- These include keeping physically fit, eating a healthy and balanced diet, not smoking or drinking alcohol to excess, and keeping mentally and socially active as we age.
- Certain conditions including type 2 diabetes and high blood pressure can also increase our risk of developing dementia, but these risks can be reduced by managing these conditions.
- The single biggest risk factor is actually hearing loss, which can often be identified and treated.
- Evidence emerging during the pandemic identified just how much social isolation and lack of stimulation leads to decline and increase in symptoms.

Overall, living a good life, feeling in control, and continuing to do the things you love with the people you love can improve the health of your brain and may reduce your risk of developing dementia, or slow disease progression for some people living with dementia or MCI.

USEFUL LINK

Brain Health

Ruby and Dennis really want to go out together and do some of the things they have always loved: dancing, the cinema, and eating out. They know what makes them feel good and that is being with other people who understand, being able to have space to go out and relax. They want somewhere that is:

- Easy to get to
- Busy but not too busy
- Clearly signed
- Well lit with no dark shadows
- A welcoming and calm atmosphere
- Run by people who are approachable and understanding

Maybe no one can stop Ruby from having some foggy days, because that's part of her dementia, but we can make sure she and others living with dementia have lots of good days, together and apart.
Take a look at this **Tool Kit** for people living with dementia and carers made by them, that gives hope for the future; get inspired through examples of real-life experiences; learn about ideas to help people live their life as they choose.

As a society we need to improve our attitude to ageing, and to dementia in particular. If we believe that life with dementia will be miserable and that nothing can be done to make a difference, then we won't try. But many people live well with dementia for a number of years and some live well to the end of their lives. So it's everyone's responsibility to make things better for people with MCI and dementia.

Let's make this happen for Ruby and Dennis and all the people living with dementia in Greater Manchester. Don't stop them now!

Play Additional Audio 3 - What or Who Can Help Ruby & Dennis?

How can organisations make the environment and customer-facing staff & volunteers dementia-friendly (attitudes, individual actions, organisational change)?

People living with dementia have said that organisations and venues need to consider: **people**, **programme**, and **place** in order to help them to participate.

Consider the following:

1. People:

- Have all your staff and volunteers had dementia awareness training?
- Do they have the right attitude, and are they willing to be friendly and helpful when needed?
- Do any of them want more training to increase their knowledge?
- Do you and your team discuss what you can do or do better?
- Do you reflect and support each other when something has not gone well with a customer?

2. Programme:

- Do you offer activities that are suitable for (or designed for) people with cognitive or mobility difficulties?
- Do you run those sessions at unhelpful times such as in the mornings? (It's often impossible for people with dementia to get up and out before 11am).
- Can you have additional volunteers at your venue so that there is extra help available for these special activities?
- Do you allow time at the end of the session for people to sit and chat over a drink?
- Do you need additional training or a new policy to ensure that people with dementia stay safe when they're joining in?
- Can you find creative ways to enable someone who is reluctant to participate?

3. Place:

Your physical environment needs to be 'dementia enabled', adjusted so that someone with cognitive impairment can confidently find their way around.

- Have you asked people with dementia and carers to visit your venue and audit it for accessibility? Follow this link to learn how to carry out an audit. Ruby and Dennis would have been able to point out all the things that would help or hinder them in using your venue.
- What can you change to make your activity and venue welcoming as soon as the person comes through the door?
- Is there good public transport to the venue?
- Is the building/room too noisy, cold or crowded?

The following videos about successful dementia-friendly activities can be used to refresh people's understanding and awareness of dementia and inspire your group or service to change.

USEFUL LINKS

- Golf in society
- Dementia Friendly Swimming
- Dementia Friendly Walking Football
- Dementia Friendly Gurudwaras
- Gymnastics - Love To Move Program
- Dementia Friendly Cinema

USEFUL LINK

Becoming Dementia Friendly

This free online guide provides a practical step by step resource for any group or organisation.

Every organisation is different and some will be able to change their provision more easily than others. You might need to get senior managers to take the lead or to agree to the changes you want to make. You might want to find a fellow 'Dementia Champion' to help you persuade colleagues and managers to make these changes. Every small change is a step in the right direction.

What Are The Benefits To Us All?

- Services that are helpful to people with MCI or dementia are usually helpful to us all – good signage, helpful staff, bright lighting, a warm welcome.
- Most of us will already know someone who is living (or lived with dementia). In fact, we may have upsetting memories of how tough life became for our friend or relative. In the future it might be any one of us who develops MCI or dementia. We all want to know that there will be places we can go to stay healthy, active and socialise.
- When we give other people a good experience they are usually very grateful and so this makes us feel better. If you and your organisation can prevent someone with MCI from getting dementia or if you can keep people like Ruby and Dennis happy and well for longer then you will have made a fabulous difference!
- What's more, if we do our best to make our activities or venues accessible and helpful to people like Dennis and Ruby then we know that we've complied with the Equality Act 2010 that protects people with dementia from being discriminated against and overlooked in the services we all use.

Remember:

Recent evidence suggests that up to 40% of dementia cases may be potentially preventable through modification of life-course risk factors. And growing evidence suggests that people living with mild to moderate dementia can improve their wellbeing and perhaps slow the progression of the disease by improving their brain health and managing lifestyle factors which pose a risk to the health of their brains.

So, helping people with MCI or dementia to stay active and engaged in exercise and activity is really important for all of us!

We would like to express our deepest gratitude to the co-creators for their courage and openness when they shared their lived experiences with us.