Home is Where the Heart is: Training for home care supporters for people living with dementia from diverse cultures

Resource Handbook

The Association for Dementia Studies
University of Worcester
Henwick Grove
Worcester
WR2 6AJ
UK

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Authors: Michal Herz and Kate Read

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by The Association for Dementia Studies

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University of Worcester
Association for Dementia Studies

Welcome to a resource handbook designed to support you in training your domiciliary care workforce to provide more culturally competent person centred dementia care.

We have devised three short training sessions, each of which you can deliver in approximately 90 minutes. To enable your team to build confidence in cultural competence person centred dementia care, you should deliver all three sessions. This can be done as a series of three sessions on different dates or as a full day training.

In this resource handbook you will find a powerpoint presentation with detailed notes for each of the sessions, detailed notes on exercises and the video clips associated with each session.

There are also eight case studies of people with dementia who have a diversity of cultural and ethnic backgrounds. In each of the sessions there is an opportunity to use one or more of the case studies. We would invite you to choose the case studies which best meet the needs of your workforce. However, the case studies are illustrative and by no means reflect all of the diverse communities your work force may encounter. So if you have a good knowledge of the culture and ethnicity of groups that you and your staff work with, you could chose to create your own case studies. We have also included some guidance notes to assist, if you wish to do that.

We have also added an additional exercise which could be used as an adjunct to any of the sessions which would enable participants to explore the use of a modified culturagram (Goodrally 2015) to support culturally sensitive assessment and understanding of a person with dementia and their family within their cultural context.

If you have any questions about any aspect of the training, or wish to receive more advanced training in person centred dementia care, please contact us:

Email: dementia@worc.ac.uk Tel: +44 (0) 1905 542531

Association for Dementia Studies,
University of Worcester,
St John's Campus,
Worcester
WR2 6AJ
Website: www.worcester.ac.uk/dementia

Programme structure

This programme is made up of three sessions. The resources for each session are together in a single folder. Each session file contains:

A presentation (PowerPoint Show)
A printable copy of the presentation with trainer notes (PDF)
A video file
Exercises described in the trainer's notes can be found in this handbook

All documents and presentations can be printed as required.

Session structure

On the whole, the three sessions follow the same structure:

1. Aim of session and warm up exercise – 10-15 minutes
2. Information about the topic – 15 minutes
3. Consolidation – video clip and discussion – 20 minutes
4. Embedding information, exercise – 15 minutes
5. Understanding the individual, applying to the case studies – 15 minutes
6. Reflections and summary – 10-15 minutes

These timings are provided as a guide to ensure that you can complete all of the content in 90 minutes. They are not included to constrain the way that these resources are used, but are intended to help the less experienced trainer to develop a learning session that is suitable for your group of staff. As you familiarise yourself with the content and through preparation and teaching of the content, you will develop timings that work for you.

Contents

Case Studies

To support your use of this education resource we have created eight case studies of people who have a diversity of cultural and ethnic backgrounds:

Brian Durkan – aged 76

Magdalena Groshvitz – aged 92

Desiree Jackson – aged 70

Ibrahim Jassatt - aged 72

Nasrin Kabila - aged 73

Inderjit Multani –aged 72

John Whitby - aged 63

Ngozi Orijekwe: aged 61

Working with the person's life story will be a theme which runs through all three sessions.

Depending on you and your group, there are different ways you can teach these case studies:

1. Give out all eight case studies
2. Select a few of them which best reflect the issues your staff encounter
3. Choose one of the case studies and give it in full
4. Choose one case study and divide it up to give information in sections as you go along
5. Choose one case study and give different groups different parts of the information
6. Read out one case to the group and then discuss it (preferably read it in first person)
7. Shorten it and give less written information, but make sure you keep the wealth and complexity elements in
8. Use one case study for all 3 sessions, so participants feel they are becoming more familiar with this person and the diversity of their needs
9. Choose different case studies according to the sessions

The case studies are a teaching aid, therefore, explore what works best for you and your participants.

Additional Guidance on writing your own case studies

We appreciate that when training it is important to encourage your staff to apply the learning to real situations and people, the case studies are written to help you do this. However, if you know well the culture and ethnicity of groups that you and your staff work with, you could choose to create your own case studies. If you do so, here are some guidelines to creating a case study:

1. Do your research – read up about the history of that community, when did they come and why? Where from? Where did they settle in the UK? Any main fields of work/occupation?
2. Describe their life holistically to create a relevant case study. If it is a person who migrated, tell the story of what life was before and after, and why they moved. Those gaps are often key in understanding somebody's world perspective.
3. Keep to the central story line – this training is about cultural competency and its impact on person centred dementia care. Keep that focus. It is very easy to talk about all elements of a person's life, such as the complexity of their family relationships, medical history, financial circumstances, their pets. Unless these are relevant to their culture and ethnicity, avoid them in this exercise. You want to help your participants stay focused. Other topics are good for different learning outcomes.
4. Things to try and touch on: Names, language, choice about religious practice and beliefs (food, community, rituals), close family relationships.

Case Study: Brian Durkan – aged 76

Brian was brought up in devout catholic family in County Cork where he met and married Siobhan. They started a family (twin girls Chrissie and Clare) followed swiftly by Connor, their first son. In the1960s Brian and some of his friends saw an opportunity to better provide for their families by moving to England to work on the building sites and roads. Initially they lived in B&Bs in Birmingham, working hard all day, going to the pub for a few drinks at night and sending money home to provide for the family. In the early days Brian went back to Ireland to see his expanding family (they now had 5 children, Declan and Josephine were born whilst he was living mainly in Birmingham); but as costs increased and he knew less of their lives, he stayed in England for longer and tried to send more money home to make up. However, over the years work became harder to get and Brian's drinking got heavier.

He got thrown out of B&Bs and slept on floors of friends and ultimately in a hostel. By this time he had little or no work, was sending little to Siobhan in Ireland and made excuses not to visit so that they wouldn't see how bad things were.

He moved from hostel to hostel usually when his drinking became a problem to staff and other residents. Brian's physical health also deteriorated. He had chronic arthritis, recurrent chest infections and ate poorly.

Hostel staff were concerned about the impact of Brian's drinking on his health, but he rarely stayed long enough to address issues. One hostel however persevered and Brian was referred by the assigned GP to mental health services which after a period of assessment diagnosed an alcohol related dementia, Wernicke-Korsakoff syndrome[1], which helped the hostel staff make sense of his confusion, behaviour and difficulties.

Brian has been supported by the hostel and has received treatment (thiamine and vitamin B) and made efforts to drink less frequently. They have now found him a place in a sheltered housing scheme with domiciliary care support, but Brian finds it lonely and has started drinking more often.

Brian had lost all contact with family and friends in Ireland but then, following the death of Siobhan, one of his twin daughters, Clare, had made contact to inform him of their mother's death.

As she now lives in Manchester Clare has been to see Brian. The other children have strongly said they don't want anything to do with him and have told Clare that she shouldn't bother. It has caused a particular rift between Clare and Chrissie. Clare seems to expect that the

Please turn over

[1] Korsakoff syndrome is a brain disorder that is usually associated with heavy drinking over a long period. Although it is not strictly speaking a dementia, people with the condition experience loss of short term memory. https://www.alzheimers.org.uk/site/scripts/services_info.php?serviceID=65

domiciliary care staff will police his drinking and has requested that they remove all alcohol from the flat if they find any. She is also adamant that they must make him eat. When she rings him, Brian tells her very convincing stories of his progress and involvement in activities and she finds it hard to believe staff who tell her that he is neglecting himself and refuses to do anything other than go to the pub.

Case Study: Magdalena Groshvitz – aged 92

Magdalena was born in Krakow to a wealthy family who were important members of the educated upper class. Magdalena was a gifted student and musician and was predicted to have a great future as a violinist. She went to the conservatoire in Warsaw where she met Leonid, a pilot in the Polish army, when he was on leave. After a quick romance, they got married (much to her parents' disapproval). In 1940 when the Polish government went into exile in the UK, she was transferred with Leonid to become part of the RAF. She was desperate to get her parents out, but they refused her help. As she couldn't continue to play her beloved violin, she became very active supporting the newly created young migrant community and engrossed herself in studying English.

Leonid's plane was shot down in the Battle of Arnhem in 1944 and he was MIA for 18 months until he was pronounced dead. After the war, it emerged that due to starvation and illness, her mother had passed away and the family home had been bombed.

Magdalena was devastated. She found staying with the close knit community of Polish/RAF families unbearable, as families were being reunited and children were arriving. Magdalena decided to move away and went to the teacher training college in Worcester to dedicate her life to children. She spent her working life as an English teacher. She moved to Birmingham and from her RAF widow's pension and salary bought a house in a central location in Birmingham. She was devoted to her primary school pupils and had a passion for English – her emphasis was on pronunciation, grammar and punctuation. She was referred to as Mrs Greenvit all her working life.

Magdalena stayed in the same school all her working career, becoming the head teacher there for nearly 30 years. She continued to volunteer at the school well into her late 70s. She was very active in supporting the arts (particularly classical music) in Birmingham and was a patron of the City of Birmingham Symphony Orchestra and attended everything they put on.

Magdalena always had lots of acquaintances and two close friends, both of whom have died. She embedded herself in the local community and has no contact with her Polish roots (with her Queen's English people are surprised to find out she is from Poland). She is very private about her life, and besides one picture of Leonid beside her bed, there are no other personal items around the house.

Magdalena is fiercely independent, and manages on her own. She goes to the local shop daily for the food she needs. When a neighbour noticed they hadn't seen her for a few days, (they meet nearly daily), they tried to call on her. When there was no answer, they called emergency services. She was on the floor with a broken hip, where she had been for 36 - 48 hours.

After 2 months in hospital she was discharged with a diagnosis of mild to moderate Alzheimer's. Your agency has been commissioned to provide her support.

Case Study: Desiree Jackson – aged 70

Desiree was brought up in rural Jamaica, she had strict churchgoing parents. Randolph, her husband grew up nearer to Kingston. They married when Desiree was 18 and within a year had twins, Leroy and Patsy. When the twins were two, Randolph moved to the UK to take up work on the buses in the West Midlands and was followed by Desiree and the twins a couple of years later. By this time Randolph had established a life as a single man going to the pub with mates to play dominoes and partying at weekends. He and Desiree had 2 more children, Audrey and Robbie, but the time apart had created tensions within their marriage. Desiree regretted moving to the UK, she found it cold and unfriendly, even the local church, and she hated to see Randolph continuing to party and have friends who lived on the edge of legality. She adopted a "spare the rod, spoil the child" approach to parenting to ensure her children didn't follow him. She focused on bringing up the children and found some solace when a neighbour introduced her to the New Testament Church of God. This became essential to her life and she believed it supported her to maintain her marriage even though the distance between her and Randolph increased.

All of the children have left home: Patsy is a nurse in the USA, Leroy lives in London and Audrey and Robbie both have their own families and live in different parts of Wolverhampton, but both are within 3 miles of Desiree. Six weeks ago Desiree had a serious stroke and after a period of assessment and rehabilitation, the hospital said she was ready to return home with a domiciliary care package to meet her personal care needs. (She is now extremely weak on her left side and is incontinent.) Your company has been contracted to provide this care twice a day. Randolph at 10 years older than Desiree has a range of health issues and has indicated that he is unable to care for Desiree and doesn't think she should be at home.

Patsy shares her father's view and thinks the NHS should provide all her mother's care, probably in a hospital. From the USA she has raised a complaint about her mother's discharge and is putting pressure on her younger brother and sister not to pay more to add to the care provided, as she feels that may undermine the complaint and demand for NHS care. Robbie recognises that living with Randolph in the family home is not practical, but feels his mother would be happier and supported well in an extracare scheme with an extended package and has tried to persuade his siblings to contribute financially and is offering to add to the package by visiting his mum daily. But Patsy clearly holds the power in the family, even though so far away.

When you make calls to Desiree it is clear that tensions are high between her and Randolph and with and between the children and there are series of "complaints" that Desiree is at risk. Although Robbie was always her favourite she often doesn't recognise him when he visits. Also she is thought to have tried to smack one of Audrey's children. Desiree often cries and begs you to take her home. The situation appears to be escalating but no one in the family (even Robbie) is willing to discuss anything until Patsy comes for her annual visit.

Case Study: Ibrahim Jassatt - aged 72

Ibrahim's family moved from the Punjab to East Africa in 1947 around the time of partition in India. Ibrahim was the eldest of 3 sons. Ibrahim's mother was pregnant with his younger brother when they left India. The family subsequently moved to Rhodesia in the 1960s as his father had work building railways. However, by the 1970s the political situation in Rhodesia had deteriorated and having done national service, it appeared that Ibrahim might be recalled to the army. He didn't want to do this and in 1972 applied for a PhD studentship at Keele University in the UK. Following his PhD, he was offered a post as a lecturer at Sheffield Hallam University and moved to Sheffield in 1979. He became a UK citizen in 1982. He met his wife Emily in Sheffield and they settled there and had 2 sons, Faisal and Babu. He has never talked of life in Rhodesia, which became known as Zimbabwe in 1980, but his younger brother, Ishmael, stayed with him for some time in the early 1980s, whilst seeking asylum after torture. Ishmael indicated that discrimination and racism was prevalent in Rhodesia and latterly Zimbabwe, with tensions between white and black African communities and both seemingly discriminating against Asian people. Sadly, Ibrahim didn't see his parents after 1972, Emily believes they understood why he left Rhodesia but were sad to see him leave. Ibrahim is a firm believer family should always step up and help each other and has kept in touch with both his brothers, who are now in Canada.

When Ibrahim and Emily married they found a house in a fairly multicultural part of Sheffield. However, although there were other Muslim families in the street, Ibrahim didn't particularly mix with them and didn't actively engage with the mosque. He had been pleased when Emily converted, but didn't put undue pressure on her or the boys. He is very British in dress and in interests, loving football and a committed Labour Party member. He wanted the boys to go to university and have successful careers (both studied medicine). Ibrahim himself retired from the university as a senior lecturer; although his work was well regarded, he was passed over for promotion several times.

Both sons have their own lives. Ibrahim has always told his wife Emily and their sons that he believes women are equal and should be treated as such. But Emily is doubtful, she sees Ibrahim as strongly male father figure, although she knows he relies on her strength. He nearly went to pieces when Emily had breast cancer, but his sons came home and Emily recovered. She is planning reconstruction surgery.

Ibrahim was diagnosed a year ago with a vascular dementia; it became clear to his sons when Emily was ill that Ibrahim had problems and they pushed for a GP appointment (although Emily was also not keen). By this point it was clear that Ibrahim was struggling with many daily living tasks, he can't cook and rarely remembers to eat or drink even if he is left a snack. Ibrahim also has high blood pressure and diabetes. He has limited understanding of dementia. He assumes it is a mental illness and refuses all help and forbids family to talk about it outside the home.

Please turn over

Emily wants to arrange reconstruction surgery, but both boys are going to be working abroad for the next couple of years. Therefore, she wants to bring in some domiciliary care to provide support for when she is in hospital and recovering at home.

Case Study: Nasrin Kabila - aged 73

Nasrin Kabila was born in 1943 in Tehran. Her early memories were of the British forces in the city, whom she remembered fondly. She grew up in a middle class non-religious family, who actively supported the Shah's regime. She studied pharmacy and married Imad who was a businessman.

They had a pleasant and successful life together and enjoyed the vibrant community of family and friends in Tehran. By the time of the revolution (1979), they had three children, Jasmin, Yasif, and Layla. The family business, which was a chain of retail shops, was very successful and had ties with the UK and USA. It was targeted during the revolution, as it was seen as a very 'westernising company' which was 'corrupting our youth and encouraging immodesty'. The leaders of the revolution referred to it and it became a slang term for what the fight was against. One night, all of the shops were vandalised, and the head office burnt down. It was reported as a 'people's response to western corruption'. Nasrin and Imad packed the family up the next day, left for the UK with their three children with whatever they could take, leaving everything else behind.

They spent the first few weeks in London with an acquaintance, who help them sort out their first steps. Nasrin didn't like London, so they decided to establish themselves in Manchester, with a few other Iranian families who had moved there too. Imad and Nasrin were both hard working and motivated to make the best of the situation. Imad found work very quickly working in local shops and Nasrin focused on settling the family in, helping the children settle in to their new schools. Within a couple of years Nasrin had a reputation as the person to go to if 'you are new to town' to help find accommodation, etc. Imad said they could make a lot of money from her 'eye for what people wanted'.

They decided to take another big risk and together opened a property focused company, doing anything they could, starting as estate agents, and then buying and developing. They were incredibly successful and were highly loved and respected.

The three children went to university and chose their own pathways. Jasmin and Yasif have their own businesses and are married to people from an Iranian origin. Layla works as the accountant in the family company. She is married to an Englishman, who is a lawyer that she met at the family firm. They have 7 grandchildren between them and they all congregate at the family home every weekend.

Five years ago, Layla became concerned about her mother's decision making and had been finding irregularities in the company. She discussed this with her husband and they decided to talk to Imad, who dismissed it in anger and said they were trying to take over. However, as things were getting worse, Layla talked to her siblings and together they spoke to their mother without Imad. She cried and confessed she was worried that she was ruining it for everybody and she felt she was going mad.

Please turn over

Nasrin went for assessment without telling Imad. When the results came back that she had Alzheimer's disease, she read up about the medication and decided not to take it. She then told Imad all about it, saying that she was quitting her job. Imad was stunned and furious.

Nasrin has since withdrawn into the home, refusing to go out and is neglecting herself. Imad thinks she is 'putting it on'. The children are concerned about her health and personal hygiene, she is hardly eating and very withdrawn. Her speech is becoming incoherent. The children are paying privately for your care agency to come in on a daily basis to try and support her. Imad is refusing to engage with the care staff.

Case Study: Inderjit Multani –aged 72

Inderjit is aged 72, his family had moved from Punjab to East Africa before he was born. Inderjit was the eldest of 5 children. Although all of Inderjit's childhood was spent in Africa he was steeped in the Sikh traditions by his parents, family and friends. His father had become a successful businessman in Nairobi and Inderjit was destined to follow in his footsteps. Inderjit had just started to work in his father's haulage business when his family moved suddenly from Kenya to the UK. The Kenyan government had changed laws relating to immigration and his father was refused a license to continue his business, Mr Multani could see that the situation was deteriorating and (like many of his associates who had shops or businesses) decided to bring his family to Britain.

Inderjit and his brothers and sisters initially found the move hard, they knew nothing of Hounslow where the family settled and Inderjit drifted for the first year. In an effort to help him to settle Inderjit's parents arranged a marriage with the daughter of friends. Manjit, Inderjit's wife, moved in with his family and the marriage worked well, the two bonded through their shared past experience of Africa and they began to enjoy life together. Finally through a friend of his father, Inderjit found work driving and for the last 20 years before he retired, he drove London buses which he enjoyed. Inderjit has always been proud of his Sikh heritage and wore the outward symbols of Sikhism with pride, but over time he developed a similar sense of pride in living in Britain and became a UK citizen in 1982. Inderjit and Manjit had 2 daughters, Simarjeet and Harlaj and, although sad not to have a son, Inderjit loved his daughters (Manjit would say he spoilt them). He was a firm believer in family standing together and they were in regular contact with all his brothers and sisters and their families and as, Manjit's family also lived nearby, family occasions were usually huge boisterous affairs.

Simarjeet became a nurse, married and had her own family. Harlaj graduated from university and went travelling around the world which worried Inderjit and Manjit. Whilst Harlaj was away Manjit was diagnosed with ovarian cancer, the prognosis indicated that Manjit was terminally ill, so Harlaj came home and moved in with her parents to help care for Manjit. However it quickly became clear to her that Inderjit also had problems, it was evident that Inderjit was struggling to care for himself let alone his wife. He was easily distracted and frequently forgot key medication and appointments. However his daughters put this down to his distress at Manjit's rapid deterioration. In the months following Manjit's death, Harlaj continued to live at home and rapidly the sisters realised that Inderjit could not cope on his own. They took him to his GP and after tests and a referral to a specialist service, Inderjit was diagnosed with a mixed dementia. The sisters had some understanding of the implication of this, but Inderjit appeared to have little wish to know anything or think about the future. He assumed it was a mental illness and refused all help and forbad both girls to talk about it outside the home, even to wider family. He refused point blank to attend the Gurdwara in which he had been heavily involved for many years.

Please turn over

The sisters decided that Harlaj would try to find some part time work and live with Inderjit to provide care and Simarjeet would deal with any paperwork and provide cover for Harlaj to work when Inderjit's symptoms become worse. This worked well for some time although the girls were saddened that Inderjit never mentioned his wife or recognised her photo and Harlaj admitted to feeling trapped and that life was passing her by.

The situation has come to a head now, as Inderjit is frequently incontinent and refuses to let Harlaj wash him or change the pads prescribed by the Continence Service. When Simarjeet tried to persuade him to wash he became uncharacteristically angry and threw her out of the house. Realising what her sister is trying to cope with, Simarjeet has contacted your agency asking for a morning and evening call to deliver personal care.

Case Study: John Whitby - aged 63

John was born in a small village and was the eldest son to a family of proud farmers. He was a very bright and handsome child. However, from a young age he felt 'not quite right' and preferred staying indoors helping his mother with the cooking and cleaning chores, and looking after his youngest siblings, rather than going out and helping his father with the 'lad's work'. This became even more apparent in high school, when despite having all the physical potential for joining the local rugby team, John showed no interest.

One evening on the way back from the pub, John's father heard John's voice talking 'lovey-dovey' to somebody. When he got closer, he discovered to his horror that this was to George, John's best friend, with whom he disappeared for long weekends rambling together. When John got home that night, his father was waiting for him, with a suitcase packed and told him he would not have 'such sick scum living under his roof' and he was not part of the family anymore. When John tried to protest, his mother woke up and tried to defend him and saying to wait and see if 'the doctor could do something' and 'let's all have a cuppa, go to bed and we'll talk in the morning'. Before she could finish her sentence, her husband slapped her saying it was all her fault. John tried to help her and his dad started punching him saying 'I should have beaten this demon out of you years ago'. His mother got his suitcase and pushed him out of the door shouting at him to go before his dad killed him.

John spent the next few years of his life living in London. He used his cooking skills to get jobs in restaurants and kept himself going, but never stayed in one place for long. He was part of the gay community and occasionally got himself arrested and questioned. In the 1980s a few close friends died of AIDS and he helped nurse them through the difficult times, but this left him deeply upset.

He decided to leave the UK and spent the next 15 years travelling around Europe. In the 1990's he settled down in Berlin, where he met Hans, a civil servant, originally from East Germany. Hans met John when he was working in a local restaurant and befriended him. When John moved in with Hans, He felt it was the first real home he had had. After a few years, they decided to move to the UK to try and help John settle down. John said he couldn't cope with the German language, which was why he couldn't hold a job.

However, moving back to the UK wasn't easy. Hans could only find administration jobs at a lower level, due to language barriers. John tried to work in restaurants but still could not hold down a job for long, and they seemed to move location every few years. Recently, there has been a lot of conflict between them.

John has been losing his temper and swearing that Hans was a 'Nazi pig'. Hans is very upset and withdrawn. In one of the fights, John started throwing things and the police were called. John tried to escape and fell and fractured his leg and ribs. In hospital he was diagnosed with

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frontotemporal dementia[2]. He was highly agitated in hospital and they put him on strong medication (including anti-psychotics). Hans was by his side all of the time, crying that 'this is not my John'.

Your agency is part of the discharge package, as Hans is still working and his is the only income they have.

[2] Frontotemporal dementia is one of the less common forms of dementia. The term covers a range of specific conditions. It is sometimes called Pick's disease or frontal lobe dementia. This factsheet explains what frontotemporal dementia is, who gets it, and the symptoms. It also describes how it is diagnosed and the treatment and care that is available.
https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=167

Ngozi Orijekwe: aged 61

Ngozi and her husband, Femi, left Nigeria in 1975 to study in London. In addition to their studies both worked hard in a series of part time jobs to support themselves and to send money home to help their extended family in Nigeria. Femi flourished in London and quickly gained a place to study engineering. Ngozi took a series of courses in health and social care and finally was accepted to do a course to become a state registered nurse. Just as she was about to start this course she discovered that she was pregnant with their daughter Mercy, Femi had graduated and had a good job so she deferred for a year. At the end of that year they decided to set up a private fostering arrangement for Mercy to give her stability whilst they strived to make careers for themselves. They also thought it would give them the flexibility to travel back to Nigeria as needed without disrupting Mercy's routines. So they placed Mercy with a family recommended by the pastor of their church.

Ngozi gained her general nursing qualification and after several short periods of employment in the NHS she took a post in a care home and continued to work in various care homes for the remainder of her working life. It is unclear when Femi and Ngozi drifted apart but at some point he began to work more in Nigeria whilst she remained in London. He died in 2000 leaving Ngozi with the small house they had bought just off the Old Kent Road. However there was no other income beyond what Ngozi earned as a residential team leader in a care home for older people.

It would seem that Mercy had been brought up almost entirely by her privately arranged foster parents and there appears to have been little contact between Ngozi and Mercy over the years since Femi's death. Ngozi had made a life for herself which revolved around her work and her involvement in her Pentecostal church in Southwark. It would seem that Ngozi now has a niece and nephew also living in South London but it is unclear whether they are in touch with Mercy or indeed how much contact they have with Ngozi. She has however a large number of friends who have provided increasing support.

When Ngozi was 58 her work colleagues noticed many changes in her work, she became less reliable and was described as "losing her grip". For some time friends covered for her but eventually the home manager intervened and persuaded Ngozi to go to her GP. It took over a year for Ngozi to be diagnosed as having dementia. She was initially prescribed Citalopram by her GP as she had lost all her zest for life and was distressed on many occasions. Following her dementia diagnosis she was also prescribed Aricept, however it appears to have had limited impact. Ngozi is no longer working and has become very withdrawn. Her church friends had prevailed on Ngozi to "help" with lunch clubs and activities the church provided but she refused. In desperation they had appealed to social services who had assessed Ngozi and agreed to a minimum care package, largely to support her in taking medication. (She also has medication for blood pressure and diabetes). There is a concern that she has been taking medication erratically and living on tea and biscuits.

Please turn over

Your organisation has been contracted to provide a morning call, largely to support Ngozi to manage her medication. However despite best efforts it has been difficult to develop a rapport with Ngozi, sometimes she shouts at you to go away, sometimes she lets you in but then criticises everything you say and do, and in many respects the hardest times are when she sits crying and asking God to take her. You feel there must be something else that could be done to make her life better, she is still relatively young.

The Onion Exercise:

Preparation

Print one copy of the onion exercise per participant

Background:

Before you peel an onion, you don't know what it will be like.
Providing care can be like peeling layers off an onion – it can be painful and make you cry.
People living with dementia can be experiencing difficulties and loss, and we need to proceed with care, respect and sensitivity.

An onion as an analogy to understanding culture:
Points to consider –

- It is complex
- It has lots of layers
- The older/bigger the more complicated it can be
- It can be very unpleasant if you get it wrong
- It adds depth and taste to everything
- Different elements can have different importance depending on the stage and time of life.

The exercise:

What makes up our onion?

Ask the group for topics that make part of ourselves: religion, politics, language, sexuality, livelong habits, family, community, where I live, where I lived and more.

Get people to try and create their own onion, what is in the centre, the nuclear of who they are, and what goes around it?

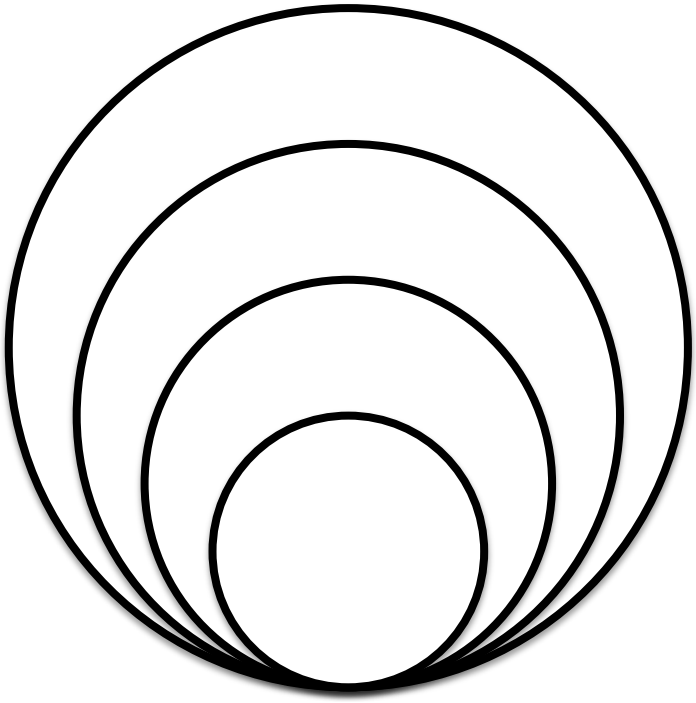
What important information is required for each layer?

Give about 5 minutes. Discuss this with the group. Is it easy to define? Did anything surprise them?

This could lead to two important questions:

1. If they were receiving care, how could this information help?
2. Would two people with a similar 'profile' have the same onion?

Onion Exercise



Culturagram Exercise:

Preparation and resources required

Flip chart paper
Flip chart pens
Case study Ibrahim Jassatt Print one copy per participant
Culturagram framework Print one copy per participant
Culturagram example Print one copy per participant
A3 blank culturagram, one per pair, if required.

Aim of the Exercise

Demonstrates a framework for understanding the history, dynamics and cultural context of the person with dementia and their family.

Key learning points

Illustrates a framework for understanding the history, dynamics and cultural context of the person with dementia and their family.

Time required

20 minutes plus approx. 5 minutes to debrief

What to do

1. Divide the group into pairs
2. Ask participants to read the pre-prepared case study of Ibrahim Jassatt
3. Give everyone a copy of the culturagram framework
4. Ask each pair to work together to draw the framework onto a page of flip chart paper leaving room to complete each section. (Alternatively the blank template in this pack can be pre-printed as A3 and given out)
5. Ask each pair to add on to the culturagram all the relevant information they have gained from the case study of Ibrahim and his family
6. Facilitate discussion by asking:
   what were the key factors they identified from their culturagram
   how would that impact on the care plan and how care is delivered
   was the culturagram framework useful in helping them pull out information on the cultural context of the family
7. Give everyone a copy of the example culturagram.

Time in community

How long have you lived here?
Settled?
New to country?
Adapted to UK way of life?

Health beliefs

What do you think caused the memory loss?
Any explanation of why it started when it did?
Health and illness beliefs and practices within this family
What kind of treatment do you think you should receive?
What types of healing practices do you engage in?
Coping strategies used

Reasons for relocation

Join /be near others
Economic/war/persecution

Family

Who makes decisions?
Major support people
Role of eldest male/female/children

Experiences

Health and Social care
Other services
Stigma/community responses to help seeking

- **Person living with dementia**
- **Main carer**
- **Others**

Work & education

What kind of work have you done?
Importance and need to work and/or continue education

Crisis events

Able to go back home e.g. holidays/special events
Adolescence issues in family

Communication

Speaks/reads English
Bilingual
Loss of second language/dialects
Hearing impairment
Language barriers with siblings/others
Use of interpreters

Entitlements

In receipt/ eligible for Attendance Allowance
Carers Allowance
Council Tax reduction
Made plans for the future
Needs info/signposting

Religious/ spiritual needs

Importance of religion/icons
Food likes/dislikes/healthy eating
Links with temple/church/social clubs/groups

Goodrally, V. in Botsford, J. & Harrison Dening, K. (2015) **Dementia, Culture and Ethnicity**. Jessica Kingsley: London. - Adapted from the work of Dr Elaine Congress

Example completed culturagram for Ibrahim Jassatt

Time in community

Ibrahim came to UK in 1972.His wife and family all were born in UK. He moved to Sheffield in 1979 and has stayed there. He and his family feel they have assimilated into British culture

Health beliefs

Ibrahim has limited understanding of dementia. He assumes it is a mental illness and refuses all help and forbids family to talk about it outside the home.
He has reluctantly taken medication for his physical conditions but refuses to make any lifestyle changes. He has a fatalistic approach to life and his health.
Couple had coped by Emily covering for all of Ibrahim's difficulties, Ibrahim panicked when she became ill.

Reasons for relocation

Ibrahim's family moved from Punjab to E Africa around the time of partition and subsequently Rhodesia as his father had work building railways. Ibrahim came to UK as a PHD student when political situation in Rhodesia deteriorated.

Family

Ibrahim is quite patriarchal and likes to be seen to make decisions. Emily understands this and knows how to guide him without making him feel less in control. His sons are very close and both would do anything for their parents. Nominally Faisal as the eldest feels greater responsibility and has been trying to persuade his parents to put their affairs.

Experiences

Until Emily became ill the couple rarely saw a doctor and had had no need to seek help from other services as Ibrahim had always worked. Emily's experience of health services was largely positive
Ibrahim has experienced racism and discrimination throughout his life in both Rhodesia and UK. His work at the University was well regarded but he never became a professor. He chose an area in Sheffield where there were a number of Muslim families, though he engaged with them very little.

- **Person living with dementia: Ibrahim**
- **Main carer: Emily**
- **Others: sons Faisal and Babu**

Work & education

Ibrahim has been in universities all of his working life in Britain, firstly as a PhD student and subsequently as a lecturer. Work and education is important to him and he ensured that his sons got a university education. He is proud of their careers and was unhappy when they both took extended leave to support them when Emily was ill, he wants them to be successful. His salary, Emily's part time work and more latterly their pensions have maintained the family.

Crisis events

He doesn't talk of life in Rhodesia /Zimbabwe but his younger brother, stayed with him for some time in early 1980s whilst seeking asylum after torture. Ibrahim never went back to Zimbabwe or to see his parents after 1972. He has never been to visit his brothers and rarely goes to stay with his sons.

Communication

Ibrahim is bilingual, speaking and reading English fluently to gain his PhD and lecture he also speaks Shona (though he would say he is rusty) he also has some words of Urdu

Emily and the boys only speak English

Entitlements

Ibrahim might be eligible for Attendance Allowance, particularly as his condition develops. They were urged to apply for a Council Tax reduction when Ibrahim was diagnosed, but may not have done so. Faisal has attempted to encourage them to take out LPAs – still to be done.

Religious/ spiritual needs

Ibrahim is nominally Muslim but until recently has shown little interest in mosque, sometimes he chided sons to maintain traditions, but happy for them to find own way. Has always worn very British clothes and was a fervent labour party member.

Example developed by the Association for Dementia Studies using Framework by:
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Time in community

Health beliefs

Reasons for relocation

Family

Experiences

Work & education

Crisis events

Communication

Entitlements

Religious/ spiritual needs

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Home is Where the Heart is: Training for home care supporters for people living with dementia from diverse cultures

The Association for Dementia Studies
University of Worcester
Henwick Grove
Worcester
WR2 6AJ
UK

Telephone: 01905 01905 542531
Email: dementia@worc.ac.uk
www.worcester.ac.uk/dementia

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