

A black and white close-up portrait of an elderly woman with white hair, wearing a patterned headscarf and a matching patterned garment. She has a gentle expression and is looking directly at the camera.

# Dementia and diversity

A guide for leaders and managers



# Acknowledgements

Skills for Care is pleased to thank the following organisations who contributed to this guide:

- Age UK and Age UK Doncaster
- Age Exchange
- Alzheimer's Society
- Beth Britton
- Camden Memory Service
- Croydon BME Forum
- Davies Court Rotherham
- Derbyshire County Council
- Doncaster CVS
- Doncaster Metropolitan Borough Council
- East Riding of Yorkshire Council
- Gloucestershire County Council
- Heritage Healthcare in Trafford
- Kent County Council
- London Borough of Tower Hamlets
- London Borough of Havering
- Mindcare Dementia Support
- Northamptonshire BME sub regional partnership
- Northamptonshire lesbian, gay and transgender questioning forum
- North Lincolnshire Council
- Public Health Rotherham Metropolitan Borough Council (RMBC)
- Rotherham MBC
- Rotherham Dementia Action Alliance
- Royal Borough of Kingston
- South Thames College
- Social Works Ltd
- The Good Care Group

# Preface

Thank you for taking the time to engage with Skills for Care's Dementia and Diversity resource which has been developed in conjunction with social care providers across England.

The resource has been developed to enable leaders and managers to support and develop their teams working with people living with dementia who are from a diverse range of cultures and backgrounds. This is an important area of focus because as dementia progresses, it is likely that a person's characteristics will change, and often culture and background will play an increasingly important role in the care and support that a person prefers to receive.

The guide gives practical advice and good practice case studies relating to each stage of employing social care workers from recruitment and induction, to further and ongoing development. It provides suggestions, as well as scenarios that can be used to consider how you and your team should manage a particular set of circumstances.

We hope that by using this information it will support your organisation to further develop your workforce to more effectively support people living with dementia from a diverse range of cultures and backgrounds.

We welcome your feedback and comments on this guide so please feel free to get in touch with Skills for Care staff or contact us via email at [info@skillsforcare.org.uk](mailto:info@skillsforcare.org.uk).

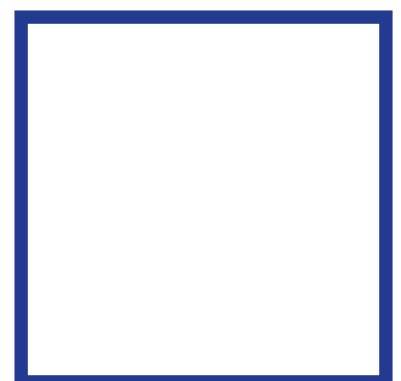


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# 1. Introduction

This resource has been developed with Department of Health funding. It's main aim is to enable leaders and managers in social care to support and develop their workforce who are working with people with dementia from different cultures and backgrounds. The particular focus will be for leaders and managers supporting staff working with:

- people with dementia who are from a black, Asian or minority ethnic background (BAME)
- people with dementia who are lesbian, gay, bisexual or transgender (LGBT)
- people with young-onset dementia.

## Why is this so important for providers to consider?

The delivery of care and support that is in line with the needs and wants of the individual is critical to ensure that the person receives personalised care and support. A person's culture and background are clearly significant components of their identity.

It is worth reminding ourselves exactly what we mean by personalised care and support, or personalisation.

### Think Local, Act Personal defines personalisation as:

Personalisation is fundamentally about better lives, not services. It means working with people, carers and families to deliver better outcomes for all. It is not simply about changing systems and processes or an individual's funding through personal budgets and direct payments, but includes all the changes needed to ensure people have greater independence and enhanced wellbeing within stronger, more resilient communities.

Not only does the definition provide clarity and focus, it also highlights the importance of communities with respect to personalised care and support. While communities in the UK will differ in their diversity, they all have an important role to play in care and support and ensuring an individual's needs are met.

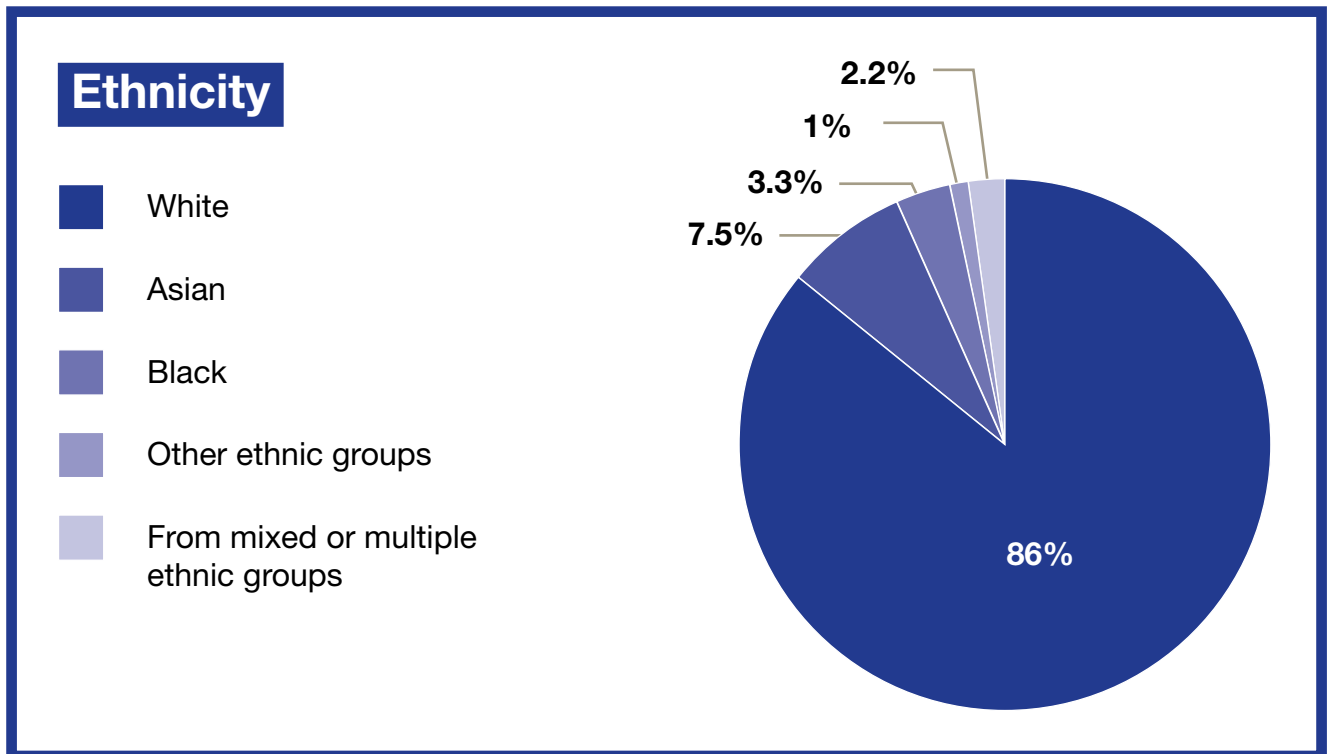
## Additional support and advice

For some time, social care providers have asked Skills for Care for additional advice and support around this issue. There are a number of reasons for this:

- staff requesting advice and support
- examples of care and support that are not in line with a person's needs and wishes
- people with dementia behaving in ways we may find challenging because of unmet needs (this may be due to care and support being provided in ways that are not normal to them in respect to their background or culture)
- wanting to improve the quality and rating of services.

If your organisation does not currently provide care and support to people from a BAME or LGBT background, the demographics of the UK population mean that you probably soon will. As you will see in the case studies featured in this resource, it has been to everyone's benefit where diversity has been embraced and supported by leaders, managers and social care teams.

While diversity varies by area across the UK, the 2011 census for England and Wales highlights the ethnic makeup of England and Wales:



In 2014 the Office for National Statistics (ONS) carried out research into sexuality of the UK population:

|                         |       |
|-------------------------|-------|
| Heterosexual / Straight | 92.8% |
| Gay / Lesbian           | 1.1%  |
| Bisexual                | 0.5%  |
| Other                   | 0.3%  |
| Don't know/refuse       | 3.9%  |
| Non-response            | 1.4%  |

Source: Integrated Household Survey, Office for National Statistics, 2014

It is also worth considering that these figures may be lower than the true figures because people may not wish to disclose their sexuality.

In addition, there is no national validated survey for people who identify themselves as transgender. However, an ONS position statement highlights that estimates have been placed at anywhere from 65,000 - 300,000 people.



## Young-onset dementia

Finally, in terms of young-onset dementia (people under 65), the Alzheimer's Society estimates there are approximately 42,000 younger people with dementia in the UK. This equates to 5% of all people with dementia. This is an important consideration for organisations providing care and support services.

As well as the demographic context, there is also a political context to consider. The provision of 'culturally competent' care to people with dementia is highlighted in the Prime Minister's Challenge on Dementia 2020.

In addition, the All Party Parliamentary Group for dementia (APPG) published a report in 2013 'Dementia does not discriminate' which focussed on BAME communities' experiences of dementia and care and support services. In summary, the APPG came across examples of BAME communities receiving poor care and support that did not meet cultural needs.

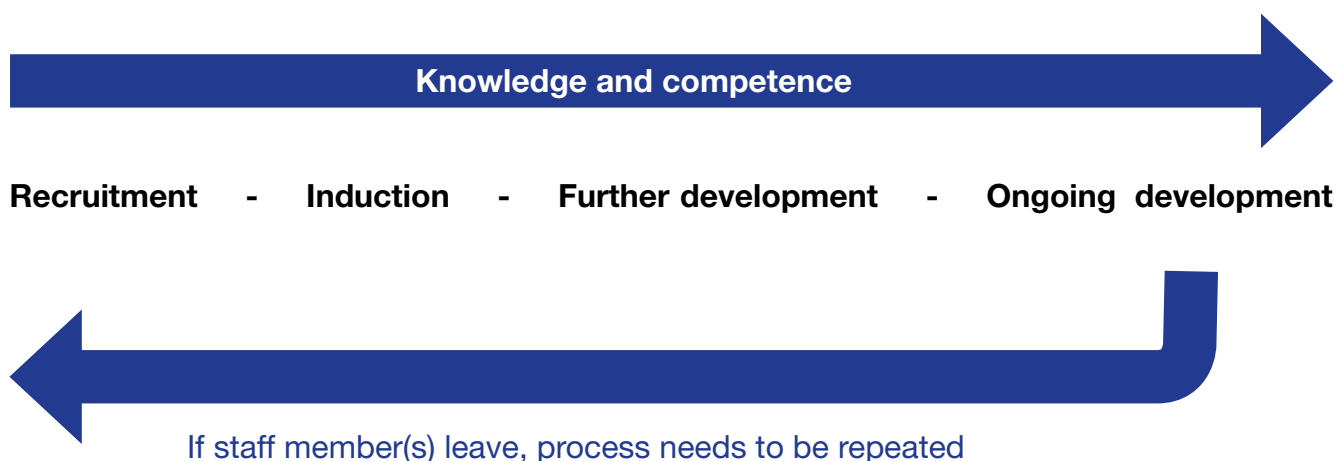
The report also said that care providers needed to be sensitive to cultural stereotypes that mean some communities are assumed to 'look after their own', resulting in services that do not reach out to individuals and families from BAME communities.

In addition to this, in May 2016, a strategic partnership of organisations will publish their Dementia Equity and Rights report. The report highlights the importance of services being able to support people with dementia from diverse backgrounds and cultures.

## How can I support my team better?

At this stage, you may be asking yourself the question: "I understand and recognise that my team needs to embrace diversity, but how can I support my team to ensure best practice?"

This resource is structured to enable you and your team to focus on the different stages of the employment cycle:





## How to use this guide

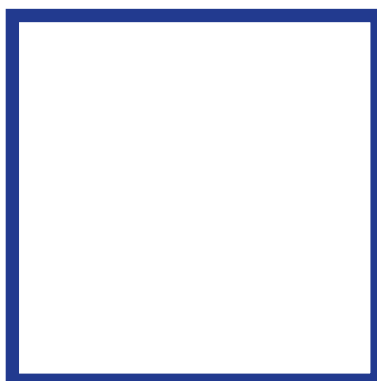
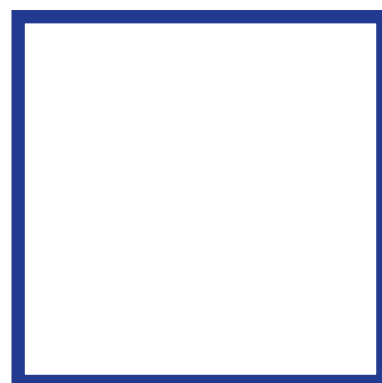
In each section of this resource there is an outline of key areas to consider when supporting your team. Links are included to existing Skills for Care resources that can support you in your role as a leader and manager. In addition, case studies and scenarios will be provided in each section for you to consider with your team.

You're welcome to use this resource however you wish, for example, in team meetings, in supervision sessions or even developing your own learning and development session, or commissioning one. However you decide to support your team in this area of their development is very much up to you, and you're free to use this resource in whichever way you wish.

## Working with others

The final point to make in this section is that we should recognise the importance of the individual, their family, and their friends at this early stage when thinking about different cultures and backgrounds. In order to deliver high-quality care and support to people with dementia, we need to work in conjunction with the individual, their family (including family carers), and their friends.

Often, it is these people who can help us develop a sense of the individual (if they themselves lack the capacity to communicate), their life story and their likes and dislikes. This is particularly important when we are working with people from a different background and culture from our own because it allows us to provide the personalised care we all would wish for.



## 2. What you need to know about people with dementia from different cultures and backgrounds

When considering key things the workforce needs to know and understand when thinking about dementia and diversity, there is one indisputable fact: dementia itself does not discriminate.

For reasons that are subject to on-going research, developing the diseases that cause dementia can affect anyone. It is known though that there are specific risk factors, such as increasing age, associated with a greater chance of developing dementia. If you are interested in finding out more, the Alzheimer's Society has an excellent factsheet on dementia risk factors ([www.alzheimers.org.uk](http://www.alzheimers.org.uk)).

### What to look out for

While there are a number of factors for providers to consider when planning the care and support for someone with dementia, the effects the condition has on individuals are likely to be similar.

However, there will also be individual characteristics which personalised care and support should address. Things to look out for in people with dementia include:

- loss or lapses of recent memory
- mood changes or uncharacteristic behaviour (in later stages this will become more pronounced)
- poor concentration
- problems communicating
- getting lost in familiar places
- making mistakes in a previously learned skill (e.g. cookery)
- problems telling the time or using money
- changes in sleep patterns and appetite
- personality changes
- visio-spatial perception issues (i.e. the brain does not process images as normal).

Source: *Common Core Principles for Supporting People with Dementia – Skills for Care and Skills for Health, 2010*



However, despite these similarities, diversity may bring additional factors for care and support to consider. For example, it is likely that people with dementia who have English as a second language will revert back to their primary language as the condition progresses. For care and support teams this means communication may become more challenging.

Section one of this resource referred to the importance for the social care workforce to work with family carers and friends to ascertain information about the individual and their needs. It is reasonable to ask questions to get as much information as possible from their families to ensure the care and support provided meets needs and does not cause any offence. This will also assist with a common area of concern linked to dementia and diversity - fear of getting it wrong. There is much sensitivity about making mistakes or causing offence with respect to diversity. Providers can support staff in this area with equality and diversity training which, alongside working with the family and friends, is an excellent way of supporting staff to overcome these barriers.

### **Black, Asian, minority ethnic (BAME)**

With reference to BAME communities, it is important to highlight that:

- there may be a stigma connected with dementia and diagnosis in some cultures/communities
- some languages and cultures do not recognise dementia - research has found that simple explanations are the best way to manage this
- people may be more reluctant to access advice and services - sensitive communication will be needed
- particular events may have a particular significance for some cultures. A good example would be the Holocaust for people of Jewish faith
- as the dementia progresses, people will regress to a previous time/times in their life. If this was in a different culture / country / language, this is likely to have a profound impact. It is particularly important to engage family and friends in finding out as much information as possible
- it's important to be aware of communities within communities – e.g. the traveller communities within Irish communities.

### **Lesbian, gay, bisexual or transgender (LGBT)**

For LGBT people with dementia, it is important to highlight that:

- older LGBT people are more likely to be single and more likely to live on their own than heterosexual people
- they are much less likely to have children or regularly see family members
- they are more likely to need to use social care services for help because they do not have support from family
- often LGBT people feel services will not meet their needs or be sensitive to them
- older LGBT people may feel out of place in traditional support groups
- care and support staff need to be very sensitive to comments or behaviour that may be construed as homophobic
- people who are LGBT with dementia may not have previously identified as being LGBT due to having been inhibited due to stigma or discrimination.

With respect to both groups, it is important the workforce is aware that their own experiences and beliefs will shape their own perspective. While this is entirely appropriate, staff need to ensure this does not negatively influence the care and support provided.

Equally, just as the person with dementia from a different culture and background has a moral and legal right to have their beliefs respected, so does a member of the workforce who is from a different culture and background to the person with dementia.

## Young-onset dementia

For people with young-onset dementia, providers need to consider the provision of care and support that is age appropriate. The needs of younger people are likely to be different and younger people are less likely to have another condition alongside dementia.

In addition, it is also important to highlight that people with a learning disability are more likely to develop dementia at an earlier age.

For clarity, in the UK, there are nine protected characteristics enshrined in law (source Equality and Human Rights Commission):

- age
- disability
- gender reassignment
- marriage and civil partnership
- pregnancy and maternity
- race
- religion and belief
- sex
- sexual orientation

All of these protected characteristics also have legislation in place to ensure equality in law and protection from any type of discrimination.

## Case study

# Supporting gay people living with dementia



## Dementia Education and Training Strategy for Gloucestershire

**Malcolm is 83 and is living with dementia. He has vascular dementia and has difficulties with speech and swallowing. Malcolm also has expressive communication difficulties and is unable to coordinate his movements to write or point to pictures. Not being able to find the words he needs has been extremely distressing for him. Malcolm is highly educated having gone to grammar school and then university before becoming a political journalist, travelling all over the world.**

Malcolm met Nigel at university, where they both studied politics, and have lived together as partners since 1956. They have continued to describe themselves as friends due to the discrimination they witnessed gay friends experiencing at that time.

Over the past year Malcolm has experienced increased difficulty swallowing and almost continual chest infections. In addition, he is no longer able to bear weight.

Malcolm receives private home care visits three times a day; usually from a care worker called Moira, with whom Nigel is very close. Malcolm's GP, who is also a family friend, is very supportive and they receive regular visits from the Alzheimer's Society dementia advisor - Celia.

Nigel is caring and constantly with Malcolm. However, in his grief Nigel was becoming increasingly distressed and angry, blaming Malcolm's lifestyle for his illness as Malcolm used to enjoy smoking, malt whisky and long afternoons in the pub.

Malcolm and Nigel's partnership has not been formalised and there is no lasting power of attorney. This can be frustrating

for Nigel as he feels his opinions are not listened to and that he is not being included in decisions about Malcolm's care and support, even though he often has helpful suggestions about Malcolm's preferences from their life together.

One day when Nigel was feeling particularly frustrated he spoke to Celia and told her how he had been feeling. Celia told Nigel to also speak to their friend, Malcolm's GP and she would look into arranging additional support.

A Mental Capacity Act Best Interest Meeting was set up between Nigel, Moira and her supervisor, Malcolm's GP and a social worker where they decided to provide palliative support but discontinue the current course of antibiotics which had become ineffective in treating Malcolm's repeated chest infections.

Nigel is now very involved in Malcolm's care planning. He's involved Malcolm in reminiscence work, looking through some of the old papers that Malcolm used to work on. This has encouraged Malcolm to use some of the articles to help him find words to communicate his preferences.

Nigel now feels much more involved and supported. He and Malcolm are getting on well and Malcolm is spending more time out of bed during the day, with the help of a hoist provided to help him get out of bed.

Malcolm and Nigel's story shows the importance of involving a partner in care planning and also the role the mental capacity act can play even when the partnership has not been formalised, as is often the case in LGBT relationships, particularly for those of an older generation.

## 3. Recruiting staff with the right values and cultural awareness

This section covers the recruitment of new staff. It provides you with advice on how to ensure you are recruiting staff with the right cultural and background awareness to ensure your organisation can provide care and support to a diverse range of people with dementia. This will include a particular focus on attracting the right candidate, and the selection process.

For further advice about recruiting new staff, there is a wealth of resources on the Skills for Care website including a toolkit 'Finding and keeping workers'.

### Get your advertising right

At the first stage of recruiting new staff, there needs to be an advert or announcement that you are recruiting. In terms of competence or awareness linked to equality and diversity, there are certain ways this can be highlighted as important in the advert and person specification. However, you need to ensure you do not discriminate under any of the nine protected characteristics (highlighted in the last section) during recruitment processes. This is particularly important in the advertisement and job description / person specification.

So for example if your organisation was primarily supporting a particular ethnic group, your job advertisement could say knowledge of a particular language would be advantageous for the successful candidate. What you could not say is that only a member of a particular ethnic group could apply for the vacancy. Another example would be that you could not say that you are looking for someone 'young' as this would be age discrimination.

### Equality and diversity policy

Your job advert / person specification should highlight your organisation's equality and diversity policy, and highlight a need for a commitment to these principles by the successful candidate. If a commitment to equality and diversity is stated, this can be assessed during the formal recruitment process which we will consider later in this section.

### The profile of your workforce

It is also good practice for the demographic profile of your workforce to reflect as closely as possible that of the community you are operating in, so it is representative. So while highlighting a commitment to equal opportunities, you could also highlight that you welcome applications from under represented groups in your workforce, whichever these may be.

This is known as 'positive action'. However, the candidate that scores most highly in the recruitment process is the one that should be appointed.



## If in doubt, seek expert advice

Employment law and recruitment is a complex area governed by a significant amount of legislation. Leaders and managers are strongly advised to work with human resources professionals or legal professionals if in any doubt.

Later on in the recruitment process, when selecting candidates through the interview or assessment process, you can include questions and exercises designed to explore cultural and background awareness. For example, in an interview you could ask “Give me an example where you have supported equality and diversity in a previous job.” Or “What would you do if you felt someone you were supporting was being disadvantaged due to their disability?”.

## Cultural awareness

Moving this on a stage further, it would be possible for your recruitment process to assess cultural and background understanding and awareness. As part of the recruitment process you could invite people into the unit where they will be working. You could observe interactions with people with dementia and/or their families and your team, to assess how people interact with people with dementia whose backgrounds are different to their own.







## Case study

# Recruitment, young-onset dementia

### Certitude

**Paul has lived for most of his adult life in his own flat, in a property shared with a number of other people with learning disabilities. A few years ago it became clear that Paul's memory and ability to maintain his independence were deteriorating and he was subsequently diagnosed with dementia.**

Paul's wishes were discussed with him from the start and he made it clear to staff he wanted to remain at home, rather than being moved into a care home or other setting. He was also supported to discuss this with the friends he was living with.

However, the five hours support he was getting at the time was not sufficient to keep him safe and well. Therefore, it was agreed that a full-time support team should be recruited to support him in his own home.

Initially, a team of agency staff was used to cover the increased support. But it became clear that Paul needed a consistent team with some specific attributes.

As Paul's dementia advanced and affected both his physical and cognitive functioning, the team that had known him for a number of years worked with him to draw up the profile of who could best support him.

This process involved creating a profile based on Paul's wishes and needs, including his characteristics, interests and hobbies, as well as the skills of the staff he wanted to support him.

### The key attributes which mattered to Paul were:

- a general connection – having staff who would share and understand his history and relate to the popular culture he connected with, going back to when he was younger
- people who placed utmost value on communication and their relationship with the individual, who would talk to him and reflect on what was going on; whether or not he responded
- people who valued his independence and would be willing to spend much longer on activities such as eating and not rush him, or take over to support him too soon
- people who got on with him as a person and would positively represent him to others, such as medical staff, when he needed to be admitted to hospital
- people who placed a value on his other friendships and relationships and supported him to maintain those.

The recruitment process involved a competency-based interview and potential staff were invited to meet Paul in his home, spend time with him, other support staff, and his friends who'd known him for many years.

Those who knew him well spent time observing, assessing and reflecting on the interactions between the candidates and Paul, and how both parties responded. Not only was Paul able to give his views, but candidates were also able to get to know what the role would entail and consider their own perspectives. This process was clear and transparent and explained to candidates.

## Scenarios

1. You're working in a service that primarily supports people with young-onset dementia. Previously you have been criticised for recruiting staff who did not have a good rapport with the people your service is supporting, so those staff left. How will you ensure you get it right this time?

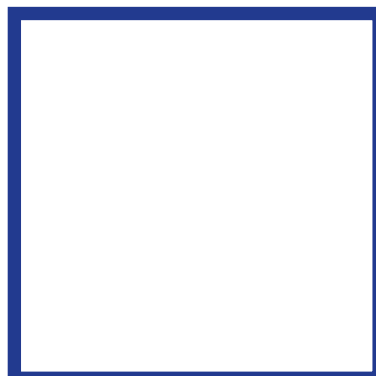
### Things to consider

- Whose views do you need to take into account?
- How will you improve your recruitment process?
- What is legal, what isn't?

2. You work in a service that supports people with dementia from an Afro-Caribbean background. You work in a diverse area of England and the majority of your workforce are also from an Afro-Caribbean background. Your team has been a little unsettled of late. What can you do to make sure you recruit workers who meet people's needs, are responsive, and fit into your existing team?

### Things to consider

- Whose views do you need to take into account?
- How will you improve your recruitment process?
- What is legal, what isn't?



## 4. Induction of staff and supporting cultural and background awareness

When people join your organisation it is important to demonstrate the leadership and management team's commitment to supporting people from diverse cultures and backgrounds. As well as having a policy in place, it is worth considering additional ways your organisation can ensure its commitment to diversity is central to everything it does. Common ways include the development of organisational or team values and further training. Perhaps this could be covered in team meetings or in supervision settings.

With a clear policy and commitment in place, you can expand on the themes highlighted within the recruitment process during a new employee's induction. Identifying staff perceptions and preconceived ideas about cultural differences and dementia are important to pick up on at an early stage.

### The role of the Care Certificate

This area is covered by the introduction of the Care Certificate for all new care workers in social care from April 2015 and ensures new entrants to social care should undergo specific development in:

- dementia awareness
- cultural and background awareness and sensitivity

There are a significant number of resources on the Skills for Care website to support leaders and managers to implement the Care Certificate. It is strongly recommended that these are used with new staff.

Specific development in these areas should ensure people who are new to your business demonstrate a level of empathy with those who have dementia who are from different cultures and backgrounds. If you feel people need additional development and support in these areas, you could consider shadowing / buddying up new members of the team with more experienced members.

### Good practice in action

This will provide a safe and supportive mechanism for people to see good practice in action and most importantly ensure the culture that you want to develop around dementia and diversity is embedded across the organisation.

With respect to dementia and diversity, it may be helpful to further expand on some of the themes identified in section two.

## The importance of life stories

People with dementia are clearly all different, however one common factor is that as the disease progresses, people regress to a previous time/times in their life. If someone's life history means they are not originally from the UK, it is likely this will be an important feature of who they once were and also who they are now. An example could be someone who grew up in India and moved to the UK decades ago as a young adult and had their children (who are now adults) in the UK.

When the person was growing up in India, they may have used a different language and eaten different food. It may be that as their memory fades, their taste for food changes, possibly back to preferring the food they grew up with. In addition, they may revert back to a language other than English, but their children may only speak English. This can make communication difficult between family members.

This example illustrates two key points. Firstly the importance of personalised care and understanding the life story of the person. Secondly how important working with the family is while also considering how personal culture and background is important and unique and will probably differ even in immediate families.

Once the life story is understood, reminiscence can be used, alongside meaningful activities that are relevant to the individual, while ensuring activities are sensitive to their culture and background.

## Sexuality and dementia

We also need to consider different backgrounds such as people who are LGBT. Similar principles of life story, reminiscence, and meaningful activity can be used and we need to support staff to do this. However, we also need to be mindful of the points raised in section two about the need for sensitivity and tact when exploring these areas. In short, some people may be very open, others less so, so staff teams need to work collectively to ensure everyone has the chance to engage with activities, regardless of their background and culture.

Sexuality and dementia is an area that raises important areas for staff to think about; for people who are heterosexual as well as LGBT. Dementia can cause some people to lose their inhibitions. For some, this may mean they make inappropriate sexual advances and staff need to manage this appropriately and sensitively. Staff should also be aware that sometimes behaviour may appear sexual but may not be. For example, expressing a need for affection or mistaking someone for their current (or previous) partner.

People working in residential care homes need to be aware that people with dementia may wish to have a sexual relationship, including with other people living there. Key questions to ask include whether mutual consent is taking place, and whether both individuals have the capacity to make the decision. Capacity is judged according to the following criteria:

- the ability to understand information that is given
- the ability to retain that information long enough to be able to make a decision
- the ability to assess the information available to make a decision
- the ability to communicate their decision by any possible means.



## Case study

### Working with the family

#### Housing 21

**Mrs Li is a 93-year old Asian lady who lives in a nursing home. She has Alzheimer's disease and speaks no English. Her son is concerned she is not eating very much. She has significant contractures in both legs which makes positioning her difficult and therefore she spends all of her time in bed in a semi-recumbent position. Mrs Li does not like to be assisted to eat and so the care team give her sandwiches and she feeds herself.**

A staff member had a conversation with Mrs Li's son and asked what Mrs Li would have eaten at home. He said that she would normally eat steamed fish and rice.

The staff member contacted an occupational therapist for a seating assessment and obtained the advice and equipment so that Mrs Li could sit out of bed for her meals. The staff member then asked the kitchen to provide Mrs Li with food she could recognise and that was familiar to her palate.

The staff member also invited an interpreter to assist her in assessing Mrs Li's mood. Mrs Li scored moderately on the geriatric depression scale, though she was unable to understand some of the questions due to her dementia.

The staff member looked at Mrs Li's room and felt it was not very stimulating. She spoke to the son and suggested ways to make Mrs Li's room more stimulating and interesting. She also spoke to the doctor, who commenced Mrs Li on a low dose of antidepressants.

After a month, Mrs Li was assisted to sit in a chair for her meals and was given culturally appropriate food. A mobile made from crystals which caught the light was added to her room, giving her something to focus on. Rather than the television playing English programmes, Mrs Li's son recorded Chinese TV and radio and staff played this to her.

Mrs Li appeared much more engaged with her surroundings and started to eat much better.

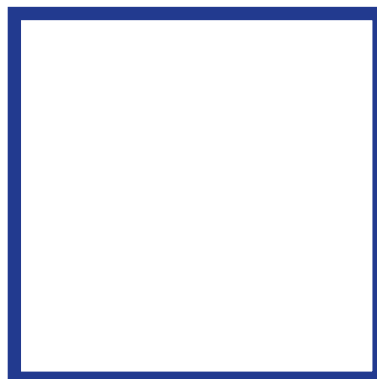
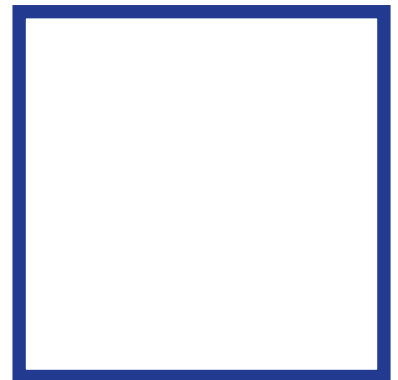
People with dementia can require care for a significant period of time. Staff need to be able to understand and recognise the changes in a person's health that may indicate they require an alternative approach to care. By working closely with other agencies involved in care provision, the person with dementia may be able to remain in their home and receive individualised and person-centred care.

## Scenarios

1. The establishment you manage is providing support to two women with young-onset dementia. One of your team has noticed the two women seem to be very close and appear to want a closer relationship – possibly as more than just friends. How do you manage this?

### Things to consider

- The capacity of the individuals.
  - Your organisational approach (equal opportunities policy).
2. A staff member you have recently recruited expresses thoughts that while not discriminatory, are offensive to some older people with dementia you are supporting – how do you manage this?



## 5. Further development of staff

When considering further development for existing staff who are supporting people with dementia from different backgrounds and cultures, the sort of opportunities that can be considered are numerous. These may include undertaking additional learning, either off-the-job and/or on-the-job; gaining qualifications, or developing additional responsibilities as a dementia or diversity champion (or both).

Additional learning off-the-job may include undertaking non-accredited training to help staff develop their skills and knowledge with respect to dementia and diversity. Typically, this would be a short course.

However, best practice would be for all direct care workers to undertake further qualifications to support them with their role. In particular, this may be the Health and Social Care Diploma at level 2 or 3, or specific dementia units and qualifications. The Skills for Care Skills Selector can help you identify appropriate learning opportunities for your team:

<http://skillselector.skillsforcare.org.uk>

### Develop specialists

You may consider developing specialists in your team. These are staff you can provide with additional training to develop specific expertise in a particular area. Examples would be dementia champions and equality and diversity champions.

When looking at on-the-job development opportunities; once dementia/equality and diversity champions are in place, you can use these staff to disseminate knowledge and skills to the rest of your workforce.

### Developing yourself

You also need to consider your own development as a leader and as a manager. Ultimately it is your responsibility to make sure your service can respond appropriately to the needs of people with dementia from different cultures and backgrounds.

In terms of how you approach on-the-job training; well-trained champions and leaders and managers are excellent at ensuring high-quality dementia care is put in place for everyone - regardless of their culture and background.



## Additional support and resources

Skills for Care, in conjunction with Health Education England and Skills for Health, has produced the Dementia Core Knowledge and Skills Framework. The framework highlights the different levels of training and development that employers should consider in relation to their team. Both the level you train your staff to, and also how you do it, is entirely at your discretion.

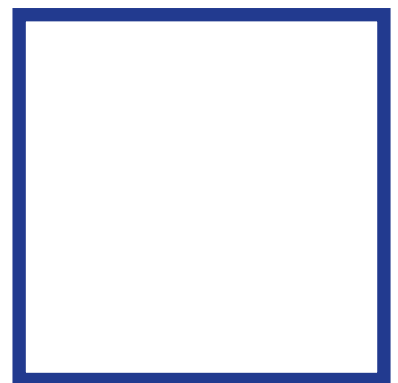
However, it's worth considering that the better you train and support your staff, the better the care they will provide to people with dementia, and the longer they will stay with your business. The framework is available here:

[www.skillsforhealth.org.uk/dementiacstf](http://www.skillsforhealth.org.uk/dementiacstf)

Finally, a really positive way for your organisation to ensure you are always considering your development needs is for your organisation and staff to sign up to the Social Care Commitment. Most importantly this also demonstrates your organisation is committed to providing high-quality care and support.

[www.thesocialcarecommitment.org.uk](http://www.thesocialcarecommitment.org.uk)

An example of the use of informal development to support people with dementia from different backgrounds and cultures is shown in the next case study.





## Case study

### Staff development

#### Irish Memory Loss Alliance

**In the Irish community dementia risk is exacerbated by high rates of cardiovascular disease, limiting long-term illnesses, common mental disorders, and social isolation. In addition, although Irish people have lived in England for decades, many have not integrated well. As memory fails, memories of earlier times are more accessible and can be a source of stimulation and pleasure if harnessed through personalised services. But equally, past memories of hostility and discrimination can impact on behaviour and can be misunderstood.**

To address these issues, a national campaign called the Cuimhne Strategy (Cuimhne is the Irish word for memory) is being delivered by the Irish Memory Loss Alliance. The campaign aims to address the needs of all Irish people in Britain who are living with memory loss (this term is used rather than 'dementia' as there is less stigma attached for the Irish community). It also aims to reduce isolation and improve access to assessment, diagnosis and professional support.

The Cuimhne approach challenges contemporary notions of dementia and focuses on how we think and act towards people with memory loss. It attempts to understand the experience of memory loss, open our hearts and minds and welcome those affected.

A key part of the campaign is to improve understanding and awareness.

- Cuimhne workshops are being delivered across the country. These workshops emphasise specific cultural issues which impact how Irish people experience dementia and how to address these needs in culturally appropriate ways. Organisations offering services to older people or those with dementia have been prioritised in terms of receiving this training.
- The workshops also emphasise the diversity of the Irish community and the particular needs of travellers, LGBT people, people of mixed heritage and those who are survivors of institutional abuse.
- Organisations that work with older people and those living with dementia are being supported to develop culturally sensitive reminiscence resources using personal stories, reflections, Irish music, poetry and artefacts.

There is also a London-wide programme to train 'Cuimhne Champions' to work with different organisations to ensure environments are dementia friendly and that activities are meaningful and stimulating. The campaign is still in the early stages but there has already been a noticeable increase in discussions of dementia within the Irish community.

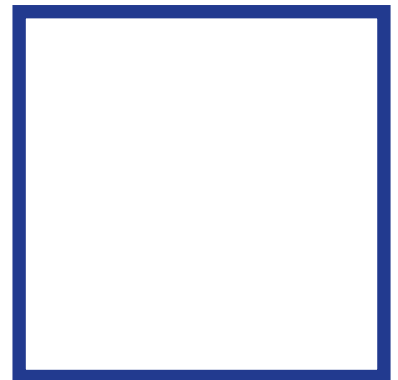
For more information visit [www.irishinbritain.org](http://www.irishinbritain.org)

## Scenarios

1. You are working in a home care service that you feel is really struggling to meet the diverse needs of the people you are supporting. You have had some informal comments from some family members that your staff team does not seem to support people with dementia from a BAME background very well. What can you do to support and develop your staff team?

### Things to consider

- Are the comments fair?
- What policies do you have in place?
- Current development programmes for your team?
- What else could you put in place?



## 6. Ongoing development of staff

Leaders and managers can support staff by identifying learning, development and support needs through supervision and appraisal. Managers have a key role to play here. Ensuring these development needs are met will support the improvement of service quality, improved staff retention and increased continuity of care.

### Reflective learning and effective supervision

For staff supporting people with dementia, we know reflective learning through supervision with their line manager helps staff think through any challenges they are experiencing in relation to the people they are supporting. Skills for Care has produced a resource to support leaders and managers to deliver high-quality and reflective supervision to their teams:

[www.skillsforcare.org.uk/Document-library/Finding-and-keeping-workers/Supervision/Providing-Effective-Supervision.pdf](http://www.skillsforcare.org.uk/Document-library/Finding-and-keeping-workers/Supervision/Providing-Effective-Supervision.pdf)

It's important to recognise there may be very specific needs linked to supporting someone from a particular background or culture. These needs may be supported by working with the local community. An example of this is shown in the case study below.

### Case study

#### Support of the community for different backgrounds and cultures



#### Anchor

**Molly was a Roman Catholic and her faith was extremely important to her. Her priest had arranged for an escort to take Molly to church.**

When her priest died the new priest who took over the parish acknowledged that her attendance was important to her. He felt that due to Molly's dementia she was too unsettled to attend and instead he would visit her to take communion.

During this time, it was noted Molly was less engaged with others.

Following a discussion with the priest, it was agreed the visits to the church should resume. One of the care team members who shared Molly's faith attended the church with her. From arrival, Molly became animated and engaged in her surroundings. Without prompts or support, Molly received communion and could recite whole prayers.

Over the coming weeks, the church community embraced Molly and started to visit her in the care home. As Molly's illness progressed and she was unable to attend the church, the nuns from the local convent visited her daily. This enhanced the last weeks of Molly's life.

It would also be good practice to ensure some involvement from people with dementia, and or their carers, in the training and development of staff.

## A different perspective

As is the case with recruitment processes, a different perspective can be immensely valuable to ensure that we are all challenged in our thinking. This can be particularly valuable when considering people with dementia from different backgrounds and cultures and understanding the person receiving care and support.

It can be the case, for example, that staff may make supportive assumptions with the best of intentions, but that these assumptions are proved to be incorrect. Our next case study illustrates this very well.

### Case study

## Working with the family



Davies Court, Rotherham Metropolitan Borough Council

**Mrs A is an 82-year-old lady who was born in Jamaica. She came to the UK in the 1950s with her husband and settled in South Yorkshire. The couple went on to have three children. When her husband passed away, Mrs A went to live with one of her daughters.**

Mrs A was diagnosed with Alzheimer's disease in 2011. This made it difficult for her daughter to take holidays as it was not safe for Mrs A to be alone. After an assessment, Mrs A went to Davies Court for respite care while her daughter had a break.

Mrs A was a very quiet lady who liked her own company. The team found it difficult as she often declined to get out of bed, or allow anyone to give her help to shower or get dressed. She also declined meals and although the team had asked what she would like, when it was presented to her she would leave it. The team presumed that she preferred spicy chicken or other Caribbean foods, so they tried buying what they thought she would enjoy, without success.

Mrs A's other daughter visited her every evening and raised concerns about her being in her room and not eating, as her mum would tell her she was very hungry when she visited. Her daughter also assisted her to shower and brought her a takeaway in every evening.

The situation became so difficult that the deputy care home manager decided there needed to be a meeting with all her children to find out exactly what her routine was at home and look at developing a plan for all the staff to follow.

The meeting was very productive and the team got lots of very useful information from the daughter that she lived with. She informed the staff that it is usual for her mum to not want to get out of bed but that given time she would eventually get washed and dressed at her own pace.

The team also discovered that Mrs A has always been a person who likes her own company and who never socialised or had a big circle of friends. The most surprising fact for the team was that Mrs A likes to eat chicken dippers, hot sausage rolls, chicken drumsticks, pizza, omelette, mashed potatoes and gravy, and toasties.

However, the key was she only would eat the food if it was piping hot! It had been assumed that because Mrs A was Jamaican she would like Caribbean food but in fact her tastes had changed over the years. A meeting with the cooks took place to ensure the appropriate foods were being ordered and prepared for Mrs A.

## Integrating health and social care

The final area of this section and the final case study focus on integrated working across health and social care and how people with dementia from different backgrounds and cultures are supported by the system. Clearly, better integrated services benefit people with dementia and their families, whatever their background. Their feedback is often that systems are fragmented and do not talk to one another. So a good question to end with is: “What can your service do to integrate more effectively to better support everyone with dementia?”.

An excellent example is highlighted in the case study below.



### Case study

### Working in an integrated way

#### Worcestershire Health and Care NHS Trust

**Worcestershire Health and Care NHS Trust is the main provider of community and mental health services in Worcestershire. A post has been established for a young-onset dementia development officer to look at establishing a clearer idea of the support that people living with young-onset dementia (diagnosis under the age of 65) and their families need. Although employed by an NHS trust, the post involves liaising with staff working across a number of sectors, including health care, social care, education, and the voluntary sector.**

There is no dedicated service for people living with young-onset dementia in Worcestershire. However, it is well recognised that people who develop dementia at a younger age and their families experience very different problems (Rayment and Kuruvilla, 2015).

Providing education is one of the remits of the young-onset dementia development officer's post. A special interest group has been set up for staff to attend (this runs six times a year). Staff from all sectors are welcome to attend (i.e. health care, social care, education and the voluntary sector) and this generates lots of discussion, ideas and sharing of information.

To support the further development of staff, the hope is that by increasing staff awareness about the different issues that can impact people living with young-onset dementia, needs will be better met. Due to the training being provided in a multi-agency environment, staff have the opportunity to learn about each other's services. This promotes improvements in understanding of how the different groups can work together to support people.

Some of the topics that have been covered/ are planned for the education sessions include:

- listening to the experiences of younger people and their families of living with dementia
- interventions in young-onset dementia
- living with semantic dementia
- living with posterior cortical atrophy
- living with progressive non-fluent aphasia
- issues of grief and loss in people living with young-onset dementia and their families.

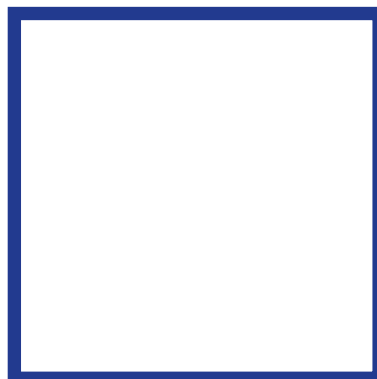
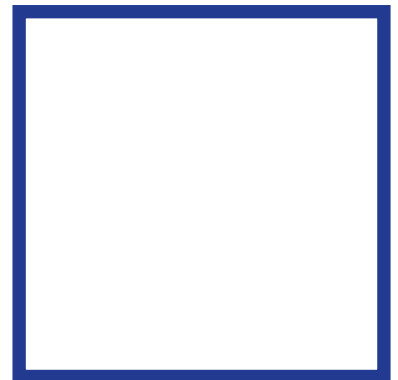
Reference - Rayment, D. and Kuruvilla, T. (2015) Service Provision for Young-Onset Dementia in the UK, Progress in Neurology and Psychiatry, July/August 28 – 30.

## Scenarios

1. Your organisation is supporting a person with dementia who is white. The person needs to go into hospital for a routine operation which will involve an overnight stay. You have heard the person use language that is not politically correct with respect to other backgrounds and cultures. How do you support the individual and the hospital to manage the situation?
2. On another occasion, the person in scenario one needs to go into hospital as an emergency. The ambulance arrives and the person expresses concern about entering the ambulance because the paramedic is from a different culture. How do you support the individual and the paramedic team?

### Things to consider

- How can you meet everybody's needs?
- How can you ensure that no one is subjected to behaviour that may offend them?





## 7. Summary

We've covered a lot of information in this resource. Here is a summary of the main points.

- A person's culture and background forms a fundamental part of their identity.
- It is important to consider a person's background, culture, beliefs and preferences when planning and delivering care and support for someone with dementia.
- It is important to recruit staff with the right values and cultural awareness.
- Ongoing training and development is important to maintain the right values and to provide ongoing support for staff within your organisation.
- The leadership and management team must demonstrate a commitment to supporting people with dementia from diverse cultures and backgrounds.
- There are lots of resources available to help you support your team.

We hope this resource with its good practice examples, case studies and scenarios has been useful to you and your organisation. We hope it can be used to improve the knowledge and skills of your team while supporting you to further improve the care and support you provide to people with dementia, from all backgrounds and cultures. At the centre of all of this, is of course, person-centred care.

### Your role as a leader and manager

Care and support that is tailored to the individual and meets all their needs is the ultimate goal. In addition to this, your role as a leader and manager in your organisation is critical to set the standards and expectations for high-quality personalised care for all the people with dementia you are supporting.

#### Tell us what you think

If you've used this guide and it's made a difference to your organisation, we want to hear from you. Please email [marketing@skillsforcare.org.uk](mailto:marketing@skillsforcare.org.uk) and tell us about your experience.



## 8. Further reading and resources

Dementia, equity and rights report, Race Equality Foundation, 2016

[www.raceequalityfoundation.org.uk/sites/default/files/publications/downloads/Dementia%20report%20SCREEN.pdf](http://www.raceequalityfoundation.org.uk/sites/default/files/publications/downloads/Dementia%20report%20SCREEN.pdf)

Dementia Core Knowledge and Skills Framework, Skills for Health, Skills for Care and Health Education England, 2016 [www.skillsforhealth.org.uk/dementiacstf](http://www.skillsforhealth.org.uk/dementiacstf)

*Service Provision for Young-onset Dementia in the UK, Progress in Neurology and Psychiatry*, July/August 28 – 30, Rayment, D. and Kuruvilla, T. (2015)

<http://onlinelibrary.wiley.com/doi/10.1002/pnp.391/pdf>

## 9. Skills for Care resources

Care Act learning materials [www.skillsforcare.org.uk/thecareact](http://www.skillsforcare.org.uk/thecareact)

The common core principles for supporting people with dementia (2011)

Better domiciliary care for people with dementia; Best practice case studies from domiciliary care employers developing their workforces to support people with dementia (2014)

Dementia and carers together - A guide for social care workers on supporting the family and friends of people with dementia (2012)

Dementia and carers: workers' resource - Information for care workers supporting the family and friends of people with dementia (in partnership with Dementia UK) (2012)

Providing Effective Supervision, Skills for Care

[www.skillsforcare.org.uk/Document-library/Finding-and-keeping-workers/Supervision/Providing-Effective-Supervision.pdf](http://www.skillsforcare.org.uk/Document-library/Finding-and-keeping-workers/Supervision/Providing-Effective-Supervision.pdf)

Supporting dementia workers A case study-based manager's guide to good practice in learning and development for social care workers supporting people with dementia (2012)

Supporting people in the advanced stages of dementia

A case study-based manager's guide to good practice in learning and development for social care workers supporting people in the advanced stages of dementia (2013)

All these resources can be downloaded at [www.skillsforcare.org.uk/dementia](http://www.skillsforcare.org.uk/dementia).



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