Caring for Dementia:
Exploring good practice on supporting South Asian carers through access to culturally competent service provision

Meri Yaadain Dementia Team
5th Floor, Olicana House
Chapel Street
Bradford
BD1 5RE
Telephone: 01274 431308

Akhlak Rauf
This publication has been made possible with the support of:

- Yorkshire & Humber Improvement Partnership
- Bradford Metropolitan District Council
- Meri Yaadain Dementia Team
- Saheli Group
- A number of community groups
- People who live with dementia
- Carers of people with dementia.
Caring for Dementia:
Exploring good practice on supporting South Asian carers through access to culturally competent service provision
This booklet is an attempt to touch on some of the issues facing South Asian carers. It is not, nor professes to be, an exhaustive guide to all the issues that may affect carers – especially those who care for older relatives suffering from dementia.

What is dementia?

Dementia covers a multitude of memory-related conditions which are often associated with older people, even though many younger people suffer from it. Whilst there are approximately over 750,000 people suffering from dementia in the UK, this number is growing due to the fact that older people are living longer.

Given the ever-increasing costs of treating and supporting people with dementia, the Government has recognised a need to tackle this area. Simply put, the memory loss in an individual affects many others around them. It is imperative therefore that the individual suffering from dementia gets all the help they can, as well as the carer being able to continue caring which in turn helps reduce the financial burden on the state.

However, there is also a growing recognition of the difference in the way that different communities are able to access the information and services that they need.

Who are the South Asian communities?

About 3% of the people of Britain are considered to be from South Asia, or are of South Asian heritage. This means that they are directly or indirectly of Indian, Pakistani or Bangladeshi descent. However although this means that approximately 1.5 million people are grouped together as a community, there are many variations within the community itself. This is what we define as ‘communities within communities.’ It may be that someone is defined as being of Indian origin, but are they Hindu, Muslim, Sikh or Christian? Do they speak Hindi, Urdu, Punjabi, Gujerati? Or it may be that the Punjabi-speaking Brit may be of either Indian or Pakistani origin, depending on whether they are (generalising here) Indian Sikh because they speak Gurumukhi Punjabi, or Pakistani Muslim because they speak Mirpuri Punjabi. Similarly a South Asian Muslim might be Indian, Pakistani or Bangladeshi – with a whole range of varying cultural differences.

South Asian communities also differ in their level of literacy depending on origin of migration and class. South Asians from East African origins are more middle-class whilst the vast majority who arrived in the 1950s, 60s and 70s...
Caring for Dementia

were from the villages and essentially agricultural backgrounds. This means that the pattern of settlement in Britain led to the type of work the South Asian migrant communities took up. In turn we have South Asian communities where some speak little or no English while others are educated to postgraduate level and beyond. However, attitudes and experiences are commonly shared across the various communities despite the level of employability, place of settlement or indeed the level of articulation.

Which factors play a pivotal role in how South Asian communities are able to interact with outside agencies?

1. The concept of belonging to a biraderi (family clan) – Migrant families have traditionally continued to hold on to extended family structures to support and help the family as a collective. This influenced people from either the same family kinships or geographical localities moving to settle nearer each other in Britain. However, in some areas like Keighley, this has led to communities being sceptical of ‘confidential’ services given that everyone is seen to know about everyone else’s business. It has also led to pressures on families that need support to supplement the care they provide at home by making them feel inadequate in fulfilling their caring duties. Families are easily persuaded (or forced) to concede support services where it is felt that the ‘community’ or ‘family kinships’ know better than the service provider on how best to look after the person needing care.

2. Power roles within the family – Men are almost always seen as the power base in most South Asian households. It is the husband, the father, the grandfather that is viewed as the decision-maker on behalf of the family. Whilst this may be true in many respects, the complexities of this go far beyond the public face of the family. For example, the eldest son might decide whether and how they will access support services for their frail father. But, looking at the family dynamics more closely, the women of the household (often the eldest) will make many of the decisions which precede the involvement of the ‘head of household’.

The women of the household are usually the carers within the family (not too dissimilar to English families), but they may not have the same authority to influence or veto decisions made by the men. This creates a situation where the carer might be struggling to cope with caring whilst they may not be able to convince the need for support. Equally too it may be that the

South Asian men came to Britain as a result of active recruitment by the British Government to meet the labour shortages post World War II.
male family member seeks support services, but the female carer feels it is a discredit to her if she is not able to carry out her duties as a wife, a daughter or a daughter-in-law.

3. Izzat (honour) and Sharam (shame) – These two notions are not easily understood by many westerners. Essentially it is how the actions of family members affect the social standing of the family. Across African and Asian cultures it is usual for the men to be ‘spokesman’ for the family whilst the women are more the ‘spokeswomen’ for family affairs within the home. Women may have a stronger role in issues such as arranged marriages, family relationships and supporting the running of family affairs. Izzat and Sharam of the family usually rest on the female – eg a daughter’s decision which may not be favourable with the family and the biraderi will cause disrespect and humility for the family. The family is expected to conform to expected norms.

This issue may hinder the carer from disagreeing with the leading male of the household. The women may say that they are able to cope with caring at home for fear of the wider community seeing them as a failure in their duty to care.

Who or what is a carer?

The word ‘carer’ is often thrown around by various service providers, as well as ministers in the Government, without necessarily spelling out what it actually means to the lay person. A basic definition of ‘carer’ is someone who looks after another person with or without a disability, a friend, a neighbour or a relative, possibly with an illness, or someone who is old and infirm. The carer does not usually get paid for this, although there are paid carers such as people who work for Home Care services through local authority services or care staff in hospitals, residential or nursing homes.

For the purposes of this guidebook we will be referring to a ‘carer’ as someone who looks after an older relative with dementia. Having said this, the recommendations and conclusions are applicable to a variety of settings – ie the person being cared for does not have to have dementia in order to benefit from this guidebook.

Are carers recognised by statutory services?

The Care Services Minister Paul Burstow MP made clear the Government’s recognition of the contribution made by Britain’s six million carers during
Caring for Dementia

Carers’ Week in June 2010. Whilst acknowledging that about a million of these carers undertake more than 50 hours of care a week, he made it clear that the health and social care sector needs to make better arrangements to incorporate support to carers.

This recognition has been further strengthened by the publication of the Department of Health document ‘Recognised, valued and supported: next steps for the Carers’ Strategy’.

The strategy addresses a key area, which is to get carers to recognise themselves as such earlier in their care-giving role. This would enable them to have a more pivotal role in shaping care packages as well as the design of local care provision.

It goes further still to look at the individual status of the carer, ie as a carer they should not lose out on education and employment. To support the care role, the strategy wishes to install personalised support for the carer and the person cared for so that both can have a more meaningful community and family life. And finally, perhaps as equally important is the desire to have early recognition, to support carers to remain mentally and physically well.

Carers are also recognised by the provision set out through the Carers (Equal Opportunities) Act which came into force in 2005. It stresses the need for carers to be able to access assessments in their own right. This means that local service providers would need to understand the demands placed on the carer as well as the carer’s own aspirations to work, study or access leisure opportunities.

Why are carers important?

There are approximately 5 million carers in the UK, about a million of whom look after someone for more than 50 hours a week. This gives us an indication of how much the state benefits by the tax payer not having to pay for care within care institutions.

With regard to dementia, we know that about two-thirds of older people who suffer from dementia are looked after by family members within the community setting. With older people now living longer lives, there is a clear correlation with the increase in the number of older people with dementia. It therefore becomes important that the government reflects on the role played by carers, who far too often do not see their duties as ‘care’ but as the normal expectation of family members.

The recognition afforded to carers in recent years reflects the contribution that carers make in keeping people they care for out of ‘state care,’ ie this frees up
make in keeping people they care for out of ‘state care,’ ie this frees up residential and nursing home beds, keeps GP budgets lower and the burden upon the NHS minimised. However, in order to continue this, carers need to have their own health and well-being looked after so that they are able to care for their loved one for longer whilst at the same time looking after themselves.

The rights of carers are being strengthened but carers must also know what they are entitled to, both in terms of welfare benefits provision and the services that they and the person they care for can access.

The cultural context of caring

Whilst carers usually get on with the job of caring without necessarily worrying about their own ability or difficulties, there has been an acknowledgement of the problems encountered when they try to access services from mainstream statutory providers such as social services, hospitals, memory assessment clinics, Community Mental Health Teams etc as well as some voluntary/community organisations. The problems frequently stem from the inability of the service provider to understand the service user’s and carer’s cultural expectations and requirements.

Organisations have been working towards a better understanding of diversity and its implications. But to simply have staff who have undertaken cultural awareness training is not enough: they should also know how to put this understanding into practice. Cultural competency should therefore become a way forward when administering services to people who are culturally different to ourselves.

Culture encompasses a wide range of issues which can include ethnic background, language, religion, diet, sexuality, ability, values and personal preferences. It is this makeup of the individual that drives their ability to access appropriate care provision. If carers are worried that the statutory service provider may not be able to understand the cultural needs of their family member, they will be less likely to take up services available to them.

The scope for including cultural competency needs to be incorporated at all three stages of assessment and service delivery — pre-assessment, assessment and post-assessment — so that the service user can access the relevant services they require.

How do carers feel about caring?

There is now quite a wide range of information available from research into
carers’ issues. However research into dementia, and in particular into Black and Minority Ethnic (BME) carers looking after relatives with dementia, is still very limited.

During the 1990s many researchers showed evidence of the continuing widespread inequality and exclusion of BME communities. This included poor health, high poverty, poorer quality housing (including overcrowding) and unemployment. Access to health and social care was a replication of the other socio-economic characteristics. Communities and service users have regularly complained about access to GP and hospital appointments and poor quality GP and hospital consultations.

It comes as no surprise then that carers too take comfort in their own cultural norms and traditions, where caring is seen as a duty, rather than put the person they care for into care beyond the family setting. In 2008 the Institute of Psychiatry reported that South Asian and Black Caribbean people were far more likely to view caring as virtuous, natural and expected. In contrast indigenous English carers see caring as a restrictive activity which places their own lives on hold while they undertake caring responsibilities.

It is this traditional view of virtue and expectation that adds to the linguistic, cultural and social barriers preventing carers from engaging with a variety of service providers, especially if care responsibilities are seen to be shared with outsiders. An added difficulty for carers of older relatives with dementia is that the carer may not understand why the person is undergoing behavioural changes, while something more physical such as a stroke is clear to see and to cope with.

Carers with strong religious beliefs and values are very likely to want to play a large part in the planning and care of their relative, as religious connotations dictate virtue through looking after elderly parents. Others see caring for older parents as a way of reciprocating the care and support their parents gave them during their own childhood.

**How do BME carers view statutory service providers?**

People from the black and minority ethnic communities struggle with the concept of ‘carers.’ However given the growth in the number of older people and their respective illnesses and disabilities connected with old age, caring is an activity that many families face out of necessity rather than choice.

In order to make life easier for the carer there has to be a good relationship...
between service providers and service users. Many people do cite examples of good practice but many more quote examples of mistrust, being ‘passed off’ or simply not listened to.

When it comes to carers who look after a relative with dementia, there is a double problem faced by BME communities: on the one hand there are difficulties with encouraging the relative to access services to get a diagnosis in the face of community and family taboos concerning mental health. On the other hand, service providers do not have appropriate or sufficient cultural competence to meet the service needs of such carers and families.

What are the difficulties/barriers experienced by BME carers of people with dementia?

1. Community or family expectations

Many carers said that the wider family members were often unaware of the demands of caring, and as such they were naïve to simply expect the lone carer to be burdened with an ageing relative with dementia. Community taboos meant that they did not want to ‘bring shame’ on the family by owning up to the fact that someone in the family was suffering from a mental condition.

The religious expectations of duty to care cut across Islam, Hinduism and Sikhism. Carers from all three religions said that their faith placed a responsibility on them to care for the person suffering from dementia. This meant that you either accepted the situation as a test from God (ie in your ability to be patient and to persevere in caring) or you failed in your duty by expecting outside services to support you in the caring of your family member.

Even when the carer or immediate family recognised that health and social care services existed to support them in their caring, outside pressures from the wider community meant that they were either not encouraged to access support or were simply seen as struggling to carry out religious obligations to look after the elderly person.

It is also important to stress that the service providers have to be very careful not to assume that just because there is an extended family, the ‘family looks after their own’.

Understanding of how stigma affects awareness, care and access to relevant services will improve the take up of appropriate services.
2. Access to services

There is a strong feeling of not knowing enough about the different types of services available to carers and the person they are caring for. Many carers have said that even if they approach their doctor, they are often ‘fobbed off’ and never get through to getting a diagnosis from the memory assessment teams.

Other carers have said that mental health issues were difficult to grasp from a community (cultural) taboo aspect, but then service providers had little or no cultural competency awareness of what they could offer families. This was in relation to accessing appropriate services rather than using a ‘one size fits all’ approach.

3. Assessment

Carers told us that it was hard to get service providers to understand the real complexities of being a BME carer struggling against community barriers, whilst service providers were unable to appreciate that the assessment process should be made more effective.

There was a recognised need for assessors who understood cultural needs, community politics and taboos as well as perhaps religious and linguistic differences in how people perceive duties of caring, and the extent to which they could access support and services outside the home setting.

Assessors were seen to have little understanding of family dynamics – eg the carer of someone within an extended family household may not be the decision maker, and may also be very isolated in family expectations for them to continue to care alone.

Carers were very suspicious of social workers getting facts wrong, thereby jeopardising the resolve of the family unit to access support against the expectations of wider family and community expectations. It was a common feeling that assessors should know more about the family setting before they should undertake an assessment – ie the religion of the family and how this impacts on decision-making, the role played by the different genders within the household (the male might be the decision maker, but the female may be the carer) and the impact on service user and carer by the extended family members or even the head of the household.

Many of the older women carers felt that they were not treated the same as someone who perhaps spoke fluent English. They argued that not knowing what was available put them at a disadvantage in being able to
suggest what was needed. This included comments such as, “If you did not know that respite care was available, how could you ask service providers for that type of help?”

The use of interpreters

Unfortunately there are still mixed messages regarding the use of interpreters and communication with the patient. Carers tell of numerous examples where they have had a member of their family acting as an interpreter. For many of them there was comfort in having a family member to interpret as they would know the home situation. However, carers also reported that on many occasions, where the carer would have preferred to use a friend or family member to interpret, the service providers have said that their policy requires an independent interpreter. It is important to explain to the individual the reasons for not using family interpreters – they could be biased or misinterpret a question or response.

Sending mixed messages to the carer has added to the frustrations and mistrust of service providers, especially those in mental health and of social workers. Given the suspicions that already exist of letting outsiders into the house, the mixed messages of who the service will talk to (or use as an interpreter) add to the likelihood of carers struggling alone rather than approaching service providers.

Interestingly though, this leads to more BME carers accessing support from third sector advice centres for welfare benefits support – Disability Living Allowance, Attendance Allowance and Carers’ Allowance instead of services such as respite, Home Care and nursing care.

Lack of appropriate referral

GP}s have come under much criticism from the carers who have contributed to this good practice booklet. They argued that GPs on the whole neither listen to the stresses of the carer, nor refer the patient on to memory assessments so that a diagnosis can at least be obtained.

One carer even went as far as paying for private treatment through the Yorkshire Clinic to enable his wife to obtain a memory assessment and subsequent diagnosis of dementia.
Caring for Dementia

Comments made by carers about the impact of caring for someone with dementia:

“I don't really see my dad as my dad any more – his behaviour is different, he talks in slurred sentences about things that don't always make sense”

“My wife really struggled to accept that I was noticing her forgetfulness – this led to tensions in our relationship”

“I feel very isolated as my siblings don’t really appreciate the pressure I am under to care for dad’s dementia. All they see is that I am benefiting from his pension and benefits – but are they worth it?”

“I wish sometimes that I could really tell the doctor what I think of him, but I’d get struck off – he is totally useless”

“Mum goes to a monthly support group, which helps as I get a break and the people there are in similar positions as me”

“No religion says you can’t get help from outside services, our communities can be so backward in their thinking sometimes. But it isn’t until you care for someone with dementia that you realise how hard this kind of caring is”

“It took us a long time to get the help we needed from Social Services. All they keep telling you is that there isn’t enough money or the waiting lists are too long.”

Cultural differences and similarities

Like any others, the South Asian communities are no different in wanting to access appropriate, timely and high quality care for their loved one suffering from dementia. Again it is important to recognise that whilst many South Asian carers fear the community stigma related to mental health and the support of external services, there are those carers who want to continue caring at home but with supportive care services from relevant providers. So too, the communities also vary in what they see as necessary care services and what they see as optional – eg choosing between a nursing home or palliative care at home.

People need to be treated as individuals. No two families behave in the same way – listen to the carer.

It has already been mentioned that South Asian communities are made up of lots of variant communities, with individuals who follow cultural norms
and those who do not. The difference in cultural, linguistic and religious traditions will dictate the extent to which carers will access support services, or the ability of service providers in being able to understand the need for cultural competencies rather than simply cultural awareness.

Cultural competency implies the ability of an individual to utilise their cultural awareness into practical understanding and support with appropriate service provision.

1. Culture:

Culture incorporates the traditions, rituals, customs, ceremonies, dietary variations and language(s) of the community. Within these are a wide number of aspects that service providers need to take into account when discussing services and service provision with carers.

2. Traditions, rituals and customs:

All the South Asian communities are fairly strong in their religious identity. Given this, many of the traditions and rituals are based on the religion of the individual whilst others may relate to geographical or historical norms rather than religious dictates. For example the wearing of salwar kameez by Sikh and Pakistani Muslim women is more to do with the Punjabi culture than a religious edict. Similarly, Bangladeshi and Hindu women may wear a sari, but the Muslim women will not have their waist exposed whilst Hindu women (most likely) will. Though this may be a subtle difference, Muslim women will wear their sari in this way due to the Islamic instructions of not exposing parts of the body.

The wearing of a turban could highlight the religion of the individual, ie a Sikh or a Muslim, but there will be differences in the way the turban is tied according to the individual’s religion.

Other traditions, such as the care of elderly parents, are strongly advocated by all three main South Asian religions: Islam, Sikhism and Hinduism. It is therefore more difficult for a carer and the family to choose outside help – especially residential and nursing homes – due to this being perceived as a failure in the ability to care. Instead, services such as regular respite and Home Care will offer the carer a break.

3. Food and diet:

Once again there are vast differences as well as similarities in what South Asian people will and will not eat. It is important therefore that service
and those who do not. The difference in cultural, linguistic and religious traditions will dictate the extent to which carers will access support services, or the ability of service providers in being able to understand the need for cultural competencies rather than simply cultural awareness.

Cultural competency implies the ability of an individual to utilise their cultural awareness into practical understanding and support with appropriate service provision.

1. Culture:

Culture incorporates the traditions, rituals, customs, ceremonies, dietary variations and language(s) of the community. Within these are a wide number of aspects that service providers need to take into account when discussing services and service provision with carers.

2. Traditions, rituals and customs:

All the South Asian communities are fairly strong in their religious identity. Given this, many of the traditions and rituals are based on the religion of the individual whilst others may relate to geographical or historical norms rather than religious dictates. For example the wearing of salwar kameez by Sikh and Pakistani Muslim women is more to do with the Punjabi culture than a religious edict. Similarly, Bangladeshi and Hindu women may wear a sari, but the Muslim women will not have their waist exposed whilst Hindu women (most likely) will. Though this may be a subtle difference, Muslim women will wear their sari in this way due to the Islamic instructions of not exposing parts of the body.

The wearing of a turban could highlight the religion of the individual, ie a Sikh or a Muslim, but there will be differences in the way the turban is tied according to the individual’s religion.

Other traditions, such as the care of elderly parents, are strongly advocated by all three main South Asian religions: Islam, Sikhism and Hinduism. It is therefore more difficult for a carer and the family to choose outside help – especially residential and nursing homes – due to this being perceived as a failure in the ability to care. Instead, services such as regular respite and Home Care will offer the carer a break.

3. Food and diet:

Once again there are vast differences as well as similarities in what South Asian people will and will not eat. It is important therefore that service
providers listen to carers and the person suffering from dementia to ensure that appropriate food is provided in settings such as day care, respite care etc.

Muslims for example eat only Halal meat, with the prohibition of pork in any form. They will also not drink alcohol. Sikhs on the other hand may well choose to eat meat, but not Halal meat. Hindus are almost always vegetarian, with a large majority also being vegan. Not only will Hindus not eat meat, but cows are sacred in their religion. Hence you would need to reflect these sensitivities where you provide food for South Asian service users. It would be very risky to perceive the South Asian service users as a homogeneous group – people have many likes and dislikes as well as personal preferences, irrespective of religious requirements. The best advice therefore is to ask and listen to the individuals.

It is also worth noting that South Asian families (particularly the older generation) may be very pushy in offering refreshments as part of cultural hospitality.

4. Religious obligations:

Many South Asian families take part in religious activities whether these are in the form of prayer, chants, fasting or festivals. However, there are no hard and fast rules about which day is good or bad for visiting a family. The different religions do have some set days and dates, eg Muslim prayers on a Friday afternoon, a Hindu family deciding to fast on a set day every week, or a Sikh family taking part in ‘Kanpat’ (the complete recital of the Holy Book at the Gurdwara.) It is therefore best to speak to the carer before making any decisions about care packages, or making appointments to visit people at home.

Another issue may arise around the wearing of outdoor shoes in the house. For some people there may be a set place in the house for undertaking prayers and they would not wish to make that unclean by someone walking over it with outdoor shoes. Other people may have small children, so the family will remove their outdoor shoes when they enter the house.

You may be asked to remove your shoes when you visit a family. It is important not to feel offended or belittled – you need to be aware of this. Depending on your task, as long as you are professional in your approach and manner, you may simply be able to explain that health and safety requires you to keep your footwear on, or make some arrangement with the family to avoid walking through their house in your shoes.

Similarly, what the professional wears may also affect their relationship with the service user. Whilst many in the western world do not always understand why some Muslim women may choose to wear the ‘nikab’ (face
why some Muslim women may choose to wear the ‘nikab’ (face veil), South Asian communities do not always look favourably on women who wear short skirts or low necklines, for example.

How can support services help carers from South Asian families?

1. Information:

Carers vary in their ability to access information. The word ‘dementia’ does not exist in the main South Asian languages (at least at layman’s level). So the first barrier is getting over a concept that may or may not be understood by the carer.

The carer may not be able to read or write in their own community language (especially older carers), so it becomes vital that any communication is carefully thought through.

Printed material can be of use only where the family may collectively deal with the matter – eg an English-reading son or daughter may be able to translate for the non-English speaking older member of the family.

The use of interpreters needs to reflect the cultural dynamics of the family – ie is the interpreter known to the family, are they able to speak the same language/dialect, does the interpreter know enough about the subject they are interpreting about (ie dementia) so as not to give their own version?

Promotion of services needs to reflect the way in which the various communities access information. Not everyone has the internet at home, while others may prefer information via the internet as opposed to speaking to a social worker or ringing an automated phone line. Service providers need to understand how and where the information contact point is accessed by various communities and different types of people, eg young, old, English speaker, non-English speaker, working or housebound person etc.)

2. Communicating non-verbally (body language):

Another issue is that of body language. There are different world views as to what is right and wrong, what is acceptable and what is considered rude or offensive. Body language is one of those issues that can either help your communication or act as a barrier.
In some communities, for example, it is rude to stare at people whilst in others eye contact helps communication. Not making eye contact may even be seen to be submissive; however in most of the South Asian communities this would be a sign of respect, rather than the ‘arrogance’ of looking or staring at people in the eye.

Similarly, sitting with arms or legs crossed may give different messages to people – frustration, arrogance, importance, etc.

3. Providing access to services:

Services need to be promoted and information made available before people are able to access them. Many, if not most, of the BME older carers we come across complain that appropriate agencies are not aware that referrals to their services are suspiciously low.

Dementia may not be well understood by BME carers, but there is evidence of a lack of referrals by GP practices to the Community Mental Health Teams and to the Memory Assessment clinics for a diagnosis. Follow-up is also reported to be difficult to access primarily due to language and communication difficulties for the older carers, whilst younger carers report a sense of being sidelined by some service providers.

Bradford Council has been at the forefront of promoting health and social care services to communities including specific efforts to reach out to the BME communities. It was recognised quite a few years ago that it is not good enough for service providers to wait to be contacted by potential service users. On the contrary, services are promoted to the communities through a variety of means. Reaching out to communities may include face-to-face work through running community roadshows in community centres, places of worship, sheltered housing and day centres. The ‘harder to reach’ are offered information about services through community radio stations such as Radio Ramadhan, Radio Hajj, Keighley Festival Radio, Bradford Community Broadcasting and Sabrang Radio.

Other ways of promoting services to(potential) service users is through community newsletters such as ‘Community Pride,’ a Council-produced newsletter sent out to every household in the District. Staff are made aware of initiatives run by the Council through the Internet and through a departmental staff newsletter – ‘Spotlight’ – as well as a Council-wide staff newsletter, ‘Pride@Work’.

The Adult & Community Services department (Bradford Council Social Services) has a long tradition of running a monthly older people’s Focus
Group, which can attract up to 200 older people. These inform the organisers about the concerns of older people living in the District. There are also regular conference-style events run across the District with the harder-to-reach groups of carers and older people in general – these disseminate information and consult people on areas of need and service development.

4. A listening ear

The biggest difference a service provider can make is to give the carer an opportunity to express their concerns and fears. The BME carers that we have spoken to have on the whole said they would find a lot of comfort in being able to make service providers understand how they feel, and the frustrations they experience when trying to communicate with them.

This is particularly important where the main (sole) carer is a woman. She will know what she needs in the form of support for herself rather than listening to the main decision-maker within the family, who perhaps may not realise the pressure she is under.

Families are informing us that they do want help and support, but this must be what the families need and not what service providers think they need. A classic example of this is where Social Services carry out assessments for care needs but the families do not accept the care package as it does not meet their needs.

Services such as the Sitting Service (Time Out) are not able to meet the needs of the families due to two main reasons – a lack of BME volunteers/staff who can communicate with the person needing care, and the inappropriateness of the timing available – ie someone might need a ‘sitter’ during the night whilst the service provider can only provide it during the day. It is therefore very important not to raise false expectations when promoting services, while at the same time ensuring that the needs of carers are considered through cultural norms and traditions – as well as practical issues such as a mother with school-age children who is also the carer for her mother-in-law.

Carers get frustrated when service providers do not listen to the viewpoint of the person living with the service user, for example asking the husband to sit in the waiting room whilst the wife has her consultation or assessment through an interpreter. It would make more sense to keep the carer on board by listening to their views as well as those of the service user, rather than simply citing confidentiality clauses and putting on a show of ‘professionalism.’ It is imperative to keep the carer in the loop so that they understand what is happening, to both mediate between the service providers and the service user.

**Appropriate services need to be commissioned as the existing daycare provision is not easily able to manage care of people with dementia.**
provider and user and to inform the service provider of any changes within the individual’s behaviour at home.

Summary

It is important that people are respected as individuals and individual families rather than seen as generalised conceptions of stereotypical groups. The carer within the family is pivotal in the delivery of care and as such is probably the best placed person to advise service providers of the needs – both social and physical – of the person who is in need of care, as well as for the carer themselves.

Cultural awareness needs to move on to cultural competency when undertaking assessments and planning care packages. Unless the practitioner is able to understand the context within which the carer is working, they will not be able to get a fuller picture of the setup in terms of delivering care within the family setting – eg most carers are women, but many of the decision-makers within South Asian households may be men. This does not imply that women have no say or are subservient, but that the two genders have differing roles to play both within and outside the family setting.

The biggest service any practitioner can provide is to listen to the views of the carer(s). They are often best placed to give a realistic picture of the impact caring is having on their own life, as well as the needs they have as a family for help and support from external agencies such as the NHS and Social Services.
Early onset dementia is three times more common in BME communities than the general British population.

Useful contacts

Meri Yaadain Dementia Team
5th Floor Olicana House
Chapel Street
Bradford, BD1 5RE
Telephone 01274 431308
www.meriyaadain.co.uk

Bradford Adult & Community Services
Olicana House
Chapel Street
Bradford, BD1 5RE
Telephone 01274 431308
www.bradford.gov.uk

Alzheimers’ Society Bradford
16-18 North Parade
Bradford
West Yorkshire, BD1 3HT
Telephone 01274 733880
National Dementia Helpline:
0845 300 0336
www.alzheimers.org.uk

Carers’ Resource
Unit 15
Park View Court
St. Paul’s Road
Shipley, BD18 3DZ
Telephone 01274 449660
www.carersresource.org

Age Concern Bradford
32 Kirkgate
Bradford, BD1 1QN
Telephone 01274 391190

Carers’ Connection
Manningham Health Centre
Lumb Lane
Bradford, BD8 7SY
Telephone 01274 323323

NHS Choices
www.nhs.uk

NHS Bradford and Airedale
Douglas Mill
Bowling Old Lane
Bradford BD5 7JR
Telephone 0845 111 5000
www.bradford.nhs.uk

Carers’ UK
www.carersuk.org/information

Dementia UK
www.dementiauk.org
Caring for Dementia

Meri Yaadain Dementia Team

Meri Yaadain (My Memories) is a nationally recognised initiative run by Bradford Council’s Adult & Community Services. The Meri Yaadain Dementia Team work to break down the misconceptions about dementia and make people aware of what the condition is, whom it affects and the help available to individuals and their carers.

The team raise awareness of dementia amongst the South Asian communities as well as encouraging service providers to work in more open, innovative and culturally competent ways. Specific work with carers includes home visits, telephone support, information and signposting as well as a monthly support group and a bimonthly newsletter.

Referrals come from all avenues: community groups, mental health teams, social workers, GP practices, family and friends and self-referrals. Meri Yaadain Dementia Team have been successful mainly as a result of being able to gain the trust of the local communities by spending time to listen to the needs of people with dementia and their carers.

Following the winning of two national awards good practice from the project has been shared through local, regional and national events. A website and a dvd about dementia and the work of the team have also made it possible to communicate with (potential) service users and to share the good practice nationally.

For more information contact Akhlak Rauf on Bradford 01274 431308, email: akhlak.rauf@bradford.gov.uk.

More awareness raising, challenge the stigma, listen to carers and treat people as individuals.
New approaches are needed to have culturally appropriate tests for cognitive impairment.